Reports from Scotland and Wales are attached.
UPDATE FROM THE SCOTTISH GOVERNMENT

The Scottish Government’s new organ donation marketing campaign was successfully launched on 4 July and has received very positive media coverage. The campaign is based around the message ‘we need everybody’ and features TV adverts and a social media campaign. The advert can be viewed at: https://www.organdonationscotland.org/resources

We are continuing to work on developing a consultation on ways of increasing organ and tissue donation, including a soft opt out system. The consultation will be launched this autumn. Separately, Mark Griffin MSP has indicated that he intends to introduce a new Members’ Bill in the Scottish Parliament – expected to be similar to the proposals in former MSP Anne McTaggart’s Members’ Bill (the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill). It is not clear if he will still wish to proceed with his legislative proposals once the Scottish Government has launched its own consultation.

The Scottish Government is working with NHSBT’s Regional Manager for Scotland and her team to take forward a project to develop Scottish guidance for clinical and other staff on paediatric and neonatal donation. This work will be developed alongside, and informed by, the sub group of NHSBT’s National Organ Donation Committee, which is developing UK-wide guidance on paediatric and neonatal donation. The project will also work to update the current agreement on donation between the Crown Office and Procurator Fiscal Service and the Scottish Donation and Transplant Group to ensure that this fully takes account of paediatric and neonatal donations.

We are also working with NHS Scotland on a project to increase numbers of living kidney donors which will link in to Living Donor Kidney Transplantation: A UK Strategy. The project aims to:

- establish a more proactive approach to identifying potential living donors by creating a network of nephrologists and specialist nurses with an interest in transplantation;
- raise awareness of directed and non-directed donation; and
- provide consistent patient information across Scotland in order to ensure equitable and timely access to all treatment options for end stage kidney disease.

Finally, we expect to announce details on the new Scottish Lead Clinician arrangements in relation to Organ Donation and Transplantation soon, following recent interviews.

Scottish Government, July 2016
Vaughan Gething AM, has been appointed as Cabinet Secretary for Health, Well-being and Sport. He gave an oral statement in plenary on 14 June on the Human Transplantation (Wales)Act 2016: Six months post enactment. Some points from the transcript:-

- I would also like to thank numerous stakeholder organisations for their unstinting support. I would especially like to thank all the patients and families who helped with our public information campaign by generously sharing their moving experiences to personalise the campaign.

- The latest omnibus survey in February 2016 showed that 74 per cent of the Welsh public are aware of the changes unprompted compared with 53 percent in 2012.

- As of 28 May 2016, just over 167,000 people in Wales, that is 5 per cent of the population, are registered on the NHS organ donor register to opt out. This is far less than anticipated in a June 2015 survey which showed 14 per cent of Welsh residents would register to opt out. In addition over 1.1 million people in Wales, 35 per cent of the population, have now registered to opt in.


Table 1: The period covers a period where deemed consent did not apply. Therefore data is for all consented donors. Data supplied by NHS Blood and Transplant.

<table>
<thead>
<tr>
<th>Period</th>
<th>Consented donors</th>
<th>Proceeding donors</th>
<th>Organs donated</th>
<th>Organs transplanted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 December 2013 - 31</td>
<td>31</td>
<td>21</td>
<td>62</td>
<td>42</td>
</tr>
<tr>
<td>May 2014</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 December 2014 - 31</td>
<td>38</td>
<td>23</td>
<td>76</td>
<td>51</td>
</tr>
<tr>
<td>May 2015</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 December 2015 - 31</td>
<td>42</td>
<td>31</td>
<td>84</td>
<td>60</td>
</tr>
<tr>
<td>May 2016</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2 is a subset of the information provided for the same period in table 1.

<table>
<thead>
<tr>
<th>Period</th>
<th>Donors consented under deemed consent</th>
<th>Proceeding donors</th>
<th>Organs donated</th>
<th>Organs transplanted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 December 2015 - 31 May 2016</td>
<td>18</td>
<td>10</td>
<td>37</td>
<td>32</td>
</tr>
</tbody>
</table>

Of the 8 cases where consent was deemed there were 5 occasions for which the family went on to override the deemed consent. There were 3 cases where the deemed consent decision was supported by the family but donation still did not proceed due to medical unsuitability.

For the time period 1 December 2015 - 31 May 2016 there have been no cases where an opt-out decision has been overturned by a family.

There were however 21 patients that met the eligibility criteria for organ donation who were found to have opted out and therefore did not go on to donate any organs.

The latest public attitudes survey has been undertaken and results will be published in September during organ donation week.

**NHSBT and WG communications strategy from April 2016**

Our organ donation campaign has commenced, we are running our campaign bursts at the same time as NHSBT to increase the amount of talk and coverage which is likely to spill over from joint activities. We have used the results of our regular awareness surveys as the basis of our targeting.

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
All Wales Blood Service (AWBS)

July 2016, the AWBS is developing the project completion activities report for submission to the Implementation Group’s meeting on 25 July. NHSBT is represented on this group. If agreed, the report will then go through the governance process – Planning & Committee, Quality & Safety Committee and Velindre NHS Trust Board by the end of September. A Gateway Realisation Review will be undertaken during November. This follows the first Gateway Review in November 2015 that reported:

• the overall delivery confidence assessment was Amber/Green (successful delivery to time, cost and quality appears highly likely with no major outstanding issues);
• strong governance arrangements are in place to continue programme management towards a more agile delivery focus for the final phase; and
• there are clear critical path assurance points.

Welsh Language

We await the publication of the report on the investigation into the Welsh Language provision to record an organ donation decision at the NHSBT call centre from the Welsh Language Commissioner.

Welsh Health and Specialised Services Committee

Until this financial year the Welsh Government directly funded NHSBT. In March 2015, Professor Mark Drakeford, the previous Minister for Health and Social Services, agreed that the Welsh Health and Specialised Services Committee (WHSSC) should commission organ donation from NHSBT from 1 April 2016.

Civil Service Live

Officials were invited to participate in the London Civil Service live workshop on 13 July. The topic for the session “Developing and sharing policy responses to universal challenges” We contributed to the session by delivering a presentation on The Human Transplantation (Wales) Act 2013: From development to implementation and beyond.

Officials also gave a similar session as part of the One Civil Service Live interchange shadowing scheme in Cardiff last month The aim of the week is to build networks across Whitehall and the devolved administrations through shared learning and knowledge.

Welsh Government
July 2016