Together for Health

Organ Donation Annual Report 2017
1.0 Introduction

Our annual report is a tribute to the individuals who have consented to and whose family have supported donation proceeding to save and transform the lives of people in need of a transplant. The improvements made to organ donation in Wales have only been possible through the dedication and commitment of staff working in both NHS Wales and the UK.

The changes to the infrastructure, the introduction of a soft opt out system and the Welsh Government communication campaign have delivered significant improvements with an overall upward trend for organ donation in Wales.

It is however important to remember that the success of organ transplantation depends on clinicians recognising the potential for organ donation and donation proceeding through a unique collaboration between NHS staff, patients and their families. This collaboration has in Wales manifested in a significant improvement in consent rates. There have been annual fluctuations in recent years with consent being as low as 48.5% in 2014/15 but rising to 59.2% in 2015/16 and 64% in 2016/17.

Despite the improvements seen further work needs to be undertaken to reduce the number of missed donation opportunities. It is still family refusal to support donation despite consent being established that represents our biggest challenge. Improvements in families supporting consent and donation proceeding is an important opportunity to increase the number of organs available for transplant. We need to promote greater discussion of organ donation within families to ensure decisions are shared and supported if and when donation is a possibility.
1.1 Summary of Donor and Transplant Activity

Activity in Wales in the financial year to 31 March 2017, compared with the previous year:

- there was a 5% fall in the number of deceased donors donating in Wales to 61
- the number of donors after brain death (DBD) increased by 11% to 40, while the number of donors after circulatory death (DCD) fell by 25% to 21
- the number of living donors donating in Wales increased by 20% to 36, accounting for 37% of the total number of organ donors
- the number of patients transplanted in Wales whose lives were saved or improved by an organ transplant fell by 9% to 92

The fall in DCD coincides with a fall in the approach rate 2016/17 to 36% from 47% in 2015/16 and below the UK average of 43%. This can be explained following changes in the clinical donor screening for organ suitability. Families are not approached where their relative has been screened as not suitable for organ donation.

The total number of patients registered for a transplant residing in Wales has increased slightly, so that:

- there were 235 patients waiting for a transplant at the end of March 2017, an increase of 43 people compared to the same time period 2015/16 with a further 121 temporarily suspended from transplant lists
- 22 patients died while on the active waiting list for their transplant compared to 28 for 2015-16 and a further 26 were removed from the transplant list. The removals were mostly as a result of deteriorating health and ineligibility for transplant and many of these patients would have died shortly afterwards.

Some of the other key messages from this report are that, compared with last year, there has been:

- an increase of 33% in the number of pancreas transplants
- a fall of 7% in the total number of kidney transplants

There are no specific reasons for this; Welsh residents are allocated organs as per the UK organ allocation policy.

- an increase in the overall consent/authorisation rate for organ donation from 59.2% to 63.8%

All donation and transplantation figures quoted in this report are as reported to NHS Blood and Transplant:
1.2 Our Achievements

Awareness of the changes to the organ donation system
The latest omnibus survey in July 2017 shows that 73% of the Welsh public are aware unprompted of the changes to the organ donation system. A decrease from 76% in June 2016

Engagement with the changes to the new organ donation system
The Organ Donor Register (ODR) is just one measure to gauge support for the opt out organ donation system in Wales. By the end of March 2016/17 just 6% (174,806) of the population opted out on the organ donor register, up 1 percentage point from 2015/16, and 33 people have appointed a representative to make the decision on their behalf.

Registering yes on the Organ Donor Register
People in Wales continue to register their opt in decisions on the ODR. By the end of March 2016/17 38% (1,171,300) of the population were registered as opt-in on the Organ Donation Register, up by 2 percentage points since 2015/16.

Referrals to the organ donation services teams
The referral rate of potential organ donors to the organ donation services teams that work in Wales continues to increase from 88% in 2015/16 to 89.1% in 2016/17

Impact of Specialist Nurses Organ Donation (SN-OD)
SN-OD involvement in the approach to families of eligible donors for an organ donation decision continues to be a focus across the whole of the UK. Consent rates are greatly improved when a SN-OD is involved in the approach. The proportion of family approaches in Wales involving a SN-OD has increased from 86.6% in 2015/16 to 87.9% in 2016/17.

Consent rates
We have seen significant improvements in the combined DBD and DCD consent rate over the last five years. Although improvements started to be seen before enactment of the Human Transplantation (Wales) Act 2013 we are not able to determine if the improvements are as a result of the increased media/communication campaign, the pending and actual change in legislation or a combination of both.

- 2011/12  59%
- 2012/13  50%
- 2013/14  54%
- 2014/15  48%
- 2015/16  59%
- 2016/17  64%

The overall consent/authorisation rates (combining DBD and DCD) for England, Scotland and Northern Ireland were 63%, 63% and 64%, respectively.

1.3 Areas to improve

We know there is much more to do:

Increase the number of living donors
The number of Welsh transplant recipients who received a living donation is relatively small, just 52 in for 2016/17, an small increase from 46 the previous year. We need to continue the safe and
sustainable expansion of the living donor pool with the aim of increasing Live Donor Transplantation.

**Increase the number of actual deceased multi organ donors**
The Human Transplantation (Wales) Act 2013 was given Royal Assent on 10 September 2013. For the financial year 2012/13 there was 52 multi organ donors, over the next few years this figure increased year on year to a high of 64 in 2015/16. In 2016/17 this figure dropped slightly to 61. It is reasonable to assume that this slight drop falls within annual fluctuations seen when donor numbers are small however the potential that exists demonstrates that there continue to be missed opportunities to further increase the number of organ donors.

**Improve the consent rate**
Despite the excellent improvements seen in the organ donation consent rates more needs to be done to continue the increases. We continue to have a number of families who are not able to support either a registered yes to donation on the ODR or support deemed consent. In 2016/17 there were 21 occasions where family members overrode their relatives registration on the ODR to donate, or did not support deemed consent, this compared to 8 for 2015/16 (Deemed consent only applied from 1 December 2015). We have to get the message out there that it is not the family member’s decision for organ donation to proceed but that they should be supporting their relative’s organ donation decision.

**The number of patients on the active transplant waiting list**
Unfortunately the total number of patients on the transplant waiting list has increased in 2016/17 an increase of 43 from 2015/16. This is predominantly patients waiting for a kidney transplant. It is important to note that increasing the organs donated in Wales means that they may be used for patients in other parts of the UK, and vice versa. This wider pool means that a person on the waiting list for an organ is more likely to receive a match. This co-operation increases the chance of a suitable recipient being found, ensuring that precious organs do not go to waste.

We have seen some significant progress but there is still much to do over the next few years to drive continuous improvement on all aspects of organ donation and transplantation. We are working hard to maximise every opportunity for organ donation to ensure that more patients have the opportunity of a successful transplant and that their long term survival rates are maximised.

Dr Andrew Goodall  
Chief Executive – NHS Wales

Abigail Harris  
Chair, Organ Donation Implementation Group
2.0 Summary of organ donation and transplantation activity

Since the enactment of the Human Transplantation (Wales) Act on 1 Dec 2015 there has been much scrutiny on what effect changing the law has had on donor numbers in Wales. Although it has only been a short time the expectation is that we will see an improvement in actual donor numbers and resulting transplants.

It is important to note that the change in the organ donation system here in Wales has not changed the allocation of organs across the UK. Organs donated in Wales may be used for patients in other parts of the UK, and vice versa. This wider pool means that a person on the waiting list for an organ is more likely to receive a match and increases the chance of a suitable recipient being found.

Figure one shows that the number of patients actively waiting for a transplant in Wales has, despite a fall over recent years, has now risen to 235 at 31 March 2016/17. Between 1 April 2016 and 31 March 2017, Wales had 61 deceased solid organ donors from Welsh hospitals, resulting in 161 transplants across the UK. Of the 235 Welsh residents waiting for a transplant 135 received a transplant from a deceased donor and 52 received a transplant from a live donor. Welsh residents requiring heart, lung, liver and small bowel transplants are transplanted in England.

Figure one: Organ donation, transplants, donors and waiting list for Wales

<table>
<thead>
<tr>
<th>Year</th>
<th>Deceased donors</th>
<th>Organs donated from Welsh residents</th>
<th>Transplants on Welsh residents</th>
<th>Transplant list</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011-12</td>
<td>200</td>
<td>150</td>
<td>125</td>
<td>200</td>
</tr>
<tr>
<td>2012-13</td>
<td>180</td>
<td>130</td>
<td>110</td>
<td>180</td>
</tr>
<tr>
<td>2013-14</td>
<td>160</td>
<td>120</td>
<td>100</td>
<td>160</td>
</tr>
<tr>
<td>2014-15</td>
<td>150</td>
<td>110</td>
<td>90</td>
<td>150</td>
</tr>
<tr>
<td>2015-16</td>
<td>140</td>
<td>100</td>
<td>80</td>
<td>140</td>
</tr>
<tr>
<td>2016-17</td>
<td>130</td>
<td>90</td>
<td>70</td>
<td>130</td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant

Figure two highlights the challenges faced in trying to increase the number of suitable organ donations and transplants. Annually over 30,000 people die in Wales, of which around 18,000 will be in hospital; however of these only around 400 people die in circumstances where they can potentially become a donor, approximately 300 of these are eligible to become donors. In 2016/17 only 61 proceeded to solid organ donation in a Welsh hospital with 161 transplants undertaken and 197 organs donated.
Figure 2: Wales – Potential deceased organ donation population – 1 April 2016– 31 March 2017

Data source: NHS Blood and Transplant

1,2,3 ONS data
4 2016-17 data: NHSBT, Potential donor audit
5 Potential donor – patients who met the criteria for neurological death tests i.e. those for which neurological death was suspected or patients for whom treatment was withdrawn and death was anticipated within four hours
6 Eligible donor – potential donor with no absolute medical contraindications to solid organ donation
7 2016-17 deceased donor data: NHSBT, UK transplant registry (from Welsh hospitals)
8 Transplanted to Welsh recipients (based on residence)
2.1 Awareness of organ donation

Changing the organ donation system and normalising organ donation as part of good end of life care is seen as the best way to increase the number of people wanting to donate their organs in the event of their death.

Since the initial public consultation on The Human Transplantation (Wales) Act and the communication campaigns designed to ensure the population of Wales understand the new system and the organ donation choices that people have in Wales, the consent rate has fluctuated from 59% in 2011/12, a fall to 50% in 2012/13 and then a steady year on year rise to 64% in 2016/17.

Further increasing the consent rate is one of the factors that could have the most significant impact on increasing the number of organs available and reducing transplant waiting lists.

Since December 2015, the focus of the communication campaign has been on explaining to people what their choices are under the organ donation system – opt in, opt out or do nothing. This included a secondary message around the role of families during the process. This resulted in some confusion about the role of the family and so in an effort to reduce the confusion and the number of families not supporting a registered yes on the Organ Donor Register (ODR) or deemed consent, the campaign changed to focus on encouraging people to clarify their organ donation decision and to share that with those closest to them and asking family members to honour that decision.

Welsh Government working in collaboration with NHS Blood and Transplant (NHSBT) has produced a Welsh schools education pack which information on how to access the pack has been sent to all schools in Wales. Co-created with teachers, educators and clinicians, it is hoped that these lessons will prompt debate amongst students themselves and encourage them to discuss this important subject with their families. The pack can be found at: http://organdonationwales.org/resources-section/students?lang=en

A ‘rising-18’s’ letter is sent from the NHS in Wales to all young people approaching their 18th birthday. The letter explains the system for organ donation in Wales, telling them what their choices are and encouraging them to talk to their loved ones about their decision.

In order to monitor the effectiveness of the communications campaign, regular information has been collected on public awareness, understanding and attitudes to changes in the legislation in Wales. In order to support this, Welsh Government commissioned questions in the Wales Omnibus Survey. Data has been collected at regular intervals since June 2012. This has and will inform future developments in the communications campaign. The latest data shows:

- In June 2012, 53% of respondents were aware of the changes, unprompted, to the organ donation system. This increased to 76% in June 2016 but fell to 73% in March 2017.
- Respondents were asked ‘Have you ever discussed your wishes regarding organ donation after your death with a family member?’ The proportion of respondents who had discussed their wishes has increased from 38% in June 2012 to 48% in June 2016 and up to 51% in March 2017.

The use of case studies forms a significant part of the communications campaign. The power of using real people who have been affected by organ donation, either because they have received, donated or are waiting for an organ, has been demonstrated many times over. You are able to read all those who want to share their stories at: http://organdonationwales.org/Your-Stories/?lang=en
3.0 Deceased organ donation

The removal of organs for the purpose of organ donation requires consent in accordance with the Human Transplantation (Wales) Act 2013 either from the deceased before death, an appointed representative, deemed consent or from their next of kin if deemed consent does not apply after death.

Many people incorrectly think that because we have a soft opt out system of consent family members do not need to be involved when organ donation is a possibility. The law has been designed to make it easier to become an organ donor but family are always involved in end of life discussions where organ donation is possible.

As family are involved it is very important that the Welsh Public decide for themselves what they want to do and have the discussion with their family and inform them of their organ donation decision. Families are more likely to honour and support their relative’s decision if they know what that decision is.

NHS Wales ensure all those individuals who are eligible to donate are given every opportunity to do so but family support is crucial to enable donation to proceed.

Keane Price (22) from Abergavenny has felt strongly about organ donation for some time. He felt inspired to tell others about the difference becoming an organ donor can make to others, so now he and his family know what each other’s decisions are. He explains:

“I applied for my provisional driving licence which prompted me to register my decision as an organ donor, but didn’t think to share my decision with anyone.”

“Earlier this year, I had to renew my car tax and I saw a reminder to register my organ donation decision. This time, I was also encouraged to tell my loved ones so I told my family what I had decided. I also gave them the link to sign up online so that they could do the same. Sharing this information triggered our family to talk about organ donation. So if any of us are ever in the position to be able to donate we know what every member of the family has decided to do.

“For those unsure of their decision, it’s so important to remember that should anything happen to you, you can give somebody else a better life. I believe that, after someone has died, there is no longer a physical need for the body or organs. So why not leave a great legacy by giving someone the gift of life and let your heart beat in someone else’s chest or help somebody to see again”

3.1 What are referral rates for organ donation?

The steady increase continues in the referral rates for organ donation across all the UK nations over the last six years as shown in figure three.
Performance for Wales against the UK targets for the referral rate is excellent for both DCD donors and DBD donors as can be seen in figure 4. For DBD donors the referral rate is 98% up from 95% in 2015/16 and higher than the UK average of 96%. For DCD donors the referral rate is 87% up from 86% in 2015/16 and higher than the UK average of 86%.

Data source: NHS Blood and Transplant
Table one highlights the reasons why patients were not referred. For DCD patients 20% were not identified as a potential donor or organ donation was not considered. 26.7% were thought to be medically unsuitable and 35.6% had medical contraindications. Numbers are relatively small so caution should be used when looking at percentages. However of the 45 patients that were not referred only 9 of these were because they were not identified as a potential donor or organ donation was not considered.

<table>
<thead>
<tr>
<th>Reason</th>
<th>DBD N</th>
<th>DBD %</th>
<th>DCD N</th>
<th>DCD %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not identified as a potential donor/organ donation not considered</td>
<td>1</td>
<td>100.0</td>
<td>9</td>
<td>20.0</td>
</tr>
<tr>
<td>Medical contraindications</td>
<td>-</td>
<td>-</td>
<td>16</td>
<td>35.6</td>
</tr>
<tr>
<td>Thought to be medically unsuitable</td>
<td>-</td>
<td>-</td>
<td>12</td>
<td>26.7</td>
</tr>
<tr>
<td>Pressure on ICU beds</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>2.2</td>
</tr>
<tr>
<td>Clinician assessed that patient was unlikely to become asystolic within 4 hours</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>2.2</td>
</tr>
<tr>
<td>Patient had previously expressed a wish not to donate</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>6.7</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1</td>
<td>100.0</td>
<td>45</td>
<td>100.0</td>
</tr>
</tbody>
</table>

If ‘other’ or ‘medical contraindications’, please contact your local SN-OD for more information, if required. Please note that patients may appear in this table more than once if they met the referral criteria for both DBD and DCD donation.

**Data source:** NHS Blood and Transplant

### 3.2 What percentage of eligible donors is approached for organ donation?

The organ donation approach rate gives an indication as to how many families, carers or relatives of patients who die in critical or emergency care units, aged 80 or under, are approached to consider organ donation following the death of their relative.

In 2016-17 the approach rate for DBD fell slightly to 93% from 94% in 2015/16 but remains above the UK average of 92%. For DCD the approach rate fell in 2016/17 to 36% from 47% in 2015/16 and below the UK average of 43%. The fall in approach rate for DCD can be explained following changes in the clinical donor screening for organ suitability. Families are not approached where their relative has been screened as not suitable for organ donation.
There are many reasons why families are not approached despite the patient appearing to be a potential organ donor. The main reasons in 2016/17 have not changed compared to 2015/16 and were because the patient’s medical condition meant that their organs were not suitable to be transplanted as either the organ function would not support it being transplanted or the patient’s medical history did not enable transplantation to be considered. – see table two below.

### Table 2: Reasons given why family not formally approached, 2016/17

<table>
<thead>
<tr>
<th>Reason</th>
<th>DBD N</th>
<th>DBD %</th>
<th>DCD N</th>
<th>DCD %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family stated that they would not support donation before they were formally approached</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Family untraceable</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Coroner/ Procurator Fiscal refused permission</td>
<td>1</td>
<td>25.0</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Patient’s general medical condition</td>
<td>2</td>
<td>50.0</td>
<td>78</td>
<td>48.8</td>
</tr>
<tr>
<td>Other medical reasons</td>
<td>1</td>
<td>25.0</td>
<td>18</td>
<td>11.3</td>
</tr>
<tr>
<td>Pressure on ICU beds</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>-</td>
<td>31</td>
<td>19.4</td>
</tr>
<tr>
<td>Not identified as a potential donor/ organ Donation not considered</td>
<td>13</td>
<td></td>
<td></td>
<td>8.1</td>
</tr>
<tr>
<td>Patient had previously expressed a wish not to donate</td>
<td>13</td>
<td></td>
<td></td>
<td>8.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>4</td>
<td>100.0</td>
<td>160</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*Data source: NHS Blood and Transplant*
3.3 How many people are registered on the organ donor register? (ODR)

People in Wales do not have to record a decision to be a donor in a specific manner in order to be regarded as wanting to be one. The option to formally record a decision to be a donor on the ODR still remains and is hugely important for families when talking to healthcare professionals about organ donation. Knowing that their relative wanted to become an organ donor and having this information available to them when organ donation is being discussed helps families honour and support their relative’s decision at such a difficult time.

Figure six shows that the percentage of the Welsh population that have recorded a decision on the ODR to donate after their death. Despite now being able to have consent deemed in Wales registrations are continuing to increase now at 38% (1,171,300) of the population. This means that an additional 58,210 people have opted onto the register to donate between 1 April 2016 and 31 March 2017.

![Figure 6: Percentage of people registered on organ donation register in Wales](image)

Data source: NHS Blood and Transplant

Figure seven shows the number of people in Wales who have opted out on the ODR since the new system was introduced. At the end of March 2017, 174,806 Welsh residents had opted out on the organ donation register, which is just over 6% of the population. As can be seen in figure seven the majority of these opt outs occurred during November and December 2015 coinciding with the implementation of the new act and enhanced communication campaign.
3.4 What is the consent rate for deceased organ donation?

NHSBT data show that consent rates are higher where consent status on the ODR is known. This highlights the importance of promoting public awareness of organ donation but also of individuals making their decision known to family and loved ones. In Wales the consent rate where ODR status is known, has been consistently high and comparable to other UK nations, as seen below in figure eight.
Following implementation of the 2008 Organ Donation Taskforce recommendations the consent rate in Wales remained stubbornly low. It was for this reason that Welsh Government, after public consultation, chose to change the law and created a system of consent for deceased organ donation in Wales. Whilst the majority of the provisions in the Act did not come into force until 1 December 2015, certain sections commenced on Royal Assent, most notably Section 2, which relates to Welsh Ministers’ duty to publicise the arrangements contained within the Act.

The law provides a lever for a cultural shift in behaviour and attitudes towards increasing consent rates for organ donation and in order for the system to be implemented smoothly and successfully, it was accompanied by a public information campaign to ensure that the Welsh population were aware of the changes and understood how this would affect them. The public information campaign was launched on 1 December 2013.

Table three shows the consent in Wales just prior to the start of the public information campaign up to 31 March 2017. The consent rate has fluctuated from 59% in 2011/12, a fall to a low of 50% in 2012/13 and then a steady year on year rise to 64% in 2016/17. In view of the consistent rise it is likely that the public information campaign had a significant affect on the consent rate. Unfortunately we also see that there were 21 occasions where consent had been ascertained but the family did not support the consent and donation did not proceed.

The DBD consent rate was 78% in 2016/17 which is above the UK average of 69% and also above the national target of 72%. The DCD consent rate was 56% in 2016/17 below the UK average of 58.1% and well the below the national target of 68%.
Table 3: Organ donation consent rate in Wales

<table>
<thead>
<tr>
<th>Financial year</th>
<th>Potential donors</th>
<th>Eligible donors</th>
<th>Total consent ascertained</th>
<th>Consent rate</th>
<th>ODR overrides</th>
<th>Deemed consent overrides</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/12</td>
<td>504</td>
<td>250</td>
<td>91</td>
<td>59</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>2012/13</td>
<td>461</td>
<td>244</td>
<td>81</td>
<td>50</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>2013/14</td>
<td>507</td>
<td>366</td>
<td>90</td>
<td>54</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>2014/15</td>
<td>419</td>
<td>334</td>
<td>83</td>
<td>48</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>2015/16</td>
<td>394</td>
<td>282</td>
<td>93</td>
<td>59</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>2016/17</td>
<td>392</td>
<td>307</td>
<td>92</td>
<td>64</td>
<td>9</td>
<td>12</td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant

Table 4: Reasons why families did not support organ donation

<table>
<thead>
<tr>
<th>DBD</th>
<th>DCD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td><strong>%</strong></td>
</tr>
<tr>
<td>Patient previously expressed a wish not to donate</td>
<td>5</td>
</tr>
<tr>
<td>Family were not sure whether the patient would have agreed to donation</td>
<td>-</td>
</tr>
<tr>
<td>Family did not believe in donation</td>
<td>-</td>
</tr>
<tr>
<td>Family felt it was against their religious / cultural beliefs</td>
<td>-</td>
</tr>
<tr>
<td>Family were divided over the decision</td>
<td>-</td>
</tr>
<tr>
<td>Family felt the patient had suffered enough</td>
<td>-</td>
</tr>
<tr>
<td>Family did not want surgery to the body</td>
<td>2</td>
</tr>
<tr>
<td>Family felt the length of time for donation process was too long</td>
<td>4</td>
</tr>
<tr>
<td>Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)</td>
<td>-</td>
</tr>
<tr>
<td>Family concerned that organs may not be transplanted</td>
<td>-</td>
</tr>
<tr>
<td>Strong refusal- probing not appropriate</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant
4.0 How effective are specialist nurses in the organ donation conversation?

A specialist nurse for organ donation, referred to as SN-OD, plays a key role in hospitals in the coordination and facilitation of organ donation. The SN-ODs receive detailed training in communication and family support, enabling them to recognise and avoid factors that inadvertently lead to the family not supporting their relatives consent or not supporting deemed consent. NICE Clinical guidance G135 and NHSBT Best Practice Guidance on approaching the families of potential organ donors reinforces that every approach to those close to the patient should be planned with the multidisciplinary team, should involve the SN-OD and take into account the known decision of the patient. The Organ Donor Register (ODR) should be checked in all cases of potential donation and this information must be discussed with the family as it represents the eligible donor’s legal consent to donation. If deemed consent can be applied then the family must be informed that legal consent is in place for donation to proceed.

There is evidence\(^1\) to show that early referral to SN-OD and SN-OD involvement in the approach to families does have a positive impact on the consent rate. Early referral to the SN-OD is important to enable the opportunity for donation to be maximised and triggers should be in place to ensure all donors are identified to the SN-OD to allow the family to discuss their relative’s organ donation decision. The SN-OD also supports and advises the clinical team caring for a patient, managing the donation process so that the maximum benefit can be attained from the donation providing the highest number of donor organs in the best possible condition through optimisation of donor physiology.

In Wales the focus to make sure SN-OD involvement in the donation conversation occurs in all potential DBD donor situations has seen an increase from 94% in 2015/16 to 96% in 2016/17. Three percentage points above the UK average of 93%. For DCD the rate has increased from 83% in 2015/16 to 84% in 2016/17, four percentage points above the UK average of 80%. There are a number of factors which affect the SN-OD involvement, i.e. travel logistics, timing of the referral and clinician's reluctance to involve the SN-OD during the end of life conversations.

Figure nine compares the approach rate of SNODs working in Wales with the rest of the UK.

Figure 9: % of approach rate where the SNOD is involved, DBD and DCD

Data source: NHS Blood and Transplant

Lucy Barnes works as a Specialist Nurse - Organ Donation. She is one of 12 Specialist Nurses employed by NHS Blood and Transplant in South Wales. The SN-ODs are the focal point of contact for organ donation in the hospital which includes the identification and referral of potential organ and tissue donors. The role also has an on-call element to support the facilitation of organ donation for transplantation. She explains:

“I provide information and support to the family of a potential organ donor in collaboration with the critical care team. I lead the donation process and ensure that families are provided with the information and support they require to support their relative’s decision about organ donation. It’s both a hugely demanding and rewarding role and I am privileged to be part of the support given to families who find themselves in this situation”

“Organ donation is a very personal decision and can never minimise the grief of a bereaved family but many families have said that it provides some comfort knowing that their relative has been able to save and transform the lives of others”

“I can say from experience that families who know their relative’s decision at the time of their death find the conversation with health care professional so much easier when organ donation is discussed. As I say organ donation is a personal decision so whatever you decide you’d like to do, make sure you tell your loved ones; if you do choose to donate it could save or transform the lives of up to 9 people.”
5.0 How many deceased people from Wales donate organs?

Between 1 April 2016 and 31 March 2017, there were 61 deceased solid organ donors, from Welsh hospitals 9 of whom were non Welsh residents. In addition there were 16 Welsh resident donors donating outside of Wales; resulting in 68 Welsh residents donating organs for transplantation.

![Figure 10: Number of organs donated from a Welsh resident donor](image)

Data source: NHS Blood and Transplant

5.1 How many deceased organ donors from Welsh hospitals are there and what is the number of organs donated?

Despite much scrutiny it is too early to say what impact the changes to the organ donation system in Wales are having. Although we know from the latest omnibus survey in July 2017, 73% of the Welsh public are aware unprompted of the changes to the organ donation system. Embedding a change in behaviour towards supporting organ donation could take many years. Long-term changes in behaviour can involve multiple actions and adaptations over time while some people may not be ready to support the change and others may have already have begun accepting and implementing the change.

The evidence to date indicates a positive change in the number of people supporting and donating organs for transplantation. The Human Transplantation (Wales) Act 2013 was given Royal Assent on 10 September 2013. For the financial year 2012/13 there was 52 multi organ donors, over the next few years this figure increased year on year to a high of 64 in 2015/16. However in 2016/17 this figure dropped slightly to 61. It is reasonable to assume that this slight drop falls within annual fluctuations seen when donor numbers are small, however the potential that exists demonstrates that there continue to be missed opportunities to further increase the number of organ donors.
Table 5: Donors from Welsh Hospitals and the total number of organs donated

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased donors</td>
<td>67</td>
<td>52</td>
<td>54</td>
<td>60</td>
<td>64</td>
<td>61</td>
</tr>
<tr>
<td>Organs donated</td>
<td>178</td>
<td>150</td>
<td>140</td>
<td>149</td>
<td>222</td>
<td>197</td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant

5.2 How many living organ donors are there?

Living donation plays a vital role in saving and transforming lives and offers patients with end stage kidney disease the possibility of a successful transplant. In the UK 97% of living donors donate a kidney. Living donations contribute to approximately one third of the organs that are available for transplant every year in the UK.

Most living kidney donor transplants are ‘directed’. This means that a kidney is donated to a specific recipient known to the donor - a close family member or friend.

The number of living donors residing in Wales is relatively small, just 36 for 2016/17, an increase from 30 in 2015/16. When the number of donors per million population is considered, Wales performance is consistent with other parts of the UK, with the exception of Northern Ireland, who on a per million population basis perform very well. (Figure 11).

![Figure 11: Number of living donors per million population](image)

Mike Stephens Consultant Transplant and Organ Retrieval Surgeon also cares for patients who donate and receive a kidney from someone who is living. He explains:

“It’s also possible to donate in life. Even if you don’t know someone who is in need of a kidney transplant, there are increasing numbers of people who come forward and donate a kidney to a stranger. It really brings to light that people are donating their organs every day, in life and death, to enhance the quality of someone’s life
Lewis Evans from Ceredigion moved to Cardiff in 2015 but suddenly started to suffer terrible sickness two months later. Shortly afterwards, he was shocked to be diagnosed with chronic kidney disease, before undergoing dialysis three times a week for nearly two years. He explains how his life has turned around since:

“I was really fit and healthy pretty much right up to my diagnosis, so it came as a complete shock to both myself and my family when I was told that my kidneys had stopped working and that I needed a kidney transplant.”

“My family were tested as possible living donors, and I was extremely lucky that my mum and my sister were both matches. My mum decided to donate because she felt it was her responsibility and didn’t want both her children undergoing surgery at the same time. I had the transplant in January 2017 and the operation went really well. In just a few months I was up on my feet and I’m working full time again. It’s amazing to see the difference it has made to my health, and I’m so grateful to my mum for the gift she has given me.”
6.0 How many Welsh residents are on the organ transplant waiting list?

There have been a number of improvements in recent years aimed at increasing the number of organs available for transplantation. Despite these improvements, there are still not enough donated organs to meet the current need. We had made considerable progress in Wales in reducing the number of patients waiting for a transplant but organs are a UK wide resource and the changes to the organ donation system did not affect the allocation of organs. The only transplant waiting list held in Wales is the Kidney and Pancreas list at the University Hospital of Wales Cardiff. All patients requiring other organ transplants are referred to transplant centres in England and subsequently their details are added to their transplant waiting lists.

Patients requiring a Kidney and or Pancreas transplant living in South Wales are referred to the Cardiff Transplant Unit which provides a comprehensive renal transplant programme. They participate in the UK national organ retrieval service being one of two out of the total of seven abdominal teams that share the on call responsibilities, each being on-call for different weeks of the year. These factors help ensure a sustainable and safe transplant service with highly favourable outcomes, typically as good and often better than the UK average. The one and five year graft survival rate at the Cardiff Transplant Unit is 98% and 88% compared to the UK average of 94% and 86%.

Patients requiring other organ transplants from South Wales are referred to hospitals in England as are patients requiring all solid organ transplants in North Wales.

The number of Welsh residents waiting for a transplant in 2016/17 increased from 192 in 2015/16 to 235.

The waiting lists for a:

- Kidney transplant increased from 141 in 2015/16 to 170 in 31 March 2016/17.
- Kidney and Pancreas combined increased from 3 in 2015/16 to 14 31 March 2016/17
- Pancreas remained the same at 1,
- Heart fell slightly to 7 in 31 March 2017 from 10 in 2015/2016,
- Lungs decreased to 2 at 31 March 2017 from 17 in 2015/16,
- Heart lung combined increased from 1 2015/16 to 2 at 31 March 2017
- Liver decreased slightly from 21 in 2015/16 down to 18 at 31 March 2017.
6.1 How many die whilst on the transplant waiting list?

Organ transplantation is often the only treatment for end state organ failure and although end stage kidney disease patients can be treated through other renal replacement therapies, kidney transplantation is generally accepted as the best treatment for quality of life. Unfortunately due to a shortage of organs many patients don’t get the life saving transplant. In Wales the number of Welsh residents who died waiting for a transplant in 2016/17 decreased to 22 from 27 in 2015/16. There continue to be more people waiting than the number of organs available. The push to reverse this trend continues.
Table: 6 Deaths while on transplant waiting list

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Wales</td>
<td>29</td>
<td>21</td>
<td>16</td>
<td>28</td>
<td>23</td>
</tr>
<tr>
<td>England</td>
<td>463</td>
<td>493</td>
<td>448</td>
<td>471</td>
<td>377</td>
</tr>
<tr>
<td>Scotland</td>
<td>45</td>
<td>40</td>
<td>39</td>
<td>43</td>
<td>50</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>15</td>
<td>13</td>
<td>18</td>
<td>10</td>
<td>13</td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant

6.2 Organs transplanted by type

Table 7: Number of organs transplanted by type from donors in Welsh hospitals, 1 April 2016 - 31 March 2017,

<table>
<thead>
<tr>
<th>Donor type</th>
<th>Kidney</th>
<th>Pancreas</th>
<th>Liver</th>
<th>Heart</th>
<th>Lung</th>
<th>Small bowel</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBD</td>
<td>66</td>
<td>9</td>
<td>37</td>
<td>7</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>DCD</td>
<td>34</td>
<td>1</td>
<td>8</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>DBD and DCD</td>
<td>100</td>
<td>10</td>
<td>45</td>
<td>7</td>
<td>8</td>
<td>0</td>
</tr>
</tbody>
</table>

Data source: NHS Blood and Transplant

Table seven shows the number of deceased donor transplants carried out in 2016/2017. Transplants from donors after circulatory death are increasingly common for renal and liver transplants and with ongoing improved technologies lung transplants.
7.0 Number of Welsh residents receiving a transplant by type

Between 2015/16 and 2016/17 there has been a fall of 7% in the total number of kidney transplants, a 33% increase for those receiving a pancreas transplant, a 16% decrease in receiving liver transplants and a 19% decrease for those receiving cardiothoracic transplants. There are no specific reasons for this; Welsh residents are allocated organs as per the UK organ allocation policy.
8.0 Paediatric / neonatal organ donation

Paediatric donation in Wales has over the years been significantly less than the rest of the UK. There have been cases where babies diagnosed with anencephaly and other life limiting conditions have been able to donate organs and tissues following their death. However, this remains a rare event and the likelihood of donation occurring under these circumstances is small. For those children and neonates who have been admitted to ITU and who will not survive the illness; if the decision has been made to withdraw treatment or perform brain stem tests, they may (following discussion with parents) be suitable to donate organs for transplantation. The topic of donation has become a routine part of end of life care.

All paediatric eligible donors in 2016/17 were referred to the specialist nurses but none proceeded to donation.

Losing her husband, Stuart, and young son, Fraser, in a tragic accident in December 2015 created an irreplaceable void for Anna Louise Bates. To have the courage and strength to agree to the donation of their organs takes a very special person.

Anna-Louise, says:

“You never think such a tragedy could happen to you.

Following the accident I was approached about the possibility of organ donation. I was only glad Stuart and I had talked about and I knew what they both would have wanted. So many people do not have that conversation with loved ones and it’s simply too late should the time ever come.”
9.0 Conclusions and looking ahead

There is still work to do to achieve the ambition of the Taking Organ Transplantation to 2020 strategy and Welsh Action plan to be among the best in the world. However we are in no doubt that there has been steady progress in Wales over the last few years and recognise that we are limited by the fact that organ donation is a very rare event and can only take place in specific circumstances. As most people do not die in these circumstances we must continue to work hard to maximise every opportunity for organ donation. Thus ensuring that more patients have the opportunity of a successful transplant and that their long term survival rates are maximised.

Overall last year there was a small decrease in the number of deceased organ donors and transplants, however the combined consent rate has increased but unfortunately this has not been reflected in a rise in donors overall. Despite the slight decrease the figures are encouraging with the trends moving in the right direction. The steady rise in the consent rate for organ donation shows the support organ donation and transplantation gets from the Welsh Public although we need to continue and strengthen the message that everyone should consider what their organ donation decision is and to either register on the NHS organ donor register and/or tell their family of their decision whilst asking them to honour their decision.

The improvements in the consent rate can also be attributed to the result of the hard work undertaken by staff in the NHS ensuring that each step of the process is undertaken within best practice guidance. Both the referral and approach rates are the highest they have ever been and their maintenance is crucial in ensuring every opportunity for organ donation is considered.

We have not been unique in the challenges experienced to increasing the number of people who consent to organ donation but we are currently the only UK country to change their legislative framework to an opt out system. There has been significant interest in what we have implemented and in the findings from the evaluation of the effectiveness of the change and impact of the new law, published 1 December 2017. The findings show that we have made progress in the last two years but that we need to have several more years’ data to draw firmer conclusions around the impact of the change on donor numbers in Wales.

Living donation’s unique contribution to the organ donor pool offers more patients with end stage organ failure the possibility of a successful transplant whilst adding to the overall supply of available organs for all those who are waiting. Further work is required to ensure that all suitable recipients have equity of access to transplantation including raising public awareness and confidence in Living Donation.

Although this annual report focuses on the statistics of organ donation and transplantation, we must not forget that behind every figure is a person. Our thanks go out to all those who choose to donate organs in life or after they die without their generosity others would not get their transformative transplant.