

Nawr yw'r amser i siarad am roi organau
Time to talk about organ donation



Llywodraeth Cymru
Welsh Government

Human Transplantation (Wales) Act 2013

Report laid before the National Assembly for Wales
under Section 2.(3)

December 2018

Human Transplantation (Wales) Act 2013: Report laid before the National Assembly for Wales under Standing Order 2.3

Introduction

1. The Human Transplantation (Wales) Act 2013 (“the Act”) was given Royal Assent on 10 September 2013. The Act has created a system of consent to deceased organ donation in Wales. On 1 December 2015, Wales moved to a soft opt-out, or “deemed consent” system of consent to organ donation. This means that unless a person has stated otherwise, their consent to donation may be deemed to have been given and they will be treated as having no objection to becoming a donor. By making this change in the legislation and as it develops as “the norm”, Welsh Government expects to see an increase in donation over a period of time.

2. 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.

3. In addition, Section 2 (3) of the Act places an obligation on Welsh Ministers to report annually to the National Assembly for Wales for five years from September 2013 on work undertaken to:

- Promote transplantation as a means of improving the health of people in Wales;
- Provide information and increase awareness about transplantation;
- Inform the public of the circumstances in which consent to transplantation activities is deemed to be given in the absence of express consent; and
- Ensure that the resources available to local health boards include the specialist skills and competences required for the purpose of this Act.

4. This report is the fifth of five annual reports outlining the work undertaken to support this. The report covers the period of 15 November 2017 to 16 November 2018.

Background

5. The Human Transplantation (Wales) Act 2013 provides a framework for the introduction of a consent system to organ donation. This system is known as a “soft opt-out” or “deemed consent” system. The law provides a lever for a cultural shift in behaviour and attitudes towards increasing consent rates for organ donation.

6. In order for the system to be implemented smoothly and successfully, it was accompanied by a full public information campaign to ensure that the Welsh population were aware of the changes and understood how it affects them.

7. The primary role of the communications work between December 2013 and March 2016 was to: inform people of the legislative change; explain clearly the choices available to register an organ donation decision (express consent or express refusal) and the implications of not registering a decision, where an individual's consent may be deemed. However, the work was undertaken in the broad context of positive messages about organ donation and the difference it can make to the lives of individuals and their families. People were also being encouraged to talk to their loved ones about their decision.

8. From April 2016 the communications focused on reminding people of their choices and also encouraging them to talk to loved ones about their decision.

9. There was still some confusion among the public about the role of the family so in 2017, based on the latest evidence, we changed the focus of our communications work to encourage people to clarify their organ donation decision and to share it with those closest to them. This aims to address the issue of the family overriding a registered yes to donation on the organ donor register and not supporting deemed consent. It seeks to increase awareness of the role families/ partners have in honouring the decision of their loved ones, as well as encouraging people to share their decisions.

Objectives

10. The overriding policy objectives from the legislation are:

- Increase the number of organs available for transplantation;
- Create an environment where organ donation becomes the social norm.

11. Policy objectives for the current comms campaign:

- Reduce the number of families who override a registered yes on the organ donor register or who do not support deemed consent;
- Increase consent rates for organ donation;
- Increase donors and transplants;
- Increase the number of people who register a decision either on the organ donor register or by telling family and friends.

12. Communications objectives:

- To increase the number of people having a discussion with loved ones – this could be family, partners, or friends - about their organ donation decision (54% in September 2017);
- To increase understanding of the choices people have under deemed consent (70% in September 2017).

Budget

13. The budget for all organ donation communications activity in 2018-19 is £310k, having increased to £350k in 2017-18 to accommodate the new advertising campaign (up from £200k in 2015-16).

Approach

14. The campaign launched on 1 November 2017 with TV, radio and digital advertising supported by public relations and social media activity. The first phase of campaign activity (from 2017-18 budget) comprised three bursts of advertising and sustained PR work. Other notable activity took place to introduce a new awareness week for Living Donation (April 2018), and further activity for Organ Donation Week in September 2018. A second phase of TV, radio and digital advertising started on 3 September, with a second burst of advertising in November 2018.

We have continued to use case studies as part of PR activity as they have been successful in terms of coverage and reach.

Key Messages

- It is important to discuss your organ donation decision with your family.
- Your family would always be involved in discussions about whether organ donation should go ahead. It's important they know your decision so they can honour it.
- You can register a decision at any time by calling 0300 123 23 23 or visiting <https://beta.gov.wales/talk-about-organ-donation-campaign> or by telling your family and friends.

Call to Action

15. New campaign materials (TV and radio adverts) prompt viewers to search Organ Donation Wales.

As part of a move to update the Welsh Government website, all organ donation information and the campaign website moved to a new address in August 2017: <https://beta.gov.wales/organ-donation-guide>.

Our social media channels are: Twitter @OrgDonationCYM and Facebook @OrganDonationWales.

Key Achievements

Public Relations

16. PR work, including proactive social media, was running throughout 2017-18 and continued in 2018-19. The messages aimed to maintain understanding of the organ donation choices in Wales; promote conversations among loved ones, and encourage people to register a decision. Proactive stories have consistently generated positive coverage across the national and local titles online, in print and on broadcast channels. It supports advertising activity by providing stories of people who have been impacted by organ donation and the transplantation process.

Website

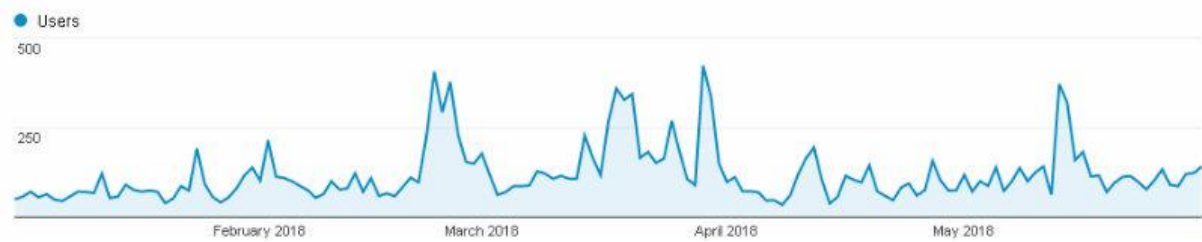
17. Our campaign website continues to be our major call to action, providing lots of useful information about organ donation and the new system in Wales. The content has been integrated with organ donation policy pages on the main Welsh Government site with a user-friendly guide. The following graphs show the traffic to the old campaign website from Nov 2017 to August 2018, and visits to the new campaign page since the move at the end of August.

The dedicated website for organ donation in Wales received over 59,271 visits from 50,260 users, of which 90% were new visitors. This is an increase of around 45% in relation to visits and users from the previous year.

November – December 2017 (New campaign launched in November. TV/ radio ads running 4-19 December. Publicity around anniversary of new law on 1 Dec)



January – May 2018 (Living Donation Week, April 2018/ TV and radio advertising running in May)



June – August 2018



September - November 2018 (Organ Donation Week/ new TV/ radio advert started on 3 Sept)



Schools pack

18. On Wednesday 14 March 2018 the first organ donation education resource for schools in Wales was launched. The bilingual education pack was developed for pupils aged 11-15 (key stage 3 & 4).

The lesson guide is the result of collaboration between the Welsh Government and NHS Blood and Transplant (NHSBT), and contains a lesson plan, activities, short case study films and guidance for teachers.

The pack aims to encourage pupils to:

- Describe how organ donation saves and improves lives;
- Explain some of the reasons why people decide to become organ and tissue donors;
- Understand why it is important to join the NHS Organ Donor Register;

- Understand how to talk to people about organ and tissue donation;
- Understand what options about donating they must consider under the system in Wales;
- Understand the decision to donate is their own, and the importance of sharing that decision.

The pack is available with other resources for secondary schools on Hwb:

<https://hwb.gov.wales/resources/resource/f8c5e75f-f280-440d-b3b2-c5a33b0b031b/en>.

The pack has been used by NHSBT staff as part of outreach work with schools in Wales, as well as independent use by teachers. We will evaluate the usage and will adapt the pack in line with feedback received from participating schools.

Officials have had discussions with the Believe charity about developing resources for younger pupils to support the charity's work to raise awareness with its Fraser Bear video.

Information Materials

19. We have continued to promote and distribute a range of materials, including the A5 information leaflet with a prompt to tell your family your decision.

Information is available in alternative and accessible formats including easy read, braille, large print, audio, British Sign Language video, as well as a range of ethnic minority languages.

Social media

20. Bilingual Facebook and Twitter channels support the campaign. Our approach has been to respond proactively to comments and questions where appropriate to aid understanding of the system. The Facebook page has continued to be promoted through advertising. This has proved successful in terms of increasing reach. The page increased its 'likes' from over 4,000 (stats from 13/10/14) to 16,872 (15/11/2018). There was a correlation between advertising periods on Facebook and increases in 'likes'.

Our dedicated twitter channel now has 1,500 followers (correct at 15/11/2018).

Twitter: @OrgDonationCYM

Facebook: Organ Donation Wales

Stakeholder engagement

21. A stakeholder e-bulletin has been issued at key times in 2017-18. The newsletter is sent to 289 people.

22. During Organ Donation Week in September stakeholders including Kidney Wales, British Liver Trust and transplant recipients hosted exhibition stands in Welsh Government's Cathays Park office lobby in partnership with Organ Donation Wales to engage with staff and visitors.

Focus on Living Donation, April 2018

23. For the first time, living donation was given the spotlight by Organ Donation Wales with the aim of building up to establishing an official 'awareness week'.

A press notice was issued, with case study and social media activity in support.

<https://gov.wales/newsroom/health-and-social-services/2018/living-doner/?lang=en>

The focus on living donation took place over a fortnight and generated:

- 1,220 visitors and 1,369 visits to our campaign website – an increase of 48% and 39% respectively;
- over 224 views of a new web page about living donation;
- Approx. combined reach of over 42K people across 12 Facebook posts (6 English, 6 Welsh);
- Almost 35K impressions and 95 retweets across 10 tweets (5 English, 5 Welsh);
- 10 – 15 enquiries to the South Wales living donor co-ordinator. These queries were received within the fortnight of our activity but this is around the number of enquiries usually received within 3 months.

Summer roadshows

24. We had a presence at four events across Wales for a series of #TalkOrganDonation summer roadshows in a bid to get more people sharing their organ donation decision with their friends and families.

A survey revealed that 48% of us have our most important life-changing chats while sitting on the sofa, so we created a pop-up mobile living room to encourage members of the public to sit down and have the organ donation chat then and there.

The events aimed to:

- Give the people of Wales the opportunity to open up and have the chat about organ donation with their friends and family;
- Encourage more people to tell their loved ones about their organ donation decision;
- Provide the people of Wales with all the information they need to register their decision;
- Increase the number of people having the chat about organ donation.

Venues: Pembrokeshire County Show, Nation Radio Cardiff 10K, National Eisteddfod, The Big Cheese weekend (Caerphilly)

	Caerphilly Big Cheese	Eisteddfod	Pembrokeshire Show	Cardiff 10k
Engagements	450	970	1300	600
Stand attendees	177	365	325	20
Conversations	25	27	25	3
Future conversations	22	35	85	10
Decisions registered	12	64	67	3
Future decisions	8	40	25	10

Organ Donation Week, 3 – 9 September 2018

25. During Organ Donation Week, the campaign focussed on the launch of a new phase of advertising, backed by PR activity to encourage people to discuss their donation decision with family.

Welsh Government news: <https://gov.wales/newsroom/health-and-social-services/2018/donate18/?status=closed&lang=en>

Wales Online article, including case studies, Cabinet Secretary quote and embedded campaign advert: <https://www.walesonline.co.uk/news/health/journey-organ-donation-desperate-patients-15117997>

The journey of organ donation by desperate patients, grieving families and those on the road between death and life

Despite 30,000 people dying in Wales each year, as few as 70 of them end up becoming organ donors.

SHARE 597 SHARES

7 COMMENTS

By **Mark Smith** Health Correspondent
12.25, 7 SEP 2018 UPDATED 13.06, 7 SEP 2018

NEWS

Enter your postcode for local news and info

Enter your postcode

In

Go



Other examples of media coverage:

CARDIFF TIMES

YOUR QUALITY LOCAL MAGAZINE

Summer sofa tour aims to get people of Wales talking about Organ Donation

A special sofa will be hitting the streets of Wales this month for a series of #TalkOrganDonation summer roadshows to get more people sharing their organ donation decisions with their friends and families.

A new survey has revealed that 48% of us have our most important life-changing chats while sitting on the sofa. So, the Organ Donation Wales team is creating a pop-up mobile living room to encourage members of the public who are out and about at events over the summer to sit down and have the organ donation chat then and there.

The survey found that the sofa was the top spot to have an important chat with loved ones, while 37% of people prefer to talk at the dinner table and just 3% have their important discussions in their local watering hole. The #TalkOrganDonation summer tour will launch at The Caerphilly Big Cheese on July 28-29, before moving to The Ceredigion on August 7-9, and concluding at the Pembrokeshire show on August 14-16.

Wales became the first country in the UK to introduce a soft opt-out system. This means that everyone over 18 who lives and dies in Wales and does not have a registered organ donation decision will be treated as having no objection to becoming a donor when they die. While 70% of people in Wales are aware of the legislation, most people are unaware that their families can override their decision to donate their organs even though they are opted-in.

In 2016-17, there were 21 cases in Wales of families overriding their deceased relatives' decision to be a donor, so to make it easier for your family to support donation tell them what you want to do. Organ Donation Wales is keen to get the people of Wales sharing their decisions about this important subject with their families.

Sarah Crosby, Specialist Nurse in Organ Donation said: "When a family member or close family friend know that their loved one wanted to donate their organs after death, they are far more likely to support that decision. It's much more difficult if there is uncertainty. Letting your family know your organ donation decision will make it much easier for them to support what you want."

"Before the opt-in system, in 43% of cases where organ donation was possible, families said no to donation simply because they didn't know whether their loved one wanted to be a donor. From experience, we know that if family members are aware of a person's decision on organ donation, nine times out of ten, families will support their choice."

When Jason Leigh's father-in-law had a heart transplant in November 2005, he and his wife Laura had discussed organ donation and agreed that if anything happened to either of them, they would donate their organs. Sadly, nine years later, in September 2015, Jason (who was 30 at the time) was faced with just that when Laura, who he had married just five months earlier, suffered a cardiac arrest and passed away at just 31 years of age.

Jason said "Organ donation was regularly a topic of discussion for us. For me, donating Laura's organs when she died was a no-brainer. It was what she wanted, to be able to give someone the opportunity to live when there was no other hope. The ultimate gift."

Vaughan Gething, Cabinet Secretary for Health and Social Services said: "We hope that by running these roadshows and giving the people of Wales the opportunity to open up and have these important chats with their friends and family, it will encourage more people to share their organ donation decisions with their loved ones."

"Talking about your decision can help benefit so many people across Wales and the rest of the UK so we're keen to make sure people have that all-important chat, wherever they feel most comfortable."

You can register a decision at any time by calling 0300 123 23 23 or visiting www.organdonationwales.org. But whatever you decide, tell your family and friends too. How will they know what you want if you don't tell them? And don't forget to ask them what they want as well.

Carmarthen Journal

Son's 'food poisoning' was organ failure – but mum saved his life

MARK SMITH

WHEN Lewis began feeling terrible sick, he initially put it down to a nasty bout of food poisoning. But it turned out the 25-year-old was suffering from chronic kidney disease which would require a transplant.

And after seeing him endure countless hours of dialysis, Lewis's doctor urged him to step forward to donate a kidney to save her precious son's life.

Lewis, from Trosgoff, Ceredigion, said his mum gave him the "best gift" anyone could ask for.

"Since the operation and everything that's happened to me, I feel like my mum and I are closer than ever before. We now have such a special bond," said Lewis.

"I always try to show her how thankful I am, and most like to listen to her music on her birthday and Christmas. I don't think a simple card will suffice."

Lewis, a talented rugby player, had just started working for Natural Resources Wales in Cardiff when he started feeling unwell.

After getting blood tests done at his GP surgery, he was told to visit the University Hospital of Wales to get the results.

"I didn't think much of it at the time," he added. "When I saw the look on the nurses' faces when I

arrived, it was clear they were expecting someone who looked much more unwell than me."

"When they told me my kidney had failed on me, I just told them to give me the medication and I'd be on my way."

"It was only at the point where they were insisting on calling my parents and keeping me in hospital that I realised how bad things were and how desperate."

Lewis spent a month on a drip while doctors tried to measure the damage to his kidney.

And while he was on the transplant waiting list, which took 18 months in total, Lewis underwent dialysis three times a week at hospitals in Cardiff, Carmarthen and Aberystwyth.

"I added: 'That's all my life consisted of, I'd wake up, wait for dialysis, have dialysis and then receive from dialysis.'

"I couldn't do any physical activity as I was just to rest."

Following tests, it was discovered that Lewis's mother, Gay, and his six-year-old brother, Leo, were both suitable matches to donate their kidneys. Brave Gay, who said she didn't want both of her children in hospital, decided that she would be the donor.

So in January 2017, Lewis and Gay went under the knife for the transplant

at DHEW.

"I was so lucky that members of my family were a match and able to donate but that's not the case for so many," he added.

Lewis had always been athletic, but during his dialysis treatment, he decided to add value to his life again.

After getting his condition, he found out about the Transplant Games and started training at National Indoor Athletics Centre in Cardiff.

"Focusing on competing in the games literally gave me a new lease of life," he said.

"I had to be careful after my operation limiting my weight I was using, but I really enjoyed overruling people who are lucky enough to have two kidneys on the running track."

After competing at the British Transplant Games in 2017 and the European Transplant Games in Cardiff this year Lewis has continued to run hard.

At the Westfield Health British Transplant Games he bagged a gold medal in 100m and 200m, a silver in 400m relay, discus and javelin and a bronze medal in the 1500m semi-long relay – the first time he's ever competed as a winner.

The 41st edition of the games, held in Birmmgham, featured competitors from across the UK,

all of whom had received either kidney, liver, heart, lung, pancreas or bone marrow transplants, or were dialysis patients.

"I was so emotional winning all these medals, especially the 100 metres sprint as that was the big one."

"There was a bit of confusion over who won it but soon as they said my name, I went wild. I burst into tears and threw my running spikes on the floor – I just couldn't believe how far I'd come."

"I called my mum straight away to tell her and to thank her for giving me the best gift."

Wales became the first country in the UK to introduce a soft opt-out organ donation system, which means that everyone over 18 who has not registered their organ donation decision will be treated as having no objection to being a donor if they die.

While more than 70% of people in Wales are aware of the legislation, most people are unaware that their families can override their decision to donate their organs even though they are opted-in.

In 2017-18, five families overrode their loved one's known organ donor registration to donate, and in the 48 cases where a decision was applied, there were 16 cases where the family did not support the decision.

Organ Donation Wales

A young man who went from thinking he had food poisoning to having organ failure

His life was saved by his loving mum who donated her kidney to him

When Lewis Evans began feeling terribly sick, he initially put it down to a nasty bout of food poisoning. But it turned out the 25-year-old was suffering from chronic kidney disease which would require a transplant. And after seeing him endure countless hours of dialysis, Lewis' loving mum stepped forward to donate a kidney to save her precious son's life.

Lewis, from Treparan, Ceredigion, said his mum gave him the "best gift" anyone could ask for. "Since the operation and everything that's happened to me, I feel like my mum and I are closer than ever before. We now have such a special bond," said Lewis.

"I always try to show her how thankful I am and treat her to a little bit more on her birthday and Christmas. I don't think a simple card will suffice now."

Lewis, a talented rugby player, had just started working for Natural Resources Wales in Cardiff when he started feeling unwell.

After getting blood tests done at his GP surgery, he was told to visit the University Hospital of Wales to get the results.

"I didn't think much of it at the time," he added.

"When I saw the look on the nurses' faces when I arrived, it was clear they were expecting someone who looked much more unwell than me.

"When they told me my kidneys had failed on me, I just told them to give me the medication and I'd be on my way.

"It was only at the point where they were insistent on calling my parents and keeping me in hospital that I realised how bad things were and broke down."

Lewis spent a month on a 14-hour bed while doctors tried to remove the cancerous toxins from his body. And while he was on the transplant waiting list, which took 16 months in total, Lewis underwent dialysis three times a week at hospitals in Cardiff, Carmarthen and Aberystwyth.

He added: "That's all my life consisted of. I'd wake up, wait for dialysis, have dialysis and then recover from dialysis.

"It couldn't do any physical activity as I was just so weak."

Following tests, it was discovered that Lewis' mother Gay and his sister Angela were both a suitable match to donate their kidneys.

Brave Gay, who said she didn't want both of her children in hospital, decided that she would be the donor. So in January 2017, Lewis and Gay went under the knife for the transplant at UHW.

"I was so lucky that members of my family were a match and able to donate but that's not the case for so many," he added.

Lewis had always been athletic, but during his dialysis treatment he decided to add value to his life again. After Googling his condition, he found out about the Transplant Games and started training at National Indoor Athletics Centre in Cardiff.

"Focusing on competing in the games literally gave me a new lease of life," he said.

"I had to be careful after my operation limiting my training sessions and the weights I was using, but I really enjoyed overtaking people who are lucky enough to have two kidneys on the running track."

After competing at the British Transplant Games in 2017 and the European Transplant Games in Sardinia this year Lewis has continued to train hard.

HEALTH

CAROLINE JONES COLUMNIST

Saving lives through the gift of organ donation

Despite 30,000 people dying in Wales each year as few as 70 of them end up becoming organ donors, Mrs. Specialist Nurse in Organ Donation (SNOD) Sarah Crosby explains what it's like asking family members if they like their dying relatives' organs donated.

...with complex organs, but ...

...if your family aren't happy, the ...

...I think the people don't seem to ...

...I think the people don't seem to ...

Social media:

















26. Examples of social media content and top engagement/ views:

Top English posts

Post	Reach / Engagement	Type of content
<p>Speak up or someone else may speak for you 🙏 Here's what</p>	46.6K 5.8K 903	Custom content created for social media
<p>To all the teams that helped complete 6 kidney transplants in</p>	17.2K 867 565	News
<p>Do you know what a SNOD is? Specialist Nurse Organ</p>	16.7K 900 235	Case study
<p>You wouldn't let your family decide the colour of your</p>	15.1K 381 28	Custom content created for social media
<p>You wouldn't let your dad decide your baby's name 🤔 so why let</p>	13.9K 575 23	Custom content created for social media
<p>Want to be an organ donor? Why wait? 190 people in Wales</p>	13.9K 184 127	Living Donation Week

 "People say that losing a twin is like losing your spouse, but	12.6K 	337 513 	Case study
 Mike is a Transplant Surgeon based in Cardiff  Listen	11.1K 	969 384 	Case study / part of Living Donation Week

Top Welsh posts

Post	Reach / Engagement	Type of content	
 Mae'n Wythnos Genedlaethol Adrodd Straeon. Gwnaeth	8.2K 	528 138 	Case study
 Siaradwch cyn i rywun arall siarad ar eich rhan  Dyma	6.1K 	276 45 	Custom content created for social media
 Roedd Lewis yn byw bywyd heini cyn dioddef methiant	5.4K 	22 30 	Case study
 Edrychwch ar ein hysbyseb newydd am drafod rhoi organau	4.6K 	64 51 	New TV advert
 "Mae pobl yn dweud fod colli efaill fel colli cymar, ond rwy'n	4.5K 	134 54 	Case study

Welsh Government internal communications

27. As well as the stakeholder sessions mentioned above, a poster campaign, intranet news item and merchandise including bilingual donor card fridge magnets and donor card key rings were used to promote conversations among Welsh Government staff and their families.

Advertising: TV, radio and digital campaign running in 2017-18/ Second phase launched 3 September 2018

28. The campaign continues to address the issue of the family overriding a registered yes to donation on the organ donor register and not supporting deemed consent. It seeks to increase awareness of the role families/ partners have in honouring the decision of their loved ones, as well as encouraging people to share their decisions.

Evidence

29. Data published by NHS Blood and Transplant (NHSBT) for the financial year 2017-18 shows:

- There were 21 cases where families have either overridden their relatives' decision on the organ donor register, or not supported deemed consent. With an average of 3.1 organs donated per donor this could have resulted in an additional 65 transplants;
- 74 deceased organ donors in Wales, which is 13 more than in the previous year;
- 137 deceased organ transplants, compared to 135 in 2016-17;
- 234 people waiting for a transplant, this is a decrease of 9 from 2016-17.;
- 31 living donors, 5 less than in 2016-17;
- 42 living donor transplants 10 less than in 2016-17;
- 16 people died whilst on the waiting list compared to 24 in 2016-17.

Social attitudes research

30. Questions about organ donation were asked in Wales Omnibus Surveys (run by Beaufort Research) since 2012. It is likely that the lack of support from family can be partly attributed to the fact the survey reports that the number of people who have discussed their decision with their loved ones remained relatively low despite an increase from 38% in June 2012 to 54% in September 2017.

The current campaign focuses on the role of families on the process and the importance of having conversations with families/partners.

The Welsh Government will continue to undertake on-going research using the quarterly Wales Omnibus Survey to understand levels of awareness and reach of key messages.

31. Omnibus survey results showed that:

- In September 2017, 54% of respondents had discussed their wishes with loved ones. This increased from 51% in March 2017;
- 73% of respondents agreed that if an individual chooses not to register a decision, this should be treated as a decision to be a donor which families should be encouraged to accept. The proportion of respondents who agree with the statement has fluctuated between two thirds and three quarters since this question was first asked in wave 11 (March 2016).

- In March 2018, 82% of respondents were aware of the current organ donation system, up from 70% in September 2017 – this coincides with the timing of increased campaign activity and the reintroduction of TV and radio advertising between September 2017 and March 2018.

The latest reports are published here:

<http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

32. The campaign encourages people to **“talk about organ donation, or someone else may speak for you”**.

Type of advertising

Specific channels

- TV (ITV, S4C) - running in three distinct bursts: 4-19 December 2017; 13-30 June 2018; 3-16 September 2018.
- 4oD
- Sky Digital
- ITV Hub
- Commercial radio (Heart South Wales, Heart North Wales, The Wave, Radio Ceredigion)
- Online In-read digital ads
- Facebook
- Twitter
- Instagram
- Google search ads

Examples of advertising

33. The TV adverts can be found on our Facebook or Twitter pages and the videos are hosted on Youtube:

1. <https://www.youtube.com/watch?v=iXPknPeUQMc>
2. <https://www.youtube.com/watch?v=eeVqnMuNdpE>
3. <https://www.youtube.com/watch?v=AxFLDewjPkg>
4. <https://www.youtube.com/watch?v=m85PI5MIBGM>

Organ Donation Digital Update

34. Traffic to campaign website

During our advertising burst in September 2018:

- Our web pages received 7,526 sessions from 6,534 users.
- 85% of people visiting the website were first time visitors.

We received 3370 clicks from our advertising. This included:

- 686 clicks from Facebook advertising
- 2458 clicks from Twitter advertising
- 104 clicks from Instagram advertising.

Facebook

During the September campaign, we averaged a reach of over 10,000 people a day.

Post Reach

The number of people who had any posts from your Page enter their screen.



Facebook video adverts:

English advert:

Displayed 272K times, watched to completion around 9K times, and provided over 12K clicks

Welsh advert:

Displayed 108K times, watched to completion 2.3K times and provided almost 3K clicks.

Twitter

During this time we achieved:

- 240K impressions;



Targeted communication activities

Students

35. We have continued an arrangement with UCAS to communicate directly with students who have accepted places in Welsh universities. This includes a direct e-mail and letter to their family home to ensure their family are aware. The e-mail and direct letter were sent to 7,252 and 7,000 students respectively, who are from outside of Wales. The e-mail achieved a unique open rate of 61% with a click-through rate of 1.4%. This resulted in 281 visits from 251 visitors to our webpages.

16-18 year olds

36. A 'rising-18's' letter is being sent to everyone approaching their 18th birthday. It explains the system, tell them what their choices are and encourages them to talk to their loved ones. During the months of November 2017 to October 2018, over 36,000 letters were sent out.

BAME communities and faith groups

37. We will work to review and add to our existing contacts and resources to target BAME and faith communities. We met with representatives of the Welsh Government's Race Forum and staff network to discuss tailored engagement and targeted messaging for specific groups in Wales. This work will feed in to a plan to be developed in 2019.

Welsh Government is represented on the steering group for NHS Blood & Transplant's community investment scheme which was launched in September 2018. The scheme aims to reach groups by funding projects led by organisations which already have established links with those communities. Applications for the scheme were sifted in October 2018 and there are three projects covering Wales which have been accepted for funding and delivery in 2019.

Skills and Competencies within the NHS

38. The Welsh Government has been working with NHS Blood and Transplant, the special health authority with responsibility for managing organ donation in Wales, to ensure that the operational management of the change in the consent system complies with the Human Tissue Authority Code of Practice on the Human Transplantation (Wales) Act 2013.

Specialist nurses in organ donation (SNOD) continue to undertake donation conversation training and work is ongoing to support the SNODs to manage the conversations. Activity in 2017-18 includes:

- Training sessions for SNODs regarding auditing and consistency of data input;
- Robust discussions about how best to audit complex scenarios;
- Shared practice meetings to discuss individual approach conversations and learn from experience;
- Peer review and feedback in practice at approach conversations;
- Education with clinical healthcare colleagues to ensure awareness of best practice relating to donation conversations and access to additional national education resources within NHS Blood and Transplant;
- An established practice development specialist service to provide education, training and ongoing support to the SNOD workforce;
- Introduction of a Specialist Requestor (SR) role, specialist nurses with advanced training to focus on family support and conversations, commenced September 2018;
- Following the results of the Bangor Study (Family attitudes, actions, decisions and experiences) post implementation of deemed consent and the Human Transplantation (Wales) Act 2013, additional work on communication exploring opportunities with facilitators outside of the NHS has been provided for the team.

Evaluation

39. Research and evaluation specifically for communications work includes regular public awareness and attitudes surveys.

Survey of Public Attitudes to Organ Donation: Wave 15

40. We have commissioned questions in the Wales Omnibus Survey to obtain regular information on public awareness and attitudes to changes in the organ donation system. Data are being collected at regular intervals between June 2012 and March 2020.

Wave 15 was conducted between 26 February and 11 March 2018 (1,011 respondents).

Key findings

41. In Wave 15 awareness of the recent television and radio advertising campaign was assessed. Each advert was played to individuals and they were asked whether they had seen or heard it before. Overall, 57% of respondents reported that they had seen the TV advert, and 39% had heard the radio advert.

Two-fifths (40%) of respondents who had seen or heard the advert said that they had discussed their wishes with their family. A further 18% stated that they had already discussed their wishes, before seeing the advert.

Full information in the report:

<https://gov.wales/docs/caecd/research/2018/180906-survey-public-attitudes-organ-donation-waves-15-en.pdf>

Forward Look and Priorities

- 42. Wave 16 of Wales Omnibus Survey published in January 2019;
- 43. Continued PR and advertising to March 2019;
- 44. Community Investment Scheme, NHSBT;
- 45. Living Donation Week, April 2019;
- 46. British Transplant Games, Newport – July 2019.