



Llywodraeth Cymru
Welsh Government

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Human Transplantation (Wales) Act 2013

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

October 2014



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Welsh Government



Nawr yw'r amser i siarad am roi organau
It's time to talk about organ donation

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Human Transplantation (Wales) Act 2013: Report laid before the National Assembly for Wales under Standing Order 15.2

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Introduction

1. The Human Transplantation (Wales) Act 2013 (“the Act”) was given Royal Assent on 10 September 2013. The Act will create a new system of consent to deceased organ donation in Wales. From 1 December 2015, Wales will move to a soft opt-out, or “deemed consent” system of consent to organ donation. This generally means that unless a person has stated otherwise, then their consent to donation may be deemed to have been given. By making this change in the law, the Welsh Government expects to see an increase in the donation rate of around 25 per cent.
2. Whilst the majority of the provisions in the Act will 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 activates 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 first of five annual reports outlining the work undertaken to inform the public and ensure the NHS is prepared for the new legislation. The Report covers the period of September 2013 to October 2014

Background

5. The Human Transplantation (Wales) Act 2013 provides a framework for the introduction of a new consent system to organ donation. This new system is known as a “soft opt-out” or “deemed consent” system. The new law provides

a lever for a cultural shift in behaviour and attitudes towards increasing consent rates for organ donation

6. In order for the new system to be implemented smoothly and successfully, it needs to be accompanied by a full public information campaign to ensure that the Welsh population are aware of the changes and understand how this will affect them.
7. The primary role of the communications work, therefore, is to inform people of the legislative change and explain clearly the choices that are available with regards to registering an organ donation decision (express consent) and the implications of not registering a decision, where an individual's consent may be deemed. However, the work is 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.

Policy Objective

- To increase the consent rates for organ donation by creating a culture in Wales where organ donation becomes the 'norm'

Communication Objective

- To inform the Welsh population on the changes to the legislation, the options that will be available; to signpost the mechanism for registering a decision if they wish; clearly explain the implications of not registering a decision
 - To prompt discussion of organ donation within families and friendship groups to ensure individuals know the organ donation decision of those closest to them
8. Together the new system and the communications aims to encourage people to **clarify** their organ donation decision and to **share** this with those closest to them.

Budget

9. The budget is set out over three years as follows:
 - Year 1 (2013/14) £383k;
 - Year 2 (2014/15) £808k;
 - Year 3 (2015/16) £2,215k

Approach

10. The two year public information campaign was launched on 1 December 2013 and is being delivered on two levels:
- Mass media advertising campaign
 - Bespoke engagement work with specific audience groups who may not be engaged in mass media
11. From Royal Assent in September 2013 through to launch in December 2013, much of the communications activity was focussed on the ‘behind the scenes’ work in order to launch a campaign in December. This time was spent building a bilingual dedicated information website which was launched on 1 December 2013. The autumn months were also spent developing the creative messaging for the wider campaign. This included a period of testing via focus groups and regular refining.

Key Messages

12. The mass media campaign is being rolled out in a strategic phased approach. The messages change over time to reflect key milestones in the wider implementation of the Act. Within each phase, there are a number of advertising “bursts” – these are periods when the advertising goes live for a specified time, followed by a break, then followed by a further period of advertising.
13. Below is a summary of the strategic phases and approximate timing based on the new Organ Donation Register being launched in Summer 2015, prior to the implementation of the deemed consent system.

Phase Timing	Aim of Phase	Theme	Key message
Phase 1: Dec-March 2014:	Inform people when the law will change and rationale behind the new legislation	It's time to think about organ donation	Last year 36 people died whilst waiting for an organ donation. On the 1st December 2015 the way you choose to be an organ donor will be changing in Wales

Phase 2: April 2014 –Dec 2014		It's time to talk about organ donation	<p>In 2012/13 36 people died whilst waiting for an organ donation (Message 1).</p> <p>Only 40% of people have discussed their organ donation wishes with their loved ones (Message 2)</p> <p>From 1st December 2015, the way we choose to become organ donors will change</p> <p>Now is the time for us to understand what this means and talk about it with our loved ones.</p>
Phase 3: Jan 2015-May 2015	Provide more detail on choices available under new law and implications of 'doing nothing'	It's time to talk about organ donation	<p>From the 1st December 2015 the way we become organ donors will change and soon you'll have to make a decision whether you want to:</p> <p>Opt-In - and register to be an organ donor.</p> <p>Opt-Out - and register NOT to be an organ donor.</p> <p>Do nothing – which means you still could become an organ donor.</p>
Phase 4: Summer*-Nov 2015	Encourage people to register a clear decision and inform them of implications of 'doing nothing' from 1 Dec 2015	It's time to choose	<p>Organ donation is changing. You can now Opt-In - and register to be an organ donor.</p> <p>Opt-Out - and register NOT to be an organ donor.</p> <p>From 1st December 2015 if you haven't registered a decision you still could become an organ donor and help many people re-</p>

			start their lives.
Phase 5: Dec 2015-March 2016	Continue to encourage people to register a clear decision on organ donation and implications of 'doing nothing'	There's always time	Organ donation has changed in Wales. You can now Opt-In - and register to be an organ donor. Opt-Out - and register NOT to be an organ donor. If you haven't registered a decision you still could become an organ donor and help many people re-start their lives

***Precise date subject to the launch date of the new NHS Organ Donor register**

Call to Action

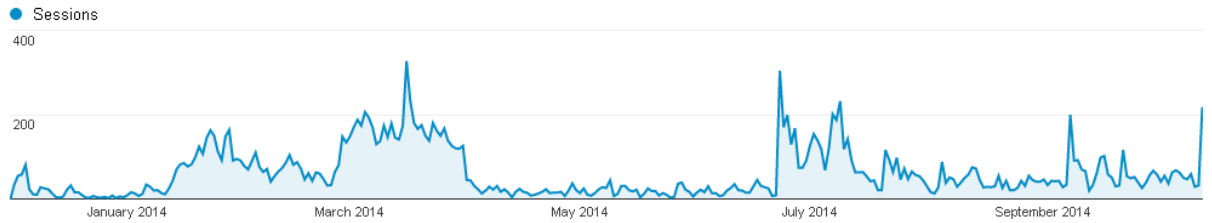
14. A clear call to action is featured on all advertising and the primary aim is to encourage the public to seek more detailed information on the website. However for those who do not have online access, we also promote the NHS Organ Donor Helpline number where staff are provided with a detailed briefing to answer any questions.

www.rhoiorganau.org / www.organdonationwales.org
Tel: 0330 123 23 23

Key Achievements from Launch of Campaign

Website

15. Since the launch of a dedicated website for organ donation in Wales, it has received over 19,400 visits and 83.5% are new visitors. It is the main call to action for the campaign and promoted wherever possible as this is where the most detailed and up to date information is hosted. The graph illustrates below the peaks of visitors and these correspond with the bursts of advertising and increased PR activity.



Advertising

16. Mass media advertising started in January 2014 with digital and press media. TV advertising started in June 2014. Mass media advertising has been bought across the platforms below. Following feedback from regular omnibus survey results, advertising is increased in areas that reveal particularly low awareness of the campaign. Main bursts of advertising activity since launch:

- Burst 1 Jan – March 2014;
- Burst 2 June – August 2014
- Burst 3 October – November 2014

TV (Burst 2 & 3)

ITV1 Wales, S4C, Sky Adsmart, ITV Player, C4oD,

Radio (Burst 1, 2, & 3)

Heart South Wales, Capital FM South Wales, Heart North Wales, Radio Pembrokeshire, Carmarthenshire, Swansea Sound, The Wave, Scarlet FM, Bridge FM, Nation, Radio Ceredigion

Online (Burst 1, 2 & 3)

Display Network advertising
Wales Media sites
Facebook advertising (Burst 2 & 3)
Twitter (Burst 3)

Press (Burst 1)

South Wales Argus, Western Telegraph, Cardigan & Tivyside Advertiser,
South Wales Evening Post, Carmarthen Journal, Llanelli Star, Welshpool County Times, Wrexham Leader, Daily Post, Caernarfon & Denbigh Herald, North Wales Weekly News, Western Mail, Metro, Cambrian News, South Wales Echo, The Voice, Big Issue, Golwyg, Campaign Series, Paparau Bro

Outdoor

Interiors of bus stops 6 sheets (Burst 2),
Shopping centres 6 sheets (Burst 2),
Student university campus sites (Burst 3)
Bus streetliners (Burst 3)
Interior Trains- Valleys lines (Burst 3)

17. Two television advertisements have been produced. The first TV advertisement includes a countdown clock featured on four characters to indicate that time is running out whilst waiting for a transplant. The intention is to illustrate the rationale behind the new law.
18. The second TV advertisement is a more simple approach featuring a voice over artist turning to camera and explaining the law will change and asks the viewer to start a conversation with their loved ones about their organ donation wishes.
19. It is the intention that both advertisements will be used throughout the next year of the campaign with slight alterations to reflect updated statistics and as we get closer to the opening of the new register. [Both advertisements can be seen on the website.](#)

Advertising Reach

20. In terms of evaluating the reach of the advertising, our specialist media buyers advise that the TV advertising on ITV1 Wales performed extremely well with just over 63% of all adults (1,550,978) in Wales seeing the commercial at least once. 32% of these adults (785,213) saw the commercial at least four times, which is the industry standard to ensure people remember the advertisement. The bus shelter panels and Cardiff 6 sheets achieved an estimated 39% of all adults in Wales (2,551,636) seeing the poster on average 7 times.
21. It is difficult to estimate what the total coverage would be of all the media added together, but the specialist media buyers estimate is that at least 75% of adults would have been exposed to the message in some format.

Still from the TV advertisement



Outdoor Poster Advertisement Burst 2

**Llywodraeth Cymru
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Yng Nghymru y llynedd, bu farw 36 o bobl wrth aros am drawsblaniad. Mae'r cloc yn tician i lawer mwy.

Last year 36 people died whilst waiting for an organ donation in Wales. The clock is ticking for many more.

O'r 1af o Ragfyr 2015 bydd newid yn y ffordd fyddwn ni'n dewis rhoi organau. Nawr yw'r amser i ni ddeddfu beith mae hyn yn ei olygu a'i drafod gyda'n hanwylaid.

Am ragor o wybodaeth, ewch i rhoiorganau.org neu ffoniwch 0300 123 23 23

From the 1st December 2015 the way we choose to become organ donors will change. Now is the time for us to understand what this means and talk about it with our loved ones.

For more information visit organdonationwales.org or call 0300 123 23 23

Nawr yw'r amser i siarad am roi organau
It's time to talk about organ donation

Infographic May 2014

Wales is **proud** to have reached

1,000,000

registered organ donors.

But there's still more we can do.

Last year **36** people died whilst waiting for an organ transplant... (that's enough to fill a single-decker bus)

...and although 87% of people in Wales support organ donation... **87%** ...only **32%** have registered.

1st Dec 2015

That's why in Wales, from 1st December 2015 the way we choose to be an organ donor will be changing.

To find out more visit www.organdonationwales.org or call 0300 123 23 23

It's time to talk about organ donation

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Public Relations (PR)

22. The aim of the PR is to ensure there is media coverage each month on the new legislation. The specialist PR company has built a very strong cohort of case studies - organ donation "champions" - comprising people who are waiting for or who have received a transplant, and their families, together with a number of families who have been involved in organ donation from their own deceased relatives. The campaign to date and the media coverage achieved has been positive in tone and based on monthly platform events or stories. Where there are no obvious related announcements, events, publications that may attract media attention, the team actively promote the real life stories of the champions to achieve coverage both in national and regional print as well as online media.

23. As a broad outline, between September 2013 and October 2014, the PR has achieved in excess of 120 pieces of online coverage, 47 pieces of print media

coverage, 17 pieces of radio news coverage and 15 pieces of TV news coverage. All of these have been proactive pieces as opposed to coverage generated from media enquiries.

24. The PR has been and will continue to focus on case study-led activity in regional publications across the country. The PR supplements the advertising, by providing real-life examples of people who have been through the organ donation and transplantation process. Their stories, used in local publications both online and print help to provide the rationale for changes in legislation, the need for additional donors and positively promote the benefits of transplantation. There are currently 22 real life stories published on the website under the 'Your Stories' section.

Events

25. National Transplant Week 2014 (7-11 July) was a key time for the PR activity. The week provided a good opportunity to promote organ donation and transplantation as well as opportunity to explain the legislative changes to the public. During the week, over 50 'Time to Talk' events were held across the Wales including talks in workplaces, talks to specific groups, drop in sessions in supermarkets and local authority offices. It is estimated the team spoke to approximately 10,000 people over the week as well as handing out information leaflets.

26. Over the past year, the Organ Donation Team has been invited to give presentations to specific events. These have included:

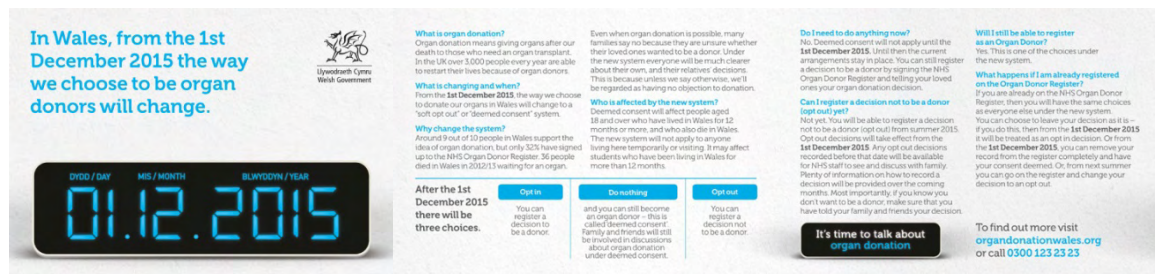
- Higher Education Communications Group – Oct 2013
- PSE Co-ordinators Group – Oct 2013
- Association of Embalmers and Funeral Directors – Oct 2013
- National Kidney Federation Annual General Meeting – March 2014
- Ynys Mon Women's Institute – April 2014
- Gwent Women's Institute – April 2014
- Mold Women's Institute – April 2014
- Newport Senior Citizen's – May 2014
- Dying to Talk Conferences in Cardiff and Llandudno – May 2014
- Cardiff Biobank – June 2014

27. In November 2013, the Welsh Government hosted the first 'Taking Transplantation 2020' Conference. This was attended by 140 delegates from NHS Wales, NHS Blood and Transplant, Voluntary Sector, Organ Donation Committee Members. This provided an opportunity to engage stakeholders on the implementation programme for the Human Transplantation Wales Act

2013 as well as share ideas on how to increase donation rates in Wales. Feedback from the event was very positive and plans are in place to hold this style conference bi-annually.

Information Materials

28. A bilingual A5 information leaflet and a smaller credit card sized leaflet have been produced to explain the changes to the legislative changes to organ donation in Wales. Initially these have been produced as giveaways at events, roadshows or meetings but opportunities are being explored to identify more widespread distribution through third party organisations such as health settings / organisations. St John's Ambulance has also been provided with a stock to distribute at their events. If this is successful a more detailed distribution model will be developed.



Social media

29. Bilingual Facebook and Twitter channels were launched in Summer 2014 to support the PR activity. The initial focus of the social media has been to increase followers on Facebook as this is the most mainstream of social media channels and is also easier to facilitate a conversation. Facebook pages have been promoted through a dedicated 'Facebook app' and advertising. This has proved successful in terms of increasing reach. Over an 11 week period of Facebook advertising, the page has increased its reach significantly from 300 'likes' to over 4,000 (stats taken on 13/10/14).

30. Following the success of the Facebook activity, a similar approach will be taken for Twitter to increase the reach of the dedicated Twitter channel.

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

Stakeholder engagement

31. Key stakeholders have received presentations relating to the advertising, PR and social media strategies and were invited to the filming of the advertisements. In addition, a “behind the scenes” film was made with the participation of stakeholders and organ donation champions which is on the website. Stakeholder groups were also sent a communications pack comprising various artwork and key messages to include on their own websites.

32. Launched in April 2014, a stakeholder e-bulletin is issued on a fortnightly basis to ensure that our stakeholders are kept informed on progress on the implementation of the Act, communication milestones as well as the wider developments on organ donation in Wales. The newsletter is published on www.wales.gov.uk/organdonation.

Specific Engagement

Students

33. Specific work to engage students coming to study in Wales has also been undertaken, as their consent may be deemed if they live in Wales for 12 months or more. Activity in September 2014 has included:
 - Over 10,000 direct emails sent via UCAS to students living outside of Wales accepting a place in a Welsh university. The email was personalised, referred to the university the individual was going to as well as referencing the date of the Fresher Fair that would have an Organ Donation Wales stand. The open rate was 63.76% which was encouraging when the industry standard is an open rate of approx. 20-25%
 - The Organ Donation Team attended 10 Fresher Fairs in Welsh Universities with an estimate of 5,000 students spoken to over the week
 - Advertising specifically targeting students in university campus sites has commenced in October 2014
 - Pro-active PR with student case studies supported with social media

Black and Minority Ethnic (BAME) and Faith Engagement

34. The key focus of this work is:
 - To raise the profile of organ donation within the BAME and faith communities given the very low levels of donation from within BAME

- groups, as well as the uncertainty which can exist about what is permissible under various religions in relation to organ donation; and
- To inform and educate the communities about the forthcoming changes to a soft opt-out system for consent to organ donation in Wales as provided for in the Human Transplantation (Wales) Act 2013.
35. A specialist agency, Cognition, has been engaged to deliver this work. Cognition have embarked on a programme of 'informing the informers' - actively engaging with representatives and congregations of all the major faiths, BME community organisations, groups supporting refugees, cultural support associations, health based groups and professional bodies. Through presentations and Q&A sessions, Cognition directly engaged with over 3,900 people at 121 events over a wide geographic spread. Cognition has since moved into the 'public engagement' phase, engaging so far with around 1,698 people. Key highlights have included presenting at an event in Cardiff hosted by the First Lady of Somalia as well as events created to engage with women from African Communities. The team have also attended 7 events specifically for refugees from different faiths.
36. While Cognition cannot claim that the cultural and religious barriers to donation have been overcome, they are convinced that since they have started their work the narrative of discussions among both BME and Faith groups is now largely centring on the needs and ethics of organ donation, and not the myths and misinformation that was prevalent before the Act was passed in July 2013.
37. Over the next year, Cognition will continue building on its public engagement work, including producing multilingual leaflets. This will include production of 3 films for communities where there is no written language to cover information on how to use the new registration system. Cognition is also exploring the possibility of a conference with international Muslim leaders and experts in the Muslim doctrinal and ethical issues regarding organ donation to help inform local leaders and clerics to help lower the cultural and religious barriers to donation, in the community with the highest need and the lowest donation rate.

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 NHS will be in a position to successfully implement the new legislation.

39. NHSBT has appointed a dedicated lead person with responsibility for the business changes associated with the implementation of the Act. In addition, a practice development specialist will be involved in developing the specific training requirements and materials. The work has started with a review of around 160 policy and procedure documents with the intention of updating where necessary. A project plan is in place to support the development and delivery of training programmes for staff directly involved with organ donation as well as the wider clinical team.
40. The Welsh Government has already undertaken some early work with Welsh GPs with the Deputy Chief Medical Officer writing to all GPs to provide details on the new law including providing answers to frequently asked questions. Awareness raising sessions will take place with the GP faculties in Wales in the next few weeks. Officials have also been considering the training needs of the wider NHS in Wales.

Evaluation

41. There is a wide ranging research and evaluation programme for the legislative changes including an impact evaluation for the introduction of the new system.
42. Research and evaluation specifically for communications work includes regular public awareness and attitudes surveys. From June 2014, the survey will be undertaken on a quarterly basis and the report covering results from June and September 2014 is expected to be published in November.
43. Findings from the most recently published survey, carried out in November 2013, show that:
- 60% of respondents had seen or heard something about the new system;
 - 57% were in favour of the new system (16% were against, with the remainder saying they need more information to decide or didn't know); and
 - 15% said they will opt out (68% said they will opt in, remain opted in or take no action, and 16% didn't know).
44. This has also been supplemented by creative development qualitative work both in autumn 2013 and another piece of qualitative research which is currently being undertaken to assess reactions to messaging and language for Phase 3 of the campaign. Other research to support the legislation change

has looked and NHS Staff attitudes, as well as the views of Specialist Nurses and Clinical Leads for Organ Donation.

45. The research and evaluation reports are published [here](#)

Forward Look and Priorities

46. Mass media advertising will continue and Phase 3 of the campaign is due to start in early 2015. A personalised door drop to all households in Wales will be a vital part of the communications strategy from summer 2015 onwards to ensure that everyone living in Wales receives information about the change in legislation.

47. This will be supplemented with automated letters to young people approaching their 18th birthday direct from NHS Wales. The intention is this will be a long term arrangement to continue for the foreseeable future.

48. Immediate priorities include additional engagement with the following communities:

- People who are Deaf, Deaf/Blind and Blind
- People with Learning difficulties
- Gypsy travellers

49. Other work to help increase the reach of information to the public will be undertaken by:

- Working with major employers and workplaces to communicate to staff through internal communications channels and /or events
- Identifying unique opportunities in rural and border communities where the normal 'mass media' opportunities are limited.

50. Further information materials to be produced as priority are:

- Easy Read versions of the information leaflets
- Information leaflets produced in languages other than English and Welsh
- Resources for schools and young people
- Training materials for NHS Staff

51. The next 'Taking Transplantation to 2020' conference will be held in September 2015