Dear Mr Macdonald,

I very much welcomed the opportunity to participate in the Scottish Parliament’s Health and Sport Committee Stage 1 scrutiny of the Human Tissue (Authorisation) (Scotland) Bill on 20 November and would like to thank you and your Committee Members for the courtesies extended to me and my colleagues Dr Katja Empson and Richard Glendinning.

I was pleased to be able to highlight to Members the changes and improvements in organ donation that have taken place in Wales since the implementation of the Human Transplantation (Wales) Act 2013 and to share our experiences. I hope my responses and reflections were useful to the Committee. I advised that I would provide further information to the Committee on a number of issues; I would also like to provide one or two points of clarification in relation to some of the oral evidence provided on the day.

The issue of families overriding deemed or express consent

Several Members of the Committee asked about the potential for family members to override the expressed or deemed consent of the deceased, and whether we in Wales considered providing a safeguard against this on the face of the legislation.

I can confirm that the role of families was discussed extensively during the scrutiny of the Bill in Wales and various opposition amendments were tabled, either to give families a final ‘veto’ or to ensure that families could not overturn the decision of the deceased. However, Welsh Ministers did not accept these amendments, because they recognised that when it comes to organ donation, there must be an acceptable amount of flexibility to take into account the circumstances. Placing rigid provisions of this type in the legislation was felt to be unworkable in practice.

Consent to organ donation, whether it is deemed or expressed, is a measure of the deceased’s view and in legal terms, makes organ donation lawful. However, it does not mean that organ donation is inevitable because a number of relevant factors may come into play to prevent it. The deceased’s organ donation decision is the basis for conversations with the family, who are
encouraged to accept that decision. Nevertheless, in the real world, families may object, even if the person was on the Organ Donor Register, and NHS staff need to be aware of the effect that pressing ahead with organ donation at all costs would have on that family. In that regard, the system is no different to the one described in the Human Tissue Act 2004.

*The age limit for deemed consent*

Members of the Committee asked several questions about the age from which deemed consent should apply and why 18 was chosen in Wales, whereas the Scottish Bill sets it at 16 years.

From responses to the White Paper consultation, there was no clear consensus expressed in relation to where to set the age limit, with people arguing both for and against. For the purposes of deemed consent, we therefore decided to set the age at 18 years, which would place the issue of understanding the concept of deemed consent beyond doubt, and also accord with the definition of ‘child’ contained within the Human Tissue Act 2004.

However, the Act does not alter the ability of a child or young person under the age of 18 to express, during their lifetime, a wish to be a donor or not to be a donor. Children and young people are able to use the Organ Donor Register to record their decision in the same way as any other age group.

I would also mention that setting the age limit at 18 years has also proved to be an advantage in communications terms. Once a person reaches the age of 18, a number of life events, such as going to university, provoke new avenues of communication with the individual. As such we were able, for example, to utilise UCAS to communicate with new students. We were also able to arrange for NHS Wales systems to generate a letter to all ‘rising 18s’ advising them that deemed consent will apply, and linking this decision to other important life changes such as leaving school, starting work, going to university, etc. This latter form of communication is ongoing on a permanent basis, so eventually we will achieve universal coverage.

*The use of organs donated by 16 year olds*

Members asked me to confirm whether it would be possible for organs to be donated from those under the age of 18 in Scotland to be used for transplantation in Wales. I can confirm there would be no impediment to this as it is covered by section 3 of our Act – Authorisation of transplantation activities - which covers the storage and use of materials for transplantation.

Section 3(3) makes the storage and use of relevant material lawful where organs and tissues have been imported into Wales from outside Wales. In such cases consent is not required, meaning that all that a person using organs need to be satisfied about is that the organ has been imported. This replicates the position under the Human Tissue Act 2004 where an organ has come into England, Wales or Northern Ireland from elsewhere (for example from Scotland).

*Mental health support for patients who are waiting on transplant lists*

I believe it is good clinical practice to offer some psychological support to patients during the transplant assessment and activation process and this is certainly the case in the transplant centre at the University Hospital of Wales in Cardiff. Whether there is enough of this support available is another matter and there is always more we can do.

In terms of donor families, organisations such as the Donor Family Network provide support to those families who have supported organ donation from a loved one.
Current engagement strategy and how the Government reaches out to the different demographics, various cultural backgrounds and ethnic minority groups in Wales

Over the last two years we have run an extensive public information campaign and made every effort to reach all communities and groups in Wales. This campaign has been carefully designed to provide clear information about the change in the law in Wales, and what this means for people in Wales. The choices people have were explained, and information about how to record a decision was included.

The campaign has been clear and factual, and representative surveys we have commissioned show that the level of understanding around the new law in Wales is generally high although the sample sizes are too small to allow a breakdown based individual characteristics. We will continue to publicise the organ donation system, and in fact the law places a duty on the Welsh Government to run an annual campaign.

We use the data received as part of the ongoing Omnibus research and advice from our media buying agency to target geographical areas and demographic groups that were showing low awareness and understanding of the law for subsequent bursts of advertising.

In terms of young people, we have continued the arrangement with UCAS mentioned above 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. A ‘rising-18’s’ letter is sent to everyone approaching their 18th birthday. It explains the new system, tells them what their choices are and encourages them to talk to their loved ones. An education pack has also been sent out to all schools to raise awareness and prompt conversation within families.

We are developing a plan for next year that will include working with the transplant unit to find more BAME case studies that are waiting for a transplant and willing to work with us. We are already working on a social media film with many people saying “talk about organ donation” in lots of different languages.

Variation in organ donation rates across Wales

Unfortunately it has not been possible to obtain information from NHSBT about the number of actual donors, broken down into specific areas in Wales in the time available. There are also concerns about the small numbers involved and the risk of identifying patients. However, I can provide the consent rate for each Welsh health board.

For the purposes of comparison, it is possibly better to compare Betsi Cadwaladr University Health Board in North Wales with Aneurin Bevan University Health Board in South Wales as they have similar population sizes and service provision.

- The consent rate in Betsi Cadwaladr UHB was 55.5% in 2014 and has risen to 67.6% in 2017. Approximately 40% of their population have opted in on and 4.5% opted out on the organ donor register.

- The consent rate in Aneurin Bevan health board was 43.6% in 2014 and has risen to 78.9% in 2017. Approximately 38% of their population have opted in on and 5.1% opted out on the organ donor register.
How to register an ‘opt out’ decision

I hope you will allow me to correct a response given to the question from Members about how the Welsh public are able to opt out. The answer given was not completely accurate as individuals are not able to opt out via the DVLA.

During redevelopment of the Organ Donor Register there were numerous discussions on the routes which should be available to people to record an opt out decision. The routes provided by the so-called ‘partner feeds’ (including the DVLA, GP registration, Boots Advantage Card) were discounted because there is a delay in the organ donation decisions from those systems reaching the ODR. It was felt that this was too great a risk in relation to opt out decisions.

The issue of pre-mortem interventions

There were some questions from Members as to how deemed consent applies in relation to the pre-death interventions which may need to take place in DCD donation. I should clarify that any such interventions must be taken in the person’s best interests as covered by the Mental Capacity Act 2005. In determining those best interests, whether not a person has consented to organ donation will be a relevant factor. In terms of deemed consent, the fact that the person had not opted out would also be a factor. We sought the advice of the UK Donation Ethics Committee who commented that in either case (deemed or express) decision makers would be expected to explore with family members the evidence of a person’s views, values and beliefs to enable clinicians to make a full and considered judgement as to what is in that person’s best interests.

Yours sincerely

DR FRANK ATHERTON