

# Together for Health

## Organ Donation Annual Report 2018

## 1.0 Introduction

This year's annual report demonstrates the outstanding support the Welsh public has given to organ donation and transplantation. In 2017/18 Wales had its highest number of donors ever seen and the highest consent rate for the whole of the UK at 70%. (England, Scotland and Northern Ireland were 66%, 57% and 66%, respectively). This means that more families in Wales have supported donation proceeding to save and transform the lives of people in need of a transplant.

The introduction of the soft opt out system, the compliance to best practice by the Welsh NHS and the Welsh Government communication campaign have all contributed to the improvements; with a continued upward trend for organ donation in Wales. More people from Wales have now registered their decision on the organ donor register with 40% registering yes to donate and 6 % registering no. We now have a total of 46% of the population with a recorded organ donation decision.

Although we are able to celebrate the success and increase in proceeding donors we must not forget all families who have lost loved ones regardless of their ability to support donation proceeding. To lose a loved one and have to consider their decision to donate or not even know their organ donation decision can make the end of life donation conversation very difficult for some families. Family support is crucial for organ donation to proceed so we will continue to promote greater discussion of organ donation within families to ensure individuals know the organ donation decision of those closest to them. We know from many studies that when family members are aware of their loved one's organ donation decision they are far more likely to support donation proceeding.

## 1.1 Summary of Donor and Transplant Activity

Activity in Wales in the financial year to 31 March 2018, compared with the previous year

- there was a 21% increase in the number of deceased donors donating in Wales to 74
- the number of donors after death determined by neurological criteria (DBD) increased by 13% to 45, while the number of donors after circulatory death (DCD) increased by 38% to 29
- the number of living donors donating in Wales fell by 14% to 31, accounting for 30% 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 8% to 85

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

- there were 233 patients waiting for a transplant at the end of March 2018, with a further 157 temporarily suspended from transplant lists
- 16 patients died while on the active waiting list for their transplant and a further 27 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 in the overall referral rate of potential donors from 89.2% to 92.9% and the proportion of approaches involving a Specialist Nurse - Organ Donation from 87.9% to 92.4%
- An increase in the overall consent/authorisation rate for organ donation from 63.8% to 70.1%
- An increase of 8% in the total number of liver transplants
- An increase of 11% in the total number of cardiothoracic organ transplants
- A fall of 8% in the total number of kidney transplants
- An increase of 40% in the number of pancreas transplants

## 1.2 Our Achievements

### **Awareness of the changes to the organ donation system**

The latest omnibus survey in March 2018 shows that 82% of the Welsh public are aware unprompted of the changes to the organ donation system; an increase from 73% in July 2017.

### **Welsh Residents registering on the Organ Donor Register**

By the end of March 2018, the NHS Organ Donor Register (ODR) held 1,234,025 opt-in registrations representing 40% of the population. This is a 2 percentage point increase from the same time period 2017. In addition there were 180,924 opt-out registrations representing 6% of the population which is the same as 2017 with 35 individuals appointing a representative to make their organ donation decision on their behalf.

### **Referrals to the organ donation services teams**

The referral rate of potential organ donors to the Welsh organ donation services teams continues to increase from 89.1% in 2016/17 to 92.9% in 2017/18

## **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 87.9% in 2016/17 to 92.4% in 2017/18.

### **Consent rate**

We continue to see significant improvements in the combined DBD and DCD consent rate. We acknowledge improvements are likely to be as a result of both the change in legislation and increased media/communication campaign.

- 2012/13 50%
- 2013/14 54%
- 2014/15 48%
- 2015/16 59%
- 2016/17 64%
- 2017/18 70%

This compares to overall consent/authorisation rates (combined DBD and DCD) in 2017/18 for England, Scotland and Northern Ireland of 66%, 57% and 66%, respectively.

### **Increase in the number of actual deceased multi organ donors**

There was a 21% increase in the number of deceased organ donors in 2017/18 compared to the previous year. The number of donors after death has been determined by neurological criteria increased by 13% to 45 and the number of donors after circulatory death increased by 38% to 29.

Of the 74 deceased organ donors in Welsh hospitals in 2017-2018, 46% had opted-in on the ODR compared with 45% of organ donors in 2016-2017.

## **1.2 Areas to improve**

We know there is more to do:

### **Increase the number of living donors**

The number of living transplants is relatively small, and has fallen to 42 in 2017/18 from 52 in 2016/17. In addition the number of living donors donating in Wales fell by 14% to 31, accounting for 30% of the total number of organ donors.

### **The number of patients transplanted**

The number of patients waiting for an organ transplants has fallen slightly to 234 at the end of March 2017/18 from 243 for the same time period 2016/17. As patients receive their transplant the numbers on the waiting list do fluctuate. There has been a small fall in the number of transplants performed as Wales only has one transplant unit this likely represents the declining and relatively small waiting list for kidney transplants.

## **Black, Asian and minority ethnic communities**

Although the number of patients in Wales from Black, Asian and Minority Ethnic backgrounds who could donate organs are small, there is a need to engage with the communities to raise awareness and encourage more people to talk about organ donation.

We have a lot to celebrate in Wales since the change in the organ donation consent system was introduced. It is heart warming to see that donor numbers are the best they have ever been in Wales and that we lead the way in the UK in organ donation consent. We have learnt a lot along our journey and have shared this with our colleagues in Scotland and England who are now also proceeding with their own opt out legislative change. We know that there are still areas where we are able to reduce even further the missed opportunities for organ donation. Whilst there are patients waiting for their successful transplant the Welsh NHS will continue to work hard to reduce any missed opportunities and maximise the number of transplant performed.



A handwritten signature in black ink, appearing to read 'Andrew Goodall'.

**Dr Andrew Goodall**  
**Chief Executive – NHS Wales**



A handwritten signature in black ink, appearing to read 'Abigail Harris'.

**Abigail Harris**  
**Chair, Organ Donation**  
**Implementation Group**

## 2.0 Summary of Welsh resident organ donation and transplantation activity

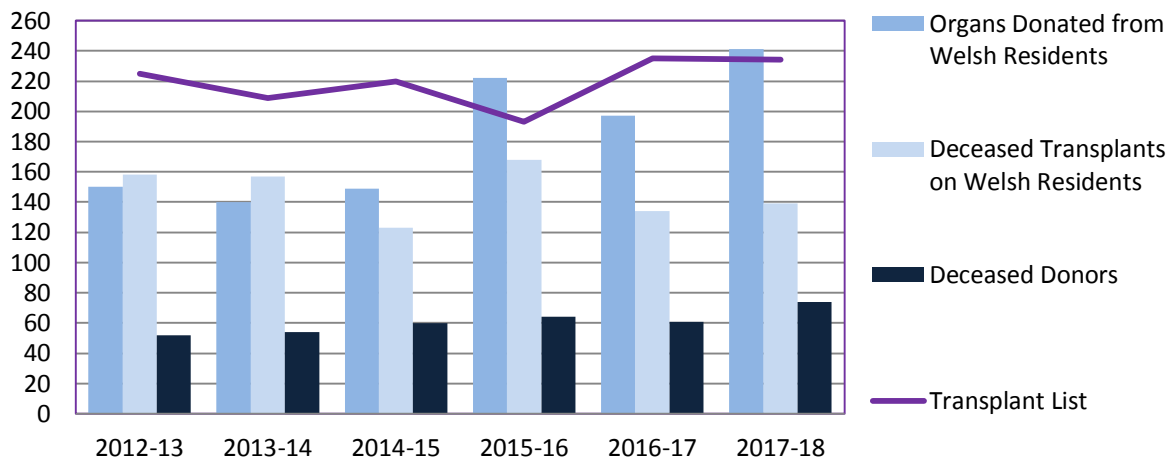
This year as of 31 March 2018 there has been an increase in both the number of deceased donors donating in Welsh hospitals, 74 compared to 61 in 2016/17, and Welsh resident donating in any hospitals 79 compared to 68 in 2016/17. There is a small increase of 2 in the number of deceased organ transplants 137 compared to 135 in 2016/17. The number of patients on the active transplant list at 31 March 2018 is 234, nine fewer than 2016/17.

A total of 179 Welsh residents received a transplant during 2017/18 which is 8 fewer than during 2016/17. There has been a fall in the number of kidney transplants from live donors from 52 during 2016/17 to 42 during 2017/18.

Figure one shows that the number of patients actively waiting for a transplant in Wales has fallen slightly to 234 at 31 March 2017/18. Between 1 April 2017 and 31 March 2018, Wales had 74 deceased solid organ donors from Welsh hospitals, resulting in 181 transplants across the UK.

Of the 234 Welsh residents waiting for a transplant 137 received a transplant from a deceased donor and 42 received a transplant from a live donor. Welsh residents requiring heart, lung, liver and small bowel transplants are transplanted in England.

**Figure 1: Organ Donation, Transplants, Donors and Waiting List for Wales**



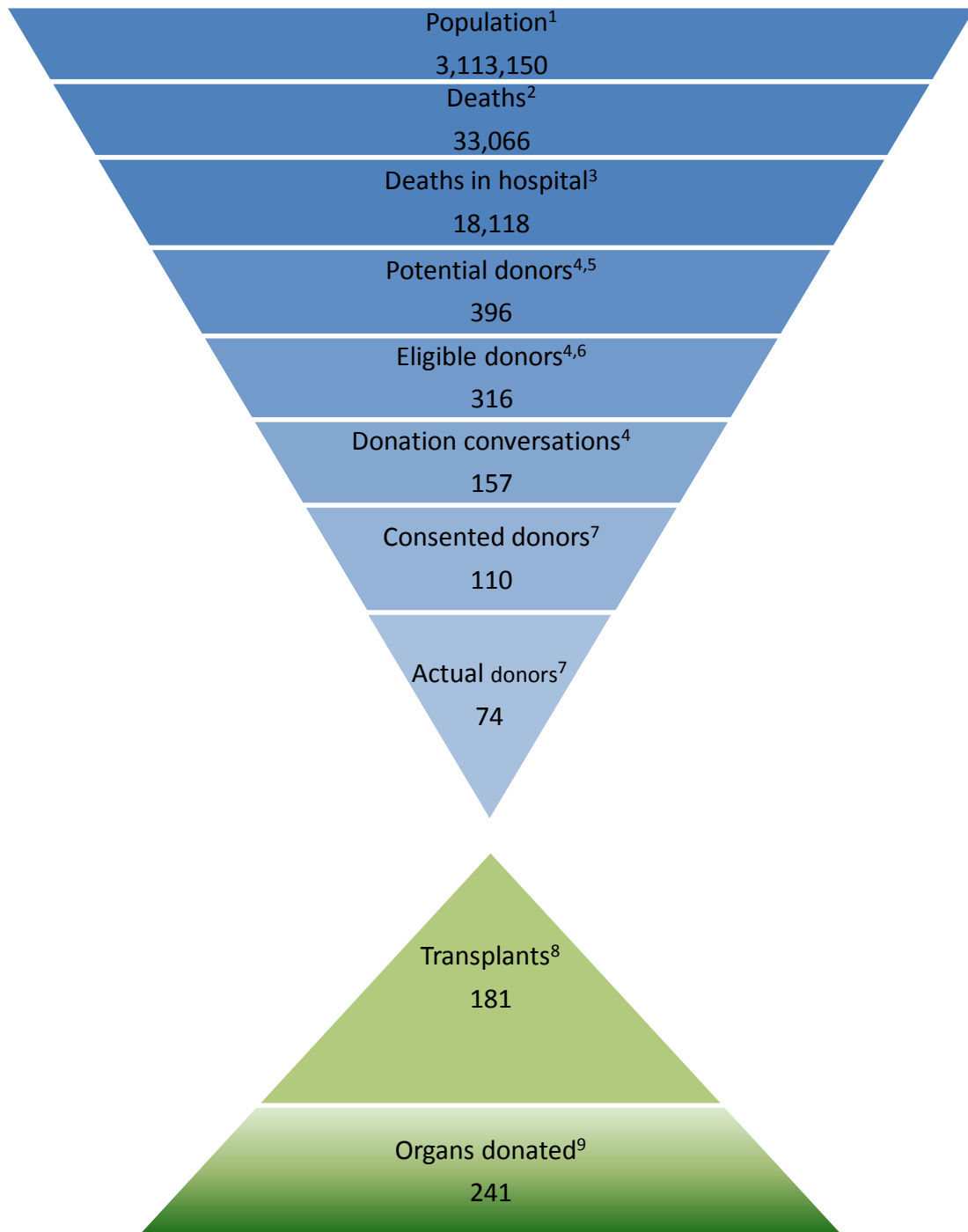
*Data source: NHS Blood and Transplant*

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 whom around 18,000 will be in hospital at the time of their death. However of these only around 400 die in circumstances where they can potentially become a donor and only approximately 300 of these are eligible to become donors<sup>1</sup>. In 2017/18 this resulted in 74

<sup>1</sup> Eligible donors after brain death (DBD) are defined as patients for whom death was confirmed following neurological tests and who had no absolute medical contraindications to solid organ donation. Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation.)

proceeding to solid organ donation in a Welsh hospital with 181 transplants undertaken and 241 organs donated.

**Figure 2: Wales – Potential deceased organ donation population – 1 April 2016– 31 March 2017**



*Data source: NHS Blood and Transplant*

1 ONS data  
2 ONS data  
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)

9 Organs from Welsh deceased donors



### 3.0 Deceased organ donation

There was a 21% increase in the number of deceased donors donating in Wales in 2017-2018 to 74, 13 more than the same period during 2016-17. The number of donors after neurological criteria (DBD) increased by 13% to 45, while the number of donors after circulatory death (DCD) increased by 38% to 29.

The numbers appear to be small however not everyone who dies can be a deceased organ donor as less than 1% of people die in circumstances where they are able to donate their organs. The biggest obstacle to increasing organ donation rates has been to ascertain consent in this small group of individuals.

During 2017-18 Wales had the highest rate of DBD and DCD donors per million per population (pmp) at 15.8 pmp and 9.6 pmp respectively, compared with the UK average of 14.5 pmp and 9.4 pmp.

Although these figures are encouraging they do highlight the need for the Welsh public to understand why it is so important that anyone that could donate is given the opportunity and family respect and honour their relative's decision. Ellie's story demonstrates what a fine line receiving an organ or missing out means.

Ellie Lacey (31) from Cardiff started to feel very tired but put it down to the fact that she'd not long got back from our five-month cycling trip around Europe, so didn't really think anything of it. After it continued, I visited my GP to have some blood tests; the results showed there was a problem with my liver but the doctor told me it was probably just a virus and I'd get better. Within a matter of weeks my body had swollen up, started to turn yellow, and I was admitted to hospital in January 2017.

"Like many others, I had never been seriously ill before and was always fit and active. My decline was so rapid that I was blue-lighted to the Royal Free Hospital in London and put on the super urgent transplant waiting list a week later. When an organ became available three days later, it was an extremely emotional moment for me and my family. I had my transplant within 2 weeks of being admitted to hospital and thankfully it went well.

"I think about my donor all the time and like to think that I can live a life full enough for us both. I think the world of her and will never stop being grateful for her decision to give the gift of life. Her family is my hero, during what must have been a traumatic time; they chose to honour her decision.

"What really hit home for me was the fact that my life changed so dramatically within such a short period of time. Waiting for a donor made me feel guilty, partly because I knew just how many other people are on the waiting list, and partly because the reality is that you're waiting for somebody else to die for you. It's a very difficult time mentally and physically.

“It’s upsetting to find out that some families refuse to support their relative’s consent for organs to be donated. It hits me hard as I could have been one of those waiting for a life saving organ that didn’t get one in time. It is so important to decide if you want to donate your organs and chat about organ donation with your family, they need to know what your decision is so they can support your decision if they are ever in that situation.”

Table one illustrates the stages where opportunities were lost pre-donation. The current patient assessment practice in DCD donation results in a significant proportion of DCD patients dropping out of the donation process at the approach stage; this is because a large number of eligible DCD donors are deemed unsuitable for donation due to medical unsuitability and therefore families or appointed representatives are not approached for a formal organ donation discussion

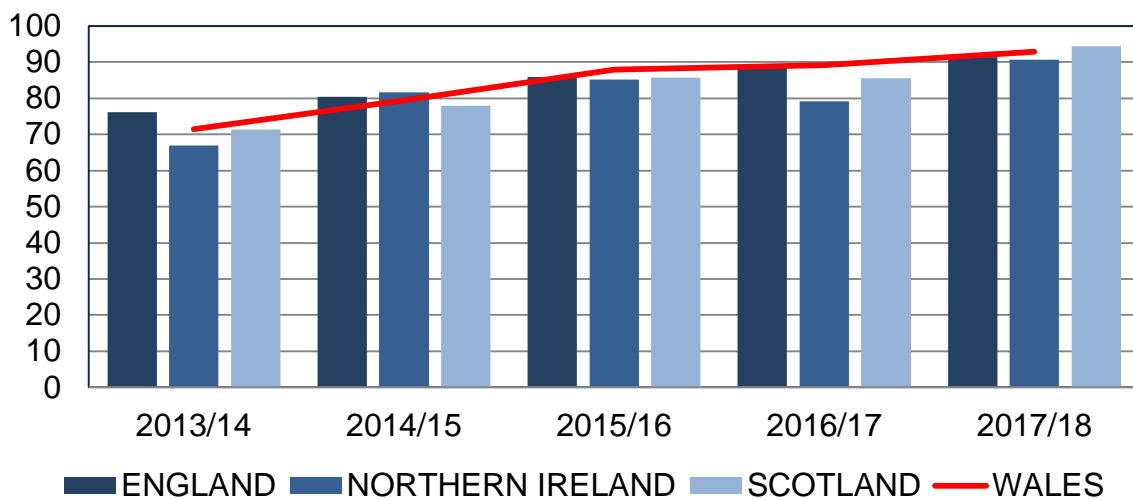
<b>Table 1: Summary of key percentages, 1 April 2017 to 31 March 2018</b>			
	DBD	DCD	ALL
Neurological death testing rate	95.3%		
Referral rate	98.8%	91.4%	92.9%
Proportion of approaches where a SN-OD was present	95.5%	90.1%	92.4%
Consent rate	80.3%	62.6%	70.1%
-when SN-OD not present for approach	33.3%	33.3%	33.3%
-when SN-OD present for approach	82.5%	65.9%	73.1%
- when patient had not expressed a decision to donate or the patient's ODR status was not known at the time of potential donation	63.3%	38.8%	48.1%
- when patient’s decision to be an organ donor on ODR and known at time of potential donation*	91.7%	90.0%	90.7%
- when patient’s decision to be an organ donor (by any method) is known at time of potential donation**	94.4%	90.5%	92.3%
- when SN-OD present for approach and patient’s decision to be an organ donor known to be on ODR at time of potential donation	95.5%	92.3%	93.8%
- when deemed consent applied***	85.7%	53.6%	67.3%
<p>* 5 families overruled their loved one's known ODR decision to be an organ donor  ** 6 families overruled their loved one's known decision (by any method) to be an organ donor  *** There were 49 cases where deemed consent applied and in 16 cases the family did not support deemed consent</p>			

Data source: NHS Blood and Transplant

### 3.1 Referral rate

All patients for whom neurological death is suspected or for whom imminent death is anticipated, i.e. receiving assisted ventilation, a clinical decision to withdraw treatment has been made and death is anticipated within four hours, should be referred to a Specialist Nurse - Organ Donation (SN-OD). For 2017/18 the DBD referral rate was 98.8% consistent with the UK average of 99% and the DCD referral rate was 91.4% slightly above the UK average of 89%.

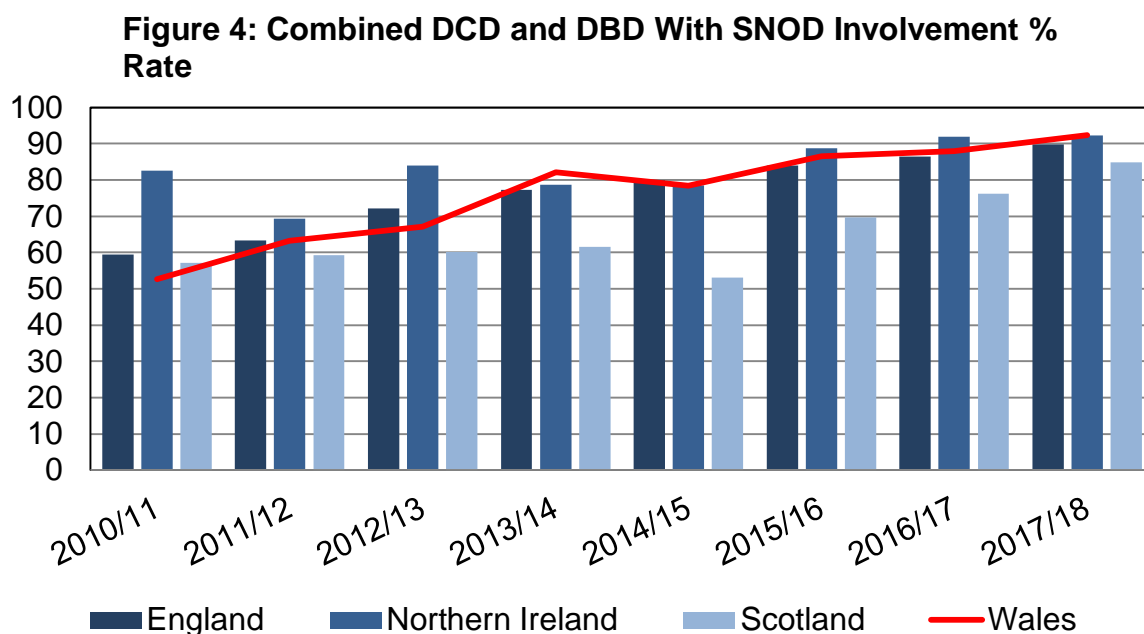
**Figure 3: % Rate Referred to SNODs , DCD & DBD, by Country**



*Data source: NHS Blood and Transplant*

### 3.2 Approach rate

All families of eligible donors were approached with a Specialist Nurse present in 95.5% and 90.1% of DBD and DCD cases, respectively.



*Data source: NHS Blood and Transplant*

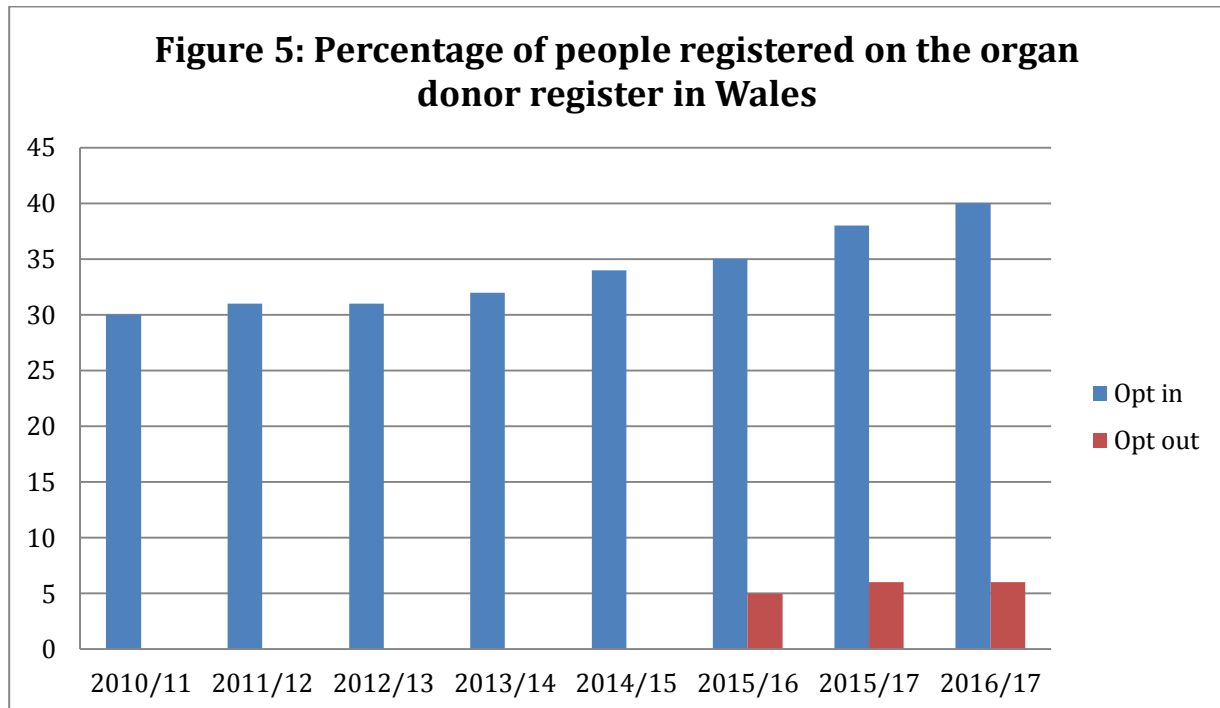
### 3.3 How many people are registered on the organ donor register? (ODR)

Even though in Wales we have passed a law which brought in the concept of ‘deemed consent’, it is still possible for people in Wales to record an express decision to be a donor on the Organ Donor Register if they wish to do so.

We know that families are more likely to support donation proceeding when they know what their relative’s decision about donation is. When the patient had not expressed a decision to donate or the patient’s ODR status was not known at the time of potential donation the overall consent rate at 31 March 2018 was 48.1% whilst when patient’s decision to be an organ donor on ODR is known at time of potential donation the consent rates rises to 90.7% and 92.3% when the patient’s decision to be an organ donor (by any method) is known at time of potential donation.

Figure five shows the percentage of the Welsh population that has recorded a decision on the ODR. The registrations to donate are continuing to increase now at 40% (1,234,025) of the population. This means that an additional 62,725 people recorded on the register a decision to donate between 1 April 2017 and 31 March 2018. In addition just over 6% of the population had opted out at end of March 2018, (180,924). This

means that an additional 6,118 people opted out on the register between 1 April 2017 and 31 March 2018



source: NHS Blood and Transplant

Gail Butterill (44) from Anglesey knows how important it is to discuss your organ donation decision with loved ones. She honoured her partner Ifor's decision to become an organ donor. Gail explains:

"Ifor told me that he felt strongly about being an organ donor when we returned to Wales and I knew he kept a donor card. In January 2017, he suffered a sudden heart attack at home and was airlifted to hospital. Unfortunately, he didn't make a recovery and died at the age of 72.

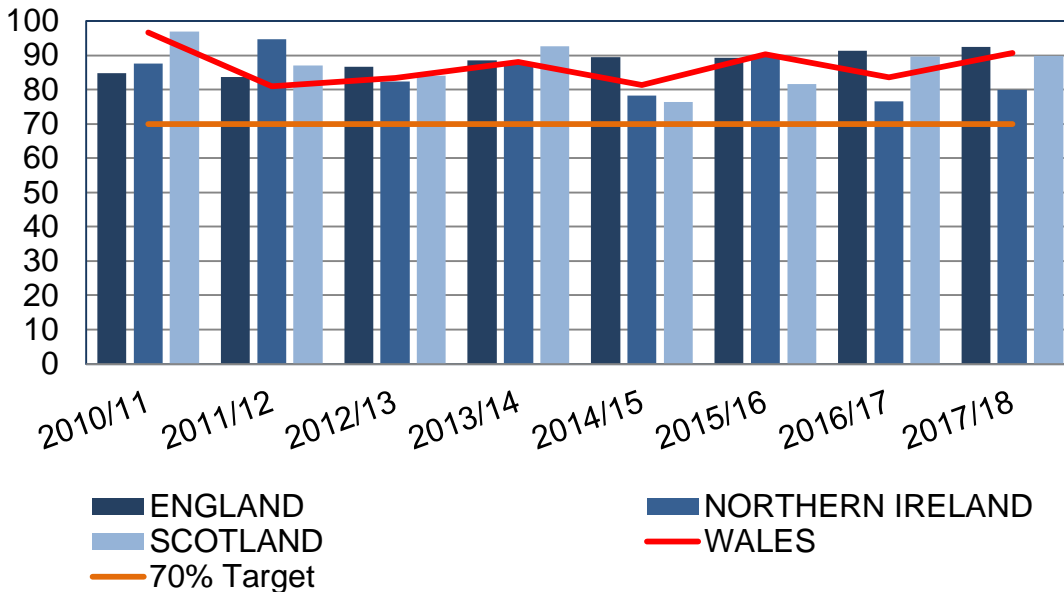
"The transplant team called me to ask about his organ donation decision. This choice could have been really difficult for us if we didn't know what he wanted, especially because it was so sudden. I found his donor card straight away and knew that he would want us to honour his decision – it was an obvious choice.

"Before Ifor died I wasn't registered as an organ donor and hadn't really thought about it. He inspired me to sign up to the organ donation register and make sure my family know my decision, so the situation is simpler for them. For me, having Ifor's donor card made the process much easier. It became clear how important it is to register your decision, whether it's to opt-in or out-out, but more importantly to tell loved ones what you want. It will make things much easier for everyone in the long run."

## 4.0 What is the consent rate for deceased organ donation?

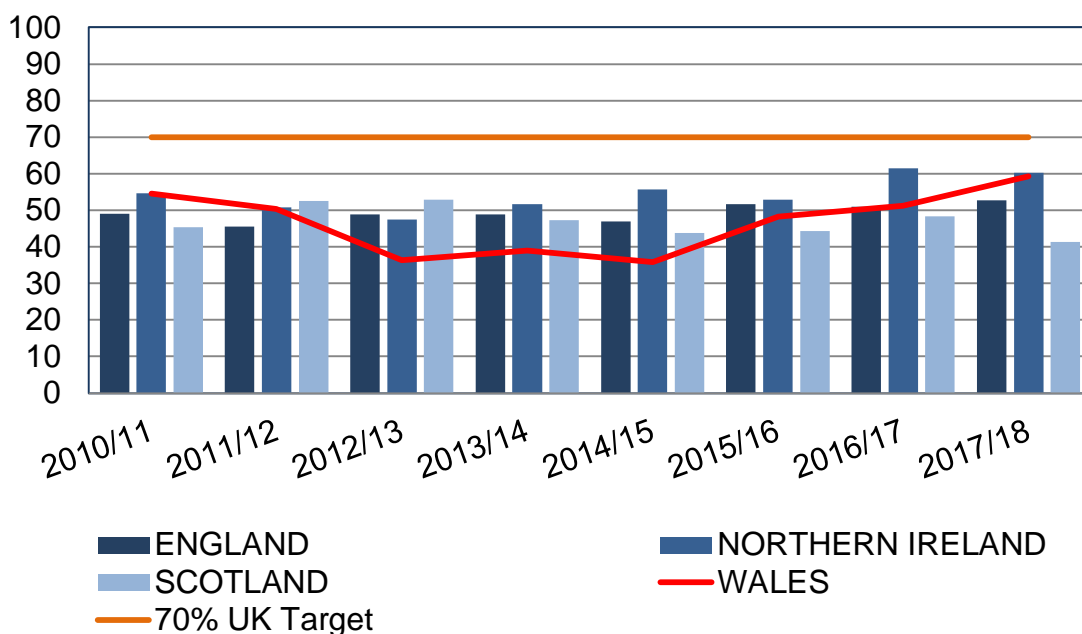
NHSBT data show that consent rates are higher where consent status on the ODR is known. This highlights the importance of promoting public awareness of organ donation but also of individuals making their decision known to family and loved ones. In Wales, the consent rate where ODR status is known has been consistently high and comparable to other UK nations as seen below in figure six.

**Figure 6: DCD and DBD Combined Consent % Rate When Patient Registered on the ODR**



Data source: NHS Blood and Transplant

**Figure 7: DCD and DBD Combined Consent % Rate When Patient Not Registered on the ODR**



Data source: NHS Blood and Transplant

Table two shows the consent in Wales just prior to the start of the public information campaign and implementation of the Human Transplantation (Wales) Act 2013 up to 31 March 2018. 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 70% in 2017/18. In view of the consistent rise it is likely that the change in the law and public information campaign had a significant affect on the consent rate. Unfortunately there has been little change in the number of occasions where consent had been ascertained but the families felt they could not support donation proceeding.

The overall consent/authorisation rates (combining DBD and DCD) for Wales's compares favourably with England, Scotland and Northern Ireland at 70%, 66%, 57% and 66%, respectively.

**Table 2: Organ donation consent rate in Wales**

Table 2: Wales potential donor audit data, 1 April 2011 – 31 March 2017 data NHSBT							
Financial year	Potential donors	Eligible donors	Total consent ascertained	Consent deemed	Consent rate %	ODR override	Deemed consent override
2011/12	504	250	91	N/A	59	8	N/A
2012/13	461	244	81	N/A	50	8	N/A
2013/14	507	366	90	N/A	54	6	N/A
2014/15	419	334	83	N/A	48	9	N/A
2015/16	394	282	93	13	59	4	4
2016/17	392	307	92	32	64	9	12
2017/18	396	316	110	49	70	5	16

*Data source: NHS Blood and Transplant*

Table three indicates the reasons why the family did not support donation proceeding 2017/18.

**Table 3: Reasons why families did not support organ donation**

	DBD		DCD	
	N	%	N	%
Patient previously expressed a wish not to donate	4	31	8	24.0
Family were not sure whether the patient would have agreed to donation	2	25	1	3.0
Family did not believe in donation	-	-	1	3.0
Family felt it was against their religious / cultural beliefs	-	-	2	6.0
Family felt the patient had suffered enough	-	-	3	09.0
Family did not want surgery to the body	3	23.0	1	3.0
Family wanted to stay with patient after death	-	-	2	6.0
Family felt the length of time for donation process was too long	1	08.0	13	38.0
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	1	8	-	-
Strong refusal- probing not appropriate	1	8	-	-
Other	1	8	3	9.0
<b>Total</b>	<b>13</b>	<b>100.0</b>	<b>34</b>	<b>100.0</b>

*Data source: NHS Blood and Transplant*

Sam Williams' stepfather, Scott passed away in 2016. His family's decision to donate Scott's organs has enabled him to speak openly with friends and family about why we all need to talk about organ donation. He explains:

"Scott had been a big part of my life since I was about 9 years old. In 2016, he was found unconscious and had to be rushed to hospital where he was cared for in the intensive care unit. The doctor told us straight away that there wasn't much hope for him. I was with my mum, Joanna, when the specialist nurse approached us to ask about organ donation. Scott hadn't registered his decision, but my mum just knew that he would have wanted to donate.

"We hadn't discussed it as a family, but I was completely supportive of my mum's decision to support Scott's consent to be deemed for organ donation. You don't need your organs when you die, and it can make a huge difference to the lives of others. Not long after Scott's death, we were told he had saved the lives of three other people. This really put things into perspective for me; I realised that organ donation is a topic all families need to talk about so that if you are in the unfortunate position to support your relative's decision about organ donation you know what that person wanted.

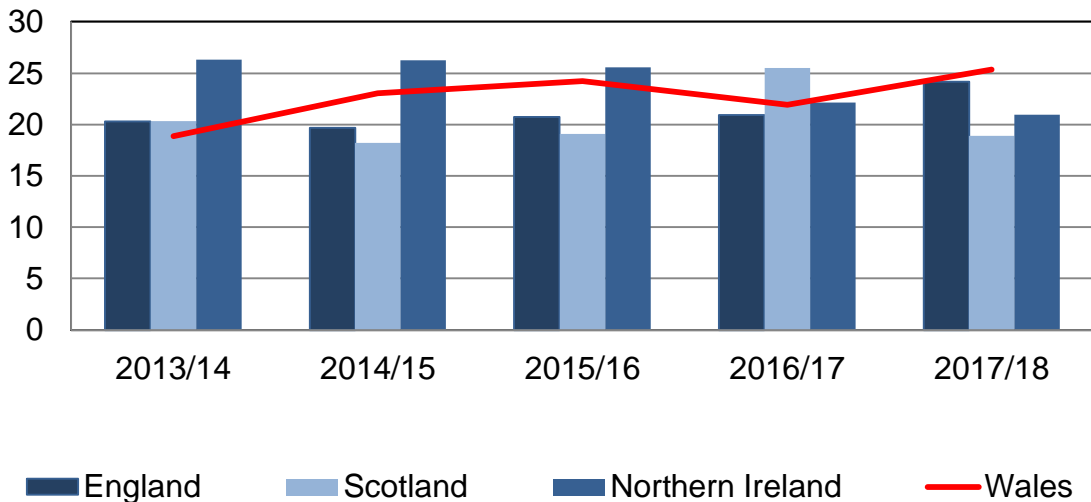
"Friends and families across Wales should make time to talk about organ donation. We would all accept a second chance at life so why stop someone else from having one?"



## 5.0 How many people donate organs in Wales?

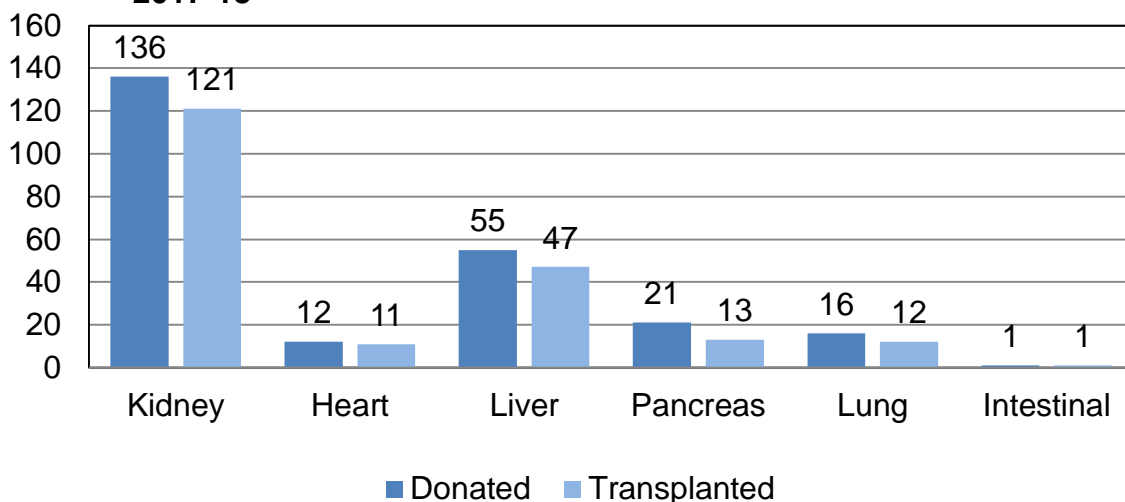
Between 1 April 2017 and 31 March 2018, there were 74 deceased solid organ donors who died and donated from Welsh hospitals. 241 organs were donated from deceased Welsh donors, but 36 were not transplanted. Figure nine gives an overview of the organs that were donated. In addition there were a further 42 living organ donation transplants for Welsh residents. A number of these will have been transplanted in English hospitals. There were 31 living organ donors from Welsh hospitals.

**Figure 8: Number of Deceased Organ Donors pmp by Country**



*Data source: NHS Blood and Transplant*

**Figure 9: Number Organs from Welsh Deceased Donors in 2017-18**



*Data source: NHS Blood and Transplant*

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

Progress continues with performance in donation rates with the combined consent rate the highest in the UK and whilst it cannot be definitively said that this is all due to the impact of the legislation, we know that deemed consent is working in practice and that there were 33 donors in 2017/18 whose consent was deemed.

We are mindful donor numbers are small in Wales and it may be several more years' to truly see what impact the introduction of the opt out system has in terms of organ donors and organs donated.

The Key findings from the latest wave (15) of research from the Wales Omnibus Survey (Feb -March 2018) include:

- 82% unprompted awareness of the changes to organ donation (up from 70%)
- 79% unprompted correct understanding of the system
- 73% agree that if an individual does not register a decision that families should be encouraged to support deemed consent (up from 69%)
- 57% awareness of the TV advert / 39% for radio advert
- 40% of people who had seen / heard the advert have had the chat
- 55% of people have had the discussion with family (up from 51%)

Table 4: Donors from Welsh Hospitals and the total number of organs donated

	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
<b>Deceased donors</b>	52	54	60	64	61	74
<b>Organs donated</b>	150	140	149	222	197	186

*Data source: NHS Blood and Transplant*

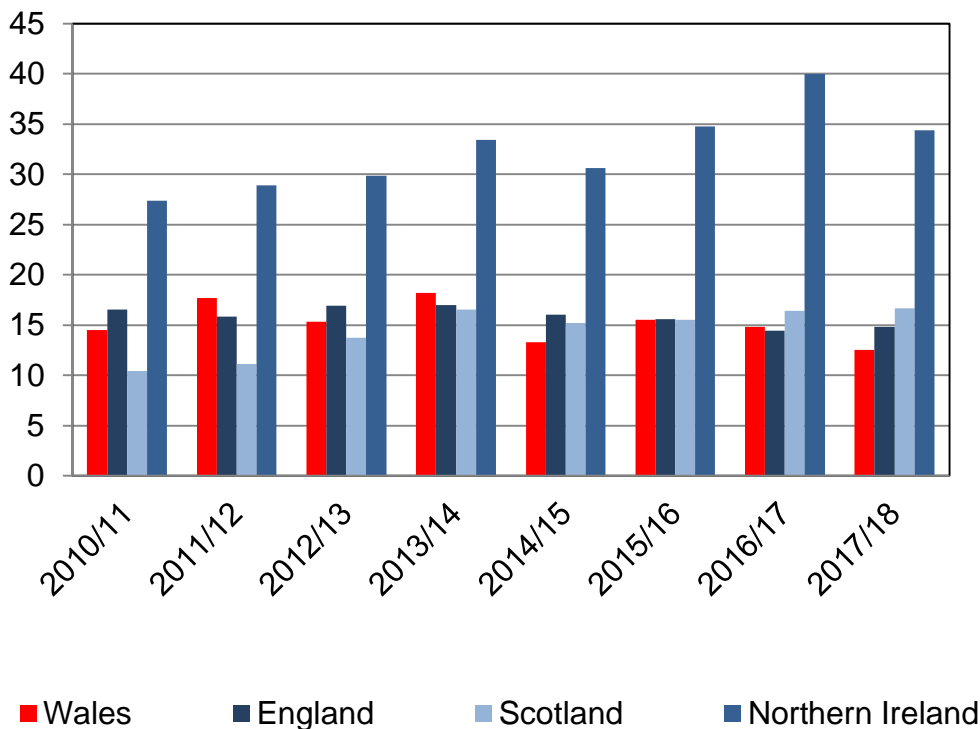
## 5.2 How many living organ donors are there?

Living organ 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 both Wales and 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 31 for 2017/18 and a decrease from 36 in 2016/17. 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 10 Number of Living Donors pmp**



*Data source: NHS Blood and Transplant*

Ann Marsden works as a Living Donor Transplant Co-ordinator at the University Hospital of Wales in Cardiff. She has helped to facilitate over 500 life-saving kidney transplants involving living donors over the past 16 years. She says:

“Kidney failure can affect any one of us at any time and living kidney donation can often be the best long-term form of treatment for a patient with kidney disease, especially if the transplant can be performed before the need for kidney dialysis. The operation success rate is excellent and patients receiving a kidney from a living donor can expect to benefit from a fully functioning kidney for 15 to 20 years on average.

I’ve seen first-hand how this selfless act of giving can transform the life of someone suffering with kidney disease. It is such a positive experience for everyone involved and hugely rewarding for people on the support team like me.

Andrew Thomas (55) from Pengam, Caerphilly, was a fighting fit karate instructor who was living life to the full until he became seriously unwell from kidney failure.

Andrew's life was transformed thanks to his brother Paul, as he explains:

"When I was in my late twenties I contracted Sarcoidosis, a disease that affects the lungs. I found it extremely difficult to breathe and couldn't even walk upstairs without turning blue from lack of oxygen. When doctors were completing checks they discovered I had an unrelated kidney disease.

"I carried on training and living a full and healthy life for over fifteen years until I started to feel unwell around Christmas 2006. Tests showed that my kidneys were starting to fail but due to my fitness levels I didn't require dialysis for another nine months. Dialysis saved my life, but I did not enjoy the experience. It was hard to hold down a full-time job while dialysing three times week, but my employers were fantastic and gave me the time I needed for treatment.

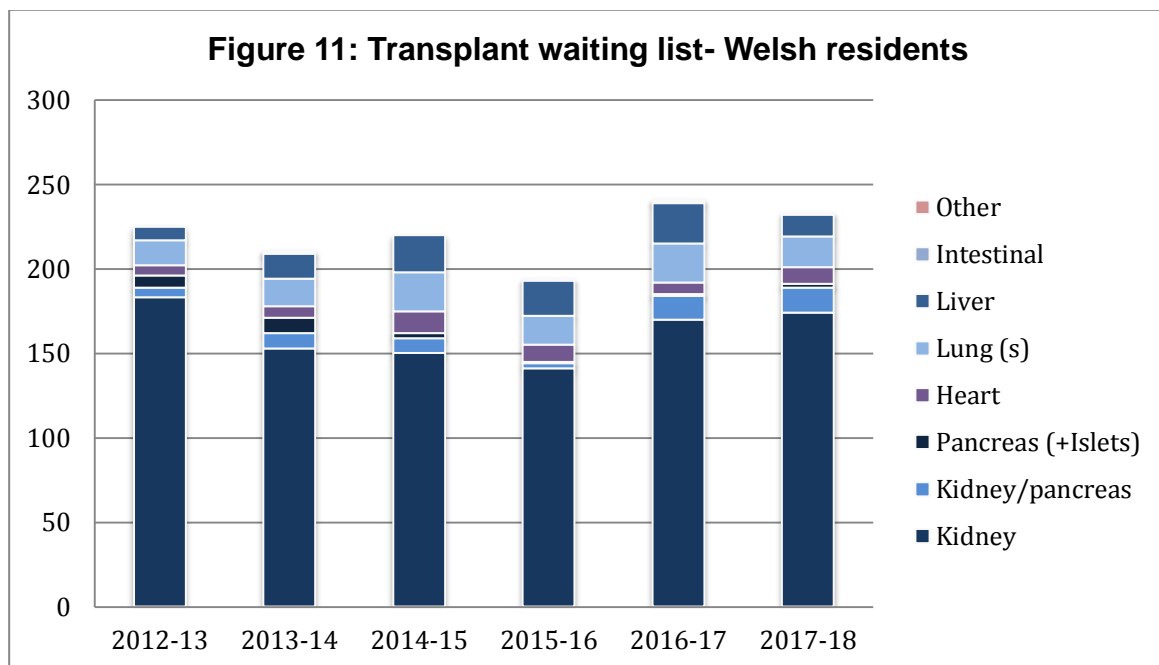
"In early 2008, my eldest brother Paul offered to be tested to see if he was could donate one of his kidneys to me. Luckily, he was a match. He hates hospitals and needles but was willing to go through with the tests and the operation to save me. The change since my transplant in May 2008 has been unbelievable; his gift has really given me my life back.

"I understand why some people don't like the idea of organ donation, particularly families who might be grieving. But at the end of the day it's such a great gift and could completely change and literally save lives. Organ donation is something everyone should consider, whatever their own personal feelings. My brother put his fears aside to give me his kidney and help me live life to the full again. That's something I will always be grateful for. My young grandson was born with chronic kidney disease, which is unrelated to my diagnosis, and will also need a kidney transplant in future. This shows how important organ donation can be as a transplant could be needed at any age."

## 6.0 How many Welsh residents are on the organ transplant waiting list?

As of 31 March 2018 compared to 31 March 2017 the number of Welsh residents waiting for a:-

- Transplant decreased to 234 from 243.
- Kidney transplant increased to 174 from 170
- Kidney and Pancreas combined increased to 15 from 14
- Pancreas increased by 1 to 2
- Heart increased to 10 from 7
- Lungs decreased to 18 from 23
- Heart lung combined decreased to 1 from 2
- Liver decreased 13 from 24



Data source: NHS Blood and Transplant

Hazel Mock (40) from Penllergaer, was determined to lead a full, sporty and healthy lifestyle until complications related to her Type 1 Diabetes became so severe that a pancreas transplant became her only chance of leading a normal life with her family.

She says: "After my second child was born I started having severe low blood sugar levels, up to twelve times a day and I would lose consciousness. There wouldn't be any warning before I would collapse. It was very frightening for my young children and worrying for my husband who'd have to stay up at night taking care of me. Once I collapsed by a main road when I was by myself with the children aged two and four at the time. My son was able to pass me some Lucozade and I was somehow able to get us all to the local library where I managed to say, 'I need a paramedic' before I lost consciousness."

"Things came to a head when we were about to go on a family holiday last year and I suffered an extremely severe episode of low blood sugar levels which the paramedic told me I nearly hadn't survived. Luckily, I had already been referred to the transplant team to talk about a pancreas transplant because of the severe episodes of dangerously low blood sugar levels. By this stage, I'd had to go off work sick because my sugar level control made it impossible to have a normal routine, so it was a relief when I was added to the transplant waiting list. I was lucky because they managed to find a pancreas for me in just three months. My fitness levels were good so I only spent three weeks in hospital after the operation, but it was still a slow recovery because I had to regain some mobility and retrain my body to function properly again."

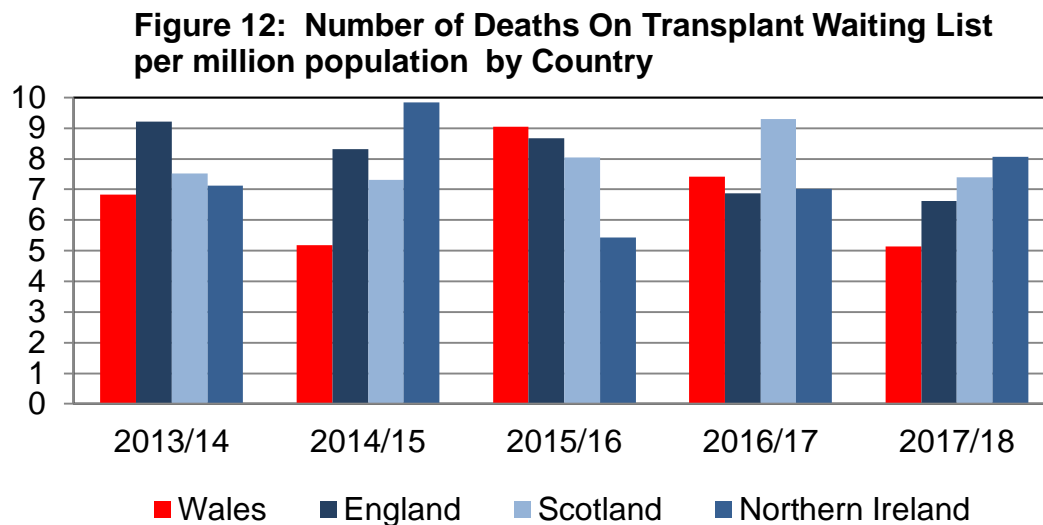
"Things have changed completely since my transplant operation. I don't have to worry about the terrible low blood sugar levels any more, I was able to go back to work again, and it's made a huge difference for us as a family. Now I can do so much more with the children, they don't have to worry about me, and my husband isn't stressed or exhausted from taking care of me every night. This year we went on holiday and it was brilliant because we were actually able to enjoy it. We could go on long walks without any risk and eat when we wanted to, not when we needed to for my blood sugar levels. We just didn't have to worry about things."

"My pancreas came from an anonymous deceased donor and it means so much to me that they opted in to the organ donor register. I look forward to saying 'thank you' to their loved ones because their generosity has completely improved the quality of life for my whole family. We've actually got a life now."

## 6.1 How many die whilst on the transplant waiting list?

Organ transplantation is often the only treatment for end stage 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 2017/18 decreased to 16 from 24 in 2016/17. There continue to be more people waiting than the number of organs available. The push to reverse this trend continues.



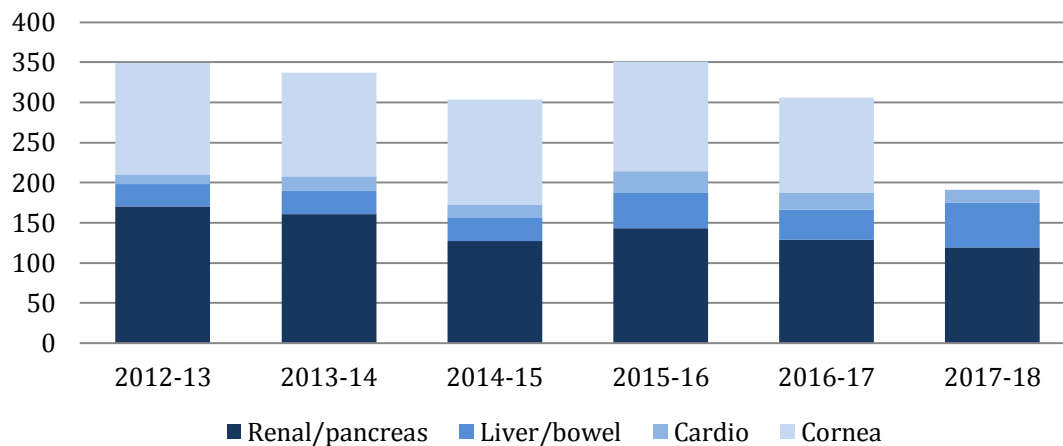
Data source: NHS Blood and Transplant

## 7.0 Update Number of Welsh residents receiving a transplant by type

Figure 13 shows the number of transplants for Welsh residents by organ type. Between 2016/17 and 2017/18, there has been an increase of 40% in the number of pancreas transplants, an increase of 8% in the total number of liver transplants, an increase of 11% in the total number of cardiothoracic organ transplants. There has been a small fall of 8% in the total number of kidney transplants performed, as Wales only has one transplant unit this likely represents the declining and relatively small waiting list for kidney transplants.

The number of transplants performed on Welsh residents does not correspond to the increase in donor numbers as organs donated in Wales may be used for patients in other parts of the UK, and vice versa.

**Figure 13: Number of transplants on Welsh Residents by organ**



Data for corneas 2017/18 not available at time of writing

Data source: NHS Blood and Transplant

Rhys Llewelyn, from Aberdare, now -31 is making the most of opportunities and living life to the full. He explains:

“I was diagnosed with cardiomyopathy – a disease of the heart muscle – at just three months old and my parents were warned that I was unlikely to see my first birthday. Doctors managed the condition with medication for 25 years which allowed me to lead a relatively normal life, but I couldn’t play contact sports and would get out of breath easily.

“When I was 21 I had to be fitted with an internal defibrillator after I fainted at the doctor’s. A few years later I developed flu-like symptoms but assumed I’d just been overdoing it. I was referred to the hospital where the consultant carried out an echocardiogram. I could tell it was bad news straight away from the look on his face. He told me my heart was failing.

“I was placed on the transplant waiting list when it was confirmed that this was the only option to save me. It was a struggle to even walk to the corner shop because I felt so unwell; I was coughing up blood and endured a handful of long term stays in hospital. I ended up admitting myself to hospital because I was so weak I could barely stay awake. They said my heart was struggling to work and put me on the transplant priority list because I needed a new heart within a few weeks or I wouldn’t make it.

“It was incredibly emotional when they found a heart for me. I had been so close to dying - thinking that someone I didn’t know was now saving my life was sad and joyful all at the same time. There were a couple of setbacks after the operation and I needed to have more surgery, so I couldn’t leave hospital for six weeks. Luckily, I managed to return to work just a couple of months later and, after nine months; I took on the challenge of climbing Mount Snowdon to raise money for British Heart Foundation Cymru.



## 8.0 Paediatric/ neonatal organ donation/transplantation

The organ donation process does not differ for children, although their consent cannot be deemed, but the logistics, emotions and reactions can be difficult. NHSBT's Paediatric and Neonatal Donation strategy supported by Welsh Government acknowledges, address and embrace these issues in its attempt to significantly improve rates of paediatric donation in the UK.

Paediatric donation in Wales is very small in number, UK wide just 57 donors were below the age of 17 representing 4% of the total number of UK donors.

Although a rare event for those children and neonates who have been admitted to critical care and who will not survive the illness; if the decision has been made to withdraw treatment or test using neurological criteria, they may (following discussion with parents) be suitable to donate organs for transplantation. The topic of donation has become a routine part of paediatric end of life care and all eligible donors in 2017/18 were referred to the specialist nurses.

An average of 4.0 organs was donated per paediatric DCD donor whilst there were no DBD donors.

All Welsh paediatric patients in need of a transplant are referred to and transplanted in hospitals in England.

For Hollie Bailey from Caerphilly, dealing with health problems has been a big part of her life since she was a baby. She was born with smaller than average kidneys, which led to full blown kidney failure by the age of 13 and her first transplant in 2006. Her health declined again in 2014 and left Hollie in need of a second kidney transplant at the age of 23.

“Having enjoyed a normal life for so many years after my first kidney transplant, I found it incredibly hard to deal with the sudden decline in my transplant kidney ten years on. Not to mention the intensive daily dialysis treatments and the prospect of a lengthy wait for my second transplant to become available,” says Hollie. “Both my mum and step dad got tested as possible donors and I was so relieved when my stepfather was confirmed as a match. I’ll always be grateful for the gift he has given me. Since my kidney transplant, I am back to full health and enjoying working full-time once again - something I could never have done before the operation, as I was so tired all of the time. I now have the energy to enjoy time with my family and friends.”

## 7.0 Conclusions and looking ahead

We have delivered many improvements to help achieve the ambition of the *Taking Organ Transplantation to 2020* strategy and the Welsh Action plan which aspires Wales to be amongst the best performers in the world. The latest figures show that we have made excellent progress with the highest ever number of donors from Welsh hospitals combined with a steady rise in the consent rate resulting in Wales having the highest consent rate for the whole of the UK.

We continue to work hard to maximise every opportunity for organ donation to ensure that more patients have the opportunity of a successful transplant and we are clearly moving in the right direction, but there's always more work to do.

We will continue to promote the role of the family in organ donation. It is important for family members to understand their role is to support their relative's decision with respect to organ donation, whether their consent is expressed, or deemed to have been given. We will continue to encourage people in Wales to talk about organ donation and make their decision known to their next of kin.

We will focus more energy in promoting living organ donation and work with Black, Asian and Minority Ethnic communities to raise awareness of the need for and generate family discussion about supporting organ donation.

We appreciate it is a very personal decision to either donate or not donate organs however many lives can be saved and changed forever as a result. We will be forever grateful to the individuals and families who support donation and transform the lives of those so desperately in need.