Evaluation of the Human Transplantation (Wales) Act: NHS Wales Staff Survey Wave 2
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GfK UK Ltd

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

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Table of contents

1 Executive Summary ........................................................................................................................................2
  1.1 Summary of findings ..........................................................................................................................2
  1.2 Awareness and support ......................................................................................................................2
  1.3 Knowledge of change to organ donation system .............................................................................3
  1.4 Answering questions .........................................................................................................................3
  1.5 Impact on job .....................................................................................................................................4

2 Introduction ..............................................................................................................................................5
  2.1 Background ........................................................................................................................................5
  2.2 Research design ................................................................................................................................6
  2.3 Questionnaire ....................................................................................................................................7
  2.4 Engagement with Health Boards ......................................................................................................7
  2.5 Fieldwork ..........................................................................................................................................7
  2.6 Analysis and weighting ....................................................................................................................8
  2.7 Notes on reading this report ...........................................................................................................9

3 Awareness of change to organ donation system and support for change ............................................10
  3.1 Awareness of the change to the organ donation system ................................................................10
     3.1.1 Support for legislation .............................................................................................................11
     3.1.2 Personal intentions ..................................................................................................................13
  3.2 Discussed with family .......................................................................................................................13
  3.3 Knowledge of changes to the organ donation consent system .......................................................14
     3.3.1 Knowledge of the role of the family .......................................................................................15
  3.4 Attitudes towards the new organ donation consent system ............................................................17
  3.5 Answering questions .........................................................................................................................18
  3.6 Sources of information .....................................................................................................................20
  3.7 Impact on their job .............................................................................................................................21

4 Conclusions and Considerations .............................................................................................................23

Appendix A – Questionnaire for Wave 2
Appendix B – Letter of reassurance
1 Executive Summary

On the 1st December 2015, the Human Transplantation (Wales) Act came into full effect, introducing a soft opt out system for consent to organ and tissue donation. In light of the change to the organ and tissue donation system, the Welsh Government commissioned GfK to carry out research to help understand NHS staff views on the change. The objectives of the project, which is part of a wider programme of research and evaluation, 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

A baseline survey was conducted with staff in December 2013 and January 2014 (i.e. before the change in the system had been implemented) and a second wave of fieldwork was carried out between November 2016 and January 2017 (i.e. after the law had come into force).

Fieldwork was conducted by Computer Assisted Telephone Interviewing (CATI) and questionnaires were designed by GfK in close consultation with the Welsh Government. Interviews were conducted with NHS staff in their workplace

Data were weighted at the analysis stage to ensure findings were representative of all NHS staff within the occupations included in the survey, and ensure Health Board regions were in-line with the national profile. The same weighting was applied to both waves.

1.1 Summary of findings

Overall, levels of awareness and support for the change to the organ donation system were high and significant increases were evident since the Wave 1 survey.

1.2 Awareness and support

Positively, the level of awareness of the change to the organ donation consent system has increased since Wave 1. The vast majority of staff said they were aware of the change (96% W2 compared with 89% W1). Levels of awareness have increased most notably among GPs (100% W2, compared with 93% W1) and hospital nurses who did not work in either A&E or ITU (98% W2 compared with 86% W1).

Levels of NHS staff support for the change in the legislation have also risen with more than four-in-five (85%) now in favour of the change (71% W1). The proportion of staff who felt they needed more information to decide whether they supported the change in legislation has halved (22% W1 against only 11% W2).

Staff were asked about their current personal status in relation to organ donation and the change to the consent system. Only 3% said that they were registered to opt out i.e. they would not be a donor, while nearly a quarter said they were either considering their options or had not thought about it.
Positively, four fifths (80%) of staff said that they had at some point discussed their decision about whether to become a donor with a family member.

1.3 Knowledge of change to organ donation system

Along with increases in awareness and support for the change in legislation, levels of self-rated knowledge have also risen. Four fifths (80%) said at Wave 2 that they knew at least a fair amount about the change to the organ donation system (up from 57% at the first wave). Increases in levels of self-rated knowledge were especially notable among GPs (79% W2 versus 51% W1); hospital nurses and doctors not working in A&E or ITU (78% W2 versus 39% W1 for nurses and 77% W2 versus 43% W1 for doctors).

Attitudes to the change in the organ donation system have remained positive and, when compared to the previous wave, stable. More than four fifths agreed that the new soft opt out for Wales will result in more lives being saved (85%) and that the system maintains freedom of choice because anyone can opt out from organ donation if they want to (93%). However, as in the first wave, hospital doctors working in A&E or ITU had the lowest proportion agreeing that the new soft opt out for Wales will result in more lives being saved (73% compared with 86% among other staff groups).

There is evidence to suggest that some staff may be misinterpreting the soft opt out message with regard to the role of the family. There was a decline in the proportion of staff who thought that the family will have a role to play in the organ donation process (84% W2 compared with 92% W1) and that if the family is in distress over the decision to donate, clinicians will not proceed (58% W2 compared with 74% W1).

However, there is indicative evidence to suggest that the letter of the law may not be being followed entirely on the ground in A&E departments. Among hospital doctors working in A&E or ITU the proportion who said it was true that the family can override the wishes of the deceased has increased from a quarter (28%) to a half (50%) – please note this finding is indicative due to small base sizes.

1.4 Answering questions

Levels of confidence in answering questions from the general public and patients about the new organ donation system have increased. Overall three quarters of staff (75%) said they were at least fairly confident in answering questions (rising from 62%). The proportion of staff who said they were very confident has doubled over the three years (from 6% W1 to 12% W2).

As seen at Wave 1, confidence increased with knowledge, with four fifths of those who said they knew at least a fair amount about the change to the organ donation consent system saying they were confident answering questions (83%, compared with 46% who did not know much or anything at all).

The proportion of staff who said they would contact a member of the organ donation team/staff, if a patient or member of the public wanted to speak to someone about the organ donation process, has increased to nearly two thirds (64% W2, rising from 54%). As seen in the first survey, staff who worked in A&E or ITU were the most likely to mention contacting the organ donation team/staff (90% for both doctors and specialist nurses).

The most commonly mentioned sources of information on organ donation included websites/helplines (47%), the organ donation team/staff (26%) and the Local Health Board (intranet, newsletter) (21%).
1.5 Impact on job

Now that the change to the organ donation system has been implemented there has been a significant increase in the proportion of staff who said that the change did not impact on their job (88% W2 versus 57% at W1). Among those staff for whom the change had an impact, the most commonly mentioned issue was time spent answering questions from patients and families of patients.
2 Introduction

2.1 Background

Organ transplantation has become one of the most successful medical procedures as just one organ donor can save or improve up to nine lives by donating their organs, and many more by donating their tissues. Surveys have long shown that up to nine out of ten adults in Wales and the rest of the UK are in favour of organ donation, but the number of people 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 must consent to their use on an ‘opt-in’ basis. These 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 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 are 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. Under this system, three choices are available:

1. register a wish to be a donor by expressly opting in and signing the new organ donor register; or
2. register a wish not to be a donor by expressly opting out on the new organ donor register; or
3. do nothing and choose to have your consent deemed.

Under an ‘opt out’ or deemed consent system, every person aged 18 or over who has lived in Wales for at least 12 months, and who has the required mental capacity, is deemed to have given their consent to organ donation unless they have specifically opted out.

The system in Wales is based upon ‘soft’ as opposed to a ‘hard’ opt out system. In a hard opt out system, families would not be consulted about organ donation if consent was either expressly given or presumed. In a soft opt out system, families and friends will be involved

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1 See for example http://www.nhsbt.nhs.uk/to2020/resources/ThepotentialimpactofanoptoutsystemfororgandonationintheUK.pdf
in discussions and may provide information to show the deceased did not wish to be a donor.

A Code of Practice underpinning the implementation of the system is in operation, including dealing with the cross-border issues that may arise due to Wales operating a different system to the rest of the UK.

In order for the Welsh Government to understand the views of NHS staff, research was commissioned in 2013 for GfK to track opinions and attitudes in relation to the change to the organ donation consent system. This strand of a wider research programme deals solely with the views of NHS staff and aims 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 Bill
- Identify any unexpected issues caused by the move to the soft opt out system

The baseline survey among NHS staff was reported in 2014 and this new report includes data from the second survey, carried out in 2016-17 (with comparisons made where possible with the original study).

2.2 Research design

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 provided 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>Wave 1 (Winter 13-14)</th>
<th>Wave 2 (Winter 16-17)</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>Total</td>
<td>280</td>
<td>268</td>
</tr>
</tbody>
</table>

2.3 Questionnaire

As with the initial survey, the questionnaire was developed by GfK in close consultation with the Welsh Government. To allow for some comparison of views between NHS staff and the general public to the changes to the organ donation consent system, questions from the public attitudes survey\(^2\) were included in the health service questionnaire.

The questionnaire mainly used pre-coded lists of responses, with the opportunity to capture further detail being possible via “other” answer options at some questions. One open-ended question was included in the survey.

2.4 Engagement with Health Boards

All Health Boards were contacted prior to fieldwork commencing, to inform them of the survey and ask for their assistance with publicising the survey. An initial letter was sent to all Medical Directors by the Welsh Government and GfK followed up this contact with the communications departments at each Health Board.

2.5 Fieldwork

Fieldwork was conducted by telephone using Computer Assisted Telephone Interviewing (CATI) and took place between the following dates:

- Wave 1: 4\(^{th}\) December 2013 and 31\(^{st}\) January 2014.
- Wave 2: 7\(^{th}\) November 2016 and 31\(^{st}\) 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. A copy of the letter is included in appendix B.

2.6 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.

<p>| Table 2: Weighted and unweighted profiles of NHS Wales Staff sample by staff type and Health Board |
|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|
| Wave 1 Unweighted | Wave 1 Weighted | Wave 2 Unweighted | Wave 2 Weighted |</p>
<table>
<thead>
<tr>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs</td>
<td>57</td>
<td>20</td>
<td>15</td>
<td>5</td>
<td>55</td>
<td>21</td>
<td>15</td>
</tr>
<tr>
<td>Hospital doctors (including Clinical Leaders)</td>
<td>119</td>
<td>43</td>
<td>51</td>
<td>18</td>
<td>109</td>
<td>41</td>
<td>40</td>
</tr>
<tr>
<td>Hospital nurses (including Nursing Directors)</td>
<td>102</td>
<td>34</td>
<td>214</td>
<td>76</td>
<td>104</td>
<td>39</td>
<td>213</td>
</tr>
<tr>
<td>Health Board</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abertawe Bro Morgannwg University</td>
<td>53</td>
<td>19</td>
<td>55</td>
<td>20</td>
<td>52</td>
<td>19</td>
<td>53</td>
</tr>
<tr>
<td>Aneurin Bevan</td>
<td>48</td>
<td>17</td>
<td>49</td>
<td>18</td>
<td>54</td>
<td>20</td>
<td>46</td>
</tr>
<tr>
<td>Betsi Cadwaladr University</td>
<td>57</td>
<td>20</td>
<td>56</td>
<td>20</td>
<td>59</td>
<td>22</td>
<td>54</td>
</tr>
<tr>
<td>Cardiff and Vale University</td>
<td>44</td>
<td>16</td>
<td>51</td>
<td>18</td>
<td>36</td>
<td>13</td>
<td>49</td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>27</td>
<td>10</td>
<td>25</td>
<td>9</td>
<td>27</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>Hywel Dda</td>
<td>43</td>
<td>15</td>
<td>35</td>
<td>13</td>
<td>38</td>
<td>14</td>
<td>34</td>
</tr>
<tr>
<td>Powys Teaching</td>
<td>8</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>

The statistical impact of the weighting reduced the effective sample size for the total sample was 154 at Wave 1 and 152 at Wave 2. 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.
2.7 Notes on reading this report

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

- The base sizes for some of the 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).

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

3.1 Awareness of the change to the organ donation system

At Wave 2 staff 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 has increased significantly (from 89% at Wave 1 to 96% at Wave 2) and is now almost universal among NHS staff. Levels of awareness have increased across almost every staff group with the exception of clinical leaders, who have remained at the very high level seen at Wave 1.

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

- GPs (93% W1 compared with 100% W2)
- Hospital nurses not working in A&E or ITU (86% W1 compared with 98% W2)
- Hospital doctors not working in A&E or ITU (79% W1 compared with 91% W2)
Chart 1: Awareness of changes to organ donation system

3.1.1 Support for legislation

Levels of support for the change in the organ donation system have increased significantly since the Wave 1 survey. In Wave 1, seven in ten NHS staff (71%) said that they were in favour of the change in legislation and this had risen to more than four-in-five (85%) at Wave 2. 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 since Wave 1 (down from 22% W1 to 11% W2).

Although at the overall staff level, a significant positive change was noted between waves 1 and 2; at the staff group level, due to base sizes, most of the changes between waves were not statistically significant (see Chart 2).
All staff were asked an open-ended question to see whether they had any further comments about the organ donation system. On the whole, the comments on the change tended to be positive, with an emphasis on saving lives. The other comments tended to be neutral rather than negative and focused on the need for more communication about the change.

Examples of the comments can be found below.

**Positive comments:**
- “I think it’s a positive change that the Welsh Government has made. I do think that despite policy, there will still be family sensitivity taken into consideration.”
- “I’m very much in favour. I think that quite a lot of people would like to donate. When family members don’t know about it then it can be difficult for doctors to discuss with them. When it’s done in advance it takes the pressure away. The soft opt out system encourages people to think about it and they know that they need to do something if they want to opt out.”
- “I think it is a very good system, I don’t think everybody agrees with it but I think it is very good. I’ve heard on the news that there have been more transplants performed as a result.”
- “I think the presumed consent with the ability to opt out is a good system because it makes more organs available.”

**Neutral and negative comments:**
- “They probably need to make more information public”
- “I need a bit more information. I feel that I should think about it but don’t really want to face it. I’d like to do something if it would help people.”
- “The Government made a big mistake with the soft opt out legal change, especially given the small number of additional donors it was suggested it would achieve. There were other means by which this increase in donation could have been achieved. They said they would achieve 9 more donors a year which we could have got through other ways. I think assuming consent for any procedure is an insult to civil liberties and potentially sets a dangerous precedent.”
• “It does depend on the willingness of the families to support it. Problems can still occur even with the new system. There is a need to educate the families about the system as they can get very distressed.”

3.1.2 Personal intentions

All staff were asked what they would do in relation to organ donation, now that the system had been introduced. Overall, nearly a half (46%) 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.

The answer options for this question were changed at Wave 2 to allow comparison with the general public data and we have therefore not included a comparison with the Wave 1 data here.

If we compare the staff survey with the general public research conducted in June 2016, 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 (Chart 3).

Chart 3: Personal intentions

<table>
<thead>
<tr>
<th>Status</th>
<th>General Public June 2016</th>
<th>NHS staff Winter 2016/17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered to opt-in</td>
<td>46%</td>
<td>17%</td>
</tr>
<tr>
<td>Nothing, happy for presumed consent to apply</td>
<td>46%</td>
<td>32%</td>
</tr>
<tr>
<td>Registered to opt-out</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Nothing but still considering options</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Nothing haven’t thought about it yet</td>
<td>11%</td>
<td>21%</td>
</tr>
</tbody>
</table>

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 2016 omnibus survey

3.2 Discussed with family

A new question was included at Wave 2 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%). A similar question was asked of the general public in June 2016 and around six out of ten (62%) reported to having ever discussed their decision regarding organ donation after their death with a family member.3

3 This question was asked of all respondents in the NHS staff survey – but for the survey of the general public it excluded respondents who answered that they ‘hadn’t thought about it yet’ or ‘didn’t know’. Therefore, these figures are indicative of differences between NHS staff and the general public but are not strictly comparable.
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 (Chart 4).

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).

Chart 4: Discussed decision with a member of the family?

<table>
<thead>
<tr>
<th>Wave 2 only</th>
<th>All staff</th>
<th>80%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist nurses A&amp;E, ITU</td>
<td></td>
<td>88%</td>
</tr>
<tr>
<td>Hospital doctors A&amp;E, ITU</td>
<td></td>
<td>86%</td>
</tr>
<tr>
<td>Other hospital nurses (not in A&amp;E, ITU)</td>
<td></td>
<td>78%</td>
</tr>
<tr>
<td>GPs</td>
<td></td>
<td>77%</td>
</tr>
<tr>
<td>Clinical leaders</td>
<td></td>
<td>76%</td>
</tr>
<tr>
<td>Other hospital doctors (not in A&amp;E, ITU)</td>
<td></td>
<td>66%</td>
</tr>
</tbody>
</table>

3.3 Knowledge of changes to the organ donation consent system

Levels of self-rated knowledge have also risen over the three years between waves 1 and 2; over this period there has been more than a twenty 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% W1 compared with 80% W2).

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% W2 compared with 51% W1)
- hospital nurses who do not work in A&E or ITU (78% W2 compared with 39% W1)
- hospital doctors who do not work in A&E or ITU (77% W2 compared with 43% W1)

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
A2. How much do you know about the changes to the organ donation consent system in Wales? Would you say ...

Base: All staff who were aware of the change (W1: 217, W2: 259), GPs (W1: 45; W2: 55), Hospital doctors in A&E or ITU (W1: 22; W2: 32), Other hospital doctors (W1: 61; W2: 42), Specialist nurses in A&E or ITU (W1: 42; W2: 35), Other hospital nurses (W1: 39; W2: 53), Clinical leaders (W1: 34; W2: 36)

3.3.1 Knowledge of the role of the family

In order to assess whether staff have understood the role of the family in organ donation under the new system when the deceased had not opted-out, they were asked to state whether four statements relating to the role of the family were true or false (Charts 6 and 7). Two of the statements were true and two of the statements were false.

<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 small number of staff may be misinterpreting the intention of the soft opt out; with the proportion of NHS staff who thought that the family of the deceased would still have a role to play in the new organ donation consent system declining to just over four fifths (84%) at Wave 2 from 92% at Wave 1. This decline was most notable among GPs (78% false at W2, compared with 98% at W1) and suggests that further communications may be required to family doctors.

There was no change between waves 1 and 2 in the opinions of staff about whether the family can 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%) at Wave 1 to half (50%) at Wave 2 – due to the small base size of this group we cannot say that it is a significant difference, rather instead the finding is indicative. It is important to reflect, given this staff group is in the front line of
organ donation, whether this finding reflects the reality on the ground at A&E/ITU departments.

**Chart 6: Role of the family: false statements**

The message given to staff 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” from three quarters (74%) at Wave 1 to about six-in-ten (58%) at Wave 2. 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 W2, compared with 71% at W1)
- all nurses (56% true at W2, compared with 76% at W1)

Again, it seems that for some staff the soft opt out in relation to the role the family may play may not be fully understood.

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 (Chart 7).

**Chart 7: Role of the family: true statements**
Another new question was included in the survey at Wave 2 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. Levels of agreement were broadly similar across all staff groups (Chart 8).

**Chart 8: Families encouraged to accept decision**

<table>
<thead>
<tr>
<th>% agree</th>
<th>All staff</th>
<th>Hospital doctors A&amp;E, ITU</th>
<th>Other hospital nurses (not in A&amp;E, ITU)</th>
<th>Specialist nurses A&amp;E, ITU</th>
<th>GPs</th>
<th>Clinical leaders</th>
<th>Other hospital doctors (not in A&amp;E, ITU)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wave 2 only</td>
<td>81%</td>
<td>86%</td>
<td>84%</td>
<td>81%</td>
<td>81%</td>
<td>80%</td>
<td>72%</td>
</tr>
</tbody>
</table>

B4. To what extent do you agree or disagree, 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? Do you…
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 (1,011)* Beaufort omnibus survey June 2016

### 3.4 Attitudes towards the new organ donation consent system

Attitudes towards the organ donation consent system were assessed by asking staff to respond to four statements relating to the new soft opt out system, using a five point scale ranging from strongly agree to strongly disagree (Chart 9). The four statements were:

- **The new ‘soft opt-out’ for Wales will result in more lives being saved**
- **Organ donation is a gift which the ‘soft opt-out’ system will take away**
- **The ‘soft opt-out’ system maintains freedom of choice because anyone can opt out from organ donation if they want to**
- **The ‘soft opt-out’ system gives the government too much control**

Overall attitudes to the organ donation consent system were stable across the waves.

In both surveys, about four-fifths (W1 80%; W2 85%) of staff agreed that the change to the organ donation consent system would mean that more lives would be saved. As in Wave 1, 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 W2’s 86% 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 Wave 1 result. GPs tended to hold a more positive view than three years ago; at Wave 1, 79% of GPs agreed that ‘The soft opt-out’ system for Wales would result in more lives being saved’ and this rose to 90% at Wave 2.
Encouragingly, very few NHS staff agreed that ‘Organ donation is a gift which the ‘soft opt-out’ system will take away’, only a fifth of staff (20% W1; 23% W2) agreed with this statement at both waves. 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% W1; 93% W2) agreeing that the ‘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 in Wave 2 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 that the change gave the Government too much control (66% W1 compared with 79% W2). This change was mainly driven by an increase in the proportion of GPs (72% W1 compared with 88% W2), hospital doctors working in A&E or ITU (63% W1 compared 88% W2) and nurses (63% W1 compared with 78% W2) who disagreed with this statement.

Chart 9: Attitudes towards soft opt out system

3.5 Answering questions

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, rising from under two-thirds (62%) at Wave 1 to nearly three quarters (75%) at Wave 2. The rise in confidence was most notable among GPs (67% W1, rising to 94% W2) and specialist nurses in A&E and ITU (65% W1 compared with 82% W2, see Chart 10).

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 (12% W2 compared with 6% W1).
C3. If a patient or member of the public asked you a question about the new organ donation system; how confident would you feel about answering that question? Would you say you would feel …

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)

As seen in the initial wave, 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 (Chart 11). 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 Wave 1 to nearly two-thirds (64%) at Wave 2. As seen at the first wave, hospital doctors who worked in A&E or ITU (90%) and specialist nurses who worked in the same setting (90%) were again 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 baseline wave, around one in ten (12%) reported that they would not know who to contact and this rose to nearly a third (30%) among GPs.
Chart 11: Who would you contact if a patient/member of the public asked you about organ donation?

<table>
<thead>
<tr>
<th>Contact</th>
<th>W2</th>
<th>W1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organ donation team/staff (NET)</td>
<td>54%</td>
<td>31%</td>
</tr>
<tr>
<td>A specialist nurse in organ donation</td>
<td>33%</td>
<td>9%</td>
</tr>
<tr>
<td>Organ donation team/transplant services</td>
<td>29%</td>
<td>17%</td>
</tr>
<tr>
<td>A clinical lead in organ donation</td>
<td>14%</td>
<td>9%</td>
</tr>
<tr>
<td>A doctor in organ donation or transplants</td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>Other colleagues</td>
<td>9%</td>
<td>16%</td>
</tr>
<tr>
<td>GP/Local hospital/Consultant</td>
<td>13%</td>
<td>7%</td>
</tr>
<tr>
<td>Internet</td>
<td>11%</td>
<td>6%</td>
</tr>
<tr>
<td>NHS website/NHS Healthboard/ NHS Trust</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>National transplant/organ donation website /helpline</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Doctors in A&amp;E, ITU</td>
<td>2%</td>
<td>7%</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)

3.6 Sources of information

A new question was added at Wave 2 about sources of information for organ donation. The most commonly mentioned sources of information were websites (47%) and the organ donation team/staff (26%). Sources of information used were fairly similar across all staff groups with the exception of specialist nurses working in A&E and ITU who were particularly likely to mention the organ donation team/staff (60% compared with 26% on average).

Chart 12: Where do you get your information on organ donation?

<table>
<thead>
<tr>
<th>Source</th>
<th>Wave 2 only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any websites/helplines (NET)</td>
<td>47%</td>
</tr>
<tr>
<td>Any mention of organ donation staff (NET)</td>
<td>26%</td>
</tr>
<tr>
<td>Websites</td>
<td>43%</td>
</tr>
<tr>
<td>Local Health Board (intranet, newsletter etc)</td>
<td>21%</td>
</tr>
<tr>
<td>Organ donation team/ link nurses</td>
<td>19%</td>
</tr>
<tr>
<td>Leaflets and Factsheets</td>
<td>17%</td>
</tr>
<tr>
<td>Welsh Government</td>
<td>16%</td>
</tr>
<tr>
<td>TV</td>
<td>15%</td>
</tr>
<tr>
<td>Specialist Nurse in Organ Donation</td>
<td>10%</td>
</tr>
<tr>
<td>My employer</td>
<td>9%</td>
</tr>
<tr>
<td>Professional bodies eg. RCN, GMC etc.</td>
<td>8%</td>
</tr>
<tr>
<td>NHS Blood and Transplant</td>
<td>8%</td>
</tr>
<tr>
<td>Newspapers</td>
<td>8%</td>
</tr>
<tr>
<td>I haven't looked for information/Don't know</td>
<td>8%</td>
</tr>
</tbody>
</table>

C5. Now thinking about sources of information, from where do you get your information on organ donation?  
Base: All staff (W2: 268). Only mentions of 8% or above are shown
3.7 Impact on their job

All staff were asked to what extent they felt that the change to the organ donation consent system would impact on their job. Now that the change to the system was in place, fewer staff said that the change would have an impact on their job. Overall, nearly nine in ten of those interviewed at Wave 2 (88%) said the change had no impact on their job compared to rather more than half (57%) who had predicted that there would be no impact on their job at Wave 1. This change was notable across all staff groups with the exception of clinical leaders, where the proportions remained stable, see Chart 13.

Chart 13: Impact of change on their job

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 (Chart 14). At Wave 2 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, as at Wave 1, answering questions but the proportion mentioning this fell from around a half to a third at Wave 2. In contrast, the number of staff mentioning more organs for transplant and making it easier to talk to the families of patients has increased over this period.
C2. In what ways has the change in the organ donation system impacted on your job?
Base: All who said that the change to the organ donation system will have an impact on their job (W1: 105; W2: 29). Only mentions of 8% or more shown.
4 Conclusions and Considerations

The change to the organ donation consent system has been well received by the vast majority of NHS staff in Wales. Awareness of the change to the system has increased across all staff groups since wave one but most noticeably among staff groups who do not have direct dealings with the organ donation process. Support for the change in the law is strong and rose between the two waves of the staff survey.

While self-rated knowledge of the organ donation system has increased among all staff since Wave 1, it has risen most notably among those who do not work in A&E or ITU. However, there does appear to be a need for more education or clarification for staff on the role of the family in the new soft opt out organ donation process. While levels of confidence in answering questions about the organ donation system have increased significantly since Wave 1, understanding the role of the family has not stood up well between the two waves. It may therefore be important for the Welsh Government to consider strengthening messaging about the role of the family for certain staff groups, including GPs.

General attitudes to change to the organ donation system have remained positive and fewer staff, compared with Wave 1, now felt that the soft opt out system gives the Government too much control.

The vast majority of staff have indicated that the change in law has not impacted on their job, despite a considerable proportion expecting it to when asked in wave 1. For those staff for whom the change has had an impact, the most commonly mentioned issue was time spent answering questions from patients and families of patients.

Occupational groups who were furthest away from the organ donation process were the least aware, knowledgeable and confident about answering questions at Wave 1, although at Wave 2 we have seen significant increases across these aspects for most staff.

Overall, hospital doctors who do not work in A&E or ITU tend to be the least engaged with organ donation; they were the least likely of all occupation groups to have discussed organ donation with their family. However, among this group, there has been a significant increase in self-rated knowledge and confidence in answering questions between waves 1 and 2.
APPENDIX A: Questionnaire – Wave 2

Organ Transplant Wave 2
272.209.0399

IV. SCREENER

INTRODUCTION 1
ALL NAMED IN SAMPLE AS GPs, SPECIALITY REGISTRARS, SENIOR HOSPITAL DRs, SPECIALIST NURSES, CLINICAL LEADERS,
SAMPLE TYPE

Please can I speak to (name from sample)? (When speaking go to intro 3)
INSERT DETAILS FROM SAMPLE
JOB TITLE (ALL SAMPLE TYPES):
SPECIALISM (FOR SPECIALIST NURSES, SPECIALITY REGISTRARS AND SENIOR HOSPITAL DOCTORS)

Yes – put through
No – not available/make appointment
No – no longer works there

INTERVIEWER ASK IF NAMED RESPONDENT NO LONGER WORKS THERE.
Please can I speak to the person who has now replaced them or who has taken over the work that they were previously doing?

INTRODUCTION 2
HOSPITAL NUMBERS – FOR GENERAL WARD NURSES, F1/F2 JUNIOR DRs
ASK IF GENERAL WARD NURSE SAMPLE / F1/F2 JUNIOR DOCTORS
Please can you put me through to a ward please?

Hello, I would like to speak to a ward nurse/ a nurse who hasn’t specialised (Ward nurse sample) / junior doctor, for example, a house officer or senior house officer now known as foundation level 1 and foundation level 2 (f1/f2 junior drs sample)
IF NECESSARY: Is there a ward nurse (Ward nurse sample) /junior doctor (F1/F2 sample) available at the moment who I could speak to?

Yes - speaking go to INTRODUCTION 3
No – go to SMS
Dk – go to SMS
INTRODUCTION 3 - ALL RESPONDENTS

Good morning/afternoon/evening, my name is ............. I am from GfK NOP, an independent research company. We are conducting a survey on behalf of the Welsh Government, among key NHS staff. The Welsh Government wishes to better understand staff knowledge and attitudes towards, one of its key policy areas. We would like to include your views in the sample – everything you say will remain confidential to the research company and your individual answers will NOT be revealed to anyone else, including the Welsh Government or your Trust:
(SPECIALIST REGISTRARS, F1/F2 JUNIOR DRs AND SENIOR HOSPITAL DOCTORS, SPECIALIST NURSES, GENERAL WARD NURSES, CLINICAL LEADERS)
Practice: (GP’S)

IF NECESSARY: The study is looking at a key policy area for the Welsh Government in relation to the NHS, in order to achieve a representative response we are not informing staff of the exact key policy area in advance. The subject matter will become clear very early in the survey.

S1 Would you be prepared to spend 10 minutes answering a few questions?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes continue to 2/S3</td>
</tr>
<tr>
<td>2</td>
<td>Yes make an appointment to SMS</td>
</tr>
<tr>
<td>3</td>
<td>I am not currently working for the NHS</td>
</tr>
<tr>
<td>4</td>
<td>More reassurance needed</td>
</tr>
<tr>
<td>5</td>
<td>No</td>
</tr>
</tbody>
</table>

ASK ALL RESPONDENTS WHO SEEM HESITANT (CODE 4 AT S1)
I have a letter from the Welsh Government which I can email to you explaining the importance of the survey and what it will cover?

Read out
S2 I can email this to you now and arrange a time to call you back? Just to let you know the email will not be sent immediately but within the next day or two.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1 Email letter and collect details. Arrange a time to call back</td>
</tr>
<tr>
<td>No – continue with survey</td>
<td>2 Continue</td>
</tr>
<tr>
<td>No – refusal</td>
<td>3 Go to SMS</td>
</tr>
</tbody>
</table>
ASK ALL GENERAL WARD NURSES, F1/F2 JUNIOR DRS
S3 Please can I just check that you have not taken part in this survey before?

1. I have not taken part in this survey before (Continue)
2. I have taken part before (go to S4)

IF A GENERAL WARD NURSE, F1/F2 JUNIOR DR WHO HAS TAKEN PART BEFORE, IE CODE 1 AT S3
S4 Please could you put me through to another {job title}?
Yes (go to introduction 2 if F1/F2 or general ward nurse)
No (go to SMS)

S5
ASK S5
If YES AT S1 CODE 1 OR S2 CODE 2 AND ORIGINAL NAMED SAMPLE OR IF WARD NURSE, F1/F2 JUNIOR DOCTOR THAT HAVE NOT TAKEN PART BEFORE IE CODE 1 AT S3.

Please can I check that you are currently a (insert Job title from sample or for GENERAL NURSE SAMPLE insert ‘general ward nurse/a nurse who has not specialised’ FOR F1/F2 JUNIOR DR’S SAMPLE insert ‘junior doctor such as a house officer or senior house officer now known as Foundation year 1 and Foundation year 2 levels’)

Yes (WARD NURSES GO TO START OF SURVEY / F1F2 JUNIOR DRS GO TO S7 / GP’s GO TO QS12 / SPECIALIST NURSES, SPECIALITY REGISTRARS, SENIOR HOSPITAL DOCTORS, CLINICAL LEADERS GO TO QS8 )
No (All go to S6 except if a ward nurse, junior doctor, then go to INTRO 2)
Dk (Go to S6 except if a ward nurse, junior doctor, then go to INTRO 2)

IF NO OR DK AT S5 OR THEY ARE A REPLACEMENT FOR THE NAMED RESPONDENT
S6 And please can I check that you are still currently working as a…
INSERT FOLLOWING WORDING AS APPROPRIATE TO SAMPLE TYPE
GP (INSERT IF SAMPLE TYPE GP)
Doctor in a hospital graded below consultant level as a specialty registrar in an area other (SPECIALITY REGISTRAR SAMPLE)
Doctor in a hospital graded as a consultant or above (INSERT IF SENIOR DOCTORS)
Specialist nurse in secondary care (a hospital nurse specialising in a certain area such as A&E or anaesthetics etc. The nurse may also work in another area such as a ward nurse)
(INSERT IF SPECIALIST NURSE)
Senior Manager as either a Clinical Director, Director of Nursing or Medical Director (INSERT IF CLINICAL LEADER)

ANSWER CODES
1. Yes (WARD NURSES GO TO START OF SURVEY, F1F2 JUNIOR DRS GO TO S7, GPs GO TO QS12, SPECIALIST NURSES, SPECIALITY REGISTRARS, SENIOR HOSPITAL DOCTORS, GO TO QS8, CLINICAL LEADERS GO TO S11)
2. Work for NHS as something else (ALL THANK AND CLOSE except if a ward nurse or junior doctor, then go to INTRO 2)
3. No longer working for the NHS (ALL THANK AND CLOSE except if a ward nurse or junior doctor, then go to INTRO 2)
Don’t know (thank and close)
ASK IF F1F2 Junior doctor AND CODE 1 at QS3
S7. And what is your current job title?

Foundation year 1 level – go to QS9
Foundation year 2 level – go to QS9
Speciality registrar – GO TO INTRO2
House officer – go to QS9
Senior house officer – go to QS9
Other – specify – go to QS9

ASK S8 IF CONSULTANT, SPECIALITY REGISTRAR OR SPECIALIST NURSE IN SECONDARY CARE
AT S5 OR S6. OR IF F1/F2 DOCTORS GO STRAIGHT TO QS9

S8. And please can I just check that you specialise in (insert from sample)?

INTERVIEWER NOTE: IF SPECIALISM IS ITU/ICU/CRITICAL CARE AND SOMETHING ELSE PLEASE CHECK
THAT THEY SPECIALISE OR WORK WITH PATIENTS IN ITU/ICU/CRITICAL CARE. IF YES RECORD AS YES.

Yes (CLINICAL LEADERS, HOSPITAL DOCTOS AND SPECIALIST NURSES GO TO S11)
Yes, I specialise in this but also work in another area (for example as a ward nurse) (CLINICAL LEADERS,
HOSPITAL DOCTOS AND SPECIALIST NURSES GO TO S11)
No (Go to QS9 EXCEPT FOR CONSULTANTS, SPECIALITY REGISTRARS OR SPECIALIST NURSES
WHO WORK IN A&E, ICU/ITU/CRITICAL CARE go to S8a)
Don’t know (Go to QS9 EXCEPT FOR CONSULTANTS, SPECIALITY REGISTRARS OR SPECIALIST
NURSES WHO WORK IN A&E, ICU/ITU/CRITICAL CARE go to S8a)

IF NO OR DK AT S8 AND A CONSULTANTS, SPECIALITY REGISTRARS OR SPECIALIST NURSES
WHO WORK IN A&E, ICU/ITU/CRITICAL CARE
S8a And do you specialise or work within any of the following areas:

A&E – go to S11
ICU/ITU/Critical Care – go to s11
Organ Transplants – go to start of survey
None of these – thank and close

If NO OR DK AT QS8 EXCEPT FOR CONSULTANTS, SPECIALITY REGISTRARS OR SPECIALIST
NURSES WHO WORK IN A&E, ICU/ITU/CRITICAL CARE OR FOR F1/F2 ALL CODES AT S7 EXCEPT
SPECIALITY REGISTRAR
QS9. Which area do you currently specialise in?
PROMPT TO PRECODES. ALLOW MULTI-CODE
1. A & E
2. Anaesthetics
3. Cardiology
4. Dermatology
5. Diagnostic Radiology
6. Endoscopy
7. ENT (Ear, nose and throat)
8. Gastroenterology
9. General Medicine
10. General Surgery
11. Gynaecology
12. Intensive Care Unit/Intensive Therapy Unit/Critical Care (ITC/ITU/Critical Care)
13. Imaging
14. Neurology
15. Neuropsychology
16. Neuroradiology
17. Obstetrics & Gynaecology
18. Ophthalmology
19. Oral Surgery
20. Orthopaedics
21. Organ Transplants
22. Palliative Medicine
23. Radiology
24. Rheumatology
25. Trauma & Orthopaedics
26. Urology
27. Other please specify
28. Dk (Go to S10) (IF F1F2 Junior doctor go to INTRO 2)
29. Refuse (thank and close) (IF F1F2 Junior doctor go to INTRO 2)
CODES 1-26 GO TO START OF SURVEY

ASK ALL CLINICAL LEADERS HOSPITAL DOCTORS AND SPECIALIST NURSES
S11. And can I just check are you ever involved in the collection of organs for transplants?

Yes
No
Don’t know

ASK ALL GPs
Q12. How long ago did you qualify as a GP?
READ OUT AS NECESSARY.
INTERVIEWER: IF RESPONDENT DOESN’T KNOW ASK FOR APPROXIMATION

Less than 2 years ago
2 years but less than 5 years ago
5 years but less than 10 years ago
10 years but less than 20 years ago
20 years but less than 30 years ago
30 years ago or more
(Don’t know)

V. MAIN QUESTIONNAIRE

A AWARENESS OF CHANGE

Base: all respondents

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.
A 1
Before today, were you aware of this change to the organ donation consent system in Wales?

There is only one answer possible.

- Yes
- No
- Don’t know

Base: ALL WHO SAID YES AT A1. OTHERS GO TO B1

A 2
How much do you know about the changes to the organ donation consent system in Wales? Would you say …

READ OUT SINGLE CODE

There is only one answer possible.

- A great deal
- A fair amount
- Not very much
- Nothing at all
- (Don’t know)

B SUPPORT FOR AND KNOWLEDGE OF

Base: all respondents

B1
Which of these statements about changes to the organ donation system in Wales best reflects your view?

READ OUT

There is only one answer possible

IF NECESSARY: People have 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 families will be sensitively encouraged to accept this. The opportunity to ‘opt in’ and register a decision to be a donor will continue

I am in favour of this change in legislation
I am against this change in legislation
I need more information to decide
Don’t know
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:

(PUBLIC)

READ OUT
There is only one answer possible per statement

- The new ‘soft opt-out’ system for Wales will result in more lives being saved
- Organ donation is a gift which the ‘soft opt-out’ system takes away
- The ‘soft opt-out’ system maintains freedom of choice because anyone can opt out from organ donation if they want to
- The ‘soft opt-out’ system gives the government too much control

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

B3
I'm going to read out a few statements about the role of the family in organ donation under the new ‘soft opt out’ system where the deceased has not opted out. Please tell me to what extent you think each statement is true.

(PUBLIC)

READ OUT
There is only one answer possible per statement

- The family will have no role to play in the organ donation process
- The family can provide evidence that the deceased objected to donating their organs but did not get around to registering during their lifetime
- The family can override the wishes of the deceased
- If the family is in distress over the decision to donate, clinicians will not proceed with organ donation

Definitely true
Probably true
Probably not true
Definitely not true
Don't know
B4
To what extent do you agree or disagree, 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? Do you…

READ OUT
There is only one answer possible per statement

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

C IMPACT ON JOB

Base: ALL WHO KNOW SOMETHING ABOUT ORGAN DONATION (A GREAT DEAL/A FAIR AMOUNT/NOT VERY MUCH AT A2)

C1
Has the change to the organ donation consent system had an impact on your job?
CODE TO PRECODES. IF YES ASK IS THAT A GREAT DEAL OR A FAIR AMOUNT
There is only one answer possible

<table>
<thead>
<tr>
<th>Yes – a great deal</th>
<th>Yes – a fair amount</th>
<th>No (no impact on job)</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

Base: ALL WHO KNOW SAID GREAT DEAL OR A FAIR AMOUNT AT C1

C2
In what ways has the change in the organ donation system impacted on your job?
DO NOT PROMPT; CODE TO PRECODES
Multiple responses allowed

- Time spent answering patients questions about the change/new system
- Time spent answering questions from patients families about the change/new system
- I will take care of more organ donation patients prior to organ collection
- Make it easier to talk to patients relatives about the possibility of organ donation
- It will create more work for me (unspecified)
- I will be involved with/undertake more transplants
- Other (specify)
- Don’t know
C3
If a patient or member of the public asked you a question about the new organ donation system; how confident would you feel about answering that question? Would you say you would feel …

READ OUT. SINGLE CODE

There is only one answer possible

<table>
<thead>
<tr>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fairly confident</td>
</tr>
<tr>
<td>Not very confident</td>
</tr>
<tr>
<td>Not at all confident</td>
</tr>
<tr>
<td>Don’t know</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?

DO NOT PROMPT; CODE TO PRECODES

- My manager
- A Specialist Nurse in Organ Donation
- A Specialist Nurse in either A&E or ICU
- A Clinical Lead in Organ Donation
- A doctor in organ donation or transplant
- A doctor in either A&E or ICU
- No-one I would answer their questions myself
- Other colleague (specify)
- I wouldn’t know who to contact

C5
Now thinking about sources of information, from where do you get your information on organ donation?)

DO NOT PROMPT; CODE TO PRECODES

- NHS Blood and Transplant
- Welsh Government
- My employer
- Professional bodies e.g. RCN, GMC etc.
- Local Health Board (intranet, newsletter etc.)
- TV
- Website/s
- Social Media
- Newspaper/s
- Leaflets and Factsheets
- Poster/s
- Advertising
- Other
- Don’t know
I would now like to ask a few questions about your views on organ donation.

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?

READ OUT. SINGLE CODE
(PUBLIC)
There is only one answer possible

- 01: Registered to opt in
- 02: Registered to opt out
- 03: Nothing – as happy for presumed consent to apply
- 04: Nothing – but still considering my options
- 05: Nothing – haven’t thought about it yet’

e: all respondents

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

Yes
No

F DEMOGRAPHICS

Base: all respondents

And finally I would like to ask a few questions about your job.

F1
How long ago did you qualify as a <doctor / nurse>?

READ OUT AS NECESSARY.

Less than 2 years ago
2 years but less than 5 years ago
5 years but less than 10 years ago
10 years but less than 20 years ago
20 years but less than 30 years ago
30 years ago or more
(Don’t know)
Base: all respondents

F2
How long have you been working for the NHS in your current role?
READ OUT AS NECESSARY

Less than 2 years
2 years but less than 5 years
5 years but less than 10 years
10 years but less than 20 years
20 years but less than 30 years
30 years or more
(Don’t know)

Base: all respondents

F3
And finally do you have any other comments about the organ donation system? OPEN ENDED
APPENDIX B – Reassurance letter

To whom it may concern,

**Re: Welsh Government Survey of NHS Staff**

The Welsh Government wishes to better understand staff knowledge and attitudes towards one of its key policy areas. We have therefore commissioned a survey to understand opinion across a range of staff of different grades, and in different job roles, across Wales. The study will seek the views of both clinicians and nursing staff. I should explain that the subject matter of the study is not specified in this letter, or in advance of staff being contacted, in order to ensure an unbiased response (i.e. we would wish to avoid attracting responses only from those staff with an interest in the topic).

The results of the study will help the Welsh Government to better plan communications with NHS staff in Wales, to ensure that staff receive relevant information.

The survey will take the form of a telephone interview and will be carried out by the independent research agency, GfK, on our behalf. GfK will contact a sample of staff from various parts of NHS organisations in Wales. The fieldwork is taking place from 7th November until 16th December. It is anticipated that the interviews will last around 10 minutes.

Your views and opinions are important to us and we would appreciate your support for this research. If you are not available to complete the interview when called, the research company will be pleased to make an appointment to call back at another more convenient time.

All responses are kept completely confidential. Data are also kept securely and processed in line with the Data Protection Act 1998, and GfK operates within the Market Research Society Code of Conduct.

If you have any further questions about this research please contact Janine Hale at the Welsh Government on 029 2082 6539 or at janine.hale@wales.gsi.gov.uk; or Sarah McHugh at GfK on 020 7890 9379 or at nhsstaffsurveywales@gfk.com.

We do hope that you will be able to help with this important research project.

Yours sincerely

Karin Philips
Deputy Director
Major Health Conditions Division
Welsh Government