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Welsh Government

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

Research Summary

Social research

Number: 33/2015

The Welsh Government is introducing a soft-opt out system of organ donation through the Human Transplantation (Wales) Act 2013 which comes into effect on 1 December 2015.

As part of the preparation for the Act's implementation, Beaufort Research was commissioned to undertake the second of three waves of qualitative research to assess the views of Specialist Nurses (SNODs) and Clinical Leads (CLODs) for organ donation, regarding the move to a soft opt-out system in Wales.

The research aims were to update understanding on expectations, attitudes and any concerns that SNODs and CLODs had regarding preparations for the move to the new system. The report presents personal views expressed by the SNODs and CLODs who took part.

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

Current working practices and revisiting the 2013 findings

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

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

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

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

Dadansodi ar gyfer Polisi



Analysis for Policy

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

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

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

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

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

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

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

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

Some did not foresee any great changes in organ donation numbers, although they hoped that it would make a positive

difference. (This view was expressed more so by SNODs than by CLODs.)

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

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

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

The 2013 research found a degree of limited awareness on how residency would be defined. In 2015, participants were more likely to be clear on what ordinarily resident meant for the Act, with only a

small number of exceptions. The uncertainty voiced in the previous research around cross-border working and residency was less prevalent in this study.

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

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

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

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

Participants therefore felt that critical care and ED staff - both senior and junior -

should be prioritised for education and training, given their potential proximity to the organ donation process and contact with families.

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

Some participants among both SNODs and CLODs had noted how families were more likely to have talked about organ donation with the patient than in the past, or at least were expecting to have the conversation with hospital staff. This development was making the situation easier to handle for SNODs and CLODs. (Welsh Government quantitative research tracking figures on whether or not individuals are discussing organ donation with their families do not reflect this qualitative finding.)

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

As a result, some questioned the effectiveness and prominence of the current communications campaign for the new system. There was also a call for

communications to state more emphatically that the legislation gives people greater choice. (The next phase of the Welsh Government's communications campaign, starting in June 2015, will explain the choices people will have under the new law.)

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

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

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

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

According to participants, success would also rely on SNODs in particular having all the appropriate guidance and being fully trained on areas such as starting the

conversation on deemed consent, using the ODR and residency in certain cross-border scenarios. Delivering on this requirement was thought by SNODs and CLODs to be in hand.

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

Conclusions and considerations

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

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

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

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

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

A point of difference with the 2013 research was how some participants felt that they were encountering more

instances of families of patients knowing the patients' wishes, or at least families who were expecting a discussion about organ donation with hospital staff. This qualitative feedback on knowing patients' wishes contradicts Welsh Government trend data. The data show that the proportion of people replying 'yes' to the statement 'Have you ever discussed your wishes regarding organ donation after your death with a family member?' has remained consistent at around four out of ten since 2012. However, it may still be worthwhile recording these instances more formally (if not already) to feed into Welsh Government's overall assessment of progress on this topic. The qualitative feedback on instances of more families expecting an approach is more in line with Welsh Government trend data on increasing awareness of the new law.

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

repeated or updated to ensure new staff are reached and any new best practice approaches on communications shared. An improvement in this area would only help with the successful implementation of the new system.

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

- The perceived effectiveness and timeliness of training and guidance received in the run-up to the implementation date. Topics to review include conversations with families, and the extent to which residency and cross-border scenarios have been clarified;
- Experiences with families of patients, including in the months leading up to the legislation change and after 1 December 2015;
- Gaps in understanding that may have emerged, and which had affected working practices;
- Areas where SNODs and CLODs still felt they required training and guidance;

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

legislation change that would need to be addressed.

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Welsh Government Social Research

30 June 2015

ISBN 978 1 4734 3726 5

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