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

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1 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).

1.1 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.

1.2 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.

1.3 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’.

1.4 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:
  o 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%).
  o 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.
1.5 Impact of the new legislation on working practices

- The majority of NHS staff reported no impact of the new legislation on their job (88% at post implementation; compared with 57% 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

1.6 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’
1.7 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.

1.8 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.
2 Introduction

2.1 Background

Organ transplantation has become one of the most successful medical procedures, as just one person can save or improve up to nine lives by donating their organs, and more still by donating their tissues. Polls have shown that the majority of the population across the UK is in favour of organ donation, but the number of people putting themselves on the actual Donor Register does not reflect this widespread support. Very few people die in circumstances under which they can become eligible donors and therefore it is vitally important to maximise the chances of finding suitable donors.

Under the Human Tissue Act (2004) for England, Wales and Northern Ireland, and the Human Tissue Act (2006) for Scotland, for organs to be available for transplantation, the individual concerned has to consent to their use on an ‘opt-in’ basis. The Acts presume that a person does not want to donate their organs unless they have expressly indicated that they wish to do so, for example by signing the Organ Donor Register (ODR) or carrying a donor card. Once opt-in consent is established, relatives are encouraged to support the deceased’s wishes, and advised that they have no legal right to veto them. If no record exists of the deceased’s wishes, their family or another qualifying individual is able to agree to or refuse donation.

In order to increase the number of organs available for transplant, the Welsh Government decided to change the organ donation system to one where consent is deemed to have been given unless the individual concerned has ‘opted-out’. To make this change, the Welsh Government introduced the Human Transplantation (Wales) Bill for deceased organ and tissue donation on 3rd December 2012. The general principles of the Bill were agreed by the National Assembly for Wales on 16th April 2013 and, with amendments, the Bill was passed on 2nd July 2013. A two year public awareness and engagement campaign was then undertaken to inform people in Wales about the change to the system and their choices under it. The change to the organ donation system became law in December 2015.

The main aims of the Act were to promote transplantation by increasing the number of organs available for donation, and to change how consent is given. It states that transplantation is lawful if done in Wales when either express or deemed consent has been given. It introduces a ‘soft opt-out’ system, in contrast to the opt-in system which is operational across the rest of the UK. Under this system, four choices are available, allowing people to:

1. register a decision to be a donor by expressly opting in on the ODR or verbally telling family.
2. register a decision NOT to be a donor by expressly opting out on the ODR or verbally telling family or friends
3. appoint a representative/s to make a decision on their behalf in regard to organ donation
4. choose to do nothing and have consent deemed.

Under an ‘opt-out’ or presumed consent system, every person ordinarily living in Wales voluntarily for longer than 12 months, aged 18 or over (the law does not apply to children) who has the required mental capacity is deemed to have given their consent to organ donation, unless they have specifically registered
a decision either on the ODR or verbally told family or friends. The system in Wales is a ‘soft’ as opposed to a ‘hard’ opt-out system (under the latter, families are not consulted about organ donation if consent is either expressly given or presumed). In a soft opt-out system, families are approached about their relative’s organ donation decision. If those close to the person object to the donation, for whatever purpose, when the person (or their appointed representative) has explicitly given their consent, or their consent can be deemed, the family are encouraged to accept the person’s decision and it is made clear that they do not have the legal right to veto or overrule the consent. However there is no requirement that organ donation goes ahead when there is express consent or consent can be deemed, when the family/friends object. The key difference for families, compared to the old system is that, in the absence of a recorded decision, they will know their relative could have opted-out but chose not to do so. This is hoped to be the trigger for families supporting donation proceeding.

The Welsh Government undertook an extensive public engagement campaign to raise awareness of the changes to the organ donation system and inform members of the public about their choices. The Human Tissue Authority (HTA) as the statutory regulator, provide practical guidance to professionals carrying out activities within the scope of the HTA’s remit and published A Code of Practice to underpin the implementation of the system, including dealing with the cross-border issues that may arise due to Wales operating a different organ donation consent system to the rest of the UK.

The change to the organ donation system is part of the Welsh Government’s commitment to the UK-wide strategy Taking Organ Transplantation to 2020; a collaborative strategy between the NHS Blood and Transplant (NHSBT) and the health administrations of the four UK countries which provides a series of recommendations to enable the UK to match world-class performance in organ donation and transplantation.

2.2 Rationale for the Impact Evaluation

Systematic reviews conducted by the University of York and Welsh Government both suggest that an association exists between presumed consent legislation and increased organ donation rate. Furthermore, Bilgel (2012) included data from 24 countries over the period 1993-2006 and estimated that countries with presumed consent legislation have on average 13-18 per cent higher organ donation rates than countries with opt-in legislation.

In addition there is some evidence to suggest that people who live in a ‘presumed consent’ country were more likely to be willing to donate not only their own organs but a relative’s organs. This was cited in Mossialos et al’s

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(2008)\(^6\) analysis of individual-level survey data from 15 European countries. They found that individuals living in presumed consent countries were between 17 and 29 per cent more likely to report willingness to donate their own organs and 27-56 per cent more likely to report that they would be willing to consent to the donation of their relatives’ organs compared to respondents living in explicit consent countries.

The Explanatory Memorandum that accompanied the Human Transplantation (Wales) Bill outlined the Welsh Government’s commitment to monitoring and evaluating the impact of the legislation, stating:

“Owing to the lack of precision regarding changes in organ donation numbers that may occur as a result of introducing an opt-out system, it is imperative that the impact of the proposed legislation is monitored and evaluated. It will be particularly useful to compare changes in organ donations in Wales with England as the opt-in system will be retained in England for the foreseeable future.”\(^7\)

The impact of the Act can partly be demonstrated by any change in deceased donor numbers after 1\(^{st}\) December 2015 (and perhaps prior to this date as knowledge built up ahead of the changes being introduced). The evaluation also compares the deceased donor trends in Wales with those across relevant parts of the rest of the UK where different efforts are being made to increase the level of organ donation. While this routine transplantation data collated by NHSBT is central to the evaluation, impact is also measured by examining trends in wider attitudes in Wales, using findings from the regular surveys of the adult population as well as from research among NHS staff. To this end, a number of qualitative and quantitative research projects have been commissioned by the Welsh Government, each with its own reporting process, as summarised in the table below (see the Appendices for summary details about the methods and objectives for each piece).


\(^7\) Human Transplantation (Wales) Bill: Explanatory Memorandum (2012, p.38)
<table>
<thead>
<tr>
<th>Evaluation strand</th>
<th>Dates</th>
<th>Supplier</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>GfK UK Ltd</td>
<td>Not published</td>
</tr>
<tr>
<td><strong>Researching the views of Specialist Nurses (SNODs) and Clinical Leads for organ donation (CLODs) in Wales (qualitative)</strong></td>
<td>First stage published August 2013. Two further stages took place: one after the passing of the Act but before full implementation (early 2015); the second in 2017 after full implementation had taken place.</td>
<td>Beaufort Research</td>
<td><a href="http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/">http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/</a></td>
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2.3 Aims and objectives of the evaluation

The overall aim of this evaluation is to assess the implementation of the Act and the impact it has had on organ donation rates in Wales. There are also specific objectives in relation to the individual strands of the process:

- Use routine data to monitor changes in deceased organ donation and consent rates over time (outcome measures);
- Assess the effectiveness and impact of the communications campaign on public attitudes to, and understanding of, a soft opt-out system of organ donation;
- Understand behaviour of individuals in relation to organ donation, and the impact that moving to a soft opt-out system has had (including whether or not individuals discuss decision with family);
- Assess the implementation and impact that the legislation has on the work of Specialist Nurses and Clinical Leads, including feedback on training, and issues regarding family consent; and
- Monitor the awareness and attitudes of NHS staff involved in the referral process about the new law, its implementation and impact.

Central to the impact evaluation is the analysis of the various research strands. Chapter 3 maps out the data and analysis techniques being employed for assessing the initial impact of the Act, in the context of Wales having a different organ donation consent system to the rest of the UK. This report synthesises and summarises the findings of the evaluation strands. The report consists of the following chapters:

- Executive Summary
- Introduction
- Analysis
- Evaluation Findings
  - Awareness of change to organ donation system and support for change
  - Knowledge of and attitudes towards the new system
  - The role of the family
  - Impact of the new legislation on working practices
  - Training and guidance in relation to the new system
  - Routine monitoring data (donation numbers)
- Conclusions and Considerations

2.4 Notes on reading this report

The following points explain the way in which the quantitative survey results have been commented upon in this report.

- The base sizes for some of the NHS occupation groups are small and therefore ineligible for significance testing. We have therefore included differences in the report that are on the ‘margins of significance’ (at 95% confidence interval). The gap between survey waves and variations in question sets and findings meant that there was little scope to do further demographic analysis, e.g. by ten year age bands or interlocking sex and age.

- In order to indicate significance or on the margins of significance we have used the following symbols: positive significant difference 🟢 between waves; 🔻 negative significant difference between waves; ⬇️ a significant difference compared with the average.
3 Data sources and analysis

3.1 Analysis planning

The analysis of routine NHSBT data focussed on monitoring the trends in Wales, in relation to number of donors, and compared them with patterns in another part of the UK with broadly similar demographic profiles. It also included examination of consent levels recorded for Wales and the rest of the UK.

Given the diverse evaluation strands and the over-riding difficulty of attributing any changes in donation rates to the impact of the Act, the evaluation set out to consider a number of approaches to analysis. One option considered was to follow the precepts of contribution analysis, an approach for inferring probable causality in real-life programme evaluations.

This analysis would attempt to assess the relative importance of any movement in public attitudes to opting out (rather than opting in) and of any changes in the attitudes and practices of medical and nursing staff to any shift in outcomes (i.e. levels of organ donation). This analysis would be informed by the coefficients in the statistical analysis of the changes and trends within the Welsh donor data and through the comparison of trends in both the UK and Welsh data.

Another possible approach was to develop a single analytical framework that would list the key evaluation questions (for example, does the programme increase donation levels?) and then populate the framework with data from the different evaluation strands. The framework would then be analysed to identify where there was stronger or weaker evidence to corroborate impact on, for example, changes in donation levels. Where the data point to the same or similar results, compelling associations could be inferred but not causality.

Although the original analysis plan suggested the possibility of conducting difference in difference analysis and regression discontinuity analysis, this has not been included in this report as these types of analysis are generally used where there is doubt as to whether an observed effect is significant (in the right direction) but we have found this to not be case in the donor counts.

The following sub-sections of the impact analysis will be discussed in turn:

- Analysis of routine NHSBT data
- Collateral data on public attitudes from regular surveys in Wales
- Synthesising evidence from the other strands of the evaluation

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Analysis of routine NHSBT data
The analysis of routine NHSBT data focussed on monitoring the trends in Wales, in relation to number of donors, and compared them with patterns in another part of the UK with broadly similar demographic profiles.

Collateral data on public attitudes from regular surveys in Wales
Collateral data has been taken from the following sources:

- Multiple waves of the public attitudes survey
- Exploring the detailed views of the public via qualitative research
- Researching the views of Specialist Nurses and Clinical Leads
- Measuring wider NHS staff attitudes

It is not within the scope of this evaluation to reproduce these outputs across the rest of the UK, although the report makes use of any other published data to inform the evaluation. Instead, to provide at least some counterfactual evidence on public attitudes, the evaluation used GfK’s Random Location Omnibus to ask a short set of questions (corresponding to key items in the Public Attitudes Survey) in England, Scotland and Northern Ireland - to provide some corresponding data for the rest of the UK. Three measures were used:

- Attitudes to an opt-out system being introduced in the rest of the UK (in favour/against/need more information to decide)
- Predicted behaviour under an opt-out system (opt-out/opt-in/do nothing)
- Whether the deceased wishes should be respected or not despite what the family thinks

Given the similar data collection methods for the Public Attitudes Survey in Wales and the Random Location Omnibus in the rest of the UK (face-to-face, in-home, quota sample design), this provides firm ground for better context for the evaluation findings.

Synthesising evidence from the other strands of the evaluation
As noted, there are four strands of evaluation evidence and the findings from these activities have been distilled into the overall report for the impact evaluation. To some extent, this reports has repeated and summarised some of the content of the original standalone outputs but the overall evaluation also looked for links across the various strands in terms of themes. For example, the need for more clarity around the role of the family has been a theme across the different strands of the evaluation.

The original analysis plan indicated that the public attitudes data could present some opportunities for secondary statistical analysis and more detailed profiling through merging data from waves where there was flat-lining in order to boost the sample size for analysis. It also suggested that,
depending on the final question sets, there could also be the possibility of using segmentation techniques to profile different groups in the Welsh population. However, the question sets for the general public survey did not lend themselves to this type of analysis and therefore was not added to the impact evaluation.

In addition to the surveys with the general public, two surveys with NHS staff in Wales (pre- and post-implementation) have also fed into the evaluation reporting.

The evaluation intended to provide the most robust practical measurement of the impact of the Act but there are potential difficulties in doing so\(^9\), such as the opt-out being introduced in Wales during a period of steady improvement in UK-wide donation rates following the recommendations of the 2008 organ donation taskforce and the continuing influence of family members over the donation process. There are also likely to be a range of lower profile interventions in other parts of the UK that might impact on donation rates in, for example, parts of England.

Below we have set out full details of each strand of the evaluation evidence.

### 3.2 General public surveys

A Public Attitudes Survey was commissioned by the Welsh Government to monitor the effectiveness and inform the development of their communications campaign relating to the donation system, and to measure levels of awareness, knowledge and support for the changes. Questions were placed on the Beaufort Research Wales Omnibus Survey at regular intervals from June 2012. In total, 13 waves of the survey had been conducted by March 2017. Around 1,000 adults aged 16+ who were resident in Wales were interviewed at each wave in their homes using computer assisted personal interviewing.

To provide some counterfactual evidence on public attitudes, one wave of the GfK Random Location Omnibus was used to collect data from across Britain (c2000 interviews) using a short set of questions corresponding to key items in the Public Attitudes Survey. The GfK Omnibus also used an in-home, face to face method of data collection, making the results comparable with those of the Welsh survey.

This report looks at the overall trends in public awareness, attitudes and behaviours over time drawing on both sources of quantitative data. In the case of the Public Attitudes Survey, the report will especially concentrate on November 2015 prior to the implementation of the legislation, and March 2016, June 2016 and March 2017 following the implementation of the legislation, drawing on demographic differences where appropriate.

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3.3 Qualitative research with the general public

Three qualitative research exercises were carried out with the general public in Wales between 2012 and 2016 as follows:

- **2012** - focus groups and in-depth interviews with a range of adults across six locations in Wales. The overall aim of this study was to explore attitudes towards organ donation in general, and the Welsh Government’s organ donation opt-out proposal. This phase of the work was carried out by Beaufort Research.
- **2014** – a mixture of focus groups and depth interviews exploring knowledge of and attitudes towards organ donation, and testing possible messaging options ahead of the Welsh Government’s communications campaign, carried out by GfK UK Ltd.
- **2016** – focus groups to explore the barriers and benefits to discussing organ donation decisions with family members, also carried out by GfK UK Ltd.

Given that the 2012 qualitative work looked at attitudes towards the proposal, three years before the law came into effect and the 2014 work looked at messaging for the communications campaign, in this report we have focused mainly on the 2016 findings which looked at barriers to discussing decisions regarding organ donation with family members.

3.4 In-depth interviews with SNODs and CLODs

Specialist Nurses for organ donation (SNODs) and Clinical Leads for organ donation (CLODs) perform crucial roles in the organ donation process. SNODs provide the link between families and the donation process, as they lead the discussion about the patient’s decision for donation with the family. Where a decision to donate is established, SNODs ensure that the relevant medical tests are carried out and discuss the patient’s medical history with the family.

CLODs work with colleagues in intensive care units (ITU) and emergency medicine departments to encourage organ donation to be viewed as part of everyday practice in end of life care. CLODs are responsible for raising the profile of organ donation and providing expert advice on ethical and legal matters.

The inclusion of SNODs’ and CLODs’ views in the research programme was critical given their frontline experience of dealing with families and communicating the changes in legislation to colleagues. Their perspectives were gathered by Beaufort Research via three waves of qualitative research (depth interviews, carried out primarily face to face); the first was concerned with preparations for the legislative change and understanding the likely impact of the legislation on working practices (2013\(^{10}\)); the second wave\(^{11}\) took place in early 2015 following the passing of the Act and in the run up to


its full implementation. The final wave\(^{12}\) took place in autumn 2016, following full implementation of the Act. This evaluation report draws, primarily, on the findings from the final wave of the research.

### 3.5 NHS Staff Surveys

In order for the Welsh Government to understand the views of NHS staff, GfK was commissioned in 2013 to assess opinions and attitudes in relation to the change to the organ donation consent system. A pre-implementation survey among NHS staff was undertaken in 2013/14 (280 interviews) with a post-implementation wave carried out in 2016/17 (n=268).

The audience for the research was NHS staff in certain occupations working for the health service in Wales. The list of occupations is shown below (quota targets were set for each grouping).

- GPs
- Hospital Doctors working in A&E or ITU (Senior and Junior doctors)
- Hospital Doctors who did not work in A&E or ITU (Senior and Junior doctors)
- Specialist Hospital Nurses working in A&E or ITU
- Hospital nurses who did not work in A&E or ITU: around half were specialist nurses (not in A&E or ITU) and half were ‘general’ ward nurses
- Clinical Leaders: including Medical Directors, Nursing Directors and Clinical Directors

This report draws primarily on the findings contained in the post-implementation (2016/17) report, which provides commentary on how awareness, attitudes and behaviours changed after the new organ donation legislation came into force.

3.6 Analysis of Routine Data from NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) provided UK-wide data on the number of organ donors from Q2 2010 (i.e. April, May and June 2010) through to Q3 2017 (i.e. July, August and September 2017). The data provided was anonymised but contained information on donor type, cause of death, gender, ethnicity, BMI, age, council area of residence and whether the donor was in a Welsh hospital.

Full details of the variables are listed in section 4.6 along with the outputs from various strands of analysis looking at quarterly figures and 12-month and 21-month rolling averages for Welsh hospital donors and Welsh resident donors.

3.7 Limitations

As with any evaluation, there are a number of limitations in terms of the data and the analysis that should be considered when reading this report.

It is very difficult for research of this kind to enter into the intricacies of family relationships. NHS routine data is limited to only 21 months since the Act came into force and it is therefore still quite early to draw firm conclusions. It is also missing area of residence for a large minority of deceased donors, especially in Wales. While the analysis includes data on consent, it does not have details about eligibility and we can only infer there has been a drop in eligibility because of the flat-lining in actual numbers of donors.

Although the evaluation intends to provide the most robust practical measurement of the impact of the Act, we are conscious of the potential difficulties in doing so. For example the opt-out is being introduced in Wales during a period of improvement in UK-wide donation rates (following the implementation of the recommendations of the 2008 organ donation taskforce) and there is the continuing influence of family members over the donation process. There are also likely to be a range of lower profile interventions in other parts of the UK that might impact on donation rates.
4 Evaluation Findings

4.1 Awareness of change to organ donation system and support for change

*Sources:* General public and NHS staff surveys, SNODs and CLODs qualitative research

**General summary**

The communications campaign to raise awareness for the soft opt-out system has been successful in some key respects:

- Awareness of the change to the organ donation system has increased among both NHS staff and the general public
- There is early evidence of waning levels of awareness among the public since the communications campaign has dropped off (measurement of staff views does not extend as far)
- Levels of support for the new system have increased significantly among NHS staff
- In 2016, one year after the new law came into force, 71% of the Welsh public were in favour of a soft opt-out system (versus 49% in the rest of the UK)
- By 2016, almost eight in ten staff (78%) and nearly two thirds (65%) of the general public said they had opted-in to organ donation or had done nothing as they were happy for deemed consent to apply. Data from the ODR in June 2017 showed that in Wales 38% of the general public had opted-in and just 6% had opted-out of the system.

4.1.1 Awareness of the change to the organ donation system

In the follow-up survey of NHS staff (November 2016 to January 2017), respondents were read a description of the change to the organ donation system (shown below) and were asked whether they were aware of this change before the interview.

“The National Assembly for Wales passed a law to change organ donation to a ‘soft opt-out’ system which came into force at the end of 2015. From December 2015 people have been given the opportunity to formally ‘opt-out’ of organ donation. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families are sensitively encouraged to accept. The law allows family members to object to donation if they know the deceased person would not have wished to consent. The opportunity to ‘opt in’ and register a decision to be a donor continues for those who wish to do so”.

Positively, overall awareness of the change to the organ donation system increased significantly between the two survey waves, from 89% pre-implementation to 96% post implementation. Levels of awareness increased across almost every staff group with the exception of clinical leaders, whose awareness remained at the very high level seen pre-implementation.

Although increases in levels of awareness were seen across the board (Figure 1), the small base sizes for some staff groups meant that some of the
differences were not statistically significant; that being said, however, we can take these increases as an indicative trend. Significant increases in levels of awareness were seen among:

- GPs (100% at post-implementation, compared with 93% at pre-implementation)
- Hospital nurses not working in A&E or ITU (98% at post-implementation compared with 86% at pre-implementation)
- Hospital doctors not working in A&E or ITU (91% at post-implementation compared with 79% pre-implementation)

**Figure 1: Awareness of changes to organ donation system: Staff**

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>All staff</td>
<td>89%</td>
<td>96%</td>
</tr>
<tr>
<td>GPs</td>
<td>93%</td>
<td>100%</td>
</tr>
<tr>
<td>Hospital doctors A&amp;E, ITU</td>
<td>91%</td>
<td>96%</td>
</tr>
<tr>
<td>Other hospital nurses (not in A&amp;E, ITU)</td>
<td>79%</td>
<td>96%</td>
</tr>
<tr>
<td>Specialist nurses A&amp;E, ITU</td>
<td>93%</td>
<td>96%</td>
</tr>
<tr>
<td>Clinical leaders</td>
<td>100%</td>
<td>91%</td>
</tr>
<tr>
<td>Other hospital doctors (not in A&amp;E, ITU)</td>
<td>79%</td>
<td>91%</td>
</tr>
</tbody>
</table>

A1 Before today, were you aware of this change to the organ donation consent system in Wales?

Base: All staff (W1: 280, W2: 268), GPs (W1: 57; W2: 55), Hospital doctors in A&E or ITU (W1: 28; W2: 33), Other hospital doctors (W1: 61; W2: 47), Specialist nurses in A&E or ITU (W1: 42; W2: 41), Other hospital nurses (W1: 56; W2: 54), Clinical leaders (W1: 36; W2: 38)

Surveys of the public showed that awareness rose strongly after the legislation came into force (see Figure 2): in November 2015, 75% were aware (having been prompted with a description of the new system), rising to a peak in awareness in March 2016, when 84% of the Welsh public said they were aware. More recent survey waves reveal some waning levels of awareness, reflecting a lower level of media activity relating to the changes: by March 2017, the proportion of people aware of the changes (after having been prompted) had dropped back slightly to 81%. A similar trend was evident when the general public were asked if they were aware of any changes taking place to the organ donation consent system, without being prompted with a description. Again, unprompted awareness peaked in March 2016 but has decreased slightly since.
Before today, were you aware of this change to the organ donation consent system in Wales?

Base: All general public (c. 1,000 respondents per wave)

Further analysis shows that there were consistent significant differences in prompted awareness by age and social groups since the pre-implementation wave, with younger age groups (16-34 year olds) and those in social groups C2DE (which includes manual workers, casual workers and those who rely on the state for income) tending to have lower awareness of the change in the law.
4.1.2 Support for legislation

Levels of support for the change in the organ donation system increased significantly among NHS staff following the legislation coming into force. Before implementation, seven in ten staff (71%) said that they were in favour of the change in legislation and this had risen to more than four-in-five (85%) in the post-implementation survey. Encouragingly, the number of staff who felt they needed more information to decide on how they feel about the change to the system has halved following the legislation coming into effect (down from 22% pre-implementation to 11% post-implementation).

At the overall staff level, a significant positive change in support was noted between pre and post-implementation. At the staff group level however, due to base sizes, most of the changes between waves were not statistically significant (see Figure 3).

![Figure 3: % In favour of change in legislation by staff group](image)

B2. I'm going to read out some statements that people have said about organ donation. I'd like you to tell me to what extent you agree or disagree with the statements.

Base: All staff (W1: 280, W2: 268), GPs (W1: 57; W2: 55), Hospital doctors in A&E or ITU (W1: 28; W2: 33), Other hospital doctors (W1: 61; W2: 47), Specialist

Staff's answers to open-ended questions about the changes to the system tended to be positive or neutral, rather than negative, with an emphasis on saving lives. Details of the exact nature of the comments are included in the NHS staff survey report.\(^{13}\)

The GfK Omnibus survey of the UK general public, which took place in December 2016 (one year after the law changed in Wales), asked people to say whether they were in favour of, or against, a change to organ donation that involved an opt-out system, or whether they needed more information to decide. In Wales, 71% of people were in favour of the change to an opt-out

system and this was significantly higher than the rest of UK (49%). Fourteen per cent of people were against the change (in line with the rest of the UK, 17%), while 13% felt they needed more information (a significantly lower proportion than across the rest of the UK, 23%). Public attitudes in the rest of the UK are therefore currently in a similar position as Wales was prior to discussions about changing the system, (June 2012): at this time 49% were in favour of the change, 22% were against and 21% said that they needed more information.

4.1.3 Personal intentions

In the post-implementation staff survey, nearly half (46%) of staff said they were registered to opt-in, a third (32%) said they would do nothing, as they were happy for deemed consent to apply and a fifth (19%) had not thought about it or were still considering their options – the remainder (3%) had registered to opt-out. If we compare the staff survey with the general public research conducted by Beaufort in March 2017, we can see that NHS staff were more likely to have registered to opt-in; in contrast the general public tended to say they were happy for deemed consent to apply (Figure 4). The actual levels of opting-in among the Welsh population is 38%, according to the 2017 NHSBT Activity report.

Figure 4: Personal intentions

E1. Now that the new system of opting out has been introduced, which of the following best describes your status in relation to organ donation?

Base: All staff (268); All general public (1,007)* Beaufort March 2017 omnibus survey

14 The answer options for this question were changed in the follow-up survey to allow comparison with the general public data and therefore no trend data is reported.
Knowledge of and attitudes towards the new system

Sources: General public and NHS staff surveys, qualitative research with general public, SNODs and CLODs qualitative research

General summary

- Self-rated knowledge about the new system rose among NHS staff following the law coming into effect (increasing from 57% pre-implementation to 80% post-implementation)
- Staff attitudes towards the new system have remained largely stable, but there has been a shift in a positive direction in terms of views of the Government’s influence, with fewer staff in the follow up survey agreeing with the statement ‘The soft opt-out system gives the Government too much control’
- In surveys of the general public carried out in March 2016 and March 2017, around three-quarters agreed that if an individual chose not to register a decision, that this should be treated as a decision to be a donor which families should be encouraged to accept

Self-rated knowledge about changes to the system

Levels of self-rated knowledge among NHS staff rose between the pre and post-implementation surveys, with more than a 20 percentage point increase in the number of staff who said they knew at least a fair amount about the change to the organ donation system (57% at pre-implementation compared with 80% at post-implementation).

 Increases in the proportion of staff who said that they knew at least a fair amount about the change to the organ donation system were most notable among:

- GPs (79% at post-implementation compared with 51% at pre-implementation)
- hospital nurses who do not work in A&E or ITU (78% at post-implementation compared with 39% at pre-implementation)
- hospital doctors who do not work in A&E or ITU (77% at post-implementation compared with 43% at pre-implementation)
The qualitative research with SNODs and CLODs revealed some doubts about clinicians’ knowledge of the new system. There were examples where clinicians and nurses assumed that the new legislation was a hard opt-out process, or they themselves had opted out because of the new legislation, without, in the participants’ eyes, understanding that it gave them greater choice. The role of the family was also not thought to have been fully grasped by some health professionals whose perspective is similar to the general public – not all are aware that the family are consulted under a soft opt-out consent system.

4.1.4 Attitudes towards the new system

Overall NHS staff attitudes to the organ donation consent system were stable before and after implementation of the new law. In both survey waves, about four-fifths (80% pre-implementation; 85% post-implementation) of staff agreed that the change to the organ donation consent system would mean that more lives would be saved. In the post-implementation wave, hospital doctors working in A&E or ITU were the least likely staff group to agree that the new soft opt-out system for Wales will result in more lives being saved’ (73% compared with 85% among other staff) – however it should be noted that due to small base sizes this difference is not statistically significant and should be treated as indicative only (although echoing the pre-implementation result).
GPs tended to hold a more positive view than three years ago; pre-implementation, 79% of GPs agreed that ‘The soft opt-out’ system for Wales would result in more lives being saved’ and this rose to 90% post-implementation.

Relatively few NHS staff agreed that ‘Organ donation is a gift which the ‘soft opt-out’ system will take away’ - a fifth of staff agreed with this statement at both waves (20% pre-implementation; 23% post-implementation). Attitudes towards the change in system in relation to maintaining freedom of choice has also remained stable, with a very large majority at both waves (86% pre-implementation; 93% post-implementation) agreeing that ‘The soft opt-out system maintains freedom of choice because anyone can opt-out from organ donation if they want to’.

The main change in attitudes following the implementation of the law related to whether staff felt that ‘The soft opt-out system gives the Government too much control’. Positively, views on this issue seem to be shifting, with a significant increase in the proportion of staff who disagreed with the statement (66% pre-implementation compared with 79% post-implementation). This change was mainly driven by an increase in the proportion of GPs (72% pre-implementation compared with 88% post-implementation), hospital doctors working in A&E or ITU (69% pre-implementation versus 88% post-implementation) and nurses (63% pre-implementation compared with 78% post-implementation) who disagreed.

Figure 6: Attitudes towards soft opt-out system

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B2 I'm going to read out some statements that people have said about organ donation. I'd like you to tell me to what extent you agree or disagree with the statements.

Base: All staff (W1:280; W2: 268)
In the Public Attitudes Survey, respondents were asked to what extent do you agree or disagree that, if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept?

In March 2016, three quarters of respondents (75%) agreed with the statement. While this figure dropped to 67% in June 2016, it had sprung back to 74% by March 2017.

Levels of disagreement with the statement fluctuated, from 10% in March 2016 to 17% in June 2016 and declining to 12% in March 2017. Aggregated levels of neither agree or disagree and don’t know stood at between 13%-17% across the three waves (with the lowest level of 13% reached in March 2017).

Figure 7: Accepting decision not to opt-out

Research among SNODs and CLODs revealed that although they perceived that there had been an increase in awareness among the general public regarding the new legislation, they also felt that the public’s knowledge of how the legislation actually worked was ‘sketchy’: ideas of opting in and opting out were thought to be understood but less so the idea of deemed consent and what this involved. Some participants also reported misunderstandings among the public about organ donation more generally, with some people thinking that they could not donate if they had had cancer or if they were already the recipient of a donated organ.

15 This question applied to Waves 11 (March 2016), 12 (June 2016) and 13 (March 2017) but not Wave 10 (November 2015).
4.2 The Role of the Family

Sources: General public and NHS staff surveys, SNODs and CLODs qualitative research

General summary

- At the last data point in each research series, 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 a minority of NHS staff do not fully understand the role of the family in the new organ donation system:
  - The proportion of staff who incorrectly identified the statement ‘the family will have no role to play in the organ donation process’ as true nearly doubled between pre and post-implementation surveys (from 7% to 13%). This was particularly the case among GPs.
  - 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 post-implementation wave of the staff survey, 80% of staff confirmed that they had discussed their decision about whether to become an organ donor with a family member. In the case of the general public, by March 2017 of the public attitudes survey, 51% had ever discussed their wishes regarding organ donation with a family member (up from 47% in November 2015).
- Qualitative research with the general public identified ways in which family discussions about organ donation could be encouraged; these may be of use in any future communications campaigns or public awareness raising exercises.

4.2.1 Knowledge of the role of the family

In order to assess whether NHS staff had understood the role of the family under the new system when the deceased had not opted-out, they were asked to indicate whether four statements were true or false; two of the statements were right and two were wrong (Figures 8 and 9).
<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the family is in distress over the decision to donate, clinicians will not proceed with organ donation</td>
<td>The family will have no role to play in the organ donation process</td>
</tr>
<tr>
<td>The family can provide evidence that the deceased objected to donating their organs but did not get around to registering during their lifetime</td>
<td>The family can override the wishes of the deceased</td>
</tr>
</tbody>
</table>

There is some evidence that a few members of NHS staff – particularly those not working in A&E or ITU – may be misinterpreting the intention of the soft opt-out: the proportion who thought that the family of the deceased would have no role to play in the new organ donation consent system increased to 13% post-implementation from 7% pre-implementation. This increase was most notable among GPs (20% thought the statement was true at post-implementation, compared with 0% pre-implementation) and suggests that further communications may be required to family doctors.

There was no change between pre and post-implementation surveys in the opinions of staff regarding the false statement about the family being able to override the wishes of the deceased. Two-fifths (40%) of staff reported that this was true, while just over half identified it as false (54%). Among doctors working in A&E or ITU, the proportion who said that this statement was true increased from about a quarter (28%) pre-implementation to a half (50%) post-implementation. Due to the small base size of this group we cannot say that it is a significant difference, rather the finding is indicative. It is likely, given that this staff group is in the front line of organ donation working in A&E/ITU departments, that they have seen families override the consent that has been given by the deceased. This would have happened under both the opt-in and opt-out consent systems if families were in distress.
In terms of the ‘true’ statements presented to staff, the message about what will happen if the family is in distress has **not** stood up across time - there has been an overall decline in the number of staff who thought it was true that “*If the family is in distress over the decision to donate, clinicians will not proceed with organ donation*” from three quarters (74%) pre-implementation to about six in ten (58%) post-implementation. The decline was most notable among the following staff groups:

- Senior hospital doctors who do not work in A&E or ITU (57% true at post-implementation, compared with 71% pre-implementation)
- All nurses (56% true post-implementation, compared with 76% pre-implementation)

There was no change in the proportion of staff who said it was true that “*The family can provide evidence that the deceased objects to donating their organs*”. At both waves three quarters of staff said that this statement was true (Figure 9).
Another new question was included in the post-implementation staff survey to determine the extent to which staff 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’. Four fifths (81%) of staff agreed that families should be encouraged to accept the decision, and levels of agreement were broadly similar across all staff groups (Figure 10).
In terms of the views of the general public in Wales, in December 2016 81% of people thought the deceased’s wishes should be honoured. In addition, levels of agreement with the statement ‘To what extent do you agree or disagree that, if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept?’ had risen from 67% in June 2016 to 74% in March 2017.

Focusing on conversations with families of patients, the qualitative research with SNODs and CLODs revealed that they often felt that the process of harvesting organs was not understood by the family. Examples were given of families changing their mind and not supporting deemed consent after finding out how long the process took, as well as examples of families thinking that donation would take place automatically (leading to staff having to explain the choices available so that the family fully understood the situation). There was a feeling that there was still work to do in terms of encouraging families to respect the decision of the donor (as would be the case with a Will). In addition, they felt that further encouraging people to register their decision...
would be beneficial – this was based on some participants’ experiences in which deemed consent cases had not been supported by the family.

4.2.2 Discussing donation with family

A new question was included in the post-implementation NHS staff survey to ascertain whether NHS staff discussed their decision about whether to become an organ donor with a family member. On the whole, most NHS staff had discussed their decision with their family (80%).

Hospital doctors who did not work in A&E or ITU (66%) were the least likely staff group to have discussed their decision with their family (Figure 11). Perhaps not surprisingly, staff who said they had at least a fair amount of knowledge about the change to the organ donation system were more likely to have discussed their decision with a family member compared with staff who said they either knew not very much or nothing about the change (85% compared with 72% respectively).

**Figure 11: Discussed decision with a member of the family?**

<table>
<thead>
<tr>
<th>Staff Group</th>
<th>Discussed Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>All staff</td>
<td>80%</td>
</tr>
<tr>
<td>Specialist nurses A&amp;E, ITU</td>
<td>88%</td>
</tr>
<tr>
<td>Hospital doctors A&amp;E, ITU</td>
<td>86%</td>
</tr>
<tr>
<td>Other hospital nurses (not in A&amp;E, ITU)</td>
<td>78%</td>
</tr>
<tr>
<td>GPs</td>
<td>77%</td>
</tr>
<tr>
<td>Clinical leaders</td>
<td>70%</td>
</tr>
<tr>
<td>Other hospital doctors (not in A&amp;E, ITU)</td>
<td>66%</td>
</tr>
</tbody>
</table>

**E2. Have you ever discussed your decision about whether to become an organ donor with a family member?**

Base: All staff (280), GPs (57), Hospital doctors in A&E or ITU (28), Other hospital doctors (61), Specialist nurses in A&E or ITU (42), Other hospital nurses (56), Clinical leaders (36); general public (691)* Beaufort omnibus survey June 2016

This issue was explored with the general public at two levels: had they ever discussed their wishes regarding organ donation with a family member; and, for those who said they had made a decision to opt in/out/ do nothing relating to the new law, they were asked if they had discussed that decision with their family.
By March 2017, around half of people (51%) had ever discussed their wishes regarding organ donation with a family member, this marked a modest increase from 47% in November 2015 and 48% in March 2016 and June 2016.

Figure 12: Ever discussed wishes regarding organ donation with a family member: General Public

Have you ever discussed your wishes regarding organ donation after death with a family member? Base: All general public (c. 1,000 respondents per wave)

In November 2015, March 2016 and June 2016 there were significant differences by age, gender and social group, with the proportion of respondents who had discussed their wishes with a family member tending to be lower among:

- 16 to 34 year olds;
- Men and
- C2DE respondents

In March 2016 and June 2016, respondents who had registered to opt in, take no action, and were happy for deemed consent to apply, or to opt-out were asked ‘Have you ever discussed that decision with a family member?’ Around six in ten of this group had discussed their decision (58% March 2016; 62% June 2016).

18 Beaufort Research Public Attitudes Survey Wave 13 (n=1035, Wales only) ‘Have you ever discussed your wishes regarding organ donation after your death with a family member?’
Some significant differences were noted by gender and social group, with the proportion of respondents who had discussed their decision with a family member tending to be lower among men and C2DE respondents.

Analysis by age also revealed some significant differences. In March 2016, the proportion of respondents who had discussed their decision with their family was markedly lower among 16-34 year olds (49% versus 61% aged 35 years or more). By June 2016, however, the proportion of 16-34 year olds who had discussed their decision was at a similar level to that among the over-55s (58% and 59% respectively).

To add further depth to the findings about discussing organ donation with family members, GfK conducted a qualitative exercise involving members of the public in Wales in 2016 looking specifically at this issue. Crucially, there was some variation in what people meant when they said they had discussed their wishes with family members. This could mean a conversation that had taken place some time ago; a conversation had taken place with some but not all members of the family; and/or a discussion that wasn’t necessarily conclusive or sufficiently in-depth.

Among those that had discussed their organ donation decision with family, the discussion(s) were typically driven by one or more of three key factors:

- Recognising the positive outcome of organ donation (the impact that donation could have on individuals waiting for an organ transplant)
- After seeing media coverage regarding the change in legislation
- Personal experiences of friends or family dying which had highlighted the importance of discussing decisions with family

Across the whole sample of individuals who took part in the research, a number of other benefits were identified during the course of the group discussions:

- Ensuring that family decisions are respected (making sure that family know their decision, and they understand their family’s decisions)
- Making things easier for next of kin
- More broadly encouraging open family discussions (although this was cited by a minority of participants)

The role of the family and making things easier for next of kin had often not previously been considered by the research participants. Thinking about this was a key turning point for many and confirmed the benefit of discussing organ donation decisions.

A key output from this research strand was the populating of the EAST behaviour change framework\(^{20}\) with research participants’ suggestions for how to encourage people to discuss organ donation decisions with their family. The results of this exercise are included below; some of these suggestions may be useful for developing the messaging in any future communications campaigns:

<table>
<thead>
<tr>
<th>Element of the EAST framework to encourage behaviour change</th>
<th>Research findings</th>
</tr>
</thead>
</table>
| **E** Make discussing organ donation decisions **easy**      | Encourage and support organ donation decisions discussions by:  
  - Providing a stepping stone to broach the topic.  
  - Tips to encourage people to start the topic.  
  - Modelling the conversation |
| **A** Make discussing organ donation decisions **attractive** | Use a positive tone and real life stories to promote the benefits of discussing organ donation decisions:  
  **Personal benefits:**  
  - Being confident that your decision is clear.  
  - Peace of mind that your family would not be left in a difficult situation of having to make a decision when they were unclear on what you wanted.  
  - Peace of mind that you know your family’s decision.  
  - Those in favour of organ donation further noted the benefit that being clear on your decision could make a positive impact on someone else’s life should you ever become a potential organ donor.  
  **Family benefits:**  
  - Being open and sharing your decisions.  
  - Respecting each other’s wishes.  
  - Making it easy for family should you ever become a potential organ donor.  
  - Avoid shocking family members who were not aware of your decision.  
  - Avoiding family arguments where family members are not aware of your decision. |
| **S** Make discussing organ donation decisions **social**     | Highlight the social benefit of organ donation as a ‘heroic’ act, making it easier to broach and discuss the topic and decisions with family. |
| **T** Make discussing organ donation decisions **timely**     | Reflect that thinking about when to bring up the topic of organ donation is a difficult decisions by encouraging people not to leave it too late whilst avoiding a pressurised feel |

\(^{20}\) The EAST framework was developed by the Behavioural Insights Team. The full framework document can be read here: [http://www.behaviouralinsights.co.uk/wp-content/uploads/2015/07/BIT-Publication-EAST_FA_WEB.pdf](http://www.behaviouralinsights.co.uk/wp-content/uploads/2015/07/BIT-Publication-EAST_FA_WEB.pdf)
4.3 Impact of the new legislation on working practices

Sources: NHS staff surveys, SNODs and CLODs qualitative research

General summary

- The majority of NHS staff reported no impact of the new legislation on their job (88% post-implementation; compared with 57% pre-implementation who thought that there would be no impact)
- 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 by SNODs and CLODs were:
  - Changes to the family conversations, with an early focus on establishing if the patient had discussed their wishes regarding 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 new system ‘work’ and a feeling that they would be held responsible if the intended outcomes were not realised

4.3.1 Impact on their job (all NHS staff)

All staff were asked to what extent they felt that the change to the organ donation consent system would impact on their job. Overall, nearly nine in ten of those interviewed at follow-up (88%) said the change had no impact on their job compared to more than half (57%) who had predicted that there would be no impact on their job in the pre-implementation survey. This change was notable across all staff groups with the exception of clinical leaders, where the proportions remained stable (although data should be treated with caution due to very low base sizes), see Figure 13.
Staff who felt that the change to the organ donation consent system would impact on their job were asked how they thought this would happen (Figure 14). In the post-implementation survey, only 29 respondents said that the change would have an impact and therefore this data should be treated with caution due to the very low base size.

The most commonly mentioned impact was answering questions about the new system but the proportion mentioning this fell from around a half pre-implementation to a third post-implementation. In contrast, the number of staff mentioning benefits such as more organs being available for transplant and making it easier to talk to the families of patients, increased over this period.
In the first wave of research among SNODs and CLODs, there was a feeling that the new legislation would have little effect on working practices. After the new legislation had been put in place, further research showed that these expectations were largely borne out.

The transition to the new system was viewed as being quite smooth. The additional administrative steps needed before approaching a family to explore the possibility of a deemed consent were not thought to be onerous, and conversations with families post-legislation were considered fairly straightforward.

The main change to working practices was the conversation with families and introducing the subject of consent. Changes to the conversation have included exploring whether or not the family knew of the patient’s decision regarding donation during the initial approach. Some believed that it would be appropriate to raise and discuss the subject of organ donation first and then seek to establish the patient’s decision.

Participants reported encountering more situations than in the past where the family were aware of the legislation and aware of their relative’s decision regarding organ donation.
However some SNODs and CLODs queried to what extent a positive outcome with deemed consent was directly the result of the new legislation. They felt it was difficult to ascertain whether in some instances the families would have said yes anyway, even if deemed consent was not in place.

This perceived trend of more ‘known decisions’ being encountered, also included examples of decisions not to consent, which had come as a surprise to some research participants and they wondered whether the Welsh Government had considered that more people may specifically not wish to donate, as the decision had been discussed.

To put this in context, there are nearly seven times as many Welsh residents who have opted in to the Organ Donation Register than have opted out.\(^{21}\)

In terms of the impact on professional relationships, the links between SNODs and clinicians was perceived to have improved, and this was put down to ongoing education from SNODs and CLODs, these specialist nurses increasingly being embedded in ICUs and a gradual cultural shift as older clinicians retired. ICU clinicians were reported as being much more likely to admit a patient solely for organ donation compared to three years ago. Changes to the law had provided an opportunity to educate staff about the specialist role of the SNOD in consent and other legal issues. Younger staff were perceived to be more open to involving SNODs and the education of trainee staff was therefore thought to play an important role going forwards.

A final point is the perceived pressure on SNODs to make the policy ‘work’. Some SNODs were concerned they might be blamed if consent rates did not improve but they felt they were working as hard as they could, trying to support the families as well as possible.

4.4 Training and guidance in relation to the new organ donation consent system

Sources: NHS staff surveys, SNODs and CLODs qualitative research

General summary

- Following implementation of the law, three quarters of NHS staff (75%) said they would feel fairly or very confident answering questions if a patient or member of the public asked them about the new organ donation system
  - GPs and specialist nurses in A&E and ITU saw the greatest increases in levels of confidence between pre and post-implementation surveys
- Asked who they would contact if a patient or member of the public asked them about organ donation, 64% of staff mentioned the organ donation team/staff (up from 54% pre-implementation).
- The most commonly mentioned sources of information were websites and the organ donation team/staff

\(^{21}\) NHSBT statistics from 30 June 2017 show that 1,186,443 people in Wales (38% of the population) had opted in, and 176,142 (6%) had opted out. See https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1518/wales.pdf
• SNODs and CLODs felt that they had received sufficient training and guidance leading to the change in the law, across a range of formats.
• In terms of the future, SNODs and CLODs suggested:
  o Refresher training and more opportunities for shared practice (particularly between the North Wales/North West England team and the South Wales team)
  o Making the subject of organ donation part of the curriculum for students in medicine and nursing
  o Further guidance for conversations with families in cases of deemed consent
  o Reviewing the wording used in public awareness messaging; ‘not registering a decision’ was deemed more appropriate than ‘doing nothing’
  o Making the subject of organ donation part of the curriculum for young people at school, to encourage organ donation to become a ‘cultural norm’

4.4.1 Answering questions (all NHS staff)
All staff were asked how confident they would feel answering questions if a patient or member of the public asked them about the new organ donation system. They were asked to rate their confidence level on a four point scale ranging from ‘Very confident’ to ‘Not at all confident’. Levels of confidence have increased significantly among staff following implementation of the law, rising from under two-thirds (62%) pre-implementation to nearly three quarters (75%) post-implementation. The rise in confidence was most notable among GPs (67% pre-implementation, rising to 94% post-implementation) and specialist nurses in A&E and ITU (65% pre-implementation compared with 82% post-implementation, see Figure 15).

In addition, it should be noted that the number of staff who said that they would be very confident answering questions has doubled over the three year period, albeit from a low base (6% pre-implementation, rising to 12%). Please note the small base sizes for certain occupation groups.
Staff confidence in their ability to answer questions was linked to the level of knowledge they had about the changes. Staff who said they knew at least a fair amount about the change to the organ donation consent system were much more likely to be confident answering questions compared to those who said they either knew not very much or nothing at all about the changes (83% compared with 46% respectively).

In addition to assessing confidence, staff were also asked about who they would contact if a patient or member of the public asked them about organ donation (Figure 16). The most commonly mentioned contact was still a member of the organ donation team or staff and the proportion mentioning this staff group has increased from just over a half (54%) at pre-implementation to nearly two-thirds (64%) post-implementation. Hospital doctors who worked in A&E or ITU (90%) and specialist nurses who worked in the same settings (90%) were significantly more likely than other staff groups (49%) to report they would contact a member of the organ donation team or organ donation staff.

As in the pre-implementation survey, around one in ten (12%) reported that they would not know who to contact and this rose to nearly a third (30%) among GPs.
Figure 16: Who would you contact if a patient/member of the public asked you about organ donation?

<table>
<thead>
<tr>
<th>Option</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organ donation team/staff (NET)</td>
<td>54%</td>
<td>64%</td>
</tr>
<tr>
<td>A specialist nurse in organ donation</td>
<td>33%</td>
<td>31%</td>
</tr>
<tr>
<td>Organ donation team/transplant services</td>
<td>17%</td>
<td>14%</td>
</tr>
<tr>
<td>A clinical lead in organ donation</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>A doctor in organ donation or transplants</td>
<td>9%</td>
<td>16%</td>
</tr>
<tr>
<td>Other colleagues</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>GP/Local hospital/Consultant</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Internet</td>
<td>6%</td>
<td>11%</td>
</tr>
<tr>
<td>NHS website/NHS Healthboard/ NHS Trust</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>National transplant/organ donation website/helpline</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>Doctors in A&amp;E, ITU</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>I wouldn’t know who to contact</td>
<td>12%</td>
<td>11%</td>
</tr>
</tbody>
</table>

C4. Who would you contact, if a patient or member of the public wanted to speak to someone about the organ donation process?
Base: All staff (W1: 280; W2: 268)
4.4.2 SNODs & CLODs

The following paragraphs draw on findings from the final wave of research with Specialist Nurses and Clinical Leads in organ donation, which took place in September and October 2016\textsuperscript{22}.

Professional training
SNODs and CLODs tended to feel that they had received sufficient training and guidance leading up to the change to the organ donation system. Training and guidance was provided to this staff group in a range of formats, including presentations, discussions and role playing.

While role playing was not a favoured method for some, on balance, this was considered an effective means of practising family conversations. Role play not only provided constructive feedback in a safe environment but also provided alternative strategies that staff may not have considered.

Printed material, such as a flowchart of the steps which had to be taken, was considered useful and some participants kept this to hand to refer to as and when needed; this was particularly the case among those with little experience of family approaches post-legislation (e.g. those working in North West England, near the border with Wales).

When the legislation changed, participants reported that senior staff had been available for SNODs to consult, for example when facing a first deemed consent approach to a family. Peer support among SNODs was important during initial conversations.

Regular team meetings continued to act as a platform to discuss experiences and share good practice. Such forums and ongoing opportunities for sharing, e.g. emails were deemed to be valuable. There was also a desire for more shared practice between SNODs in North Wales/North West England team and the South Wales team, given that those in South Wales would have more regular exposure to this issue.

Given experiences of some families not supporting deemed consent or overriding a patient’s ODR opt-in, it was felt that it would be beneficial to continue to review how the conversation is approached with the patient’s family. SNODs wished for additional guidance to ensure they had the opportunity to talk about the benefits of donation and encourage families to give greater emphasis to supporting dead patients’ decisions.

Embedding the new legislation into working practices with other health professionals

Prior to and since the legislation change, SNODs and CLODs had mainly focused their education activities on staff with close proximity to the donation process, namely critical care and A&E staff. Consequently, these staff were thought to have a greater understanding of the legislation than other hospital staff (whose levels of knowledge were deemed to be similar to those of the general public).

Finding the time when staff were available for education often proved difficult, so embedding took the form of informal conversations as well as regular audit meetings.

The main priorities for training/embedding were to encourage staff to keep organ donation front of mind and to update them with any developments related to the legislation. Some participants had changed the focus of their activities towards emphasising to staff the importance of early referral for a successful donation, rather than concentrating too much on the detail of the legislation.

Looking forwards, some SNODs and CLODs felt that organ donation should be part of the curriculum for students in medicine and nursing.

4.5 Guidance to the general public

Some SNODs and CLODs believed that further communication and education on the benefits of organ donation and how it works was necessary. A couple of SNODs referred to a statistic that they had used, namely that people were more likely to be a recipient of an organ than to be a donor. There was anecdotal evidence that sharing this information had prompted individuals to review their decision to opt-out.

There was also a view that the wording used around deemed consent in the public communications campaign should be reviewed; ‘not registering a decision’ was deemed more appropriate than ‘doing nothing’.

A small number of SNODs and CLODs felt that organ donation and the decisions around this should be part of the school curriculum so that young people were aware of their choices and the impact of discussing this with their family23. There was a feeling that this would gradually make donating a cultural norm.

23 Free teaching resources are now provided to schools with the aim of educating and engaging students about organ donation and the consent system in Wales. This is not part of the curriculum but can voluntarily be used by schools, if they choose to do so, as part of the personal, social and health education (PSHE) lesson plans.
5 Routine Monitoring Data Analysis

The analysis of routine NHSBT data monitored the trends in Welsh donors and compared them with patterns in another part of the UK with a broadly similar demographic profile. The routine data included information for seven full quarters since the change in the law, i.e. a 21 month period. The analysis also assessed movements in the level of consent recorded among families approached, both in Wales and elsewhere in the UK.

Please note that, throughout this section, quarters refer to the calendar year i.e. Q1 is January to March, Q2 is April to June, Q3 is July to September, Q4 October to December. The relatively small number of deceased donors in Wales (c. 60 per annum) means that fluctuations will inevitably occur.

General Summary
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, since the Act came into force. There is no evident positive trend in recent quarterly donation figures or in the moving annual totals either side of the change in the law.

The 21-month periods either side of the Act coming into force show 101 deceased donors prior and 104 deceased donors following implementation. This very small increase is also reflected in comparisons with earlier matched periods of time (to remove any seasonality in the data). There are five other periods in the data that correspond to the 21 months since the change was made (i.e. with two Q1s, two Q2s, two Q3s but only one Q4) and these average 99 donors, compared with the 104 for the time since implementation.

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 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 the North East of England (an area with a broadly similar demographic profile to Wales and similar opt-in rates on the ODR before the change in the law) shows lower figures for Wales than the North East but with some evidence that the Welsh position has made relative improvements in recent quarters.

Analysis of consent rates and numbers of eligible families approached indicates that consent has increased markedly in recent years, from a low point of only 44.4% in 2014 to a high of 64.5% in the most recent 12 months. From lagging over 10% behind the consent levels recorded in the rest of the UK, Wales now has higher consent than England, Scotland and Northern Ireland combined. However, this increase has not been reflected in a significant rise in the actual number of donors in Welsh hospitals over the same period, implying either lower eligibility or fewer eligible families being approached for consent.
It will be important to continue this analysis over a much longer period to assess the impact of the new law, as the current data has only around 100 donors since the turn of 2016, making it difficult to draw any firm conclusions on impact at this relatively early stage.

5.1.1 NHS data source and levels of analysis

An extensive data-file was provided by NHS Blood and Transplant (NHSBT) to cover the period of 30 quarters from Q2 2010 (i.e. April to June 2010) through to Q3 2017 (July to September 2017). This includes seven quarters since the change in the law in Wales and 21 prior to this event – Q4 of 2015 includes periods either side of the change.

The data consisted of the following details for each UK donor in the given period:

- Donor type: DBD (Donors after Brain Death); DCD (Donors after Circulatory Death); Living Donors
- Donor cause of death: Detailed cause of death
- Donor sex: Male or Female;
- Donor Ethnicity: Asian, Black, Chinese/Oriental, Mixed, Not Reported, Other, White:
- Donor BMI: Body Mass Index (Weight (in kilos)/ Height (in metres) squared) in intervals of 0.1
- DBD donor
- DCD donor
- Borough council area of donor residence: The 22 Welsh councils and all other relevant authorities across the UK
- Welsh hospital: whether or not the donation took place in a Welsh hospital
- Quarter of donation: calendar quarter (three months) of donation

The file included a total of 17,471 UK donors, with 8,060 live and 9,411 deceased donors. The donor records were quite complete, with full coverage for donor type, Welsh hospital and quarter of donation. There were some missing values, including:

- 34 unknown causes of death
- 4 cases with no sex of donor
- 40 cases with no ethnicity code (unknown and not reported)
- 698 with no BMI
- Only 2 cases without an age-band code

However, the most significant missing value was for the council area of residence. Across the overall file, a total of 2,122 records (12.1%) had invalid or missing postcode entries so we do not know where these people lived (not even whether they lived in a particular country of the UK). These missing
values were much more common for deceased than for living donors (20% vs 3.5%) but the number of missing local authority codes has reduced significantly since 2015 across all parts of the UK. We note that the annual NHSBT activity report now allocates almost every donor to a UK nation.

Within the UK file, 714 cases were recorded at Welsh hospitals, with 450 of these being deceased and 264 live donors. The Welsh figure of 63% of donors being deceased is 9% higher than for the UK as a whole.

Focussing on the 450 deceased donors from Welsh hospitals, 18 were flagged as not being resident in Wales – some of these cases were from English border counties, such as Shropshire, so a Welsh hospital will sometimes have been the closest location. A total of 308 donors had a Welsh address but 124 of the 450 Welsh hospital cases had no local authority code (28%, rather higher than the 20% for the UK as a whole). Based on this ratio of 18 (non-Welsh):308 (Welsh residents), we might expect another 6 of these un-coded 124 donors to have been resident elsewhere, giving an estimated total of 426 Welsh resident donors from Welsh hospitals.

While the main focus of the evaluation is on organ donation in Wales, there is a case to be made to extending the coverage of the analysis beyond Welsh hospitals to include Welsh resident donors identified in other parts of the UK. This covers another 60 cases, mainly from people who lived in border counties such as Flintshire but who may have received hospital treatment in Chester or in a specialist centre in Liverpool. It is reasonable to suppose that more positive views around the value of organ donation among Welsh residents could be manifested not just in Wales itself but also when potential donors have died elsewhere in the UK.

NHSBT also provided information on the number of eligible donor families approached and consented in Wales. This helps set the headline figures in a more appropriate context although we do not have any detailed information on the total population of eligible donors so we are unable to ascertain whether the overall flow of potential donors has varied across time. However, given that there are now seven quarters of data for 2016 and 2017, we might expect the usual quarterly fluctuations to begin to demonstrate a trend.
In the analysis of the routine NHS data for deceased donors, the evaluation has examined a range of different outputs:

1. Quarterly figures for all deceased donors in Welsh hospitals from Q2 2010, including Q4 2015 (i.e. the quarter in which the new law came into force)
2. As above but filtered to remove identifiable non-Welsh residents
3. Moving annual totals (MAT) for 1 and 2 (starting from Q1 2011)
4. Moving 21-month totals for these groups (beginning in Q3 2011)
5. Specific comparison for periods either side of the new Law (with Q4 2015 excluded)
6. Quarterly figures for identifiable Welsh donors outside Wales
7. Moving annual totals for this group
8. 18-month moving totals for this group
9. Specific comparison for Welsh donors outside Wales for the 21 month periods either side of the change in the Law (i.e. excluding Q4 2015)
10. Quarterly figures for Welsh resident donors since Q2 2010 (i.e. Welsh hospital donors, less non-Welsh residents, added to Welsh residents donating outside Wales)
11. Moving annual totals for Welsh resident donors
12. 18-month moving totals for this group
13. Specific comparison for Welsh resident for periods either side of the new Law
14. Comparison between residents of Wales and North East England for quarters, Moving Annual Totals and various 21-month moving totals.

5.2 Eligibility and consent

NHSBT data on donor family consent was made available for the period from Q2 2010 to Q2 2017 and this was analysed for Wales and separately for the rest of the rest of the UK. The number of ‘eligible’ donors does not provide a sensible baseline number due to the current UK screening practice in DCD donation which deems a number of ‘eligible’ DCD donors unsuitable for organ donation before families are approached. Please also note, that the data here is from the Potential Donor Audit (PDA) which collects data on the potential for organ donation within a set criteria and excludes patients over 80. Therefore, whilst largely similar, the consent and donor data are slightly different cohorts.

The quarterly data on those approached for donation vary markedly at the Wales level given the small population. The highest figure was for 50 families and the lowest for only 22.
The figures for moving annual totals are subject to less fluctuation, ranging from 137 to 172 families approached in a 12-month period. The period since the change in the law shows figures around the 140 mark, compared with 160-170 in the period leading up to implementation.
The annual Welsh consent rates (i.e. the percentage of families approached that agreed to donation) were over 60% at the start of the series in Q1 2011 but dropped sharply over the following years to a low point of only 44.4% at the end of 2014. Since then, there has been a steady rise and the most recent figure is the highest in the series (64.5% in Q2 2017). As shown in Figure 19 below, the Welsh consent rates were initially ahead of the rest of the UK but then fell a long way behind before the recent sustained recovery that now sees the conversion rates for Wales being slightly higher than for the combined data for Scotland, England and Northern Ireland.

It should be noted that the striking increase in consent rates in Wales over the last three years is not reflected in a parallel rise in the actual number of donors in Welsh hospitals. The evaluation does not have data to explain this situation but it could relate to either a long-term drop in eligibility or fewer families being approached to discuss donation.
5.3 Donation rates

5.3.1 Quarterly figures for all deceased donors in Welsh hospitals from Q2 2010, including Q4 2015

Quarterly figures for donors in Welsh hospitals show considerable variation across this period, from as few as 9 cases to a high of 24. The mean average per quarter was exactly 15 and while there is some evidence of higher flows of donation in Q4 (mean of 17), it is worth noting that both of the 21-month periods either side of the new law include only one Q4 (Figure 20).

Examination of the quarterly mean average for deceased donors in Welsh hospitals shows there is no difference between the figures for Q2 2010 through to Q3 2015 and those since Q1 2016 (both 15).
Figure 20: All deceased donors in Welsh hospitals (Q2 2010 to Q3 2017)

* Opt out system came into force during Q4 2015 (1st December)
5.3.2 Quarterly figures for all deceased Welsh resident donors in Welsh hospitals from Q2 2010, including Q4 2015

Excluding definite non-Welsh residents has little impact on most of the quarterly figures, as only 18 cases were removed out of 450. However, most of these exclusions occur in most recent quarters which drags down the average since the change in the law (Figure 21).

We have assumed that all of the cases in Welsh hospitals without a local authority code are actually Welsh residents, although, on the basis of the balance between Wales and elsewhere in cases where the council area is known, we estimate that a handful won’t actually be from Wales. There is no practical way of excluding what might perhaps be just six non-residents across the separate quarterly figures.

**Figure 21: All deceased Welsh resident donors in Welsh hospitals (Q2 2010 to Q3 2017)**

Among Welsh resident donors, the respective quarterly mean averages are 14.6 for the period before the change in the law and 13.4 for the time since then.
5.3.3 Moving annual totals (MAT) for all deceased donors in Welsh hospitals and Welsh resident donors in Welsh hospitals (starting from Q1 2011)

As the fluctuations on a quarterly basis are quite marked, the analysis also took in annual figures with rolling totals, starting from the end of the first year covered by the data (i.e. Q1 2011 in the table is the end date of the first 12-month period). There were no evident trends year on year and the figures lie in the range of 47 to 67 donors.

The final full year before the change in the Law had 66 donors while the four such periods since then had 56, 61, 63 and 62 donors respectively, so there is no evidence of an upwards trend in the headline 12-month figures compared with what went before (Figure 22).

As noted earlier, (at least) 18 of the donors in Welsh hospitals lived elsewhere in the UK and most of these were in the period since the change in the law. Hence the data for most of the rolling figures in the table above does not change when non-Welsh residents are removed. However, the most recent figures all drop quite markedly – from 56 to 52 donors (year ending Q4 2016), 61 to 52 donors (to Q1 2017), 63 to 55 donors (to Q2 2017) and 62 to 55 (to Q3 2017) – because of the recent rise in non-resident donors in Welsh hospitals.
5.3.4 Moving 21-month totals for all deceased donors in Welsh hospitals and those resident in Wales (beginning in Q4 2011)

The data available for the evaluation includes a clear 21-month period since the change in the law (i.e. all of 2016 plus the first three quarters of 2017). On this basis, all deceased donors in Welsh hospitals were analysed on a rolling basis for all of the periods of 21 months since the end of Q4 2011. The variability was again quite modest ranging from a low of 90 donors to a high of 119 (Figure 23).

Figure 23: Moving 21 month totals: All deceased donors in Welsh hospital (Q4 2011 to Q3 2017)

The counts for the 21 months up to the end of Q3 2015 show 101 donors while the same time period from Q1 2016 has 104 deceased donors in Welsh hospitals.

Given there is some evidence of a seasonal effect, with a higher level of donation in Q4, the analysis also looked at periods of 21-months in the full data that matched that since the law came into effect (i.e. those than included two Q1s, two Q2s, two Q3s but only one Q4). The post-implementation figure of 104 donors is a little higher than the average for the five earlier equivalent periods in the data (99).

The all-donor figures varied when the 18 definite non-Welsh resident donors were removed. Ten quarters were affected with a particular concentration in the period since the law changed, so the moving 21-month
total for all Welsh hospital donors is significantly lower in 2017 when filtered on residency (Figure 24).

The analysis of Welsh resident donors again looked at periods of 21-months in the full data that matched that since the law came into effect (i.e. those than included two Q1s, two Q2s, two Q3s but only one Q4). The post-implementation figure of 94 donors is a little lower than the average for the five earlier equivalent periods in the data (96).

We noted above that there has been a recent drop the number of deceased donors with no local authority coding and this is quite marked in the data for Welsh hospitals. The implication is that the figures might slightly overstate the number of Welsh resident donors in the period prior to implementation but not to the extent of changing the parity between the numbers in the previous paragraph.
5.3.5 Quarterly figures for all Welsh resident donors since Q2 2010

In total, the NHSBT data included 492 cases thought to be Welsh residents, 432 of whom had donated in Wales with 60 elsewhere in the UK. As noted above, there could be six cases among the 432 that are not actually Welsh residents but there is no way of identifying these non-Welsh donors in the analysis. Figure 25 (below) shows the estimated quarterly figures for Welsh resident organ donation - the mean average was 16.5 donors, and the range from 10 to 27 donors.

![Figure 25: All Welsh resident donors (Q2 2010 to Q3 2017)](image)

5.3.6 Moving annual totals for all Welsh resident donors since Q2 2010

The estimated moving annual totals show some fluctuations and range from 54 to 73 donors. Data for the most recent 12-month periods (65 to 69 donors) are no higher than those recorded for the times immediately before the change in the law (Figure 26).
The figure of 65 donors for the 12 months ending Q1 2017 can be compared with data from the NHSBT activity report for this year. The latter output gives a figure of 68 for the 12 months ending Q1 2017, suggesting there could be even more Welsh donors in hospitals outside Wales than indicated above. We cannot match this analysis because of the volume of donors with no local authority code.
5.3.7 21-month moving totals for all Welsh resident donors since Q2 2010

The various 21 month periods range from 93 to 130 donors, with the most recent counts (113) being very similar to those in the run-up to the new law (114 – see Figure 27).

![Figure 27: 21 month totals: all Welsh resident donors (Q4 2011 to Q2 2017)](image)

The best-matched periods are shown for Q3 (i.e. those with the same quarterly balance as the 21-month period since the new Law) and there is no consistent pattern to this data, other than a slight rising trend since the low point of 2013.

5.3.8 Comparisons between Wales and North East England

While the main focus of the analysis is on the figures for Wales, the evaluation also examined data for North East England to provide some comparisons in trends across time.

A country with a growing population has the potential for more donors: between 2004 and 2014, the growth rate of the UK as a whole has been faster than that of Wales (0.75% per annum compared to 0.45%). A suitable comparator with a similar overall population size was the North East (with a growth rate of 0.30% per annum).²⁴
Along with similar levels of opting-in to organ donation (35% vs 38% for Wales), the North East has broadly similar demographic profiles to Wales including about the same levels of non-white residents (who are known to have lower levels of consent to organ donation). On the basis of these three comparisons, we have chosen the North East as our comparator area.

A key issue here is how to define residents for Wales and the North East on a reasonably consistent basis. As noted earlier, a significant minority of deceased donor records (20%) do not have a local authority code and cannot therefore be linked to a particular nation or region. While this will presumably impact on all parts of the UK, it appears to be a particular issue in Wales (although here we have the advantage of being able to identify donors in Welsh hospitals). Hence, if we define Welsh residents purely by local authority codes, we could significantly understate the actual number of cases in Wales. Equally, if we include Welsh hospital donors with no council code, we lose comparability with other parts of the UK where no national/regional hospital code is available in the current data.

For reasons of consistency, we have filtered on definite residency (not hospital donors) and have to accept this could mean the possibility of excluding more donors from Wales than from the North East. Although the Welsh population is larger than that of the North East, the data here shows more deceased donors in this English region (419 donors) than in Wales (368 donors, made up of 308 in the country itself plus 60 who donated elsewhere).

5.3.9 Moving annual totals for deceased donors

In the initial two quarters, the Welsh figures were ahead of those for the North East but there followed a long period in which the English region was well ahead. Of late, the respective figures have generally been closer and in Q2 2017 they were the same (Figure 28).
5.3.10 Moving 21-month totals for deceased donors

The rolling 21-month data shows a more divergent pattern compared to the 12 month; with the figures for the North East ahead of Wales across the period (Figure 29).
Figure 29: Moving 21 month totals: deceased donors (Q3 2011 to Q3 2017)
6 Conclusions and Recommendations

The overall findings of the surveys among NHS staff and the general public have produced a number of positive trends in terms of awareness and support for the new approach to organ donation in Wales. This positive tone is also generally evident in the qualitative research among both groups.

Knowledge about the change peaked soon after the Act came into force but has declined slightly since then, showing the importance of keeping the new system visible to the general public. Continuing to raise awareness about the positive impact of donation, through the media and using real life case stories, might also help keep the campaign in the public mind.

The Welsh public have remained in favour of the soft opt out system and opinion in Wales in this respect is ahead of that in the rest of the UK. There is also widespread acceptance that not registering a decision should be treated as a decision to be a donor.

NHS staff in Wales are also supportive of the change in the law. Knowledge has improved among staff and they are now less concerned about the system giving the Government too much control. The vast majority of staff reported no impact on their workload from the new system.

There has been a significant increase among NHS staff in self-rated knowledge and confidence in answering questions about organ donation. However, it appears some NHS staff do not fully understand the role of the family and more communications about this part of the process might be required here.

There is a need to improve understanding among the public and NHS staff of the role of the family in decision making. This could perhaps be achieved by encouraging family discussions about donation decisions; the inclusion of organ donation awareness in the school curriculum (making organ donation a ‘cultural norm’); including more on organ donation in the training curriculum for doctors and nurses; and embedding understanding among SNODs and CLODs via refresher training and sharing of best practice.

The routine data analysis shows no consistent positive trend in terms of organ donation from either Welsh hospitals or from Welsh residents. The figures for the 21 months either side of the change in the law are much the same, and a longer period for comparison will be needed to draw firmer conclusions about the impact of the law on donation rates. The current analysis only covers a short period and is subject to quarterly fluctuations.

It will be important to continue to monitor the routine NHSBT data on organ donation in Wales, and among Welsh residents more generally, as well as observing trends in similar parts of the UK. Eligibility and consent rates will also need continued monitoring. The most recent data in this respect shows increased consent levels but implies lower eligibility, given there has been no consistent rise in donor levels.
Recommendations

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.
Appendix - Methods

Public Attitudes Survey

The Public Attitudes survey was undertaken using the Beaufort Research Wales Omnibus Survey. The Wales Omnibus Survey sample is designed to be representative of the population resident in Wales aged 16 years and over. The unit of sampling is Lower Super Output Area (LSOA) and 69 interviewing points throughout Wales are selected with probability proportional to resident population, after stratification by unitary authority and social group.

Within each sampling point, demographic quota controls of age and social class within sex are employed for the selection of respondents. Quotas are set to reflect the individual demographic profile of each selected point. The data have been weighted by age group within gender within unitary authority grouping to give each cell its correct incidence within the Wales total derived from the results of the 2011 Census.

A fresh sample of interviewing locations and individuals are selected for each survey and no more than one person per household is interviewed. Interviews are conducted face to face in the homes of respondents utilising CAPI (Computer Aided Personal Interviewing) technology.

A minimum of 1,000 adults aged 16+ who were resident in Wales were interviewed at each wave. Thirteen waves of the survey were conducted between 2012 and 2017.

NHS Staff Surveys

The objectives of the project, were to:

- Understand attitudes, expectations and level of knowledge about the new system
- Identify staff whose work may be impacted by the introduction of the new system
- Measure changes over time in the views of NHS staff and the expected impact on their work
- Identify changes to working practices as a result of the implementation of the Act
- Identify any unexpected issues caused by the move to the soft opt-out system
The target audience for the research comprised of NHS staff in certain occupations and working for the health service in Wales. The list of occupations included in the research is listed below and targets were set for each grouping.

- GPs
- Hospital Doctors who worked in A&E or ITU – both ‘Senior’ and ‘Junior’ doctors were included in this group
- Hospital Doctors who did not work in A&E or ITU – about half were ‘Junior’ doctors of Specialist Registrar grade or below, and half were ‘Senior’ doctors of higher grades
- Specialist Hospital Nurses who work in A&E or ITU
- Hospital nurses who did not work in A&E or ITU: around half were specialist nurses (not in A&E or ITU) and half were ‘general’ ward nurses
- Clinical Leaders: including Medical Directors, Nursing Directors and Clinical Directors

The contact lists for the research were provided by Binleys who hold extensive lists of health professionals in Wales and are regularly used by GfK on research among NHS staff across the UK. Named lists were available for most staff groups with the exception of general ward nurses and some junior hospital doctors. These latter groups were sampled as follows:

- In order to speak to general ward nurses, Binleys provided general reception numbers for hospitals and interviewers called these numbers and asked to be put through to a ward.
- Because of the mobility of Hospital Doctors in Foundation 1 and Foundation 2 grades, Binleys does not hold named listings of doctors at these grades. GfK interviewers called general hospital numbers and asked to be put through to a ward. When speaking with someone on the ward, they asked to be put through to a doctor at Foundation 1 or Foundation 2 grades (otherwise known as House Officers or Senior House Officers).

Table 1 shows the number of interviews completed within each occupation.

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Pre-implementation</th>
<th>Post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs</td>
<td>57</td>
<td>55</td>
</tr>
<tr>
<td>Hospital Doctors who work in A&amp;E or ITU</td>
<td>28</td>
<td>33</td>
</tr>
<tr>
<td>Hospital Doctors who do not work in A&amp;E or ITU</td>
<td>61</td>
<td>47</td>
</tr>
<tr>
<td>Specialist hospital nurses who work in A&amp;E or ITU</td>
<td>42</td>
<td>41</td>
</tr>
<tr>
<td>Hospital nurses who do not work in A&amp;E or ITU</td>
<td>56</td>
<td>54</td>
</tr>
<tr>
<td>Clinical Leaders</td>
<td>36</td>
<td>38</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>280</td>
<td>268</td>
</tr>
</tbody>
</table>
Fieldwork
Fieldwork was conducted by telephone using Computer Assisted Telephone Interviewing (CATI) and took place between the following dates:

- Pre-implementation wave: 4th December 2013 and 31st January 2014.
- Post-implementation: 7th November 2016 and 31st January 2017

Interviewing took place from GfK’s telephone interviewing centre – the company is a member of the Interviewer Quality Control Scheme (IQCS) and all interviewers were fully trained, briefed and monitored.

A letter from the Welsh Government was available to email to respondents who required further reassurance before completing the interview.

Analysis and weighting
To enable separate analysis among healthcare professionals by job role a minimum number of interviews were conducted within each occupation. Data were then weighted to give an estimate of the views and awareness of all NHS staff in Wales in the occupations included in the research. With over-sampling of certain staff groups, the effective sample size would be much reduced by the weighting process.

Weighting was applied as follows:

- Re-balancing the proportion of staff in different occupations in the sample, then
- Weighting by Health Board region.

These weights were based on the workforce number data taken from the StatWales website and were applied at both waves. The unweighted and weighted proportions are shown in Table 2.
Table 2: Weighted and unweighted profiles of NHS Wales Staff sample by staff type and Health Board

<table>
<thead>
<tr>
<th></th>
<th>Pre-implementation</th>
<th>Post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unweighted</td>
<td>Weighted</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>GPs</td>
<td>57</td>
<td>20</td>
</tr>
<tr>
<td>Hospital doctors (including Clinical Leaders)</td>
<td>119</td>
<td>43</td>
</tr>
<tr>
<td>Hospital nurses (including Nursing Directors)</td>
<td>102</td>
<td>34</td>
</tr>
<tr>
<td>Health Board</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abertawe Bro Morgannwg University</td>
<td>53</td>
<td>19</td>
</tr>
<tr>
<td>Aneurin Bevan</td>
<td>48</td>
<td>17</td>
</tr>
<tr>
<td>Betsi Cadwaladr University</td>
<td>57</td>
<td>20</td>
</tr>
<tr>
<td>Cardiff and Vale University</td>
<td>44</td>
<td>16</td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>27</td>
<td>10</td>
</tr>
<tr>
<td>Hywel Dda</td>
<td>43</td>
<td>15</td>
</tr>
<tr>
<td>Powys Teaching</td>
<td>8</td>
<td>3</td>
</tr>
</tbody>
</table>

The statistical impact of the weighting reduced the effective sample size for the total sample was 154 at the pre-implementation wave and 152 at the post-implementation wave. While the impact of this weighting may appear large, the need to structure the sample as shown above meant that weighting effects of this magnitude were expected.

**Initial qualitative research with SNODs and CLODs**

The following objectives were set for the research study:

- To gain an understanding of the working practices and experiences of Specialist Nurses and Clinical Leads under the current opt-in system of organ donation;
- To establish expectations, attitudes and any concerns that Specialist Nurses and Clinical Leads had regarding the implementation of, and impact of moving to, a soft opt-out system;
- To gain an understanding of the views of Specialist Nurses and Clinical Leads on how moving to a new soft opt-out system might impact on their discussions with family members on consent for organ donation; To determine any additional training requirements that Specialist Nurses and Clinical Leads might have in preparation for the change in legislation;
- To identify any other unanticipated issues articulated by Specialist Nurses and Clinical Leads in relation to moving to a soft opt-out system; and
- To provide recommendations for any future research undertaken with Specialist Nurses and Clinical Leads in the immediate run-up to, and following, the implementation of the soft opt-out system.
Research methodology

Given the nature of the topic, individual in-depth interviews was the primary methodology used, to allow for the exploration of views in detail and in a confidential one-to-one environment. It was also felt that individual interviews would fit better with participants’ patterns of work. Most of the interviews were conducted at participants’ places of work.

Prior to Beaufort beginning to contact potential participants, the Welsh Government sent out an email to each SNOD and CLOD outlining the purpose of the research and informing them that they might be contacted by Beaufort to see if they would be interested in taking part.

As a preliminary research stage, Beaufort ran an online bulletin board forum with an invitation to participate sent to all Specialist Nurses for Organ Donation (SNODs) and Clinical Leads for Organ Donation (CLODs), whose contact details were provided by the Welsh Government. The primary aim of the online forum was to give the entire target audience the opportunity to express their views, and to inform the design of the topic guide to be used in the individual interviews. Participants were able to post anonymously, and respond to the questions in as much detail as they wished. This method was also appropriate for what is a geographically dispersed audience. From a total population of 35 SNODs and CLODs and support staff made available, 18 participants posted at least once in the discussion with 16 posting more than twice. The forum generated 100 posts in total. All staff who were available were invited to the online forum.

Some 25 participants took part in an in-depth individual interview with Beaufort, of which 21 were conducted face-to-face and four by telephone. The numbers broke down as follows:

Based on these sample requirements set by the Welsh Government, Beaufort targeted participants from across the seven Local Health Boards in Wales and those who were in team manager and regional roles. Five Local Health Boards were represented in the final sample (including recent experience of working in a sixth Local Health Board), as well as those in team manager and regional roles.

Fieldwork took place during late February and early March 2013, with interviews lasting between 35 minutes and one hour 15 minutes.
Qualitative research with SNODs and CLODs after change in legislation

The following main objectives were set for the research study:

- Assess the views of SNODs and CLODs in Wales regarding the implementation and impact of the soft opt-out system;
- Build on the findings provided in the pre-legislation research project with this audience (2015);
- Gain an understanding of any changes in working practices and experiences of SNODs and CLODs now the legislation has been implemented;
- Evaluate any changes in expectations, attitudes and concerns regarding the implementation of, and impact of moving to, a soft opt-out system;
- Gain an understanding of how moving to a soft opt-out system has impacted on their discussions with family members about consent for organ donation;
- Determine any additional training requirements that Specialist Nurses and Clinical Leads may still have in relation to the new legislation;
- Identify unanticipated issues articulated by SNODs and CLODs having moved to a soft opt-out system.

Research methodology

Beaufort used a qualitative, individual interview method to take into account the flexibility required of SNODs’ and CLODs’ roles and working patterns. All but one of the 25 interviews were conducted face to face in a confidential environment at participants’ place of work. One discussion was a paired in-depth interview to fit with participants’ schedules. One interview was conducted by telephone owing to participant availability and geographic location.

Prior to Beaufort beginning to contact potential participants, the Welsh Government sent out an email to each SNOD and CLOD outlining the purpose of the research and informing them that they might be contacted by Beaufort to see if they would be interested in taking part. Using a database provided by the Welsh Government, Beaufort recruited:

- 17 SNODs (covering South Wales, North Wales and North West England where SNODs also covered North Wales);
- 8 CLODs from an available sample of 14 contacts (in both South and North Wales).
The 25 interviews broke down as follows:

<table>
<thead>
<tr>
<th>Region</th>
<th>SNODs</th>
<th>CLODs</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Wales / North West England</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>South Wales (also covering South West Wales, Mid Wales and Hereford)</td>
<td>10</td>
<td>5</td>
</tr>
</tbody>
</table>

Fieldwork took place late September to late October 2016, with interviews lasting between 30 minutes and one hour.

Each interview was audio-recorded with participants’ permission. The interviews were free flowing based on a topic guide agreed with the client (see appendix). The Beaufort team transcribed the conversations and analysed them by identifying and grouping points made within each transcript. Points were then developed into themes depending on how prevalent they were.

Groups – discussing decisions with the family

This research set out to explore:

- Whether people understand the importance of discussing organ donation decisions with family.
- Barriers to discussing organ donation decisions with family.
- Potential role for communications in overcoming barriers to discussing organ donation with family.
- Reactions to existing organ donation legislation communications (two bus adverts used during 2016).
Research methodology
Given the exploratory nature of the research objectives, a qualitative approach was employed. This allowed participants to speak openly about their views and feelings regarding discussing organ donation with family, using their own words. Mini-group discussions were chosen to bring people together to share their opinions, encourage debate and to support the creation of ideas for how communications could best encourage people to discuss their organ donation decisions with family.

Eight mini-group discussions were carried out. Each lasted up to 90 minutes, and six participants were recruited to each session.

The sample for the mini-group discussions was designed using existing Welsh Government data from the Beaufort Wales omnibus survey. This survey provided statistics regarding awareness of the change in organ donation legislation, and steps taken by individuals since the change in legislation had come into force. The data identified the following groups of interest that were considered key in understanding how to encourage people to discuss decisions with family:

- Those who have not registered to opt-in or opt-out of organ donation but are happy for presumed consent and have discussed their decision with family.
- Those who have not registered to opt-in or opt-out for organ donation but are happy for presumed consent and have not discussed their decision with family (in one research location this was broadened out to include those who were considering their options to reflect the survey data for the region).
- Those who have registered an opt-in decision on the organ donation register and have not discussed their decision with family.

The mini-group discussions were also sampled based on demographics to ensure a good spread of different people and circumstances across the research. This included a mix of gender, age and socio-economic group. Four locations were included across the research ensuring a spread of regions across Wales, and in two of these, one mini-group discussion was carried out in Welsh language.
NHSBT Routine Data

Anonymised data from NHSBT was available for the whole of the UK for the period from Q2 2010 to Q2 2017, and contained the following data fields:

- Donor type: DBD (Donors after Brain Death); DCD (Donors after Circulatory Death); Living Donors
- Donor cause of death: Detailed cause of death
- Donor sex: Male or Female;
- Donor Ethnicity: Asian, Black, Chinese/Oriental, Mixed, Not Reported, Other, White:
- Donor BMI: Body Mass Index (Weight (in kilos)/ Height (in metres) squared) in intervals of 0.1
- DBD donor
- DCD donor
- Borough council area of donor residence:
- Welsh hospital: whether or not the donation took place in a Welsh hospital
- Quarter of donation: calendar quarter (three months) of donation

GfK omnibus survey for GB

The comparator attitudes survey was undertaken on GfK’s Omnibus Survey. The survey provides an accurate representation of the population of UK, through a combination of random location sampling and quota controls on age, and sex within working status.

1,993 adults aged 16+ who were resident in UK were interviewed. All interviews were conducted face to face in respondents' homes using CAPI (Computer Assisted Personal Interviewing). One wave of the survey was conducted in December 2016.

GfK Quality Assurance

- GfK is a Market Research Society (MRS) Company Partner
- GfK follows ICC/ESOMAR The World Association of Research Professionals
- ISO 20252:2012 Market, Opinion and Social Research Standard
- ISO 9001:2008 Quality Assurance Standard
- A member of Interviewer Quality Control Scheme (IQCS)