

**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 2016

# **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 third of five annual reports outlining the work undertaken to support this. The report covers the period of 16 November 2015 to 14 November 2016.

## **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 has been accompanied by a full public information campaign to ensure that the Welsh population are aware of the changes and understand 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. Please note that pre-election restrictions cover the period 6 April 2016 and 5 May 2016 so no communication activities could take place during time.
9. From April 2016 until November 2016 the communications has focused on reminding people of their choices and also encouraging them to talk to loved ones about their decision. A new communication strategy has been developed for the 2016-17 campaign.

### **Policy Objective**

- To increase the consent rates for organ donation by creating a culture in Wales where discussing organ donation becomes the ‘norm’.

### **Communication Objectives**

- Maintain understanding of the new system and the organ donation choices that people have in Wales – opt in, opt out or do nothing
- Promote conversations between families and loved ones of their organ donation decision
- Encourage people to register a decision either on the organ donor register or by telling family and friends
- Explain the role of families/friends in respecting organ donation decisions
- Explain the benefits of living donation and transplantation

10. Together the system and the communications aim to encourage people to **clarify** their organ donation decision and to **share** this with those closest to them.

## Budget

11. The budget for the three financial years that these reports cover are:  
Year 2 (2013/14) £808k;  
Year 3 (2014/15) £2,215k;  
**Year 4 (2015/16) £200K** - this was reduced as it was post-introduction and followed the intensive two year implementation campaign.

## Approach

12. The campaign was delivered in two ways:

December 2015 – March 2016

- Mass media advertising campaign supported by PR and social media reminding people that the system has changed.

May 2016 – November 2016

- Media advertising campaign from 11 July until 11 September, including Organ Donation Week (5-11 September)
- Monthly themes around a specific audience or issue that featured in the PR and social media.

We have continued to use case studies to support the campaign as they have been the most successful in terms of coverage and reach. They provided the faces and the voices of the most recent advertising campaign.

## Key Messages

13. We continued to use the following overarching messages about the new system:

- Organ donation in Wales has changed.
- You have three organ donation choices – you can opt in, opt out, or do nothing. If you decide to do nothing, it will mean you have no objection to being a donor.
- Make sure you share your decision with those closest to you.

- 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 [www.organdonationwales.org](http://www.organdonationwales.org) or by telling your family and friends.

**Call to Action**

14. This has remained consistent throughout the campaign, and included the phone number for the NHS Blood and Transplant Organ Donor Helpline (0300 123 23 23) for those who do not have access to the internet, or prefer to speak to someone.

The web address is [www.organdonationwales.org](http://www.organdonationwales.org) and our social media channels are: Twitter @OrgDonationCYM and Facebook @OrganDonationWales.

**Key Achievements**

**Advertising: December 2015 to March 2016**

15. This phase focused on the theme of 'There's still time to talk' and targeted all adults aged 18+.
16. Advertising ran across the following platforms:

Type of advertising	Specific channels
TV	ITV 1 S4C  Sky Adsmart ITV Player – Wales All4 – Wales
Online	Facebook Online display campaign Videology
Commercial radio	Heart South Wales Capital FM South Wales Heart North Wales Capital FM North Wales Radio Pembrokeshire Carmarthenshire Swansea Sound

	The Wave Scarlet FM Bridge FM Nation Radio Ceredigion
Community radio	GTFM Cardiff Radio
Press	Western Mail South Wales Echo Daily Post South Wales Evening Post South Wales Argus North Wales Weekly News The Wrexham Leader Cambrian News Western Telegraph Carmarthen Journal Llanelli Star Abergavenny Chronicle Brecon and Radnor Express Golwg
Cinema	Pearl and Dean
Out of home	Bus sides Roadside – 6 and 48 sheets Train stations Retail changing rooms Train interior panels

### **Advertising Reach**

17. In terms of the implementation campaign overall (from 2013 to 2016) it achieved:

Radio overall adult coverage was 25%, with an average of 5 opportunities-to-hear (OTH) each week;

ITV achieved 91.3% coverage;

S4C 3,663,000 viewings and Sky Adsmart 1,624,244 adult impressions (when an advert is fetched from its source);

Out-of-home (bus, train, roadside and changing rooms) reached 87% of all adults with 22 opportunities-to-see (OTS);

Total Facebook impressions were 4,178 million;

Cinema advertising had at least 675,900 guaranteed admissions; and

Digital videology (film) achieved 600,852 adult impressions (when an advert is fetched from its source).

### **Advertising: July – September**

18. Due to the reduced budget for the 2016/17 financial year the campaign was targeted at a specific audience. Following feedback from quarterly Omnibus survey results, it was targeted at those with the lowest levels of awareness of the system, and were also one of groups least likely to have discussed their decision with loved ones.

They were:

- 18-34 year olds
- C2DE socio-economic groups

19. Advertising continued in 2016/17 and was bought across the following platforms.

<b>Type of advertising</b>	<b>Specific channels</b>
Commercial radio	Heart South and North Wales Capital FM South and North Wales Radio Pembrokeshire Carmarthenshire Swansea Sound The Wave Scarlet FM Bridge FM Nation Radio Ceredigion.
Community radio	GTFM Radio Cardiff Spotify
Online	Wales Online Facebook
Out of home	Bus streetliners (sides) Interiors of buses Train interiors panels (Valleys line) Cinema foyers

## Advertising Reach

20. In terms of evaluating the reach of the advertising, our specialist media buyers advise that C2DE adults had 3.5 opportunities to hear our radio advert on the commercial radio stations. There were 4 opportunities to see the bus side advertising.

21. The Wales Online advertising delivered 300,000 impressions (i.e. when an advert is fetched from its source). The Spotify advertising delivered over 330,000 impressions. Both provide click through rates which are above the industry standard. The Facebook advertising delivered a total of 589,012 impressions. Page likes have reached over 16,850.

## Examples of advertising

- Facebook advert





- Example of out of home advertising



“ Mae bod yn rhoddwr byw yn gwneud cymaint o wahaniaeth i'r rhai sydd angen trawsblaniad.

Becoming a living donor makes such a difference to those in need of a transplant.”

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

OrganDonationWales  
 @OrgDonationCYM

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“ Dwi mor falch i Mam a finnau siarad am roi organau. Pan fuodd hi farw, ro'n i'n gwybod ei bod hi am fod yn rhoddwr.

I'm so glad Mam and I talked about organ donation. When she died I knew she wanted to donate.”

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

OrganDonationWales  
 @OrgDonationCYM

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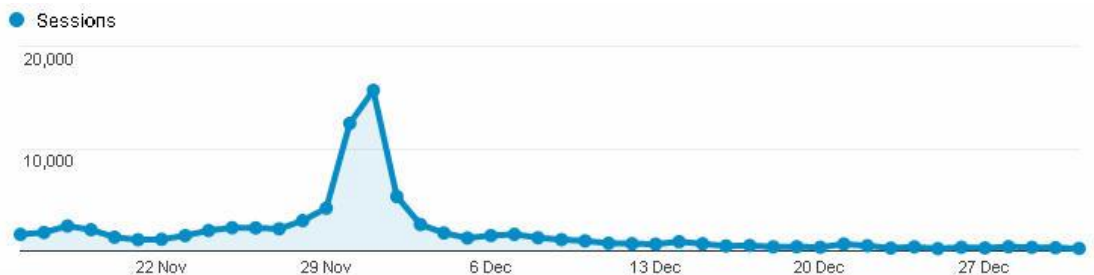
### Interior Train Advert (Valleys Line)

### Interior Bus Advert

#### Website

22. Since the launch of a dedicated website for organ donation in Wales, it has received over 311,572 visits, of which 84% are new visitors. From 16 November 2015 until 14 November 2016 there were 143,131 visits and again 84% new visitors. The graphs below illustrates the traffic to the site.

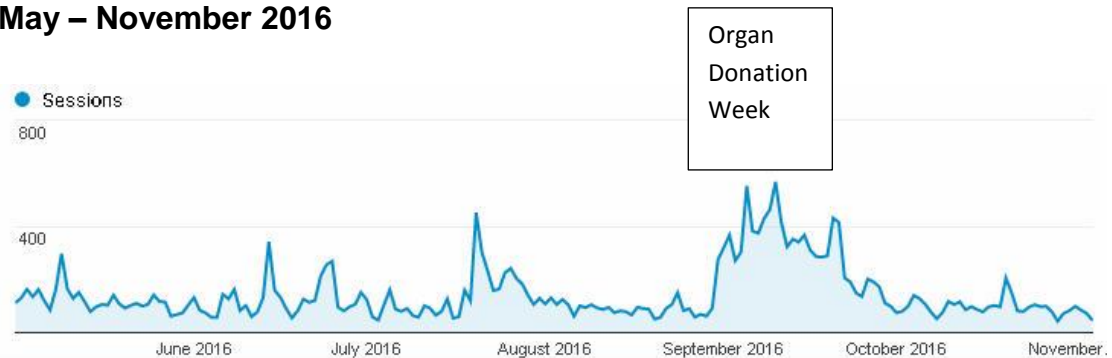
#### 16 November 2015 – 31 December 2015



## January – April 2016



## May – November 2016



### Public Relations (PR)

23. The aim of the PR was to maintain understanding of the organ donation choices in Wales; promote conversations among loved ones, and encourage people to register a decision. All the proactive stories have consistently generated positive coverage across the national and local titles both online and in print, as well as broadcast. It has supplemented the advertising by providing stories of people who have been impacted by organ donation and the transplantation process. There are currently 68 real life stories that are used by Welsh Government and provided to others, and feature under the 'Your Stories' section on the website.
24. To mark the start of the new organ donation system on 1 December an event was held in the Senedd, Cardiff Bay. The 'Moving On' production was performed by Theatr Na Nog and there were a number of speeches, including Rhys Thomas an ex-Welsh rugby player who is waiting for a heart transplant. Welsh media covered the story throughout the day in broadcast, print and online channels. The event was covered across the UK media as well as internationally, in places such as Canada.
25. As a broad outline, between 1 December 2015 and 5 April 2016 (up to the start of the pre-election period), the PR achieved at least 19 pieces of online coverage, 5 pieces of print media coverage, 5 pieces of radio and TV news coverage. This has been for Wales and the wider UK. All of these have been

proactive pieces as opposed to coverage generated from media enquiries.

26. Between May and November 2016 there were at least 80 pieces of print and online coverage, 31 minutes in total of broadcast on TV and radio as news items. This achieved an audience reach of over 15 million via the media. A week-long media partnership with commercial radio station Heart FM which included promotional trails, online features, presenter video and social media, and homepage takeover generated good levels of listener and viewer engagement.

27. Examples of the monthly themes that were covered supported by national and regionalised (where possible) case studies were:

- Living donation
- Farming and rural communities
- BAME
- Faith groups

28. Ministerial-led announcements also increased the profile of organ donation and allowed us to talk about the system and encourage people to register and talk about their decision.

They included:

- 14 June: 'New organ donation system has saved lives'. Figures showing that of the 15 people who donated in the first six months of the new system, six had their consent deemed.
- 20 July: 'Over half the population yet to join in Wales' biggest conversation about their organ donation decision'. This marked the start of the new campaign.
- 1 September: 'Rise in number of lives saved or improved by an organ transplant'. New figures released as part of the latest Organ Donation and Transplantation Activity Report.
- 14 October: 'We must continue to improve rates of organ donation in Wales'. To coincide with the launch of the Organ Donation Annual Report 2016.

## **Events**

29. Over the past 12 months, the Organ Donation Team has given presentations at specific events. These have included (but not limited to):

- Byw Nawr - May 2016
- One Civil Service' interchange programme - June 2016
- UK Civil Service Live – July 2016

- NHSBT National organ donation congress- September 2016

30. In November 2015 the organ donation team ran a roadshow that visited 17 locations over 5 days; talking to approximately 4,000 people. Our case studies joined the team and spoke to people about the benefits of registering a decision. Anecdotally, the majority of people that we spoke to were aware of the changes.

### **Information Materials**

31. We updated the bilingual A5 information leaflet to support the campaign in July. We have continued to promote and distribute a range of materials that were produced in alternative and accessible formats. This has included easy read, braille, large print, audio, British Sign Language video, as well as a range of ethnic minority languages.

### **Social media**

32. Bilingual Facebook and Twitter channels continued to support the campaign. Our approach has been to respond proactively to comments and questions where appropriate to aid understanding of the changes to the system. Facebook pages have 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 16,830 'likes' (14/11/2016). There was a correlation between advertising periods on Facebook and increases in 'likes'.

33. Our dedicated twitter channel now has 1,105 followers (stat taken on 14/11/2016).

 [Twitter: @OrgDonationCYM](https://twitter.com/OrgDonationCYM)  [Facebook: Organ Donation Wales](https://www.facebook.com/OrganDonationWales)

### **Stakeholder engagement**

34. Stakeholder groups and partners were sent the campaign toolkit to mark the start of the July campaign comprising various artwork, key messages and promotional materials to include on their own communication channels, share with staff and their own networks.

35. A stakeholder e-bulletin was issued every fortnight until the end of January 2016, when it issued every month. Since March 2016, it is now issued quarterly. The newsletter is published on [www.wales.gov.uk/organdonation](http://www.wales.gov.uk/organdonation) and is sent to approximately 400 people.

## **Specific Engagement**

### **Rising 18's letter**

36. Everyone approaching their 18<sup>th</sup> birthday receives a letter from the NHS to inform them of their organ donation choices once they reach the age of 18. This is an ongoing arrangement.

### **Students**

37. Specific work to engage students coming to study in Wales has continued, as their consent may be deemed if they live in Wales for 12 months or more.

Activity included:

- Over 8,000 direct emails sent via UCAS to students living outside of Wales accepting a place in a Welsh university. The email was personalised and referred to the university the individual was going to. The open rate was 57% which was encouraging when the industry standard is an open rate of approximately 24%
- A direct mail (letter) was also sent to students who currently live outside of Wales who have accepted a place in a Welsh university.
- Social media messages were specifically targeted at universities and colleges to support the campaign on their social media channels.

### **Military and service families**

38. We have continued to respond to requests from these groups for specific promotional materials. We also target them on social media.

### **Black and Minority Ethnic (BAME) and Faith Engagement**

39. The focus of work with these groups has included reaching out to faith and BAME community groups to seek new case studies; and targeted social media activity and messages.

## **Skills and Competencies within the NHS**

40. 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.

41. Work has begun to review how the specialist nurses in organ donation (SNOD) have interpreted the donation conversation training and what improvements can be made to support the SNODs to manage the conversations.

## Evaluation

42. Research and evaluation specifically for communications work includes regular public awareness and attitudes surveys. From 2014 until June 2016, the survey has been undertaken on a quarterly basis.
43. Surveys took place in November 2015 (wave 10), March 2016 (wave 11), and June 2016 (wave 12). Wave 10 of the survey focused on monitoring awareness levels and understanding of the change in law and included additional questions to measure awareness and recall of campaign materials. Waves 11 and 12 focused on awareness and understanding, as well as attitudes and behaviours.
44. Headline findings showed that:
  - 74% of respondents were aware of changes to the organ donation system in November 2015. This went up to 82% in March 2016, and down to 76% in June 2016.
  - 47% of respondents had discussed their wishes with loved ones in November 2015; 48% in March 2016; and 48% in June 2016.
45. The findings were used to inform the paid-for advertising campaign in July as awareness was lowest amongst 18-34 year olds and C2DE social groups (skilled manual workers; semi and unskilled manual worker; state pensioners, casual or lowest grade workers, unemployed with state benefits only).
46. The research and evaluation reports are published [here](#).

## Forward Look and Priorities

47. An event is arranged for 1 December to mark a year-on since the system changed. This will include an event with people who have benefited from organ donation over the last year.
48. Automated letters will continue to be sent to young people approaching their 18<sup>th</sup> birthday direct from NHS Wales. This is a long term arrangement to continue for the foreseeable future.
49. An annual communication strategy will be developed to continue to inform people about their choices, and prompt discussions with friends and family. There will be a continuous drip feed of messages, as well as a targeted campaign during the year.