



organ donation

Family attitudes, actions, decisions and experiences following implementation of deemed consent and the Welsh Human Transplantation Act



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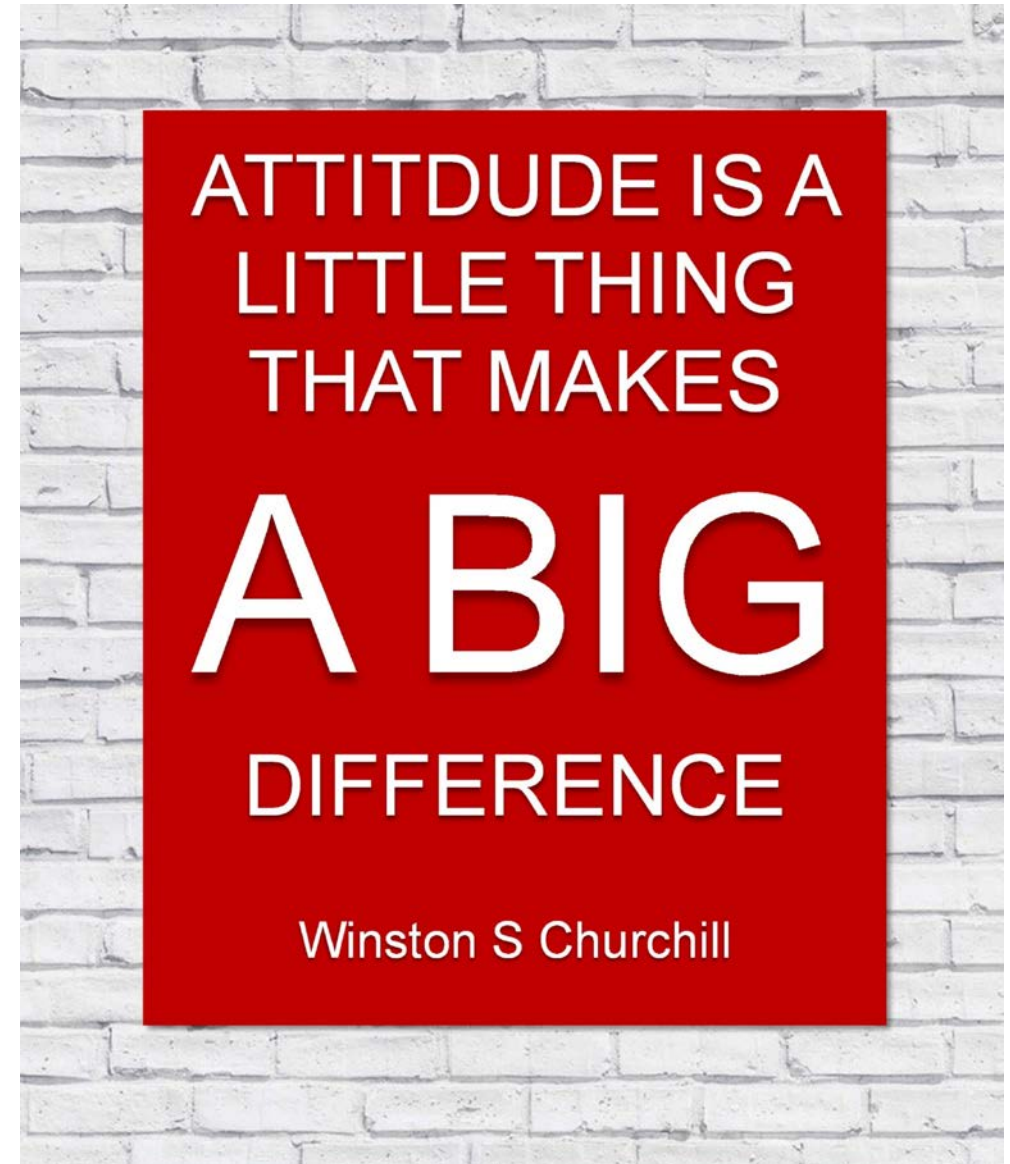
The Human Transplantation (Wales) Act 2013.


The 'soft opt' out system of organ donation assumes that if a person has not expressed their organ donation decision during their lifetime, then they have no objection to being an organ donor.

This is called **deemed consent**.

We learned about the impact of this new system on donor family **attitudes, actions, decisions and experiences**.

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Key partners in this co productive study:
North West England and South Wales Specialist Nurses In Organ Donation (SNODS)
worked with us to set up the study





Interim Findings Event
9th & 10th November 2016
Aston Conference Centre, Birmingham



50 key stakeholders, co partners and PPIs came together to give feedback and to help us interpret the interim findings.



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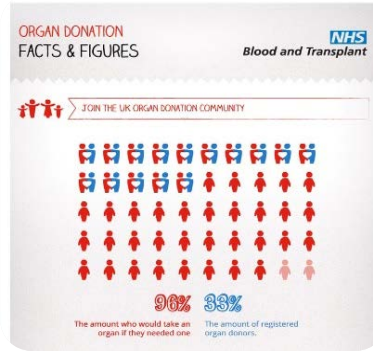


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Overview of the study



Anonymised data on all **205** approaches to relatives of potential donors in 18 months



NHSBT Publicly available figures Wales and England.



Professional and family questionnaires.



62 interviews
78 family members
58 potential donors



Patient and public engagement



Perspectives of **20** professionals



Discourse analysis of media



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Key Findings: organ donation consent rates

The good news is consent rates for cases covered by the Act was 64%

28 donors have been consented via deemed consent in 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% in Wales.

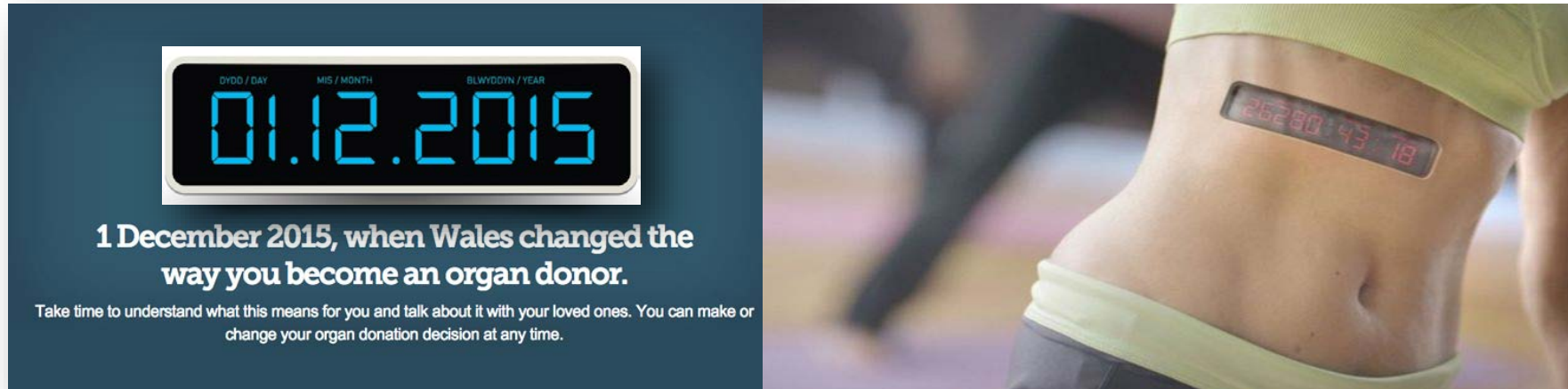


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Key findings: the media campaign worked but had limitations



- The media campaign focussed on changing behaviours of potential organ donors in Wales.
- **People in Wales did respond as intended by:**
 - Registering their decision on the organ donor register
 - Talking about their organ donation decision with their families
- But the **campaign was not memorable:**
 - Family members that we talked to did not remember the campaign images or messages until we showed them some examples during the interview
 - Family members who lived in England had not seen the media campaign

Key findings: The media campaign – lacked focus on the role of families

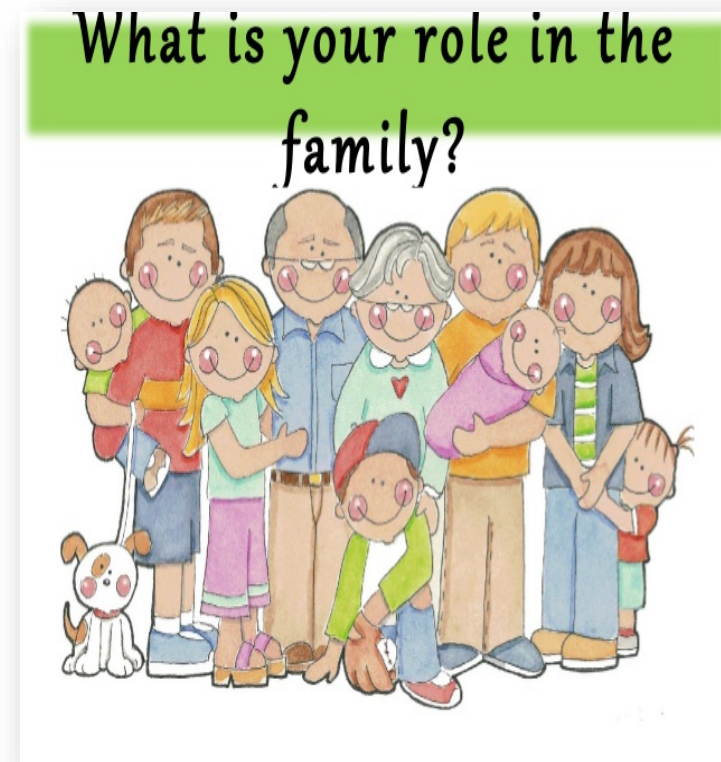


Vaughan Gething AM, The Cabinet Secretary for Health, Well-being and Sport announced that a new communication campaign will now focus on the role of the family.

The original campaign did not focus on the role of the family in supporting their relative's decision

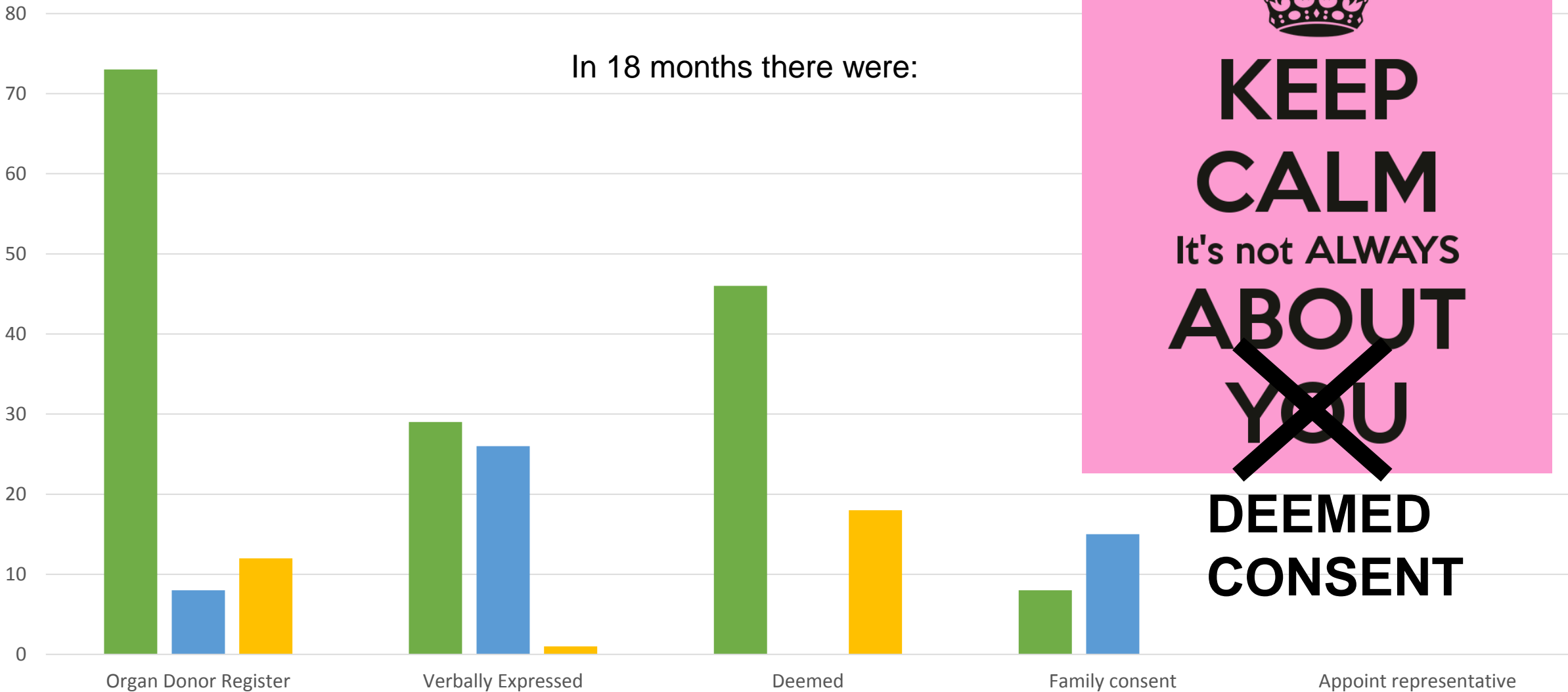
In Wales the family member(s) role has changed. They are not the decision maker with regards to organ donation anymore.

Family member(s) are required to put their own views aside to support their loved one's organ donation decision made during their lifetime.



Key Findings: Outcomes

In 18 months there were:



**DEEMED
CONSENT**



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■ In ■ Out ■ Overridden



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Key Findings: outcomes deemed consent

- In Wales 'doing nothing' means that you have no objection to becoming a donor and that your consent *might* be presumed or deemed.
- Only 15/78 family members fully accepted that 'doing nothing' was a choice. The concern was not primarily to do with support of organ donation or the Act. Families worried that they might not get it right!
- Even when deemed consent was explicitly explained. It was another leap for most family member(s) to understand that they were no longer the decision maker.



Participant A; 'Doing nothing causes problems for families. We should express a decision because if you do nothing and you don't speak about it, then how is your family going know what you want to do, they would always worry if you really wanted (or didn't) want it.'

Key Findings: outcomes deemed consent continued...

Family member(s) whose loved one's consent was deemed, and who supported deemed consent, were helped by the framework outlined in the Act. They DID feel they were doing the right thing.

Participant, 'I was aware of the law change anyway and when the specialist nurse in organ donation came and talked to me they said that they couldn't find anything to say that Dad opted out. I distinctly remember the donor nurse saying are you aware that because we can't find any objections, that his consent is deemed and I said well yes, that is fine with me.'

But families don't like not knowing and for the family that is what deemed consent meant.

KNOWING
IS BETTER
THAN NOT
KNOWING.



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Key Findings: expressed decision outcomes

- Expressed Decisions:
 - People can register their organ donation decision via a conversation during their lifetime with family member(s).
- 55 cases out of 205 were expressed decisions
 - 29 Opted In
 - 26 Opted Out

Most people interviewed did not know that you could register a decision via a conversation.



Key Findings: Family overrides of their relative's organ donation decision made in life

12/73 (9%) Organ Donor registered In decisions overridden
1/29 verbally expressed decision overridden
18/46 (39%) deemed consent overridden

The reasons documented 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)



The reasons why family member(s) override an organ donation decision vary.

A couple is seen from behind, embracing on a beach. The background is a soft, blurred sunset over the ocean, with the sky transitioning from blue to orange and yellow. The couple is positioned in the lower center of the frame, their figures silhouetted against the bright horizon.

A wish changes nothing.

A decision
changes
everything.

A legacy of nursing language proved difficult to 'shift' in practice.

Specialists often talk about donation in terms of 'wishes' rather than the language of the Act, a 'donation decision'.

Key Findings implementation: Standard of evidence to override a decision

The soft opt out system enables families to override a decision if family member(s) could provide evidence that the decision had changed (written or witnessed conversation)



This standard has been challenging to implement.

It is really difficult to separate out the deceased person's decision from the views of the (grieving) family member(s).

The Act has not helped this dilemma.

Key Findings implementation: Other findings

1. Hospital facilities for donor families were sometimes lacking
2. Sometimes the families' perception of the standard of NHS/NHS BT care affected their experience and donation decision.
3. The time taken to donation in many cases was perceived as too long.
4. Families had many unmet bereavement care needs.



1. We recommended a campaign that focussed on the family and are delighted that a new campaign will be launched to focus on the role of the family.
2. Continued training for NHS and NHS BT to establish decisions made in life and to help families honour their relatives' donation decision.
3. Improved facilities for donor families.
4. Where possible seek to reduce time to donation and/or promote this time as a more positive opportunity at the end of life.
5. Increased bereavement support services for ALL families approached about organ donation.
6. Increased capacity for ongoing research within the NHS and NHS BT.





Thank you Diolch yn fawr iawn

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