

10 January 2013

Response to the Consultation Paper on the Human Transplantation (Wales) Bill
December 2012

The observations of the Cardiff and Vale University Health Board Organ Donation Committee are as follows

1) **Re: Title of Bill**

The title of the Bill 'Human Transplantation (Wales) Bill, doesn't mention 'donation'. Will the public, if asked, be able to relate the 'opting out' legislation as mentioned in the media, to the 'Transplantation Bill' as there is no mention of donation in the title?

We accept that the ultimate aim is for transplantation to occur, but for the public it should be donation that is emphasised as it is the assent/consent for donation on the public's part that makes transplantation possible.

2) **Re: QALY**

Our understanding is that when NICE assesses cost-effectiveness per QALY for drugs, £30 000 is used as the cut-off point, above which the drug is not deemed to be cost-effective. We note the figure quoted here is £60 000. Could we have some clarification please?

3) **Re point 134 of Human Transplantation (Wales) Bill, Explanatory memorandum:**

As identified on previous occasions the increase in donor numbers estimated at 15 per year will have an impact on resources, especially in critical care. The conversion rate of DCD donors is about 22% therefore for 1 donor who goes on to donate organs we have 3 potential donors where consent is gained but who don't die in the required timeframe. The workload on the critical care departments can't be calculated by looking at donors alone ie. 15, but is more likely to be about 4 times that ie. 60 patients per year. This will have a significant impact on critical care provision as bed numbers per population in Wales is relatively low when compared to other developed countries.

4) **Re: Reasons given by relatives for refusal of consent for organ donation**

At present we monitor all potential organ donors and we review the data with the SNODS at the Organ Donation Committee meetings. We also document the reasons for relative refusal however this is only done when a SNOD is involved in the request for donation. We suggest that to assist in determining the effect of the Bill it may be useful do collect this data routinely in all of Wales, as this may identify areas where work is needed to increase donation going forward.

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5) **Re: Practical issues raised at the stakeholder and public consultation meetings which we would like to highlight.**

a) **Re:ODR**

In our view it is imperative that there is only one UK wide register for the public to express their wishes regarding donation, whether they wish to opt in or out, to ensure that opposing views are not logged on different registers.

b) **Re: Establishing residency**

There are concerns as to how the SNODS would be able to accurately identify residency of the potential donor, especially of hours, without speaking to the relatives. One of the benefits of the Bill is seen to be that the introduction to the conversation with the relatives would include the fact that the potential donor hadn't opted out, but this would not apply to those not resident in Wales and therefore it won't be possible to start the conversation with the fact that they hadn't opted out prior to establishing residency.

NB this may have considerable implications for litigation.

c) **Query re: Consent forms**

Would the Bill require a change in the current consent forms and would there be different forms required for those who are resident in Wales and those who are not?

d) **Organ Donation Taskforce Recommendations and NICE guidelines**

The Bill will not be a substitute for the Organ Donation Taskforce Recommendations made in 2008. For the Bill to be successful it is essential to adhere to the Taskforce Recommendations and the guidelines developed by NICE, in particular those in relation to referral of all potential donors and collaborative requesting.

6) **Re: Ease of opting-out**

In order to provide a balanced option the system of opting out must be clear and as easily accessible as the one for opting in.

7) It remains a concern that individuals may opt out due to the 'presumed 'nature of the Bill.