

**NHSBT Board**  
January 26 2017

**Reports from the UK Health Departments**

A report from each UK Health Department is attached.

## **UPDATE FROM THE NORTHERN IRELAND DEPARTMENT OF HEALTH**

### **Northern Ireland Organ Donation Clinical Advisory Group (ODCAG)**

The ODCAG, the ad hoc group which was formed to take forward work on implementing the statutory requirements of the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016, is continuing to progress its work with a view to developing a Departmental policy statement on organ donation and underpinning initiatives designed to implement the legislative requirements (to promote transplantation and report annually to the Northern Assembly).

The Clinical Advisory Group is pursuing 5 separate workstreams:

- Workstream 1: Organ donation communications benchmarking and improvement initiatives
- Workstream 2: Continuing professional development
- Workstream 3: Development of the organ donation policy statement
- Workstream 4: Local government code of practice
- Workstream 5: Raising young people's awareness

### **Recent Developments**

- The ODCAG is grateful to Professor John Forsythe and Ceri Rose from NHSBT for attending its meeting on 27<sup>th</sup> October to share their experience on organ donation promotion and the behaviour change strategy and provide insight into NHSBT's work.
- Following this the ODCAG agreed to develop proposals to employ a local full-time coordinator with responsibility for ongoing coordination of the organ donation promotional activities under the above workstreams, and associated monitoring and reporting.
- In a subsequent meeting with NHSBT on 8<sup>th</sup> December, DOH officials discussed the outline proposal which received the support of NHSBT. Both parties agreed to develop this concept further in 2017.
- DOH is in the process of organising a local government workshop with a view to engaging with local Councils on opportunities to work with the five Health and Social Care Trust Organ Donation Committees to promote organ donation at local level. This will take place on 26 January 2016 with the aim of developing a local government code of practice.
- While the work of the ODCAG is progressing, it has been decided that DOH would ask the Public Health Agency to re-run last year's organ donation awareness-raising media campaign during February and March (awaiting final confirmation).

## **Developing collaboration with the Republic of Ireland**

- DOH officials are engaging with their counterparts from the Department of Health in Dublin to discuss possible areas of collaboration in various areas of health, including living donor transplantation.
- NHSBT has agreed to continue to liaise with DoH Northern Ireland officials regarding ongoing discussions with Organ Donation and Transplant Ireland.

## **Wales update report for NHSBT Board November 2016**

### **One year anniversary of the enactment of the Human Transplantation (Wales) Act 2013**

There was significant media interest in the UK at the one year anniversary on 1 December 2016 with ongoing media interest from Holland, Canada and Australia, and enquires from the United States of America.

Data supplied by NHS Blood and Transplant (Annex 1) shows a slight increase in the number of proceeding donors and organs transplanted 12 months post enactment 1 December 2015- 30 November 2016 compared to the same time period the previous 2 years. This has been achieved despite a fall in the number of eligible donors where family were approached. Although the slight increase looks positive it is too early to draw any conclusions.

A BBC documentary "The Greatest Gift" undertaken in The University Hospital of Wales was also televised to coincide with the one year anniversary. The three-part series documented a year since the legislation change, with unprecedented access to donor families, and patients waiting for life-saving transplants at the University Hospital of Wales. This has been received very positively by staff and we are liaising with the maker of the programmes to see if, and how, we would be able use the programmes in the future. In particular if they could be used in schools and or vignettes to support staff training.

Whilst there did not appear to be any increase in the numbers of people opting in or out in the three weeks when the programme was broadcast (weeks commencing 5<sup>th</sup>, 12<sup>th</sup> and 19<sup>th</sup> December 2016) there is some evidence that more people accessed the Website on the dates that the episodes were shown (6 / 13 / 20 December 2016). Further detail in annex 2

### **Human Transplantation (Wales) Act 2013 annual communication report.**

The third of five annual reports, outlining the work undertaken on the public information campaign to ensure that the Welsh population are aware of the changes and understand how it affects them was published 1 December 2016. The report covers the period of 16 November 2015 to 14 November 2016. The document can be found at: <http://gov.wales/docs/dhss/publications/161201organ-annual-reporten.pdf>

## Evaluation of the Human Transplantation (Wales) Act

A five year research and evaluation programme (2012-2017) has been developed to assess the implementation and impact of the Act. It contains the following strands:

- **Public attitudes research**

- *Surveys of public awareness and attitudes*

Questions commissioned on the Beaufort Omnibus Survey. Baseline carried out in June 2012, with follow up June 2013, November 2013 and quarterly from June 2014 until June 2016. By June 2016, unprompted awareness of the changes to the legislation was 76%. Of those that were aware of changes, almost nine out of ten said that it would change to opt out or presumed consent.

By June 2016, prompted awareness had reached 83 per cent.

In the final wave of the survey, 48 per cent of respondents reported that they had discussed their wishes regarding organ donation with a family member.

Reports from all waves are available at:

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

- *Qualitative studies*

Initial qualitative work with members of the public conducted in 2012.

Further qualitative work (10 focus groups and seven in-depth interviews) undertaken in March 2014. This looked at attitudes towards and understanding of organ donation system and planned changes.

Also used to test some of the proposed messaging for the

Communications work. Report available at: <http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>

Fieldwork for final phase has just been completed. Focus on discussions with family. Report will be published Spring 2017.

- **Research with NHS staff**

- *Qualitative research with Specialist Nurses and Clinical Leads for organ donation*

Three waves of qualitative research have been undertaken with Specialist Nurses and Clinical Leads for organ donation. The first took place in 2013, before the proposals became law. The second wave took place in early 2015 and the final wave of fieldwork has recently been completed. Reports for the first two waves can be found at:

<http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/?lang=en>

The report from the final wave will be published Spring 2017.

- *Surveys of wider NHS staff*

This survey is intended to measure views and attitudes of wider NHS staff towards the change in the legislation. The first wave of this survey was conducted at the end of 2013 (being completed during December 2013 and January 2014). The report from that wave is available at:

<http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>

The survey is currently being repeated, with fieldwork anticipated to be completed by Christmas.

▪ **Impact evaluation**

This will draw together the evidence from the above strands and undertake an analysis of routine data from NHSBT.

Considering a number of approaches to analysis.

Evaluation will monitor donation trends in Wales and compare them with patterns in the rest of the UK and also with individual nations or regions with similar demographic profiles.

The evaluation will have access to up to six full quarters of routine data after the Act came into force. The analysis will also assess whether there are any signs of changes in trends in the lead up to the new system.

An analysis plan has been published and can be accessed here:

<http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>

The final report will be submitted in September 2017

**Colleague recognised in Queens New Year Honours List**

Mrs Pat Vernon, Head of Healthcare Quality Legislation. Previously policy lead for the Human Transplantation (Wales) Act 2013 has been awarded the MBE for services to Organ Donation and Transplantation in Wales.

This honour was awarded for work on the delivery of organ donation legislation, in recognition of Pat's inspirational leadership in ensuring the smooth passage through public consultation, Assembly scrutiny and implementation of ground-breaking changes to the laws governing organ donation in Wales.

## Annex 1

### **Human Transplantation (Wales) Act 12 months post enactment Data supplied by NHS Blood and Transplant**

**Table 1 - Information for all consented donors in Wales**

Period	Eligible donors where family were approached	Eligible donors where consent was ascertained	Proceeding donors	Organs donated	Organs transplanted
1 December 2013 - 30 November 2014	164	76	56	177	149
1 December 2014 - 30 November 2015	161	93	55	195	165
1 December 2015 - 30 November 2016	145	86	61	209	181

This covers some periods where deemed consent did not apply; therefore data is for all consented donors.

**Table 2 - Information for deemed consents in Wales**

Period	Eligible donors where deemed consent applied	Eligible donors where family supported the deemed consent for organ donation	Proceeding donors	Organs donated	Organs transplanted
1 December 2015 - 30 November 2016	30	18	14	50	42

Please note that Table 2 is a subset of the information provided for the same period in Table 1.

Of the 30 cases where deemed consent applied there were 12 occasions for which the family went on to override the deemed consent. There were 4 cases where the deemed consent decision was supported by the family but donation still did not proceed due to medical unsuitability.

Since 1 December 2015 there have been no cases where an opt-out decision has been overturned by a family.

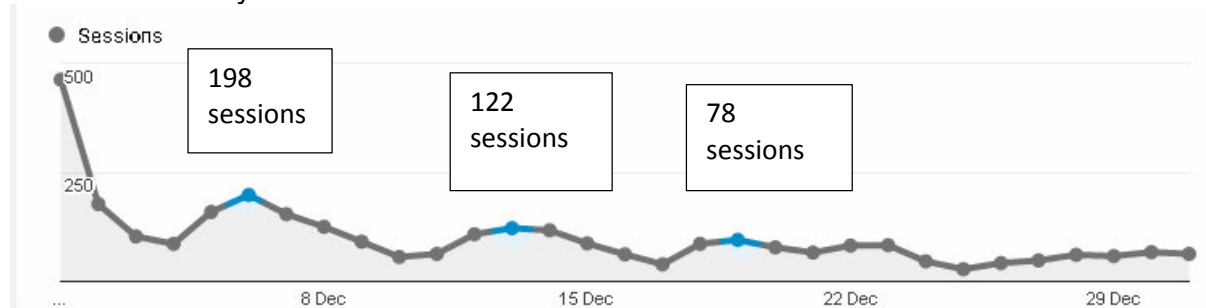
For the same time period there were 29 patients that met the eligibility criteria for organ donation whose family were approached however it was found that the patient had opted out and therefore did not go on to donate any organs. Of these 29 opt-out decisions 6 were registered via the ODR, 2 were expressed via a will, 28 wishes were expressed verbally, 0 via an appointed representative, and 0 via carrying a donor card. (Please note that patients may have registered a wish via more than one method.)



## Annex 2

### Web traffic to the Organ Donation Wales website

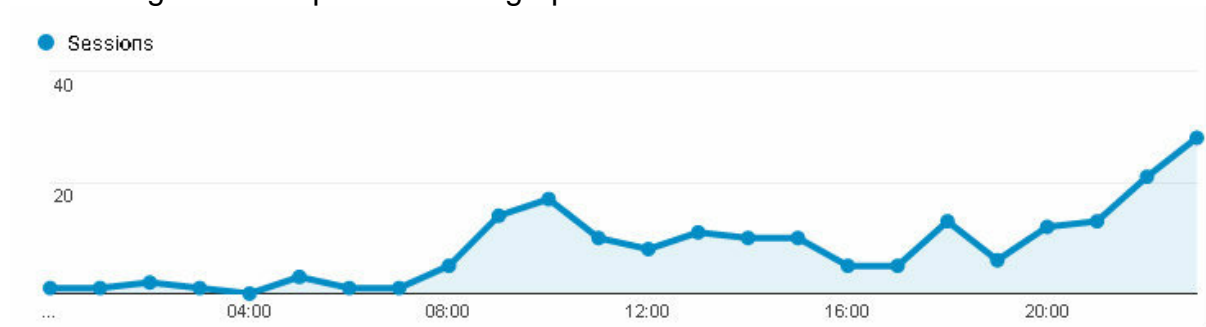
This graph shows the web traffic (sessions) as reported by Google Analytics to the website each day in December 2016. The blue points on the below graph, are the days that the Greatest Gift aired for the first time. Slight more traffick arrived at the site on these days.



### 6<sup>th</sup> December web stats – date that Episode 1 first aired

The graph below shows the web traffic to the Organ Donation Wales website hour by hour on 6<sup>th</sup> December.

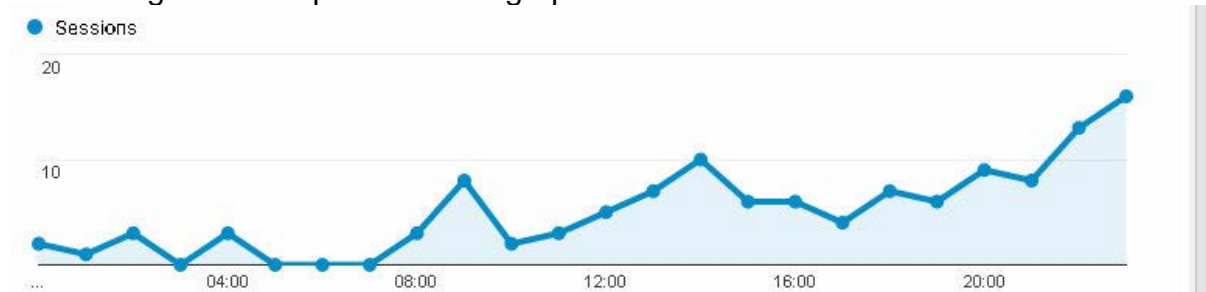
The web traffic increased around the time of the documentary (10:40pm) – which was during the last 2 points on the graph below.



### 13<sup>th</sup> December web stats – date that Episode 2 first aired

The graph below shows the web traffic to the Organ Donation Wales website hour by hour on 13<sup>th</sup> December.

The web traffic increased around the time of the documentary (10:40pm) – which was during the last 2 points on the graph below.

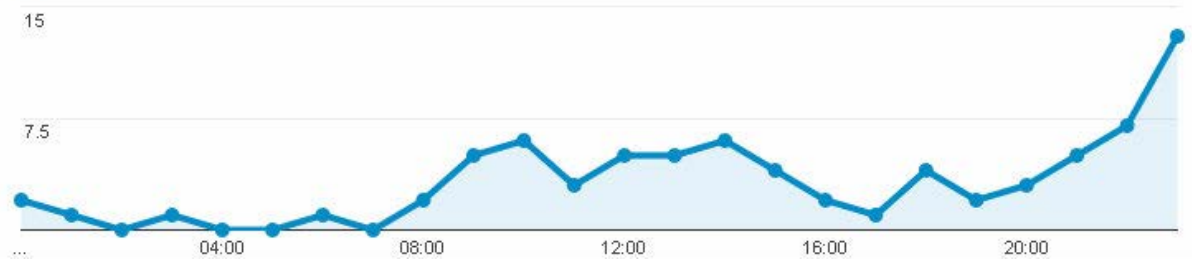


### 20<sup>th</sup> December web stats – date that Episode 3 first aired

The graph below shows the web traffic to the Organ Donation Wales website hour by hour on 20<sup>th</sup> December.

The web traffic increased around the time of the documentary (10:40pm) – which was during the last 2 points on the graph below.

● Sessions



## **UPDATE FROM THE SCOTTISH GOVERNMENT**

There has been positive progress in increasing deceased donor numbers, with 95 deceased donors in the first seven months of this year – 20 donors ahead of the same period last year. We have seen a welcome increase in the combined authorisation rate to 64.4% (from 57.1% last year). 44.2% of the Scottish population is now on the ODR – this figure will increase in the next month or so once the backlog of GP registrations has been processed.

The consultation on ways of increasing organ and tissue donation was launched on 7 December by the Minister for Public Health and Sport. The closing date for responses is 14 March 2017.

On-going work includes projects on living donation, paediatric and neonatal donation, a review of Scottish Donation Committees and promoting donation within the black, Asian and minority ethnic (BAME) communities in Scotland.

Scottish Government, January 2017