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

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

Fiona McAllister, Managing Director, Beaufort Research
Adam Blunt, Associate Director, Beaufort Research

For further information please contact:
Ian Jones
Senior Research Officer
Knowledge and Analytical Services
Welsh Government
029 2082 3411
Email: ian.jones2@wales.gsi.gov.uk

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Executive summary

Introduction

Beaufort Research was commissioned to undertake research to assess the views of Specialist Nurses and Clinical Leads for organ donation, regarding the proposed move to a soft opt-out system in Wales[1]. The focus of the research was to explore perceptions of current working practices and to establish expectations, attitudes and any concerns that Specialist Nurses and Clinical Leads had regarding the implementation of, and impact of moving to, a soft opt-out system. The report presents personal views expressed by the Specialist Nurses and Clinical Leads interviewed.

Specialist Nurses and Clinical Leads play key roles in the organ donation process. The Specialist Nurse will discuss the patient's wishes with the family. If the family consents to organ donation, the Specialist Nurse will ensure that medical tests are carried out. They will also examine the patient's medical history and may ask the family questions to confirm whether or not organ donation can take place.

Clinical Leads are typically senior clinicians in hospitals who have accepted a particular responsibility to implement recommendations made by the UK Organ Donation Taskforce[2] 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.

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[1] The Welsh Government has stated its intention to introduce a soft-opt out system of organ donation through the Human Transplantation (Wales) Bill. The proposed 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. The Welsh Government plans to bring this new law into effect in 2015.

[2] http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/guidance/organtransplant/?lang=en

The research consisted of a first-stage online bulletin board to which all Specialist Nurses for Organ Donation (SNODs) and Clinical Leads for Organ Donation (CLODs) were invited, followed by 25 in-depth interviews with SNODs and CLODs in North and South Wales. Fieldwork took place during February and March 2013.

Positive aspects of current working practices

Across the sample, participants regularly highlighted embedded SNODs[3] as a vital component of improved current working practices. They had become central to the organ donation process, and were believed to be having a positive impact on identifying cases where donation might be a possibility when the death of the patient was inevitable, and on consent rates among families of deceased patients.

The way in which SNODs and CLODs were building relationships over time with other staff and raising awareness and understanding was also considered an essential element of current working practices. The impact of the embedded SNOD was felt to be enhanced when the SNOD had previously worked in the Intensive Care Unit in which they were embedded prior to taking on the Specialist Nurse role.

Through the combined efforts of SNODs and CLODs, it was felt that clinicians were now more likely to have organ donation in their minds, especially with donation conversations now being held with other units such as the emergency department (ED). The involvement of the CLOD was thought to help with peer influence in this respect.

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[3] ‘Embedded’ SNODs work within the critical care unit of a specific hospital.

Overall, the various guidelines produced on approaching the families of potential organ donors were deemed effective in terms of providing, at a high level, clarity and consistency around best practice.

Turning specifically to the opt-in approach for organ donation, some participants explained how the system was a ‘powerful’ tool when approaching families where the potential donor was on the register: the patient’s wishes were clear and the family would not have the burden of making a potentially difficult decision.

Other positive aspects of current working practices mentioned included:

- The number of missed potential donors decreasing;
- Earlier involvement of SNODs where donation might be a possibility; and
- Having the same or similar procedures cross-border.

Less positive aspects of current working practices

According to participants across North and South Wales, clinicians could sometimes adversely affect the organ donation process for several reasons. These included: clinicians being difficult to influence in terms of best practice, or 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; inconsistency over what clinicians felt constituted a potential donor; late identification of potential donors; difficulty on the clinician’s part from an ethical perspective in referring a patient to the ICU purely for organ donation purposes, when the bed could be used to treat a patient who might survive.

Participants in North and South Wales referred to issues with SNOD availability. These situations were partly related to geography but also to resourcing issues (for example staff leaving, secondments or illness). Prompt identification of potential donors who were at the end of their life and conversations by telephone helped to overcome geographical obstacles, although best practice approaches could still be compromised.

The issue of critical care capacity was raised by some participants in North and South Wales, for example with patients who were donating occupying ICU beds for longer; or losing the opportunity to donate because an ICU bed was not available for a patient in ED.

References were made to attempting to work around this issue by using Recovery Units with ICU staff.

Additional less positive aspects of current working practices included:

- The challenge of implementing best practice in ED because of the lack of time to get to know families and difficulty in developing relationships when there was not enough room for the SNOD to be based in the unit;
- The potential for ‘burn-out’ among SNODs;
- The steps taken to the point where an organ retrieval team arrived could sometimes take a significant amount of time;
- The challenge of conversations with families where the patient had not opted in, and the family had not discussed their wishes with the family.

The proposed soft opt-out system of organ donation for Wales

In general, participants did not think that their routine working practices would change greatly if the proposed new system were introduced: they anticipated similar operational methods, similar amounts of paperwork and, on the whole, a similar amount of time taken to approach the family.

They also expected to use similar approaches to families, with minor changes to the wording of conversations which explored the possibility of organ donation as appropriate, to take into account the new system. There was reference to needing to understand how to introduce legislative changes into the conversation. It was hoped that ‘black and white’ guidance would be provided on the changes in approach required.

Cross-border working was generally not expected to be a problem providing that the register was easily accessible and clear on the status of the patient involved, including residency, although how easy this would be was questioned on occasion. Care would be needed to ensure that the SNOD remembered to use the appropriate consent forms for England and Wales.

Overall, participants reported that they wanted the soft opt-out system to be effective, were it to be introduced, in order to save more lives. There was reference to attitudes having changed over time since the new system was proposed, and a feeling that SNODs and CLODs were now accepting of the soft opt-out system.

There was, however, uncertainty and sometimes doubt over whether or not there would be any (immediate) increase in donors as a result of the change; and a view that perhaps the money which would be invested in the new system could be better spent on better promoting organ donation under the current system.

Concerns about the proposed move to a soft opt-out system

The key (potential) concern voiced by participants was avoiding a situation where a poorly informed general public were making uninformed decisions to opt out. A range of further concerns were raised, with no single theme prevalent:

- With the prospect of not approaching families where the patient had opted out, doubt was sometimes voiced over how staff could be certain that the decision to opt out was both informed and up to date;
- The workload of SNODs and CLODs could increase because of responsibilities in educating other audiences such as the wider medical

profession (although participants very much recognised the importance of this responsibility);

- Maintaining engagement with donation among some senior colleagues owing to issues around deemed consent and circulatory death;
- Pressures on critical care capacity would continue;
- Difficulty establishing identity and therefore residency with some patients.

Making the new system a success in Wales

There was a unanimous view across participants that education of a wide range of audiences was vital to the success of the proposed soft opt-out system. These audiences included: the general public in particular; hospital staff and, to varying degrees, other NHS staff.

Ideally, SNODs and CLODs were generally felt to be most qualified to provide education, but resource would have to be increased.

There was a belief that the general public needed to be reassured that family involvement was still integral to the donation process which itself was still based on choice, and that a hard opt-out system was not being proposed.

The education sector and GPs were identified as having an important role to play with informing the general public of the proposed new system, as well as organ donation more generally. Universities (and GPs) would be well placed to communicate Wales’ new system to students from outside Wales.

The success of the new system, according to participants, would also rely on a single, unambiguous and up-to-date register combining UK patient preferences. SNODs and CLODs would want to be confident that they were legally protected should they act on incorrect register information in good faith.

Limited awareness among some participants of how the new system would address residency, and how the register would function, indicated that not all were fully aware of the Bill’s content, in both North and South Wales.

Additional training requirements

Additional training requirements were expected to be reasonably minor for SNODs and CLODs. Some participants thought it vital that CLODs and other clinicians were up to date with current information in order to answer questions from colleagues and families and to be able to use the appropriate language if they had to approach a family on organ donation.

It was suggested that the legislative change could act as a way to engage more effectively on organ donation with some clinicians.

Other staff groups would benefit from raised awareness / training, according to participants: it would be useful for all those involved with patients to know the specific circumstances in which organ and tissue donation could take place as they might be asked about it by patients’ families. Ideally, all staff who might come across the subject in a professional capacity would become familiar with the process.

Conclusions and considerations

The primary focus of this qualitative research project was to explore perceptions of current working practices and to establish expectations, attitudes and any concerns that Specialist Nurses and Clinical Leads had regarding the implementation of, and impact of moving to, a soft opt-out system.

It should be noted, therefore, that some of the issues to emerge from the research did not apply specifically to participants’ comparisons between current working practices and how these might change with the proposed move to a soft opt-out system. The issues are included in these conclusions as areas for potential further exploration.

Focusing specifically on the current opt-in system for organ donation and participants’ working practices, the general picture was one of progress being made in recent years resulting from the Organ Donation Taskforce recommendations, embedded SNODs with supportive CLODs, and effective, flexible guidelines. In addition, the task of talking with the family was normally made more straightforward where a patient had clearly chosen to opt in, for example by joining the organ donor register.

The practice of embedded SNODs was clearly thought to be having a significant impact on organ donation, and that the longer a particular individual was embedded, the better the relationships with staff who could influence organ donation outcomes. This research suggests (but not conclusively) that, in order to sustain these improvements, it may be worthwhile exploring further the key pressure points within SNODs’ work with a view to establishing what could be done to alleviate any pressures.

From the perspective of their current working practices, the issues raised by participants did not appear, overall, to be directly attached to the current opt-in system of organ donation in Wales, but were more to do with organ donation in general and operational constraints. These included geographical and resource challenges; strains on critical care capacity, according to some; and reported issues with some clinicians, for example SNODs’ lack of credibility in the eyes of the clinician; not involving SNODs earlier in the process where donation may be a possibility; using inappropriate phrases when talking to families of potential donors; and the clinician choosing to have the first conversation with families about donation, rather than letting the SNOD carry out this task.

The research therefore indicates that these may be areas for further exploration and review over time. One possible approach may be to position training for clinicians on the soft opt-out system and approaching families as a requirement rather than an option, because of legislation change. Also, the perceived issue among some participants of critical care capacity points to the possibility of monitoring the success of any efforts being undertaken to deal with the issue, for example by using Recovery Theatre Units.

Turning to the proposed move to the opt-out system for organ donation in Wales, there appeared to be more of an acceptance among participants of the proposal, which perhaps might not have entirely been the case when the proposal was first put forward. There was a sense that participants assumed the Bill would be passed and that they would do whatever they could to increase organ donation consent rates and make the new system a success, in order to save lives.

Participants on the whole did not expect their routine working practices to change greatly although nuances in language with the initial approach to families were expected to be different. Some of the comments made by participants concerning aspects of the Bill, such as the implications for residency and how the register would work, point to the need for continued education on this detail which is already available in the Bill and its Explanatory Memorandum.

The key element to making the system a success was education of the *entire* general public, in participants' minds, but there were concerns that potential donors would be missed because of the general public's anticipated lack of understanding of the proposed new system. Participants were looking for communication to counter any negative PR in the media and in particular to stress that the individual can make three choices: to opt in to organ donation; to opt out of organ donation; or to choose not to opt out and therefore give deemed consent for donation – the ability, still, to choose to opt-in appeared to have been overlooked in media coverage and communications.

Some participants welcomed the way in which SNODs and CLODs were involved in working groups in relation to organ donation and the proposed move to the soft opt-out system and believed that the Welsh Government genuinely wanted to make a difference. As suggested on occasion in the research, Welsh Government staff's understanding of the SNOD's work might be enhanced by spending time with SNODs on the units.

Given the nature of the current issues described by participants, this research indicates that it would be worthwhile monitoring the following areas as the proposed 2015 legislative change draws nearer and also if and when it has been implemented (for example 12 months after implementation):

- To what extent SNODs' and CLODs' familiarity had improved with the ways in which the proposed new system would affect day to day working (for example, how the register would work, residency implications, how to begin conversations with families and explain the new system);
- How effective training / guidance received on the proposed new system had been, including any areas for improvement;
- How relationships with clinicians had developed, including the ability of the SNODs to influence them, and perceived levels of awareness, understanding and acceptance of the proposed new system;
- How perceived awareness / understanding of the proposed new system was changing among other hospital staff with whom SNODs and CLODs came into contact; and among the general public;
- How effectively any additional education responsibilities on the part of SNODs / CLODs were being resourced;
- How experiences with families were changing over time;
- What, if any, new (potential) issues or concerns had arisen in relation to the proposed new system.

1 Background, objectives and methodology

1.1 Background

The Welsh Government has stated its intention to introduce a soft-opt out system of organ donation through the Human Transplantation (Wales) Bill. The proposed 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. The Welsh Government plans to bring this new law into effect in 2015.

Specialist Nurses and Clinical Leads play key roles in the organ donation process, particularly 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, Specialist Nurses for Organ Donation (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 organ donor register. The Specialist Nurse will then discuss the patient's wishes with the family. If the family consents to organ donation, the Specialist Nurse will ensure that medical tests, such as blood group and tissue type matching, are carried out. They will also examine the patient's medical history and may ask the family questions to confirm whether or not organ donation can take place.

Clinical Leads for Organ Donation (CLODs) are appointed to key roles in hospitals to implement recommendations made by the UK Organ Donation

Taskforce[4] 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. Clinical Leads are responsible for raising the profile of organ donation and providing expert advice on the ethical and legal aspects.

There are 15 ‘embedded’ Specialist Nurses in Wales, meaning they work within the critical care unit of a specific hospital. Each Health Board has at least one Clinical Lead, 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 Specialist Nurses and Clinical Leads on the planned change to the organ donation system is critical to its success.

The Welsh Government therefore wished to understand their views through a qualitative research study.

1.2 Research objectives

The following objectives were set for the research study:

- To gain an understanding of the working practices and experiences of Specialist Nurses and Clinical Leads under the current opt-in system of organ donation;
- To establish expectations, attitudes and any concerns that Specialist Nurses and Clinical Leads had regarding the implementation of, and impact of moving to, a soft opt-out system;
- To gain an understanding of the views of Specialist Nurses and Clinical Leads on how moving to a new soft opt-out system might impact on their discussions with family members on consent for organ donation;

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[4] http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/guidance/organtransplant/?lang=en

- To determine any additional training requirements that Specialist Nurses and Clinical Leads might have in preparation for the change in legislation;
- To identify any other unanticipated issues articulated by Specialist Nurses and Clinical Leads in relation to moving to a soft opt-out system; and
- To provide recommendations for any future research undertaken with Specialist Nurses and Clinical Leads in the immediate run-up to, and following, the implementation of the soft opt-out system.

1.3 Research methodology

Given the nature of the topic, individual in-depth interviews was the primary methodology used, to allow for the exploration of views in detail and in a confidential one-to-one environment. It was also felt that individual interviews would fit better with participants' patterns of work. Most of the interviews were conducted at participants' places of work.

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.

As a preliminary research stage, Beaufort ran an online bulletin board forum with an invitation to participate sent to all Specialist Nurses for Organ Donation (SNODs) and Clinical Leads for Organ Donation (CLODs), whose contact details were provided by the Welsh Government. The primary aim of the online forum was to give the entire target audience the opportunity to express their views, and to inform the design of the topic guide to be used in the individual interviews. Participants were able to post anonymously, and respond to the questions in as much detail as they wished. This method was also appropriate for what is a geographically dispersed audience. From a total population of 35 SNODs and CLODs and support staff made available, 18 participants posted at least once in the discussion with 16 posting more than twice. The forum generated 100 posts in total. All staff who were available were invited to the online forum.

25 participants took part in an in-depth individual interview with Beaufort, of which 21 were conducted face-to-face and four by telephone. The numbers broke down as follows:

	SNODs[5]	**CLODs**
North Wales	7	3
South Wales	10	5

Based on these sample requirements set by the Welsh Government, Beaufort targeted participants from across the seven Local Health Boards in Wales and those who were in team manager and regional roles. Five Local Health Boards were represented in the final sample (including recent experience of working in a sixth Local Health Board), as well as those in team manager and regional roles.

Fieldwork took place during late February and early March 2013, with interviews lasting between 35 minutes and one hour 15 minutes.

The report presents personal views expressed by the SNODs and CLODs interviewed.

The report contains verbatim comments from participants which are provided in italics. They do not include attributions and have been edited as appropriate, to preserve anonymity. The weight attached to a particular finding is highlighted as appropriate. Where a specific point is being illustrated by verbatim comments, each comment is from a different participant. From time to time, the language of the report reflects the routine technical terms and

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[5] Although there are 15 embedded SNODs in Wales, a small number of SNODs based in the North West of England who also worked in Wales expressed an interest in taking part.

phrases used by the medical staff interviewed as they described their day to day tasks.

2 The current opt-in system of organ donation in Wales

2.1 Perceptions of roles and responsibilities of SNODs and CLODs

During the discussions, participants gave examples of what they saw as the roles and responsibilities of SNODs and CLODs. Focusing on SNODs, references were made to: implementing the Organ Donation Taskforce[6] and National Institute of Clinical Excellence (NICE) guidelines[7] at a local level in hospitals; encouraging a collaborative approach to meeting with the families of potential donors, and talking with those families; educating the clinical staff in Intensive Care Units (ICUs) particularly, and helping to keep organ donation at the front of staff's minds; and supporting patients, families and fellow nurses, even when donation did not occur.

CLODS were sometimes viewed as facilitators who aimed to ensure that appropriate guidelines, policies and protocols were in place. Monitoring of processes was also important (for example number of missed potential donors), as was staff training and 'continued engagement of senior colleagues, to make sure that they genuinely don't have issues relating to organ donation'.

2.2 Positive aspects of current working practices

Although participants often identified obstacles to efficient working (see section 2.3), they regularly highlighted **embedded SNODs[8]** as a vital component of effective current working practices, and how they had become central to the organ donation process. SNODs were felt to be having a positive impact on the identification of potential donors by clinicians and

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[6] http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/guidance/organtransplant/?lang=en

[7] http://guidance.nice.org.uk/CG135

[8] 'Embedded' SNODs work within the critical care unit of a specific hospital.

consent rates because they were able to speak with families of potential donors in a timely and professional way, with clinicians tending to be more comfortable allowing SNODs to lead on the donation conversation with families. A further benefit of the embedding approach was how SNODs ‘humanised’ the issue and, together with CLODs, were helping to increase awareness of organ donation among staff on units. They also provided an accessible source of guidance and advice. SNODs’ presence in the units acted as a ‘constant reminder’ that they should be approached when a decision was taken to withdraw[9] on a patient where death was inevitable. As one participant pointed out, the reminder was essential because, understandably, clinicians were working ‘ridiculously hard’ and remembering to think about organ donation was not their main priority.

> *What works well I think about the role is having the embedded SNOD. So the units have got ready access for opinions, advice and if there’s a family who want to speak to someone, hopefully they can speak to that person quicker than waiting for someone else to get there.*
>
> *It’s humanised the whole issue in terms of organ donation. We’re not picking up the phone to complete strangers based necessarily in remote parts of the north-west. So that’s made a big difference.*

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[9] The use of the word “withdraw” has a specific clinical meaning which requires some explanation for the reader. There are two types of 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.

> *We have a really high referral[10] rate. The odd one, one or two, might slip through over a few months' period, but generally not anymore.*
>
> *The figures from the potential donor audit show that if there is a SNOD involved in the process then the consent rate tends to be a bit higher.*
>
> *I think the consultants have come a long way and they used to do all the conversations and now they're starting to let go of that part so that we can become more involved with the families, which is good.*

In addition, the embedding approach was thought by some to be more effective where the SNOD had previous experience of working on the unit, for example as an ICU nurse, and had therefore already developed relationships with colleagues which was often deemed an integral component of the success of the SNOD's role.

> *The embedded SNOD is absolutely critical. Our SNOD used to be one of our ITU nurses, and (s)he was a very well-liked ITU nurse, and (s)he gets on very well with the nursing staff and the medical staff; and when (s)he is there then people are far more likely to remember to make a referral than they are if (s)he's not there.*
>
> *I think that is probably the most fundamental thing that has actually changed in the last five years or so really. Their presence is absolutely key and if they integrate with the staff - often they're from the units originally.*

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[10] Those patients for whom neurological death was suspected or imminent death was anticipated who were discussed with the Specialist Nurse.

> *This is my hospital and I was here as a nurse in another area so many other people and the doctors knew me.*

The broader embedded role was also seen as being vital for the education of relevant staff who might not have the time or department budgets to take themselves on courses relevant to organ donation. One-to-one training and updating staff as they worked with patients was considered an effective means of providing ongoing education. New staff also needed educating on organ donation. The example below focuses on how the day-to-day presence of the SNOD could help to reinforce the point that it was the patient or family who should make the choice about donation and not a member of staff.

> *It's not just about facilitating donors, it's about trying to educate [staff] and to try and change hearts and minds because there is a turnover of staff on the units. So you do get new people coming in and people leaving, so there is a constant need to try and ensure that people understand that actually it's not their choice as a clinician or to say whether or not somebody donates. It's the patient's and the family's choice.*

A **supportive CLOD** was also valued in helping to build relationships with other units (for example by delivering 'entertaining' training) and to encourage best practice among clinicians and staff in other units with referrals. In a small number of cases, the CLOD's credibility among peers was particularly important if SNODs found it difficult to influence the views of clinicians. Through the combined efforts of SNODs and CLODs, it was felt that clinicians were more likely to have organ donation in their minds, especially with donation conversations now being held with other units such as ED. Patients, who would previously not have been considered as potential donors, were beginning to be seen as possible donors when death was inevitable.

> *[SNODs and CLODs] are pretty effective actually. Certainly our organ donation rates are increasing year-on-year. Firstly, I think that clinicians*

> *are much more likely to think about it, much more aware of it. We're moving into newer areas like A&E, and sort of parallel areas, like high dependency units and things. I think we're looking at potential donors who would have been considered not fit for donation previously.*
>
> *I’m particularly lucky in this hospital in that I’ve got a very good supportive clinical lead for organ donation and most of the consultants here refer what they’re supposed to. . . . [The CLOD] is quite influential in influencing other people for example in the Emergency Department.*

Overall, the various **guidelines produced on approaching the families** of potential organ donors were deemed effective in terms of providing clarity and consistency around best practice. The quality and safety aspects were ‘excellent now and they are much better than they were’. Participants tended to feel that the key to success was using them as a flexible guide, given how every situation with families was different and required sensitive and skilled handling. In addition, each SNOD had their own style in approaching families.

> *Every situation’s very unique and sometimes, you know, there’s lots of guidance and there’s a very gold standard way of doing it, but sometimes a family might pre-empt you and you’re not going to be able to follow that guide.*
>
> *[The guidelines] serve a purpose definitely. I think they help and they help you to understand who to approach and who not to approach so the guidelines are always good there; but once you’re through the door, for me and I have been a nurse for [a long time] and when I walk into a room with families, I know by the feel of the families which way to angle the conversation and who to speak to.*

The ‘long contact’ model[11] with families was thought to work particularly well, and resulted from having embedded SNODs: this approach involves interacting with families during this period, not just at the point when treatment is finally ended, which allowed for relationships to develop and support to be given to families before the question of organ donation arose.

The guidelines were also thought to help clinicians to make ethical and informed decisions, and could be used to help influence clinicians that the ‘SNOD approach’ was now accepted as the norm.

> *I think [the guidelines] are brilliant. I think they are some of the best things to happen to organ donation. They have cleared up a lot of the uncertainty regarding some of the ethical dilemmas that clinicians would have faced. I think they have clarified it and it should make it easier for clinicians rather than harder.*

> *I suppose [the guidelines] give you more leverage to say to consultants that this is accepted practice elsewhere.*

Focusing specifically on the **current opt-in system** for organ donation, some participants explained how this method was a ‘powerful’ tool when approaching families where the potential donor was on the register. It gave a clear and straightforward means of introducing the subject, and the patient’s wishes had been clearly expressed which helped to remove the burden and decision from the family.

> *Because you can go to the family, and you can say ‘we’ve checked the register, and we know that your loved one is on the register and therefore it’s their wishes that they would like to be an organ donor, are*

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[11] This model involves planning the approach to families, confirming their understanding and acceptance of the situation and discussing donation. These are key stages in the process and more likely to result in a successful outcome.

> *you happy for us to carry out their wishes?' So it's very straightforward.*
>
> *I quite like the opt-in system because I believe that somebody has made a conscious decision to opt in and I like that and you know that they've taken the time to either carry a card or tell somebody or put themselves on the register so in my mind that's proper expressed consent.*
>
> *If someone is on the register it makes it a lot easier for the family and they don't feel like it's their decision.*

The point was also mentioned that, with the current system, the subject of organ donation could still be raised even when a patient was not on the register. This ability to approach all families was sometimes contrasted with expectations for the proposed new system where families of patients who had opted out would not be approached (discussed further in section 3.2).

A number of other positive aspects of current working practices were also highlighted:

- Emerging evidence from audits that identification of potential donors by clinicians where the patient was at the end of their life was increasing, and missed potential donors had decreased significantly;

  > *What works well is that we have pushed for a required referral[12]. What we have found is we have just completed a six-month audit as to how well that new initiative is working here and we found that our referral rate is excellent and so the potential donors that we may have missed a couple of years ago, actually, our true missed potential has fallen dramatically.*

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[12] This is a policy where all patients who trigger a referral as a potential organ donor according to the NICE guidelines are referred to the SNOD. The SNOD is then able to inform the unit if the patient is eligible to donate and the approach to the family is planned.

- The organ donation system becoming more structured since the move to NHS Blood and Transplant (NHSBT), with SNODS becoming more ‘valued’;

  > *Yes, I feel more central, you feel more valued as well and I think you, it sort of makes the job easier as well. I think it just makes the whole service more robust and better for everyone involved really. Moving over to NHS Blood and Transplant was the best thing they could have done.*

- Earlier involvement of SNODs where donation might be a possibility[13], and the death of the patient is inevitable, allowed the ‘on-call’ SNOD time to carry out background checks without having to spend time travelling to the hospital (which could be some distance). The embedded SNOD could then be contacted to approach the family;

  > *(S)he can find out some information but knowing that the patient is six to eight hours away from that decision being made (s)he can start those preliminary checks at 4am without having to actually go to the hospital and then at 9am (s)he can ring the SNOD who is embedded if you like, the local person, who can then go and have further discussions having done several hours of the work before. In principle it’s very useful.*
  >
  > *What we try to teach the clinicians to do is to refer to us . . . so that before they speak to that family, we’re on our way.*

- One participant explained how it was important to remind clinicians to speak with the SNOD when the SNOD was not physically present to improve the chances of a decision to donate, instead of missing the opportunity entirely;

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[13] Sometimes called an ‘early referral’ which in this context means those patients for whom neurological death was suspected or imminent death was anticipated who were discussed with the Specialist Nurse.

> *I'll encourage my colleagues to speak to the SNOD, and discuss how we're going to approach the family. Rather than miss a discussion altogether with a family, one of my consulting colleagues and a member of the IC nursing staff will sit down with the family on the basis of the information we've got available and explore issues regarding consent.*

Cross-border working tended not to be perceived as posing significant issues with current working practices, with UK-wide consistency on donation approach helping to this effect. Geographical issues were raised, for example travelling from North West England to North West Wales, as described in section 2.3 of this report. Also, moving only occasionally from hospitals in Wales to a hospital in England could require a little time on the SNOD's part to refamiliarise himself/herself with administration at the hospital in England.

> *All the intensive care is the same and we all have the same policies and processes. It's just the distance, that's the only thing.*

> *When you go to [England] you feel like a fish out of water for a couple of hours whilst you're getting used to the paperwork and the difference over there. [But] it's a single organ donor register that we can access and the problems are in-house and it's to do with familiarity[14].*

2.3 Less positive aspects of current working practices

Across the sample, several issues were raised by participants which were seen to impact adversely on effective working practices in relation to the organ donation process. In particular, the influence of some clinicians, SNOD availability, and critical care capacity, each of which is discussed in turn below.

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[14] All NHSBT documentation is the same across all four countries except in Scotland where the word 'consent' is changed to 'authorisation'.

A key theme to emerge in both North and South Wales related to interactions with some **clinicians** and their impact on the process. Some participants indicated that it could be a challenge for SNODs to influence the behaviours and beliefs of clinicians more senior to them in the organisation, for example a clinician who did not like having their practice questioned, especially by someone who had not 'earned their stripes' and therefore lacked credibility.

> *It's quite difficult to change people's views. I mean, in medicine generally, it's quite difficult to change people's views. There's a lot of practice in medicine which is not evidence based, you learn that from your senior, and so you have a view that something works or not; not based on evidence but based on what you've been taught.*
>
> *I think it is attitude. . . . Consultants that still hold that thing that it's hard to question their practice because they have always done it like that.*
>
> *You're known as the 'vulture'. You have to just ignore them; or you walk onto the unit and they are like 'there's nothing here for you' and I just say that 'I've come to see if you're all right and if you want a hand with anything'. It is a very difficult role.*

According to some participants (and despite the improvements in relationships and approaches reported in section 2.2) clinicians still sometimes had a negative influence on organ donation success for a number of reasons. Several references were made to clinicians who decided to approach the relatives directly rather than through the SNOD. Participants acknowledged that certain clinicians were extremely skilled in doing so but that there were other examples where best practice was not followed and families were approached about organ donation too early in the process; instances were also given of clinicians using inappropriate wording when introducing the subject of donation, such as 'I've been in the room and I they've said 'oh I'm sorry, but I have got to ask you this'.

> *I think there have been about [x number] in the last three months where the consultants have just gone in and not waited for one of us to be there with them.*
>
> *You can say to the clinician 'right this is the plan, will you speak to the family about the decision to withdraw treatment [where the patient's death was inevitable] and then I will come in with you, and then come and get me I will be just here' and you can see the relatives' room but you turn around and they've done it anyway, they've asked the family.*
>
> *They may think it's their role and maybe it's too early to get a SNOD involved and bring the family up and then perhaps they blurt it out: 'organ donation' before the family is ready. You get situations like that where you make a plan and it's not necessarily followed.*
>
> *There are consultants who feel they [approach families] better than us and want to do it themselves whereas it's very difficult for us to teach or change that doctor's opinion.*

While clinicians were often described across the sample as very much on board with organ donation, there were a small number of occasions outlined where this did not appear to be the case, with clinicians who did not 'want to get involved in organ donation'; and there was no obvious way to counter a clinician's decision not to consider for organ donation a patient who was at the end of their life. Moving to a 'realm of questioning the clinical decisions of a consultant' was considered a 'very tough' thing to do, with 'consultant bodies in any hospital and nationally sticking close together'; the need was raised for a more 'assertive' and 'proactive' way of reviewing missed potential donors where death was inevitable, given how clinicians could be reluctant to challenge their peers about practice.

> *My biggest complaint would be that there doesn’t seem to be any follow-up or weight to push down on the Health Boards if a clinician doesn’t want to get involved in organ donation.*

It was pointed out that clinicians were understandably focused on trying to save patients, rather than thinking about a responsibility towards patients awaiting a donor, and the possibility that an individual patient at the end of their life might be able to help several other patients. According to a small number of participants, there was also the ethical issue for some clinicians in the Emergency Department of being reluctant to refer a patient where death was inevitable to ICU purely for organ donation.

> *There is a huge disconnect between where donation occurs and where transplants occur in respect that the clinicians caring for the patients that could donate, they don’t feel that they have a responsibility for those patients that need the transplant.*

> *Ethical issues: with the consultants bringing them up from ED [Emergency Department] just for the purposes of organ donation if there is no chance of recovering; and I think they have got problems with that which I understand completely.*

In North and South Wales, education requirements were highlighted where knowledge of what constituted a potential donor among some medical staff was not always felt to be accurate, particularly if a patient had suffered illnesses in the past.

> *There are perceptions amongst medical staff that it wouldn’t be possible for that patient to be an organ donor, and they don’t refer because they’ve got misconceptions about who might be a potential donor and who might not.*

> *There are a number of organs that can be donated and just because somebody has been in hospital and they've had a heart attack and that heart attack has caused them to have renal failure, it doesn't mean that they cannot donate their liver but the clinician will say 'he is on a ventilator, he is requiring drugs to support his heart and he is on a dialysis machine – who is going to want those organs?'.*

It was explained by some participants that the identification of potential donors who were at the end of their lives on occasion was left to the last minute by the units, which meant that SNODS could not 'respond in a timely manner', and resulted in the unit staff having to make the approach to families. It was acknowledged, however, that this scenario was less common because of recent NICE guidelines.

> *Sometimes we get a referral, and the families are waiting for withdrawal of life-sustaining treatments [where death is inevitable], and the units have left it right to the last minute to call us. We can't respond in a timely manner. We may be an hour and a half away from that unit, in which case staff on that unit would then have to make the approach. And it's not the best way really, no.*

In addition, it was occasionally reported that clinicians and nurses might believe that a family should not be approached because of the pain of the family's loss, and that they should not be put through further distress, even though the conversation might benefit the bereaved family in dealing with the distressing situation.

> *The medical staff and the nursing staff are very protective about patients and quite often you'll attend a hospital because you've been referred to a potential donor and you'll be told by nurses and doctors that you can't possibly approach this family, they are just too distressed, they've had an awful time. Giving bereaved people a*

> *degree of control helps and I don't think that doctors and nurses realise that.*

Further comments made by participants related to how some clinicians did not like donations after cardiac death (DCD) in particular; and how, in one case, a clinician objected to a SNOD taking the lead, believing that it was a breach of ethics and patient confidentiality, as well as a data protection issue.

Across North and South Wales, geography and staff availability sometimes compromised the ability of **SNODs to reach a potential donor** in a timely manner (for example because of staff sickness, staff resigning, secondments, and holiday leave). SNODs explained that, in such situations, they would do what they could by phone with the appropriate staff before they reached the hospital. The absence of a SNOD could also mean that a patient was extubated[15] in ED at the end of their life without the SNOD being present to encourage consideration for organ donation.

> *If you get called at three in the morning and you live two and a half hours away and you're the last man standing, you can help and talk through and give a dialogue to the staff about what to say and stuff, and just make your way as quickly as possible. But sometimes, you know, it doesn't work.*

> *The problem that I find is not always being able to do that best practice because geographically we are a long way away from the rest of our team members. If I am in [a North Wales] Hospital which is miles away from maybe the SNOD on call who is in [North West England]. I might be on annual leave and there may be nobody closer to come and approach that family, so in the end we have to allow the staff in [the hospital] to approach that family. We have to because you can't delay*

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[15] Where a tube is removed from the body, for example a tube that was previously inserted into the trachea for mechanical ventilation.

> *any communications with the family for three hours – that would be ridiculously unethical especially when the family are asking for information [on organ donation].*

As a result, the collaborative approach and hence best practice could be affected. The likelihood of a positive donation outcome relied on the clinician having the expertise to know when to have the conversation with the family and how to raise the subject in the most appropriate way – and this did not always happen, according to some.

> *Because it's one of the things that, we're acutely aware of, is that if the approach has been made by somebody who has not had the training, the timing of that approach can be completely off.*

There was an isolated suggestion that a 'seven-day working SNOD' (compared with currently tending to work five days a week, 9.00am to 5.00pm, according to one participant) would help to mitigate issues with the time taken for on-call SNODs to reach the hospital.

A third theme, which arose in North and South Wales, in relation current working practices centred on **critical care capacity**, for some participants. It was explained that patients who were donating would take up a critical care bed for longer, owing to the process of organ donation. If an ICU bed was not available, and the potential donor was in the Emergency Department, then a decision might be taken to extubate that patient where treatment was futile - thus losing the opportunity to donate. It was reported by a small number of participants that some consultants did not agree with this aspect of the organ donation process.

> *ED [Emergency Department] is always a very busy place and there is a shortfall of resus [resuscitation] beds and having an organ donor in there where you've got patients coming in and being resuscitated, and*

> *it isn't ideal and so that is a bit difficult and there are still some consultants who don't agree with that.*

> *We have had [x] cases recently . . . where the patients come in through A&E they've been recognised as a potential donor and we have been referred but we've not approached the family because the capacity on the intensive care unit has not been so that we can facilitate it.*

Some participants felt strongly that increasing ICU capacity could increase organ donations substantially. Work was reportedly underway in certain hospitals to increase capacity by utilising Recovery Units as a 'half-way house'. Patients would not be admitted to ICU, allowing SNODS to approach families in the Emergency Department without the fear of a lack of capacity.

> *We're saying to the A&E Department 'I know they potentially could be a donor [where death was inevitable] but there's no way we can contemplate it because we don't have beds'; and we're doing that regularly. You know it's not a once every six months, this is every couple of weeks we're saying 'no'. So I think we could have a substantially increased number of organ donations even if we just had a better funded capacity with the system we've got at the minute.*

> *Do I admit a potential organ donor [at the end of their life] from A&E to intensive care into my last bed? It becomes difficult. And that's a major concern that my intensive care colleagues, however enthusiastic they are about organ donation, continue to express.*

There was also comment that it was proving difficult to convince Emergency Departments to consider patients, who were at the end of their lives, for ICU because of the 'extra workload' it would create for the Department and additional pressure it would place on their capacity.

> *The only thing they won’t do in this hospital is bring the patients up from ED and that’s what we’re working on now and trying to get them to understand that there are still people dying out there and we just need to get as many possible organs as we possibly can to help those people survive; and if that means putting a pathway into place to get those patients into intensive care, then that is what we feel we have to do but we are constantly fighting against them because they are quite dead against the extra workload it will be for them.*

Access to theatres could also occasionally pose problems: if there were no slots available, the time that families might be asked to wait could be unrealistic. A comment was made that even if a theatre was empty, ‘somebody might say that we may well get an emergency and then you’d be blocking our theatre’.

In some cases, however, capacity was deemed to be less of an issue. Examples were given of potential donor patients from the Emergency Department being transferred to intensive care at the end of their lives and, if intensive care did not have the capacity, the patient would be moved to theatre recovery areas.

> *We have got some provisions in place in North Wales whereby we have in each site kind of at the moment, informally agreed that in the scenario if a patient was to come into ED here and donation was offered and the family wanted to consider, the patient would be transferred to intensive care.*

> *The unit has actually expanded into recovery areas and we have admitted patients to the recovery areas – they’re looked after by ICU staff.*

In addition to the main themes described above, a number of further, less positive and less frequently mentioned aspects arose in relation to current working practices. Implementing **best practice in ED** sometimes proved to be a challenge because of the reduced amount of time to get to know the families' and the patients' background. Also, SNODS tended not to know the staff in ED as well as in ICU, partly because they might not have worked in that department, but also because there was insufficient space for them to be based there.

> *Within our hospital there isn't anywhere for us to be based [in ED] so whereas here we are known by the critical care staff because we worked here so we've already got the relationships with the staff. It's more difficult to get into A&E because there just isn't the space for us to work down there; and often the timeframes that they work within are so much quicker that donation isn't always something that's thought of there.*

There was also occasional reference to the **pressure placed on SNODs** by the nature of their work and the potential for 'burn-out', as well as other, unforeseen stressful situations to deal with involving family interactions. The possibility of more support for SNODs in this area was therefore suggested.

> *Sometimes they forget all the pressures we work under every day and we do take that home and you're thinking what you can do to help that family and when you walk away you feel a bit vulnerable. . . . I do think they need to look at the support the nurses need to have to stay in the job for longer.*

Focusing on the **transplant team**[16] (a separate team responsible for organ retrieval from the donor and transplantation to the donor recipient, and which may have to travel to the hospital from elsewhere in the country / UK), it was

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[16] The transplant team is a generic term for the clinical and administrative team involved in both the retrieval and transplantation process. The team can comprise nursing staff, surgeons, anaesthetists and administrators. Some specialist members of the team will have to travel to other hospitals to undertake the organ retrieval process.

suggested by one or two participants that a decision could be reached more quickly once a family had agreed to donation (an example was given of finding it difficult to track down the relevant surgeon). In addition, the time taken before an organ retrieval team arrived was considered long, on occasion. One participant in South Wales used the example of how it could take 10 to 12 hours for the retrieval team to arrive from Birmingham, taking into account offering the organs and the decision-making process.

> *Things could be quicker in that the amount of time it sometimes takes to get a decision from the transplant team or transplant surgeon. When a family are keen for donation and we're just not sure and we don't want to give anybody a false offer or false hope, you're trying to make quick phone calls; they could be in surgery, they could be in an outpatient's appointment.*

> *South Wales for retrieval purposes are covered from Birmingham – with the best will in the world, if you're going to go down to West Wales that's a three-hour journey and some of the critical care areas, by the time you've offered the organs, that can take four or five hours before it's accepted and then for them to get here easily we can be talking 10 – 12 hours before a retrieval team comes.*

There were mixed views on the **paperwork** surrounding the donation process (a prompted topic arising from the bulletin board stage of research). There was general consensus among SNODs that it was a burden and had increased over the years, for example as a result of European Union directives. However, participants also acknowledged that, although onerous, the paperwork was necessary because it provided an audit trail and helped to 'protect' the SNOD. A particularly heavy area identified was paperwork related to the actual donor, where there was felt to be some unnecessary repetition. Participants also wondered if some of the paperwork could be collected more effectively via electronic means, to help ease the burden.

> *I need a little person behind me doing the admin. That's what I need and that's what I want. Tell them!*
>
> *Our donor files we take to every single donor so you can just see the reams of paperwork [pointing to a file]. You've got four full pages of consent forms, five pages of patient assessment, and they have just introduced a donor pathway that covers every aspect of donation and we have to sign and date everything that we do; so you find that your time on call is taken up with paperwork really.*
>
> *I do feel documentation, although it maybe shouldn't be, it is absolutely a huge part of what we do, and I think a lot of it protects us as well, protects us and shows that we have completed the process as we should do.*
>
> *If you go through the court of law because you've made a mistake you want the paperwork behind you to prove you did it the right way.*

On a final note, a comment was made that the conversation with families was not always so straightforward where the patient had not opted in, and had not discussed their wishes with the family. This situation could leave the relatives attempting to reach a very difficult decision.

> *It doesn't make my job particularly easy when families have never discussed it and when we go to talk to them because it can be quite a shock and then they sit there agonising for a long time over what the right answer is.*

2.4 Conclusions: working practices and the current opt-in system of organ donation in Wales

- The introduction of the embedded SNOD combined with the leadership of the CLOD was widely perceived to play an essential role in raising awareness of organ donation among relevant staff in hospitals and improving consent rates among families where the deceased patient was not on the organ donor register. Developing relationships between SNODs, CLODs and other medical staff was key: the embedded SNODs approach was therefore believed to be enhanced where the SNOD had previously worked in the Intensive Care Unit where they now operated as a SNOD.

- Various guidelines were deemed to offer clarity and consistency on approaching families of potential donors.
- Issues persisted across North and South Wales which were thought to hamper improvements with the approach to organ donation, especially in relation to the impact clinicians could have on the process. Examples included finding it hard to encourage certain individuals to adopt accepted best practice around approaching families, inconsistency over what clinicians thought constituted a potential donor, and SNODs not being involved early enough in the process where donation might be a possibility.
- In North and South Wales, SNOD availability was sometimes felt to compromise the efficacy of the process, for example, because of the distances they might need to travel to reach the family of a potential donor outside of the working week; and because of perceived resourcing issues.
- Critical care capacity was a concern for some (but not all) participants in North and South Wales, with patients who were donating occupying ICU beds for longer, or losing the opportunity to donate because an ICU bed was not available for a patient in the Emergency Department.
- Other challenges raised with the current working practices included difficulty in developing relationships in ED because there was not enough room for a SNOD to be based there; and the potential for ‘burn-out’ among SNODs given the pressure of the work.
- Overall, therefore, where SNODs and CLODs were able to implement best practice guidelines with support from clinicians, participants believed that their current working practices had improved over time and functioned well. Their expertise enabled them to adapt to different scenarios that

arose with the families of potential donors, for example where a family was divided over whether a deceased patient should be a donor, or where the patient was not on the organ donor register, and had not discussed donation with the family.

- The references to obstacles described in current working practices indicates that further work may be required to improve the process further, for example with education and relationships involving some clinicians.
- The research suggests that issues highlighted by participants with current working practices were not generally linked to the current opt-in system itself.

3 The proposed soft opt-out system of organ donation for Wales

3.1 Overall expectations of implementation

From a day-to-day perspective, participants in general did not believe that their working practices would change a great deal. On the whole, they expected similar operational methods such as identifying donor status on a register, similar amounts of paperwork (with the only difference being that the wording on the consent form would need to be reworded) and, in the main, a similar amount of time taken to approach the family – provided it was a straightforward process to determine donor status and explain the new system to families.

> *The beauty of the new system if it comes in . . . is that I would simply ask what's their status on the ODR. A yes, a no or an unknown? If they're a yes they come up [to ICU]. If they're an unknown they come up and let the SNOD approach because we're in Wales and that's the expectation. If they're on the opt-out register they don't and I wouldn't approach the family in that situation because I think that's got to be respected - somebody's right to autonomy.*

Participants also expected to use similar approaches to families as under the current system albeit with 'tweaked' wording as appropriate. There was reference to needing to understand how to introduce the legislative changes into the conversation with families, and the 'grey area of deemed consent', but that 'everything else is pretty much the same'. (A lack of prior family discussion about the patient's wishes was also thought to present difficulties on occasion under the current opt-in system, see page 36.)

> *Realistically when you look into the nitty-gritty, apart from that initial approach, the conversation and process doesn't change – everything else will stay the same. What you do stays the same.*
>
> *I basically think that the only thing that's going to change is the initial conversation with family; otherwise our practice is largely going to be the same.*
>
> *The family may not know [the patient's wishes] but there is this grey area still where according to the law it's deemed that they have no objection and therefore they have given their consent. . . . If one of those families said 'no', we haven't had any guidance on where we go from that yet and I believe that will come. I like a positive 'yes' or a very negative 'no' and you know where you are and this grey area is there, but the law is supposed to remove this grey area but in my opinion it's still there.*

It was suggested from time to time that the potential of the new system to encourage families to discuss donation could make SNODs' lives easier in establishing the wishes of the deceased although this benefit would very much rely on an effective publicity campaign and the general public reaching an informed decision (discussed further in sections 3.4 and 4.1).

> *I can see the purpose behind it is to get people talking about it and for me as a SNOD that's easier because people are then coming to you and even if it's a 'no', we talked about it and they said it wasn't for him / her, so for me you get a real feel of what the patient wanted.*

Cross-border working was not expected to be a problem providing the registers were easily accessible and clear on the status of the patient involved, including residency. It was not always entirely clear among SNODs how residency would be applied in certain situations with the new opt-out system, for example what the implications would be for a Welsh resident who was a patient in a hospital across the border in England[17]. More generally, participants involved in cross-border working expected that any differences in working practices would be flagged to them well in advance of the proposed new system's introduction. Given that this subject is covered in the Draft Human Transplantation (Wales) Bill and Draft Explanatory Memorandum[18], this finding suggests that some participants were not yet fully aware of the Bill's contents.

> *It's OK and that doesn't worry me at all and when the system does change, because I'm sure it will, as long as we're trained properly and it's down in black and white in simple terms what the rules are, it will be fine. If anything is ambiguous then you've got the worry of things going wrong.*
>
> *What happens if it's a Welsh patient who dies in England? Which rules are you working under? But as long as everything is clarified, people will be fine.*
>
> *My understanding of it so far is that we're in England so therefore we will follow English laws so it will be the same, checking if they have registered or not but I'm not 100% certain because if they're Welsh, I don't know. Those are all the little issues that still need to be sorted.*

For those working cross-border some felt that care would be needed to ensure that the SNOD remembered to use the appropriate consent forms for England and Wales.

> *The Patient Assessment Form will have to be altered and we'll have to make sure that when you're going out to a Welsh donor that you are*

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[17] This scenario is outlined in the Draft Human Transplantation (Wales) Bill http://wales.gov.uk/consultations/healthsocialcare/organbill/?lang=en; http://wales.gov.uk/docs/dhss/consultation/120618memoen.pdf

[18] http://wales.gov.uk/consultations/healthsocialcare/organbill/?lang=en; http://wales.gov.uk/docs/dhss/consultation/120618memoen.pdf

> *using the right paperwork, the right consent form as opposed to the one that you would use if you were in England. I suppose a little safeguard thing we will have to have a system in place to make sure if we are going under the deemed consent that they're using the right paperwork and they are going to have to alter the Human Tissue Bill a bit to reflect this as well – it seems a faff really doesn't it?*

Although not prompted as a topic area for discussion, participants overall reported that they wanted the soft opt-out system to be effective, were it to be introduced. There was reference to attitudes among Specialist Nurses and Clinical Leads having changed over time since the new system was proposed, and a feeling that SNODs and CLODs now tended to be accepting of the soft opt-out system's implementation.

> *I think to begin with, when it all came out, I would say that the majority of SNODS and CLODS did not think it was a good idea, [for example] with a concern about is deemed consent really consent? I think a lot of people have a bit of 'not sure about that' but it is coming through and we have to work with the system that we're given and as long as there are safeguards and there is a system put in place then I think everybody will be OK. I think the meetings that I've gone to latterly, people aren't whingeing about it as much – it's just 'well it's coming in and we'll just get on with it now and try and make it the best that we can'.*

> *I think in the beginning we thought it was going to make huge changes to our practice but actually it's just going to be tweaking it a bit here and there.*

> *I have a really positive feeling that this will have a positive effect on our donor numbers and I hope it does increase donor numbers and I hope it does get people talking about it which will mean that the people that are in these jobs are going to get busier.*

There was, however, uncertainty and sometimes doubt in North and South Wales over whether or not there would be any (immediate) increase in donors as a result of the change. The view was sometimes expressed spontaneously that, until recently, Wales had performed well in terms of number of referrals compared with many other European countries on the basis of the current system and efforts to raise awareness. A small number of participants in different regions therefore wondered whether the amount of money being spent on the proposed soft opt-out system could be better invested in continuing communication campaigns to raise awareness and increase the number of people on the current organ donor register. This option, in their eyes, might be more easily achieved than the challenge of re-educating the general public on an entirely new system. (It should be noted that the original aim of the research was to focus on working practices rather than policy - these comments were therefore made spontaneously.)

> *In Wales we're told that we're actually ahead of the game so you wonder sometimes, why change a system that's working? But on the other hand I'm very much on the fence.*

> *My personal view is yes, any publicity is good but we had a system which was actually working and it just seems a shame why we couldn't have kept that a bit longer.*

> *I just think that [the soft opt-out system] is confused and I think it would have been better putting the money into promoting organ donation.*

3.2 Concerns about the proposed move to a soft opt-out system

Other than the significant challenge of informing the general public of the proposed new system (discussed in sections 3.4 and 4.1), no further, single theme was prevalent among participants' comments in relation to concerns about the proposed move to a soft opt-out system. A number of issues were raised within the sample, however, and these are discussed below.

It was generally understood among SNODs and CLODs that there would be **no opportunity to speak with families** whose deceased relative had opted out of the system. Doubt was sometimes expressed over how staff could be certain that the decision to opt out was both informed and up to date (for example a decision made ‘15 years ago’), particularly if they did not have strong literacy skills, internet access and so on. However, there was also acknowledgement by some that the decision to opt out should be accepted and the individual’s wishes respected; and that the family might be extremely upset to be approached despite the relative having opted out. There was also comment that the opt-out system would mean that there would be some families who could not be approached, in contrast with the current system where all families could be asked about donation.

> *I have issues with that in respect of the fact that what I decided two years ago is going to be completely different to what I might decide now and I might have changed my mind but I might not have got around to changing it on the register.*
>
> *If somebody has made an active decision to say no, and if a family asks if he could be considered as an organ donor, I would say that we could consider him but he has indicated no and therefore we won’t pursue it – I think that’s how we would go.*
>
> *I think that if people have signed themselves off the register then we aren’t allowed to approach them and they may not have the correct information – that’s the biggest thing.*
>
> *What worries me about the new system is that I’m led to believe that if somebody has opted out we wouldn’t be able to approach those families which I understand why because they opted out but at the moment, we’re approaching every family and giving every family that option and I think that works well.*

From time to time, there was concern that the **workload** of SNODs and CLODs could increase because of responsibilities in educating other audiences such as the wider medical profession. It was not clear if any additional resource provision was to be put in place to help with this objective. However, the concern was sometimes qualified with the view that it was an important part of the SNODs' and CLODs' role to educate on the subject of organ donation, and was to be expected.

> *I am slightly worried about the fact that the Welsh Government have said that they're expecting the SNODS and the CLODS to do a lot of the education, and exactly what they are expecting of* us . . .
>
> *If the idea is that the SNODS and CLODS should be educating their colleagues in the change of legislation then obviously that is quite an impact and also medical students and all other wider professions – if that's the idea then that's quite an impact for the CLODS and SNODS.*
>
> *We are a bit thin on the ground and we can't attend every single training school necessarily.*
>
> *When this eventually does come in, it's going to mean a hell of a lot of work for the SNOD in their hospital to explain it to everybody.*

Although not a view volunteered widely, there was an occasional spontaneous comment that the Welsh Government was looking for a **swift and demonstrable improvement** in donations once the soft opt-out system had been introduced. This expectation was deemed unrealistic in the context of what was believed to be required in terms of cultural change among the general public in terms of attitudes towards organ donation, which could only happen over the long term, for example through education in schools. Pressure it was thought could therefore mount on SNODs and CLODs if consent rates dropped once the new system was introduced.

> *I think the pressure is on. I think the Government are probably expecting a fairly quick fix and a big jump and the world is watching and I don't think that's going to be achievable. . . . I think it's going to take culture change and I think it's going to take years.*

In addition, a small number of participants envisaged a potential increase in pressure on SNODS, and CLODS in particular, to **maintain engagement** with donation among some senior colleagues, owing to issues around deemed consent and circulatory death. The point was made that as donation after cardiac death (DCD[19]) increased, the need for a 'robust' system of consent would become ever more important. One participant explained that certain colleagues had 'great reservations' about the move to an opt-out system in this respect: consent had historically been considered as a positive, voluntary act; and a change to an opt-out system whereby an individual was expressing consent by default appeared to be a difficult basis on which to form an opinion on an individual's choice; and also sounded like the 'State controlling their body'. This feedback suggested that the ability still to choose to opt in with the new system might not be a top-of-mind association among the general public.

> *A lot of my consultant colleagues have said to me that they disapprove of the new potential scheme in Wales because they feel that they're not being told what to do by the Government, by the State, and it's not controlling their body – that's what the doctors have been saying to me.*

> *I think it will create more pressure. I think it will put SNODS and CLODS in a more difficult situation, as I say, for the main reason being that if we're making management decisions regarding patients' pre-circulatory death, as well as relating to organ donation, on the basis of*

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[19] In intensive care, DCD is considered where the decision has been made to end life-saving treatment for a ventilated patient for whom death is inevitable. The decision is not influenced by the possibility that the patient might be a potential organ donor.

> *deemed consent, I think we will struggle to maintain enthusiasm from some areas of our intensive care colleagues.*

Views on the **potential impact on critical care capacity** were mixed (having been mentioned spontaneously by some participants, and prompted with others during the interviews as an issue raised in the online discussion). Some did not think the change in system would have much impact on capacity, with only a marginal increase expected. Even if the Welsh Government's approximate expectation of an additional 15 donors a year was achieved (based on international evidence), some still believed that this number across Wales would not amount to undue pressure on capacity.

> *I don't think it will have a significant difference, I think that if you're looking at 15 donors a year then actually that's not much, spread out across the whole of Wales and that might be another two or three patients for us a year; we can admit [several] patients overnight so it's not huge.*

However if the numbers reached or exceeded the extra 15 donors a year that had been estimated as possible, some participants did feel that pressures on critical care capacity would emerge with more donors in intensive care. There was also a concern expressed that hospitals might not be able to meet some patients' wishes to donate because of the pressure on critical care capacity which could attract negative publicity. A call was therefore made by one or two participants for the extra resource to demonstrate the extent to which the Welsh Government was determined to increase organ donation numbers.

> *The thing that might affect capacity is if we do see an upturn in the number of people wanting to donate, then those patients will then be on the ITU for longer. So we may have a problem with the capacity then.*

> *I know intensive care beds are expensive but at the end of the day, if this is something that the Government wants to do then they need to put more resources in the hospitals. . . . If they want everybody to be given the same opportunities then they need to support clinicians to facilitate people's wishes because I do worry that on occasions we're going to have to turn families down and that's not going to look very good is it?*

As a final concern, and in a small number of cases, participants felt that perhaps conversations with families would take longer because they would have to explain and attempt to clarify how the new system worked in order to help families reach a decision.

> *I think we're going to end up having lengthier conversations with families and I think it's going to be potentially difficult for them to come to a decision, really. Mainly explaining the procedure of opt-in and opt-out – you haven't done anything whereas you are on the ODR or you are not because it's three decisions now. It's gone from one option to opt in to three options now which I think is going to be difficult for people to grasp maybe.*

3.3 The organ donor register under the proposed new system

Participants in North and South Wales were not always entirely clear what the intention was for the new organ donor register (currently outlined in the Explanatory Memorandum[20]). They wanted a single organ donor register for the UK to minimise errors, and a database which would need to be easy to use and unambiguous.

> *I think the optimum would be there is one register for the UK, and on that it has an opt-in column, and an opt-out column, and a nothing*

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[20] http://wales.gov.uk/docs/dhss/consultation/120618memoen.pdf

> *column within that. I know this is what they're planning; you've got to be able to opt in and out of all the individual organs so that you can say 'yes' to some things and 'no' to some things.*
>
> *I know there is talk of the register having dual registers which is just so confusing that I think we will run into difficulties*.

Views were mixed on the potential issue of establishing residency, and familiarity on this topic varied (also currently outlined in the Explanatory Memorandum). Some felt that questions on residency could be satisfactorily answered by families, who would have no obvious reason to provide incorrect information. Families, it was felt, would need to officially sign a document regarding the residency of their bereaved relative to avoid potential problems for the clinical team. It could be more challenging, however, identifying whether a patient was resident in Wales in certain circumstances, for example from a road traffic accident, when it might take 'a couple of days' to establish the patient's details and identity.

> *You have to first of all find where their postcode is, how long they've lived there for. Are they a student in Wales from England and how long have they been a student in Wales.*

3.4 Perceived awareness among families of the proposed new system

Across the sample, participants tended not to think that the general public was very aware of, or informed about, the proposed opt-out system for organ donation. It was envisaged that awareness would grow once the new system had been confirmed, and its introduction date drew nearer.

> *I don't think there's a lot of general public awareness of it and certainly as a Welsh resident myself, I think there's been nothing at all.*

Anecdotal examples were relayed, however, of colleagues occasionally encountering families who had refused to consider donation because of the proposed change in legislation, or members of the public who stated that they had removed their name from the organ donor register because the Welsh Government was introducing a ‘mandatory’ system.

> *I have been told that we’ve had a couple of families say no to donation and they have put the ball firmly at the change in the law. Arguably you could say we would expect that probably initially because there will always be some people that feel that ‘I am not going to go with the law, I am going to do my own thing’ and again I think we have to ride that storm.*
>
> *One of my colleagues did come across members of the public who said, ‘right, I did join the opt-in register, but now that the Welsh Government wants to change the system such that it becomes mandatory, I’m taking my name off the register.’ But this was a minority view.*

Other perceptions voiced included coming across members of the general public who thought that the proposed soft opt-out system had already come into force, or who appeared to be aware that there might be a change (and were sometimes positive or ‘not bothered’ about it) but were not very clear on the details of the proposed new system or its implications. There was a feeling that the effort which had gone into communications to date was insufficient although one or two participants believed that the Welsh Government could not begin a high profile communications campaign until the Bill was approved. (The Welsh Government will be launching a communication strategy if the Bill is approved.)

> *There was a spectrum of knowledge about the potential changes to the system [when interacting with the public]. Some people thought the changes had already happened, some people, I think to be fair, most people were aware that there was something going on in terms of the*

> *change to the system. Has it happened yet, when does it happen, and what are the implications, people were a bit vaguer about.*
>
> *Most people that I speak to just say ‘I just think it’s a good thing’; they don’t even know the wording of it and they will say to you ‘before long you can take them anyway, can’t you?’ . . . So I think that over the next few years there needs to be a massive campaign.*
>
> *I am quite often approached and spoken to by members of the public who think that it is already in place this opt-out and they don’t seem to be bothered about it and it’s no big deal whereas healthcare professionals are a little bit paternalistic sometimes about things.*

There was also a concern among a small number of participants that a reported recent drop in consent rates appeared to coincide with increased media coverage around the proposed new system; and that families seemed to be discussing the subject more.

> *One of the things that’s concerning us in Wales at the moment is that our consent rates have dipped and a lot of families that I have spoken to, they’ve had the conversation. . . . Maybe because of the publicity that’s been going on recently and people have had conversations and people are saying ‘yes we have spoken about this’.*
>
> *It is very strange how since there has been much more publicity around the opt-out that our numbers have started to dip a little bit, but of course the Government can’t crack on with all their publicity or whatever they have planned because they can’t do anything until it is stamped by Westminster [sic].*

A final, isolated point made on this subject was that it was felt that members of the public from lower socio-economic groupings might be more difficult to reach with messages because personal health was not necessarily a priority for them. On this note, one participant suggested that information and communication efforts with the general public, such as roadshows, might benefit from input from SNODs beforehand on what might work best in a particular area or community.

3.5 Perceived awareness of the proposed new system among different staff groups

During the research discussions, participants were asked to what extent they believed hospital staff were aware of the proposed move to an opt-out system. Reactions to this question varied although participants tended to think that staff in ICU were becoming more knowledgeable but that staff elsewhere were less aware of, or familiar with, the proposed change. Participants had gained this impression from informal conversations with staff rather than through any more formal means. However, it was envisaged that staff education would increase via training and communications as the date approached for the legislation change.

There was an opinion expressed on occasion that some clinicians working in critical care were less knowledgeable, for example around the implications of the change and the timescales involved. Within the hospitals generally, excluding ICU and Emergency Departments, staff knowledge was believed to be little more advanced than that of the general public.

> *So awareness is not great amongst staff; getting better in ITU, still fairly minimal in the Emergency Department and probably not much better than the general public amongst the rest of the hospital.*

3.6 Conclusions: working practices and the proposed soft opt-out system of organ donation in Wales

- In broad terms, participants did not think that their routine working practices would change greatly if the proposed new system were introduced, for example with similar approaches to families (with minor wording changes), and, on the whole, a similar amount of time taken to approach the family.

- In addition, cross-border working was generally not expected to be a problem providing that the register was easily accessible and clear on the status of the patient involved, including residency.
- However, the way in which residency would apply to the new system, and how the register was likely to function, were not always clear to participants and indicated that not all were fully aware of the Bill’s content yet.
- Participants’ greatest concern with the proposed new system was with educating the public (e.g. a poorly informed general public making uninformed decisions to opt out), rather than any area of their working practices.
- A range of further concerns were raised in relation to working practices, but no single theme was prevalent. They included how: staff could be certain that the decision to opt out was both informed and up to date; the workload of SNODs and CLODs could increase because of responsibilities in educating other audiences; engagement with donation among some senior colleagues could be maintained owing to issues around deemed consent and circulatory death; critical care capacity might be affected; and difficulties might arise in establishing identity and therefore residency with some patients.
- Overall, participants reported that they wanted the soft opt-out system to be effective, were it to be introduced, in order to save more lives. There was reference to attitudes having changed over time since the new system was proposed, and a feeling that SNODs and CLODs were now accepting of the soft opt-out system.
- There was, however, uncertainty and sometimes doubt over whether or not there would be any (immediate) increase in donors as a result of the change; and an infrequently voiced view that perhaps the money which would be invested in the new system could be better spent on promoting organ donation under the current system.

4 Making the new system a success in Wales

4.1 Education

There was a unanimous and strongly held view across participants that education of a wide range of audiences was vital to the success of the proposed soft opt-out system – with the general public the most important audience on which to focus. For some, this was the only key issue they associated with the proposed new system. Other audiences included hospital staff and, to varying degrees, other NHS staff such as GPs, pharmacists and dentists; and schools and religious leaders.

> *The whole thing hinges on how well publicised it is, and what the education is, and if they get it wrong I think it'll crash and burn. If they get it right, it will do well, consent rates will increase, and the rest of the UK will follow suit and the Welsh Government will feel very pleased with themselves at being the first ones to do it.*
>
> *But I think really that education is the only key issue and [based on experience] it's quite clear that [members of the public encountered] really didn't know anything about donation and they were associating it with all sorts of things and the perception they had was very different from the reality.*
>
> *We're just very keen as a health profession, and the CLODS and the SNODS, that the implementation of it is done well because not to do so could be devastating, could set things back years; and that would be annoying 'cause the Welsh Government helped put a lot of time and a lot of effort into measures that have been very, very good. You know, and the motives are good.*

Suggestions were put forward that involving qualified staff like SNODs, CLODs and clinicians in the education programme would ideally be an appropriate approach, to both act as trustworthy spokespeople in terms of delivery and, with their knowledge of potential problems and pitfalls, to act as advisors. Their local knowledge could also be advantageous in terms of what would work best in a particular area of Wales. However, resourcing this approach would need careful planning and there was some concern over what additional pressures would be placed on SNODs to deliver training.

> *You need qualified individuals and I know it's difficult to release us to do it but they're only going to get the right information if the nurses go out and do it or a team of highly trained people who we have in fact have them taught then go out and relay the message but nobody has come to speak to us – the PR company [used to date] have had the knowledge off the Welsh Government. The Welsh Government have not come to spend a day with us and I think that's wrong.*
>
> *If we're saying that donation should be a routine part of everybody's end of life care then families may bring it up on a ward where the patient can't donate because they are not intubated*[21]*, ventilated and they don't fit the criteria and the staff should possibly have the knowledge to be able to explain that as opposed to giving the wrong information out – potentially they could still donate tissue. . . . But again, who's going to provide that?*

There was also a belief that the general public needed to be reassured that family consent was still integral to the donation process, and that it was not a hard opt-out system which was being proposed. This fundamental safeguard was not felt to have been communicated very strongly to date, along with the idea that the gift of donation was still very much a choice people could make.

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[21] Used to refer to the insertion of a breathing tube into the trachea for mechanical ventilation.

> *I think the absolute fundamental building block is well-funded and resourced and thought-out publicity from the Welsh Government, to the residents of Wales, pointing out that nobody's going to be taking organs without a family's consent. And even with the new system, if their family objects, then nobody's going to take their son's or daughter's organs. That's become a fundamental point I think that elements of the public have missed at the moment.*
>
> *Firstly they have to emphasise the choice – people have a choice – there is nothing compulsory about it if you have a choice. . . . I believe that transplantation has to be seen as a gift freely given without coercion and that whatever decisions that people make should be respected . . . and they have to get rid of this concept of being forced to do it and that it’s compulsory.*

In the context of previous experiences, education was also deemed essential to prevent members of the public potentially removing themselves from the organ donor register under the mistaken belief that they were not in a good enough physical condition to donate. The SNOD would then be unable to speak with the family even though the decision had been made erroneously.

> *If somebody takes themselves off in Wales and says ‘right I don’t want to donate’; we can never talk to that family. So how much information will they have had to take themselves off, because I’ve gone to families and they’ve said ‘he can’t donate he’s got diabetes’ when he can, or ‘he can’t donate because he smokes’, but he can. So it’s that level of information that somebody uses to take themselves off a register but then actually stops me at all speaking to that family.*

Beyond a general campaign, GPs and in particular secondary schools were identified as two key channels. It was suggested that organ donation should be part of the secondary school curriculum so that it became a routine and informed family conversation within a generation. This long-term focus, it was felt, might also reduce the need for prolonged and expensive publicity campaigns in years to come.

> *You wouldn't want to put this much effort into donation 10 or 15 years down the line. It should become the norm and once it becomes the norm, then you know you've won really, but you do have to put in a huge amount of effort for it to become the norm; you need to be targeting the younger population for it to become the norm*.

Universities, along with GPs, were also suggested as a useful channel for raising awareness and understanding of the proposed soft opt-out system among its students, including residency implications for those from outside Wales. Freshers' Fairs would also continue to be a valuable channel in reaching students with messages on organ donation.

> *I think it is a massive impact on universities to tell the students that when you come to live in Wales that after six months you are deemed as resident.*
>
> *I presume that every student has to register with a GP and that the GP would have to be duty-bound to inform them that this is the case and the necessary leaflet, but it is difficult isn't it?*

International sports events like rugby or high profile football matches were suggested as possible channels for reaching large proportions of the Welsh population with communications on the proposed soft opt-out system for organ donation.

An additional point was made in relation to the need for providing Welsh language communications for certain communities, especially in North West Wales among rural communities and a concern over who would deliver any face-to-face information through the medium of Welsh.

Also, members of the general public who lived in England but might access a Wales based hospital would need to understand the implications for them.

> *The other thing is whether there is confusion in England about coming to Wales and what happens if you die in Wales and is the communication about the six months' residency clear across the border because headline news will be 'Opt out', so is that going to affect anything else in terms of people coming into Wales*[22]*?*

4.2 Other factors affecting success of the proposed new system

For the proposed new system to work most effectively, an easily accessible and clear register was singled out as another important prerequisite. Additional factors mentioned included: the need for clear legal and ethical guidance as to what was meant by 'deemed consent' in practice and its impact on ways of working; and the need for SNODs / CLODs / clinicians to be confident that they were legally protected should they act on incorrect register information in good faith.

> *We need to have very clear legal and ethical guidance as to what is deemed consent. Because this is a new concept, and it requires amendments to the Human Tissue Act. So we need to have very clear guidance in terms of what this actually means, and what this will mean in practice, and how this will influence our practice.*

> *I would like to see a direction on exactly how they want us to function within this and what are the steps they want us to take in terms of checking the register. I want very clear guidance on that and I want the consent forms sorted out so that I am operating within a strong*

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[22] This scenario is outlined in the Draft Human Transplantation (Wales) Bill http://wales.gov.uk/consultations/healthsocialcare/organbill/?lang=en; http://wales.gov.uk/docs/dhss/consultation/120618memoen.pdf

> *framework in my practice and I just to want know that I am not going to be taken to court, really.*

Consideration would also need to be given to encouraging DVLA and Boots to continue to capture potential donors. However, there was concern that it might mean the two organisations incurring expense to update their data capture material, which could jeopardise what were seen as effective partnerships.

4.3 Additional training requirements for SNODs and CLODs

The general consensus among SNODs and CLODs was that additional training would be reasonably minor and could probably be incorporated into current training regimes (‘we’re trained up to the eyeballs’ as one SNOD put it).

> *I don't think that's very intensive, you know, we have regular regional collaboratives and things, and I think it could be incorporated into that programme easily.*

Examples of future training requirements mentioned were:

- How to check the register;
- Scenario training with which to familiarise SNODs / CLODs / clinicians including different possible residency situations;
- Understanding how a move to a soft opt-out system might alter current faith / cultural positions although the comment was made that family consent would be sought, whatever the religious background;
- The ethical and legal status of ‘deemed’ versus ‘valid’ consent so that SNODs and CLODs could be confident in dealing with any questions on this subject;
- Being aware of what impact the proposed new system might have in relation to a patient’s mental capacity to make a rational decision on opting out. The family was still considered to be a ‘pretty good safeguard’ in this respect.

Given that SNODs were not always able to attend a potential donor situation in person, some participants thought it vital that CLODs and other clinicians were up to date with current information in order to answer questions, particularly in areas such as the timings around donation and which organs can actually be donated. Knowing the appropriate language to use was also an important requirement so that non-SNODs / CLODs were confident in answering questions and talking with families.

> *Clinicians really I think [need training]. Maybe senior ITU nurses who can sometimes support and be a bit more involved with the families and supporting the junior staff especially when I've said to you that geographically we can't always be there as soon as we would like to. We are going to have to think outside the box and put a bit more resources into the training of certain grades of people in North Wales just to try and help bridge that gap a little bit.*

> *[CLODs] need to improve their communication skills – some need it full stop with everybody and some are good at doing it and are brilliant and don't need any help at all.*

It was suggested that the legislative change could act as a way to engage more effectively with clinicians who were thought to require education and training on the organ donation process, but might be reluctant to do so.

> *If it's backed by the Welsh Government and it's a requirement of the Health Boards for clinicians to attend these meetings because it's a legal change to the framework in which they work that will probably be the carrot that invites most of these clinicians to come and attend. We can then engage with them properly and we might turn some of them around.*

4.4 Other groups of NHS staff requiring training

Some participants identified training requirements for other hospital staff to improve understanding of, and familiarity with, organ donation generally, as well as the proposed new system. As one participant explained, beyond ICU, Emergency Medicine and Anaesthetics, perceptions of organ donation tended to be limited in understanding. Ideally, all staff who might come across the subject in a professional capacity would become familiar with the process.

> *It's just knowing that the key personnel are confident that they understand the system and so it's you know it's ICU, nursing and medical staff, Emergency Department, nursing and medical staff, all theatre, any relevant personnel that may encounter the organ donation process really.*
>
> *Outside ITU and perhaps Emergency Medicine and to some extent Anaesthetics, there is still a feeling that organ donation is limited to giving your kidneys, and your heart and, you know, it's an optional extra and I don't think they realise that actually often it's far more feasible to be an organ donor these days than it used to be.*
>
> *Ward staff – more intensive care staff are aware of it and maybe some ED staff but generally on the wards nobody would be giving it a second thought.*

Further suggestions made by participants for wider training requirements among staff included:

- ICU / ED clinicians, and ICU nurses who would need to have clear guidance in terms of the ethical and legal implications of changes to the system;
- Theatre staff would need a clear understanding of what the legislation meant;

- Those involved with patients who would need to know the specific circumstances in which organ and tissue donation could take place as they may be asked about it by patients' families;

> *Quite often that is a misconception that actually anyone can donate, whether they die on the roadside or whether they die on one of the medical or surgical wards. Not many people actually have the knowledge that organ donation only comes out of the intensive care department or the A&E department in very particular circumstances*.

- Consultant ICU staff across the UK who would need to know what the expectations were should they have a Welsh resident in their care;
- Nursing groups which, from experience, could be 'quite scared of the unknown and change';
- Primary care staff and GPs, who might be asked by patients about organ donation in terms of the opt-out system and the organ donation process itself.

> *Because inevitably people will approach primary care to discuss these issues. There needs to be some sort of training or education or some learning resource that the primary care staff are able to access.*

4.5 Conclusions: making the new system a success in Wales

- From the perspective of their own day to day working practices, participants were not expecting significant changes or much additional training.
- Some SNODs believed it would be essential that CLODs and clinicians were familiar with the implications of the change (and the appropriate language to use) in case they needed to field queries from colleagues and families.
- Guidance on certain aspects was expected as the legislation change drew nearer, for example understanding how to introduce legislative changes

into conversations with families, not only for SNODs but also for CLODs and other clinicians.

- The prospect of a new system and therefore the need for a new register was identified as a key aspect in helping to make the proposed move a success. As with residency, not all participants were clear on what the plan was for the register although expectations were for a single, unambiguous and up-to-date register combining UK patient preferences. SNODs and CLODs would want to be confident that they were legally protected should they act on incorrect register information in good faith.
- These findings indicate that the detail of the Bill and Draft Explanatory Memorandum was not necessarily familiar to all participants.
- Leaving aside the possible implications for the SNODs' and CLODs' working practices described above, the strongest message from participants was the importance and challenge of reaching and educating the general public in Wales. This was the key issue with the proposed move to a soft opt-out system for participants. The message would need to emphasise choice and address perceived misconceptions among the general public, for example that it would be a hard opt-out system.
- Other audiences were felt likely to have a role to play in answering queries from the general public, and potentially disseminating information, including hospital staff and other NHS staff.
- SNODs and CLODs were generally deemed to be most qualified staff to provide education but resource would have to be increased.
- The education sector (including universities) and GPs were identified as having an important role to play with informing the general public of the proposed new system, as well as organ donation more generally.

5. Conclusions and considerations

The primary focus of this qualitative research project was to explore perceptions of current working practices and to establish expectations, attitudes and any concerns that Specialist Nurses and Clinical Leads had regarding the implementation of, and impact of moving to, a soft opt-out system.

It should be noted, therefore, that some of the issues to emerge from the research did not apply specifically to participants' comparisons between current working practices and how these might change with the proposed move to a soft opt-out system. The issues are included in these conclusions as areas for potential further exploration.

Focusing specifically on the current opt-in system for organ donation and participants' working practices, the general picture was one of progress being made in recent years resulting from the Organ Donation Taskforce recommendations, embedded SNODs with supportive CLODs, and effective, flexible guidelines. In addition, the task of talking with the family was normally made more straightforward where a patient had clearly chosen to opt in, for example by joining the organ donor register.

The practice of embedded SNODs was clearly thought to be having a significant impact on organ donation, and that the longer a particular individual was embedded, the better the relationships with staff who could influence organ donation outcomes. This research suggests (but not conclusively) that, in order to sustain these improvements, it may be worthwhile exploring further the key pressure points within SNODs' work with a view to establishing what could be done to alleviate any pressures.

From the perspective of their current working practices, the issues raised by participants did not appear, overall, to be directly attached to the current opt-in system of organ donation in Wales, but were more to do with organ donation in general and operational constraints. These included geographical and resource challenges; strains on critical care capacity, according to some; and reported issues with some clinicians, for example SNODs’ lack of credibility in the eyes of the clinician; not involving SNODs earlier in the process where donation may be a possibility; using inappropriate phrases when talking to families of potential donors; and the clinician choosing to have the first conversation with families about donation, rather than letting the SNOD carry out this task.

The research therefore indicates that these may be areas for further exploration and review over time. One possible approach may be to position training for clinicians on the soft opt-out system and approaching families as a requirement rather than an option, because of legislation change. Also, the perceived issue among some participants of critical care capacity points to the possibility of monitoring the success of any efforts being undertaken to deal with the issue, for example by using Recovery Theatre Units.

Turning to the proposed move to the opt-out system for organ donation in Wales, there appeared to be more of an acceptance among participants of the proposal, which perhaps might not have entirely been the case when the proposal was first put forward. There was a sense that participants assumed the Bill would be passed and that they would do whatever they could to increase organ donation consent rates and make the new system a success, in order to save lives.

Participants on the whole did not expect their routine working practices to change greatly although nuances in language with the initial approach to families were expected to be different. Some of the comments made by participants concerning aspects of the Bill, such as the implications for residency and how the register would work, point to the need for continued education on this detail which is already available in the Bill and its Explanatory Memorandum.

The key element to making the system a success was education of the *entire* general public, in participants' minds, but there were concerns that potential donors would be missed because of the general public's anticipated lack of understanding of the proposed new system. Participants were looking for communication to counter any negative PR in the media and in particular to stress that the individual can make three choices: to opt in to organ donation; to opt out of organ donation; or to choose not to opt out and therefore give deemed consent for donation – the ability, still, to choose to opt-in appeared to have been overlooked in media coverage and communications.

Some participants welcomed the way in which SNODs and CLODs were involved in working groups in relation to organ donation and the proposed move to the soft opt-out system and believed that the Welsh Government genuinely wanted to make a difference. As suggested on occasion in the research, Welsh Government staff's understanding of the SNOD's work might be enhanced by spending time with SNODs on the units.

Given the nature of the current issues described by participants, this research indicates that it would be worthwhile monitoring the following areas as the proposed 2015 legislative change draws nearer and also if and when it has been implemented (for example 12 months after implementation):

- To what extent SNODs' and CLODs' familiarity had improved with the ways in which the proposed new system would affect day to day working (for example, how the register would work, residency implications, how to begin conversations with families and explain the new system);
- How effective training / guidance received on the proposed new system had been, including any areas for improvement;
- How relationships with clinicians had developed, including the ability of the SNODs to influence them, and perceived levels of awareness, understanding and acceptance of the proposed new system;

- How perceived awareness / understanding of the proposed new system was changing among other hospital staff with whom SNODs and CLODs came into contact; and among the general public;
- How effectively any additional education responsibilities on the part of SNODs / CLODs were being resourced;
- How experiences with families were changing over time;
- What, if any, new (potential) issues or concerns had arisen in relation to the proposed new system.

Appendix: Topic guides used in the online bulletin board and interviews

Online Bulletin board questions

1. To begin with, what do you think works well with the current organ donation system in relation to your role and responsibilities? Any examples of experiences to support your views would be helpful.
2. And what do you think works less well with the current organ donation system in relation to your role and responsibilities? Again, any examples would be helpful.
3. Those of you involved in cross-border work, what additional challenges do you currently face?
4. In practice, how easy or difficult is it to keep to the guidelines produced on approaching the families of potential organ donors? Why?
    - What are your views on these guidelines?
5. If not already mentioned, are there particular approaches when talking to families that you find are more likely than others to result in a decision to donate? If so, please tell us about these approaches.
6. This section will focus on the proposed move to the soft opt-out system. What are your expectations in terms of how the move to a soft opt-out system will be implemented?
    - What, if any, concerns do you have? Do you see any potential issues, especially in relation to your role?
        - How might these issues / concerns be addressed?
    - How might the proposed new system impact on your discussions with family members in requesting consent for organ donation?
        - Will it make it easier or more difficult in your view?
7. Have any of you noticed any awareness among families of the proposed new system?
    - If so, what sort of impact is this awareness having?
8. You may have already covered this topic in your earlier responses: those of you involved in cross-border work, what challenges do you envisage facing with the proposed move to a soft opt-out system?
9. Thanks for your efforts, that's the last question in the section - just one more, shorter section to follow tomorrow. If you have time, please do read over other people's posts from sections 1 and 2, and try and find at least one to respond to.

10. 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?
11. Thinking specifically about preparing for the change in legislation what, if any, additional training requirements do you feel CLODs / SNODs may have?
12. Are there any further points you wish to make about any aspect of the current system or the move to the new system for organ donation?

Individual interviews topic guide

A. INTRODUCTION (5 MINS)

1. *Introduce self, Beaufort Research*

2. *Purpose of interview: to explore (in more detail) the views of Specialist Nurses-Organ Donation (SNODs) and Clinical Leads-Organ Donation (CLODs) on the soft opt-out system of organ donation.*

   The focus of this project is on working practices and implementation rather than policy. Results 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 results will be presented in a way that ensures anonymity.*

4. *Obtain permission to audio-record*

B. CURRENT OPT-IN SYSTEM (20 MINS)

Focus on working practices / implementation rather than policy

1. For the first part of the conversation, I'd like to focus on the current opt-in system for organ donation, and your working practices. Overall, how effective are the processes surrounding your role and responsibilities in relation to organ donation?

   - *Probe whatever emerges*

2. What do you think works well currently in relation to your **role and responsibilities**? *Probe*

   - What helps each aspect to work?

3. (*Positive aspects mentioned during bulletin board; prompt and probe if not already covered*)

- What are your views on the practice of having embedded SNODs?
    - Where in particular are they having an impact?
- What impact do you think the emphasis on UK-wide consistency on organ donation practices is having?

4. What do you think works less well in relation to **your role and responsibilities** in implementing the current donation system?

- *Probe whatever emerges*

5. In practice, how easy or difficult is it to keep to the guidelines produced on approaching the families of potential organ donors? *Probe*

- What are your views on these guidelines?

6. (*Less positive aspects mentioned during bulletin board; prompt and probe if not already covered*)

- Do you find that all families are approached using best practice when organ donation is an option? If not, why?
- How effectively does current working practice handle a situation where a family is divided on organ donation?
- Are there ever delays with a SNOD attending?
    - If so, is there an alternative approach?
    - How well does the alternative approach work?
    - What skills do you feel CLODs require to be able to talk to families if a SNOD is not available?
- Do you feel that potential donors are ever missed? *Probe*
- To what extent can critical care capacity impact on current working practices around organ donation?
- What is the paperwork like for you with the current system? *Probe for specific examples*

If works cross-border

7. How does the fact that you work in both England and Wales currently affect the processes around your role and responsibilities? *Probe*

8. (*If not already mentioned*) Are there particular approaches when talking to families that you find are more likely than others to result in a decision to donate? *Probe*

C. PROPOSED SOFT OPT-OUT SYSTEM (20 MINS)

1. If we turn now to the proposed soft opt-out system, what are your expectations in terms of how the move to a soft opt-out system will be implemented? *Probe whatever emerges, including:*

- How might the proposed new system impact on your discussions with family members in requesting consent for organ donation?

    - Will it make it easier or more difficult in your view? *Probe*

2. How could each of these challenges you mention be addressed?

3. *Points raised during bulletin board discussion: prompt if not already covered*

   If participant anticipates any of these issues below, probe for each: How could each of these challenges be addressed?

- What are your expectations in relation to the paperwork involved for SNODs / CLODs for the new system, versus the current situation?

- How if at all do you think the soft opt-out system will affect the time taken to approach, and have discussions with, families? *Probe*

- How aware do you think different staff groups are of the proposed soft opt-out system?

    - What have you noticed to suggest this?
    - 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*

- To what extent do you think the new system will place more pressure on SNODs and / or CLODs? *Probe*

- What are your thoughts on how the register would work with the new system? *Probe*

- What are your views on determining residency with the new system? *Probe*

- How if at all do you think the proposed soft opt-out system will affect critical care capacity? *Probe*

4. Have you noticed any awareness among families of the proposed new system? *Probe*

- What kind of impact are you noticing? *Probe for examples, including what participants believe is influencing awareness, views and understanding of the new system*

- *If negative impact*: what part could SNODs / CLODs play in helping to address this issue?

5. (*If involved in cross-border work*) What challenges do you envisage facing with the proposed 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?

D. MAKING THE NEW SYSTEM A SUCCESS (15 MINS)

1. 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*

2. What are the key factors specifically in relation to the roles and responsibilities of SNODs / CLODs that need to be considered? *Probe*

3. Finally, thinking specifically about preparing for the change in legislation what, if any, additional training requirements do you feel CLODs / SNODs may have? *Probe, then prompt possible training requirement areas:*

- Understanding faith / cultural positions

- Ethical and legal status of ‘deemed consent’ versus ‘valid consent’

- Assessing patient’s mental capacity

- Determining residency

- Advanced communication skills

4. Which other groups of NHS staff do you think ought to be included in training on the implementation of the new system and how it will function? Why?

- In which areas do you think they will have training requirements?

5. Is there anything else you’d like to add that we haven’t covered on the proposed move to the soft opt-out system in Wales and how ensuring SNODs and CLODs are adequately prepared for it?