



organ donation

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

organ donation
choices. concerns. care.

What happened when the 'soft opt-out' to organ donation was implemented in Wales?

Family and professional views and experiences, and consent rates for the first 18 months

A two year co-productive study with
**NHS Blood and Transplant,
 Welsh Government
 and
 Patient and Public representatives.**

Funded by

Health and Care Research Wales.

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Main questions:

What happened to consent rates over 18 months after 1st December 2015?

What was the influence of the implementation media campaign on people's behaviour?

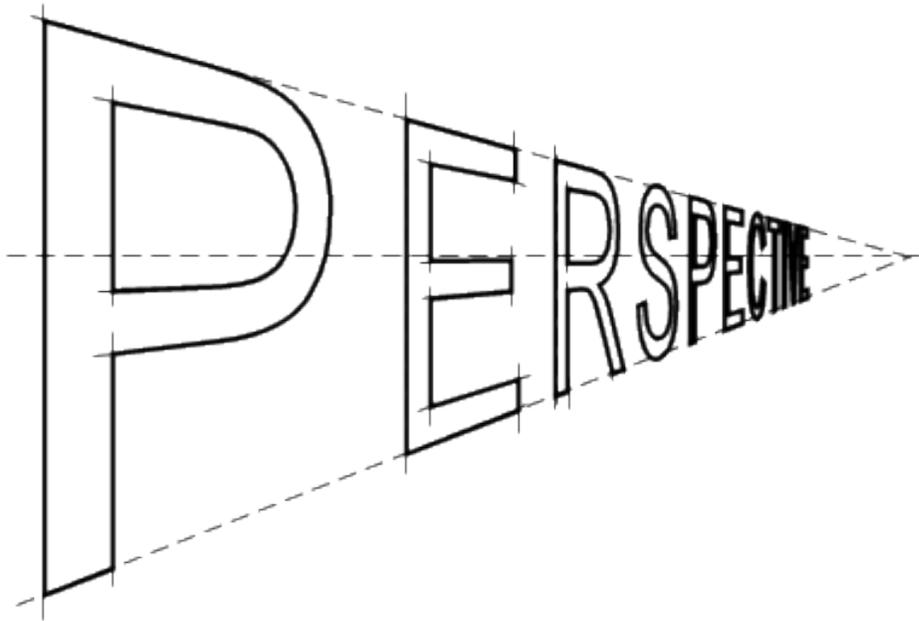
What were the views and experiences of families who were approached about organ donation?

How did NHSBT practice change to implement the Act?

Other questions:

What happened to BAME consent rates and how did BAME families experience the changes?

What happened to a small subsample of cases of Welsh residents who died in English hospitals?



n=182/211 came under the Act.
29/211 were excluded due to:
- residency
- <18
- Lacked mental capacity

Total number of approaches in 18 months = **211**

205/211 deceased voluntarily resident in Wales



6/211 deceased voluntarily resident in Wales and died in England

114 Professional questionnaires



31 Family questionnaires



19 NHS BT Professional perspectives



62 interviews
85 family members
57 potential donors

Depth data from family member(s)
60 (cases)

Additional data sources for context

5. Additional contextual data produced by the research team, (**an update of literature, discourse analysis of the press and media campaign**).

4. Additional data collection by the research team (**field notes, interim feedback from key stakeholders, weekly team meetings**).

3. Publicly Available **Welsh Government Commissioned Research** (focus groups with SNODS, Ombudsman surveys, Literature reviews).

2. Routinely collected and **publicly available NHSBT data** (UK and Wales and Organ Donor register)

1. **Anonymous data shared by NHSBT** under data sharing agreement (statistics and log with details of conversations)

Organ donation consent rates:

What happened?

The good news is consent rates for cases covered by the Act (182/211) was 64%.

Overall consent rates (including family consent that falls outside of the Act) have increased from an unexplained drop to 48.5% in 2014/15 to 61% in Wales.

The consent rate in Wales is now higher than in England



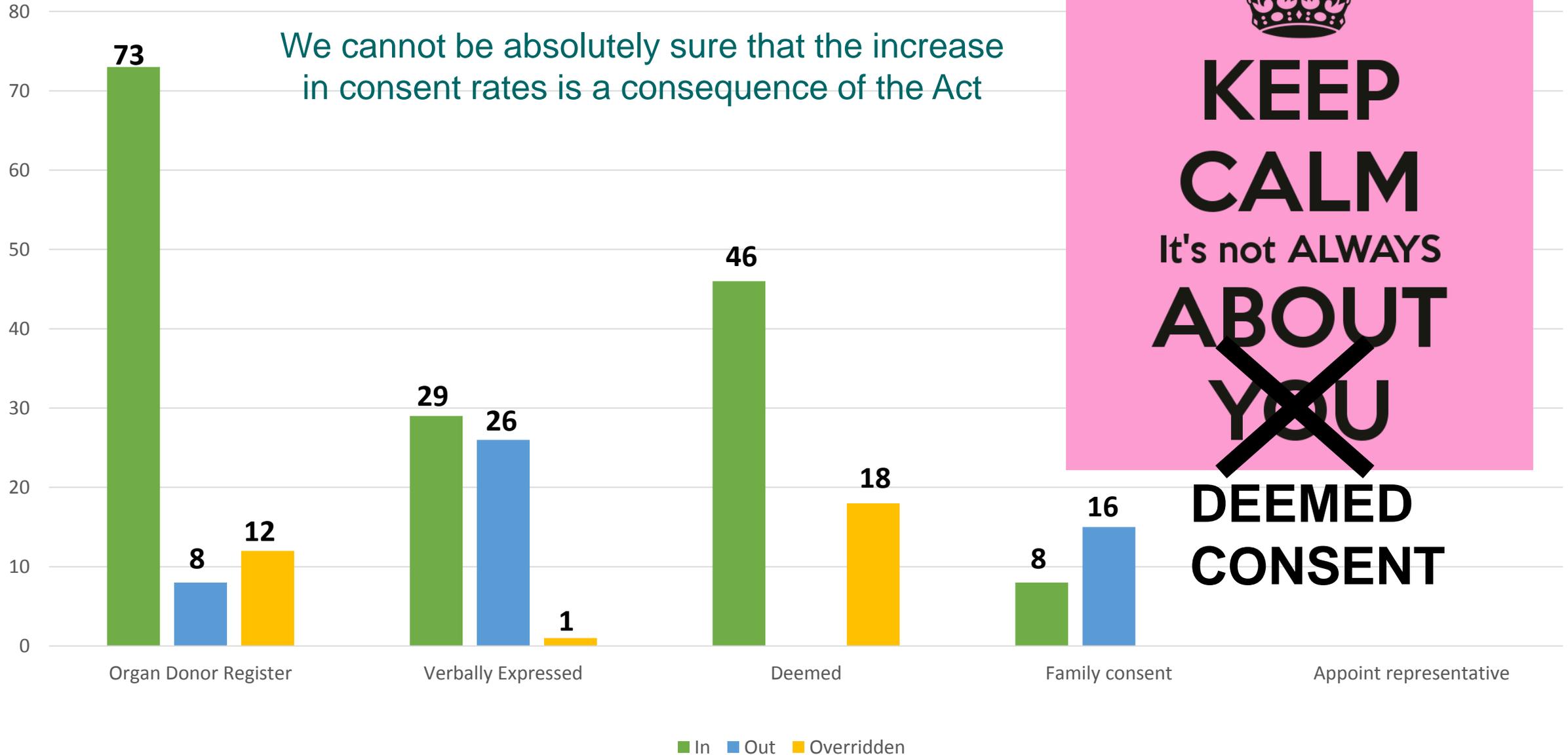
@organdonationproject_



#organdonationweek
#organdonationstudy

The way people make their organ donation decision varies.

We cannot be absolutely sure that the increase in consent rates is a consequence of the Act



**DEEMED
CONSENT**

205 cases 01.12.15-31.05.17

The media campaign, what happened?

1 December 2015, when Wales changed the way you become an organ donor.

Take time to understand what this means for you and talk about it with your loved ones. You can make or change your organ donation decision at any time.

From 1st December 2015 you can:

Opt in	Do nothing	Opt out
You can register your decision to be a donor.	You could still become an organ donor. This is called deemed consent.	You can register your decision not to be a donor.

It's time to talk about organ donation

01.12.2015

WWW.ORGANDONATIONWALES.ORG

The campaign 'worked' but there were gaps. Potential organ donors mostly behaved as intended by:

- Talking about their organ donation decision, or
- Registering their decision on the Organ Donor Register, or
- Appointing a representative, or
- Doing nothing.

The media campaign, what happened?

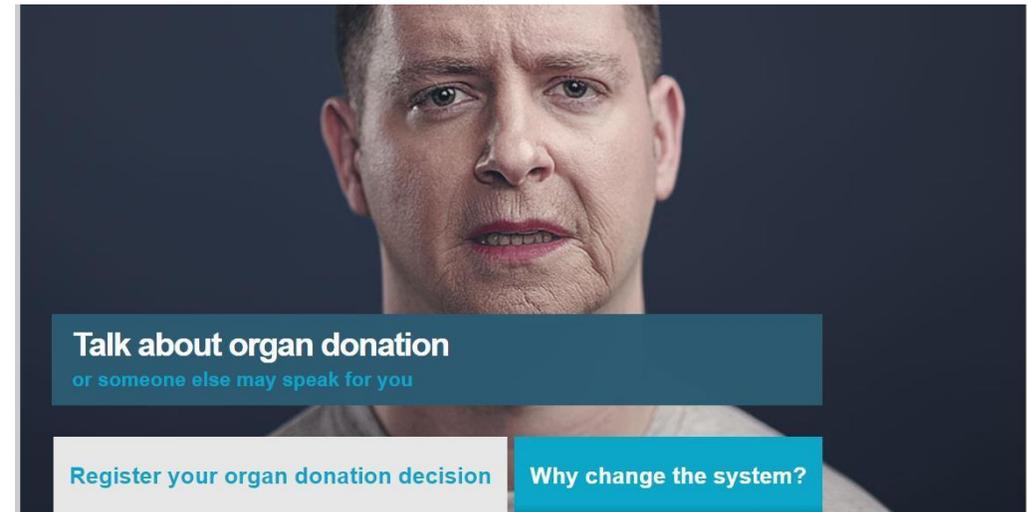
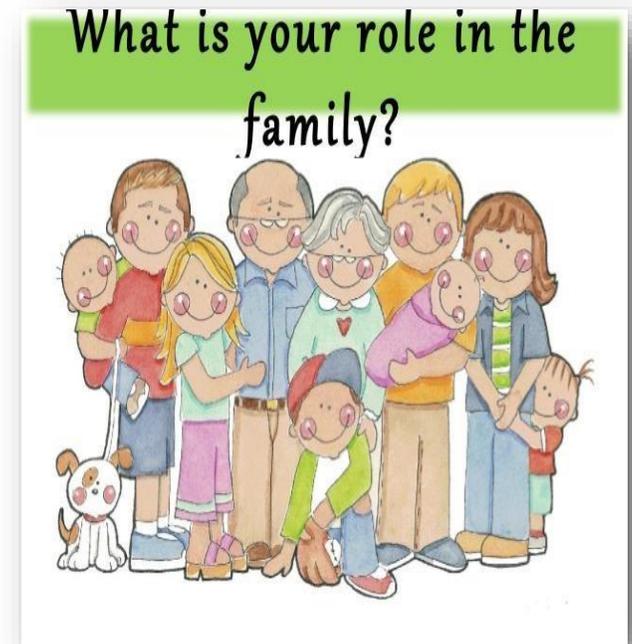
The campaign 'worked' but there were gaps

- The media campaign was not memorable.
- Family members who lived in England didn't see it.
- Unclear if the intended behaviour changes will be sustained over time without further media campaigns.

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

In Wales, family member(s) are required to put their own views aside to support their relative's organ donation decision made during their lifetime.

Immediate research impact: Welsh Government launched a new campaign to address these gaps



<http://organdonationwales.org/?lang=en>

Deemed consent. What happened?

- Only 15/85 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.

'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.

Organ Donation Decision Overrides, what happened?

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)

(out of 205 cases documented on NHS log, more than one reason might be given)



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

A person in a white shirt and dark pants stands on a beach, looking out at the ocean under a clear sky. The text is overlaid on the left side of the image.

A wish changes nothing.

A decision
changes
everything.

The Act in practice, what happened?

A legacy of nursing language proved difficult to change in practice.

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

“It is hard because it is a language that we have always used intuitively and now we are using a language that has been written for us. I mean we do loads of work around language now, but it doesn't always align itself with our language. We are used to using words like 'gift' which sits along nicely with 'a wish' and it makes sense to me, but deemed consent is a very technical language, and I think we are trying to soften it when we talk to families. This is really complicated because they are such different languages”.

The Act in practice, what happened?

“We are supposed to be having a presumptive conversation and at the same time establishing if the deceased person had ever talked about organ donation. I don’t know if you can do both really, and it has tripped us up a bit, it doesn’t really make sense when you think about it”.

The Act asked for a standard of evidence from family member(s) to override an organ donation decision (written or witnessed conversation).

This has been challenging (and potentially) unrealistic 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.

The research has highlighted the context and mechanisms leading families to support (or not) the organ donation decision.

We recommended:

1. A new media campaign that focussed on the family
2. Continued training for NHS and NHS BT to establish decisions made in life and to help families honour their relative's donation decision.
3. Improved facilities at hospitals for potential 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

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