

Briefing Paper for Dr Chris Jones - Deputy Chief Medical Officer and Professor Jean White - Chief Nursing Officer

This paper outlines the key findings of the 'Family attitudes, actions, decisions and experiences following implementation of deemed consent and the Human Transplantation Act (Wales)' 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 20 people/organisations received acclaim, especially for involving Third Sector organisations representing BAME communities.¹

Aim:

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

Data collected:

Data were collected on 211 approaches to relatives of potential organ donor patients between 01.01.15-31.05.17 (18 months) whose relative fitted the study inclusion criteria (deceased person voluntarily resident in Wales and died in Wales or England). 182/211 deceased patients came under the auspices of the Act, and represent all cases in Wales during the 18-month period.

In addition, 62 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 (Specialist Nurses in Organ Donation (SNODs), Specialist Requesters, Team and Regional Managers, Practice Development Specialists) were carried out.

Summary of key findings:

1. The overall picture following initial implementation of the Act:

- 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.
- 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.
- Consent rates for cases covered by the Act was 64% over the first 18 months.
- The target of 15 additional deemed consented donors in the first year 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*

¹ Organisations included: Race Equality First, Women Connect First, Flintshire Deaf Association, Llanelli Multi Cultural Network, Churches Together in Wales, Donor and transplant families, Big Lottery, CRUSE bereavement care.

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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.
- There have been additional implementation challenges for SNODs who have not consistently changed their practice to align with the Act.
- 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.

2. Deemed consent

- The original target of 15 additional deemed consented donors in the first year was achieved. In 18 months, there were 28 consented donors by deemed consent, 6.5 more than estimated.
- There were 46/205 (22%) deemed consent approaches in 18 months with a consent rate of 61% resulting in 28 deemed consented donors.
- The overall consent rate for all pathways covered by the Act in the first 18 months was 64% (when family consent was removed).
- Family members who were approached about organ donation **and who supported deemed consent** were helped by the framework outlined in the Act. Family members said they were comforted that they were doing the right thing by supporting the deemed consent for their deceased relative.
- Deemed consent was however too complicated for most people who were approached about organ donation to understand.
- The media campaign was not effective in conveying the message that 'doing nothing' (deemed consent) was a positive donation choice.
- Only 15 of 78 interviewees fully accepted that doing nothing was a choice. (9 males, 6 females mostly younger)
- No older women supported doing nothing as a choice.
- The media campaign was not effective in conveying the message that the Act required the family member(s) to support their relative's donation decision made in life.
- Only a very few of the 78 interviewees understood that organ donation was a personal decision made in life. Most family members still saw themselves as the main decision maker for the deceased person.
- Even when the principles of deemed consent were explicitly explained by SNODs and time was taken to help family members understand, it was another leap for most families to understand that they were no longer the 'decision maker' for their deceased relative.

2.1 Why the family member(s) overrode a deemed consent

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Deemed consent was not supported in 18/46 (39%) cases where the deceased person was established to be on the deemed consent pathway because:

- Family member(s) were unable to put their own (negative) views on organ donation aside (7)
- Family member(s) were unable to accept that deemed consent was a choice that supported organ donation (3)
- Disagreement within the family, person in the highest qualifying relationship who supported organ donation was overridden (1)
- Timeframe to donation was considered too long for the family member(s) (3)
- The perceived (poor) quality of NHS care or the approach concerning organ donation raised concerns that prevented the family member(s) supporting their relative's donation decision (3)
- Family member(s) lived outside Wales and unfamiliar with legislation and would not support it (1)
- No SNOD available (3),
(more than one reason might be given)

3. Verbally Expressed Decisions

People can register their organ donation decision via a conversation during their lifetime with family member(s).

- 55/100 (55%) cases where no organ donor registration was found and family consent did not apply were verbally expressed decisions.
- 55/205 (26%) of all donation decisions over 18 months were made via a verbally expressed pathway.
 - 29/55 (53%) to donate – 26/55 (47%) not to donate

In cases where the family member(s) said that their relative had expressed that they wanted to opt out of organ donation, the reasons documented were:

- Family member stated, 'opting out' was in their will (1)
- Opting out was a 'known wish' (15)
- SNODs were unsure of the details of the expressed decision due to a 'pre-approach' by non-NHS BT staff (bedside nurse, clinician) (2)
- NO SNOD was present (2)
- Religious grounds (2)
- Family member(s) remembered a previous conversation about not wanting to be a donor (1)
- Unknown (3)
- Family member(s) said that the patient did not want to have any surgery (1)
(more than one reason might be given)

- The majority of potential donors were not consented due to a verbally expressed opt out decision – 26/205 (13%) over 18 months.
- In Wales, if no organ donor registration is found, the default position is one which supports donation. In practice, this default position has not yet established itself as the norm. The majority of these cases are being recorded as an expressed opt out decision.
- There was only 1 case in 18 months documented as an expressed opt in decision overridden by the family member(s).
- The media campaign has worked to encourage people to talk about their organ donation decision. There were more registered and expressed decisions (102/205) than deemed consent cases (46/205).

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- The vast majority of 78 interviewees had talked about organ donation, but they did not know that people could register their decision via a conversation with a family member.
- SNODs/Specialist Requesters have found it challenging to clearly separate an expressed decision made by the deceased person in life when the family members introduced their own personal views about organ donation.
- SNODs reported in the early days of the Act being overly keen to establish a deemed consent, this potentially had the negative impact of confusing the family member(s), the family member(s) introducing their own views, and the SNODs having to work harder to establish the known decision of the potential donor made in life.
- The intended language of the Act (making a decision during life) has not greatly influenced a change in SNOD practice. Language to establish organ donation 'wishes' frequently replaced the intended language of the Act to establish 'decisions'.
- Some family members are using 'the last known decision' caveat to 'stop' consent being deemed. SNODs/Specialist Requesters have said that they have no new tools to mitigate this from happening.

4. Organ Donation Register

Decision	Total to date from 1994 – as at 18 th June 2017	Registrations between 1 st December 2015 – 31 May 2017
Opt in	1,181,709	94,446
Opt out	176,011	42,582
Appointed representative	33	9

- Registered status on the Organ Donor Register is the clearest and simplest means of establishing the deceased decision made in life.
- In July 2013 the Organ Donor Register added the option to 'Opt Out'.
- It was presumed that 10% of the population would Opt Out. The percentage is currently 6% (4% less than expected).
- The number of people registered 'In' on the Organ Donor Register is 3% higher in Wales (38%) than England (35%) .
- People registering on the Organ Donor Register has increased from 34%-38% between 31.03.15 – 31.03.17 in Wales.
- There have been no appointed representatives involved in donation decisions during the first 18 months.
- Despite the written evidence provided by registering a decision on the Organ Donor Register, family members went on to override a registered 'Opt In' decision on the Organ Donor Register 12 times out of 73 (9%) in 18 months because:
 - Timeframe to organ donation was too long for family member(s) (3)
 - Time frame to organ donation was too long for deceased person, the family member(s) felt that the deceased person will suffer more (1)
 - Family members were unable to put their own negative views on organ donation aside (3)
 - Family members were initially supportive but became increasingly distressed after some centres declined the offer of organs. Family member(s) felt that they had been through enough and decided to stand down (1)
 - Family members were unable to accept the donation decision of the potential donor (2)
 - Family dynamics;
 - Disagreement within family and the family supported the family member who did not want donation to happen (1)
 - Disagreement within family, the stronger voice(s) override the organ donation

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decision of the potential donor (1)

(more than one reason might be given)

4. Health system issues

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

- 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.

These are having a negative influence on the donation pathway for family members.

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.

5. 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.
- 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.

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6. 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.
- 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%.

7. 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.

7. Recommendations

7.1 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.

7.2 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

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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.

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.

7.3 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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