



# Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report

## Executive Summary

### Key messages

- Awareness of and support for the soft opt-out system of organ donation in Wales is high among the general public and NHS staff.
- However, there has been a recent drop in awareness levels among the general public suggesting that publicity of the law needs to be maintained.
- More clarity around the role of the family in the organ donation process is required. This should encourage discussion in families, which may help them support the decision of a deceased relative.
- NHS staff working within organ donation may also benefit from further training, particularly around the organ donation conversation with the family.
- Despite the high awareness and support for the new law, analysis of routine data does not show any consistent change in deceased organ donations in Wales, or more widely from Welsh residents.
- Analysis of consent data shows an increase in the percentage of families giving approval for donation. However, this is not reflected in a rise in donors overall, implying there has been lower eligibility over the period since implementation of the law.
- A longer period of time is needed to draw firmer conclusions around the impact of the change in the law. It will be important to continue to monitor public attitudes and the routine data on organ donation in Wales (and more generally across other parts of the UK for comparison).

## 1. Background

On the 1st December 2015, the Human Transplantation (Wales) Act 2013 came into full effect, introducing a soft opt out system for consent to organ and tissue donation. The aim of the Act is to increase the number of organs and tissues available for transplant. An extensive communications campaign was used to inform the public about the change in the law and as part of the ongoing evaluation process (in the run-up to the Act and in the period that has followed), a number of qualitative and quantitative research projects were commissioned, each with its own reporting process. This impact evaluation report draws together evidence from two surveys of NHS staff (pre- and post-implementation of the legislation); 13 waves of surveys with the general public; qualitative

research with the general public and NHS staff; and analysis of routine NHS Blood and Transplant data on donation.

## 2. Awareness of and support for the change to the organ donation system

The communications campaign has been successful in some key respects:

- Awareness of the change to the system has increased among both NHS staff and the general public
- However, there has been a slight drop in awareness among the public since the communications campaign has eased off
- Levels of support for the system have increased markedly among NHS staff and the general public since the pre-implementation measure
- One year after the new law came into force, 71% of the Welsh public were in favour of the soft opt out system (versus 49% in the rest of the UK)
- By 2016, 78% of NHS staff said they had opted-in to organ donation or had done nothing as they were happy for deemed consent to apply. By way of comparison, by June 2016 65% of the general public in Wales had opted in or taken no action to opt-out as they were happy for deemed consent to apply.

## 3. Knowledge of and attitudes towards the new system of organ donation

- Self-rated knowledge about the new system rose among NHS staff (80% said they knew at least a fair amount after the law came into effect)
- Staff attitudes towards the new system have remained largely positive and stable, but there has been a shift in an encouraging direction in terms of views of the Government's influence, with fewer staff agreeing that '*The soft opt-out system gives the Government too much control*'

## 4. Role of the family

- In the latest surveys, 81% of NHS staff and 74% of the public agreed that '*If an individual chooses not to register a decision to opt-out, this should be treated as a decision to be a donor which families should be encouraged to accept*'.
- However, there is evidence to suggest that some NHS staff – particularly those working outside A&E or ITU – do not fully understand the role of the family in the new organ donation system:
  - The proportion of staff who **incorrectly** identified that '*The family will have no role to play in the organ donation process*' as true nearly doubled between pre-implementation and post-implementation surveys (from 7% to 13%).
  - There was a decline in the proportion of staff who correctly identified the statement '*If the family is in distress over the decision to donate, clinicians will not proceed with organ donation*' as true – from 74% pre-implementation to 58% post implementation.
- In the latest staff survey, 80% confirmed that they had discussed their decision about whether to become an organ donor with a family member. Surveys of the general public show that between 2012 and 2015, around four out of ten respondents had ever discussed their wishes regarding organ donation with a family member. This figure has increased gradually since then, reaching 51% in March 2017.
- Qualitative research with the general public identified ways in which family discussions about donation could be encouraged; these may be of use in any future campaigns or public awareness raising exercises

## **5. Impact of the new legislation on working practices**

- The majority of NHS staff reported no impact of the new legislation on their job (88% post-implementation; compared with 57% at pre-implementation)
- Qualitative research with SNODs and CLODs further supported this finding, with staff feeling that the transition to the new system had gone smoothly. The main impacts reported were:
  - Changes to the family conversations, with an early focus on establishing if the patient had discussed wishes about organ donation
  - More ‘known decisions’ (either for or against donation) among the families with whom the research participants had had contact
  - Improved relationships with clinicians
  - Feelings of pressure on SNODs to make the system ‘work’ and that they would be held responsible if the outcomes were not realised

## **6. Training and guidance in relation to the new organ donation consent system**

Following the introduction of the law, three quarters of NHS staff (75%) said they would feel fairly or very confident answering questions from a patient or member of the public. GPs and specialist nurses in A&E and ITU saw the greatest increases in levels of confidence between baseline and follow-up surveys.

- SNODs and CLODs felt that they had received sufficient training and guidance leading to the change in the law but they suggested:
  - Refresher training and more opportunities for shared practice (particularly between North Wales / North West England team and the South Wales team)
  - Making the subject of organ donation part of the curriculum for students in medicine and nursing
  - Further guidance for conversations with families for deemed consent
  - Reviewing the wording used in public messaging; ‘not registering a decision’ was deemed more appropriate than ‘doing nothing’
  - Making the subject of organ donation part of the curriculum at school, to encourage organ donation to become a ‘cultural norm’

## **7. Routine Monitoring Data Analysis**

Although the surveys showed improved knowledge and more positive attitudes towards the change in legislation, analysis of the routine NHS donor data between 2010 and 2017 revealed little evidence of a consistent increase in either the number of deceased donors in Wales, or Welsh resident donors more widely, since the Act came into force.

- There was no rise in average quarterly donor levels or in the moving annual totals.
- The routine data included seven quarters since the new law came into effect. The respective 21-month periods either side of the change showed a small increase in the number of donors – 101 deceased donors prior to the Act and 104 following.
- Removing non-residents from the Welsh hospital data does lower the donor figures, most notably in the time since the change in the law. However, in the same period there has been a

rise in the number of Welsh resident donors in other parts of the UK, meaning that the overall picture shows little change for Welsh resident donation.

- Comparison between Welsh residents and those in a broadly similar part of the UK generally shows lower figures for Wales than for North East England but with some evidence that the Welsh position has shown relative improvements in recent quarters.
- Analysis of consent data shows an increase in the percentage of families giving approval for donation. However, this is not reflected in a rise in donors overall, implying there has been lower eligibility over the period since implementation of the law.
- It will be important to continue routine data analysis over a much longer period to assess the fuller impact of the new law. The current data has only a modest number of donors in Wales in the 21 months following the change in the law, making it difficult to draw firm conclusions on impact at this early stage.

## 8. Summary

The evaluation has shown positivity and support amongst both the general population of Wales and NHS staff in Wales for the soft opt-out organ donation system. Going forward it will be important to continue to monitor, over the long term, the implementation and impact of the Act to ensure:

- continued efforts to maintain awareness of the soft opt-out approach among both the general public and NHS staff;
- that the role of the family in the organ donation process is better understood by both staff and the general public;
- that people are encouraged to discuss their decision to donate (or not) with their family; and
- ensuring that SNODs and CLODs feel supported and best practice in approaches to families continues to be shared.

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Full research report available at:

<http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>

Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government.

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