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

## Research Summary

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.

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.

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.

## Social research

Number: 46/2013

### Findings: Positive aspects of current working practices

Across the sample, participants regularly highlighted embedded SNODs 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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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.

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