

Summary report for delegates attending the study celebration event, 5.9.17 Cardiff.

'Family attitudes, actions, decisions and experiences following implementation of deemed consent and the Human Transplantation Act (Wales) 2013' study.

Study summary

A two-year (01.10. 2015-21.9.2017) co-productive study led by Bangor University and funded by Health and Care Research Wales. Partners included NHS Blood and Transplant (NHS BT) and Welsh Government. High Patient and Public involvement of over 50 people/organisations received acclaim, especially for involving Third Sector organisations representing BAME communities.

Aim

To explore the impact of the Human Transplantation Act (Wales) 2013 on donor family attitudes, actions, decisions and experiences.

Data collected:

Data were collected on all of the 205 approaches to relatives of potential organ donor patients between 01.12.15-31.05.17 (18 months) in Wales. 182/211 deceased patients came under the auspices of the Act. Sixty-two in-depth interviews with 78 family members of 58 patients who were potential/actual organ donors, and 2 focus groups or individual interviews with 23 NHS BT professionals were also carried out.

The overall picture following initial implementation of the Act:

- The good news is that overall consent rates for cases that come under the new soft opt out system was 64% over the first 18 months.
- Overall consent rates (including family consent which falls outside of the Act) have increased from 48.5% in 2014/15 to 61% (01.12.15-31.05.17) in Wales.
- Overall, the media campaign achieved its aims but had some limitations. Most notably the media campaign did not address the changing role of family members in the decision-making process to one of supporting their relative's donation decision made in life.
- The media campaigns were not memorable and were time-limited. The impact may not be sustainable without further media interventions.
- The target of 15 additional deemed consented donors was exceeded.
- Implementation of the Act has however resulted in 13 consent pathways* that SNODs/Specialist Requesters must establish and document. One of which is deemed consent. **People in Wales can: Opt In/Out on the Organ Donor Register: Express a decision In/Out, Appoint a Representative, and consent can be deemed if the person has done none of the aforementioned things. Although the principle is to support the deceased person's organ donation decision made in life, each of these 6 pathways can potentially be overridden in the Welsh 'soft opt out' system – making 12 pathways for SNODs to recognise and document, plus the family consent pathway (for children < 18 years, people lacking mental capacity, persons not normally voluntarily resident in Wales), making a total of 13 pathways.*
- There have been initial challenges for SNODs and their managers in establishing and documenting what is, and who is on, a deemed consent pathway versus the other potential pathways.
- Some family members found the Act to be a helpful framework to honour their relative's organ donation decision made in life.
- Some family members continued to believe that it was their decision and overrode the donation decision made by their relative in life.
- The role of the SNOD was critically important in the organ donation process.

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- There have been implementation challenges for SNODs who have not consistently changed their practice to align with the Act. These challenges are in part linked to the finding that families have not been adequately prepared via media campaigns to change their role to support the organ donation decision of the deceased person.
- Not all aspects of the Act have been implemented as intended. Most notably the standard of evidence required to override the deceased person's organ donation decision. In practice, the anticipated standard of evidence to override a donation decision may be unrealistic to implement.

Deemed consent:

- 28 donors fell into the new category of 'deemed consent' under the new soft opt-out organ donation system in place since the 1st of December 2015 which assumes that if a person has not expressed their organ donation decision in life, then they have no objection to being an organ donor.
- It was anticipated that 15 additional deemed consented donors would be achieved, but this number has been exceeded. There were 46 (22%) deemed consent approaches in 18 months with a consent rate of 61% resulting in the 28 deemed consented donors.

Verbally expressed decisions:

- 55 of the 205 patients (26%) who were potential organ donors had verbally expressed their decision during their lifetime. 29 individuals out of those 55 who had expressed an opinion, (53%) had verbally expressed a decision to donate and opt in, while 26 individuals out of 55 (47%) had verbally expressed a decision not to donate and opted out.
- The media campaign has worked to encourage people to talk about their organ donation decision. There were more registered and expressed opt in decisions (102/205) than deemed consent cases (46/205).

The Organ Donor Register:

- People registering on the Organ Donor Register increased from 34%-38% between 31.03.15 – 31.03.17 in Wales.
- As of June 2017, 1,181,709 people in Wales had opted in, and 176,011 opted out of organ donation, which is 6% of the population and less than the Government anticipated.

Organ Donation Decision Overrides:

- Family members still went to override the organ donation decision of their loved 31 times in 18 months (18 deemed consents, 12 Organ Donor register and 1 Verbally expressed in).
- There were a variety of reasons* why family member(s) felt unable to support the organ donation decision.
- Only 3/18 deemed consent overrides were due to the family member(s) being unable to accept that 'doing nothing' was a positive decision to support organ donation.
**The main reasons documented for family member(s) overriding the organ donation decision were: Timeframe to organ donation was considered too long (8), Unable to put their own negative views on organ donation aside (10), Family dynamics, disagreements (4), No Specialist nurse available (3), The perceived (poor) quality of NHS/NHS BT care (4), Unable to accept the donation decision (organ donor register) (2), Unable to accept deemed consent was a choice that supported organ donation (3)*

Health system issues:

It is not always the negative views on organ donation of family members that override the donation decision.

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- Potential donor family members frequently travelled miles, spent a long time at the hospital, and had to juggle family, caring and work commitments.
- Distant family members with different life experiences and views were uniquely brought together and they found it very stressful.
- The facilities to support potential donor family members through the donation process have not kept pace with the standards of facilities provided for transplant recipients and their families.

The following issues commonly led to organ donation overrides:

- The family member(s)' perception of poor NHS care (for them and their relative),
- The long-time taken for donation (for them and their relative),
- The lack of facilities (for them) – accommodation, car parking, space, privacy etc.

Summary of implementation issues

It has generally been challenging for SNODs to implement the Act as intended:

- Many SNODs have generally found it challenging to change their role to supporting the deceased person's donation decision, while at the same time providing care for a grieving family.
- Some SNODs continued to feel that their main focus was supporting the family members(s) and coming to a donation decision that was right for the family.
- This was particularly evident in the language of the Act and the language of practice. There was continued use of legacy language – 'wishes' versus 'decisions,' which has been difficult for SNODs to change in practice. See also linked comments that families have not been prepared via the media campaign to support the donation decision of their relative.
- The media campaign did not focus on the changing role of the family member(s) or their new role in supporting the organ donation decision of their deceased relative.
- There has been very positive feedback from almost all interviewees on the support given to family member(s) by SNODs.
- On a very small number of occasions interviewees perceived that they received a poor standard of care from SNODs that changed their position to not supporting their relative's donation decision.
- People talking about their donation decision with their family member(s) and friends is a positive outcome of the Act.
- In some cases, however, families are using the 'last known decision caveat' to override the deceased person's donation decision from an opt in to an opt out decision.
- When opt in decisions are overridden to opt out, not all family members were in agreement but would normally align with the objecting family member.
- The standard of evidence (written and/or witnessed conversation) required in the Act to override a decision has not been implemented in practice.
- Welsh residents who die in Wales frequently have relatives who live in England.
- Families living in England have had little or no exposure to the media campaign and many heard about the changes for the first time in hospital.

Introduction of Specialist Requesters

Specialist Requesters were introduced in the North West team in September 2016. They were trained to focus on consent. This model of practice moves away from the family care role more familiar to most SNODs.

- Specialist Requesters appear to be adopting a stronger and directed language that is more closely associated with the Act.

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- In North Wales (covered by the North West team) the overall consent rate is higher than in previous years and higher than in South Wales for the first 18 months following implementation of the Act at 66.7%. South Wales was 59.8%.

Bereavement and follow up care

- NHS BT is primarily set up to support the family member(s) of successful donors. Family member(s) where donation does not happen and the family member(s) who do not support donation get little or no bereavement and follow up care and their contact details are frequently not retained.
- Many of the 78 interviewees had unmet bereavement needs.

Recommendations

Future Media Campaigns

- Initial campaigns focussed on making a donation decision, but did not touch on the role of the family members(s) in honouring that decision.
- The changed role of the family member(s) and close friends needs attention in future campaigns. A media intervention is required to help the family member(s) better understand their role in honouring the deceased person's decision. The media intervention could potentially focus on the following scenario: "Family members cannot override someone's consent for an operation, so why do they feel that they can override someone's decision and consent to be an organ donor?"
- The media campaign needs to extend to England as many relatives live in England.

Achieving target 2020 consent rates

Further strengthening of the Act and implementation as intended

- Public perception and general views about organ donation have remained positive following implementation of the Act. There is a potential opportunity to think about further strengthening aspects of the Act, that might now seem more palatable to the Welsh public. For example, making it more difficult to override a registered 'opt in' decision on the organ donor register.
- There is opportunity to revisit the implementation of standards of evidence to override a decision envisaged in the Act and implementation strategy.
- Ongoing training is required with SNODs and NHS staff to ensure consistency in use of the language of the Act (decision versus wish) to underpin and support the deceased person's decision.

Specialist Requesters

- The Specialist Requester role is designed to address some of the issues identified in this evaluation around establishing deemed consent and an expressed decision made in life.
- The Specialist Requester role has yet to be implemented in South Wales but there are plans to do so.
- Ongoing evaluation is required to determine the additional impact of the Specialist Requester role on consent rates and the impact on the wider team. E.g. knock on effect on the SNODs implementing any of the requester behaviours, SNOD consent rate increasing.

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Health systems issues that impact on consent rates

There is a need to determine whether NHS systems and processes can be reorganized to:

- Reduce the time to donation.
- Promote the use of time to donation as a more positive opportunity at the end of life for family members.
- Improve hospital facilities (accommodation, parking, meals) to match those for the family members of transplant recipients.
- Improve the perceived quality of NHS care for potential donors and their family members.

NHS BT processes

There is a need to determine whether NHS BT systems and processes can be reorganised to:

- Further strengthen and increase capacity for ongoing evaluation, audit and research that captures all potential organ donors and their family members.

Other issues not directly related to the Act:

Bereavement support

- There is a need to determine how bereavement support can be further strengthened by (for example) partnering with not for profit bereavement support organisations.

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