

# The National Assembly for Wales Health and Social Care Committee

## Submission on the Consultation on the Human Transplantation (Wales) Bill

I make the following submission to the Committee in a personal capacity. I was formerly a GP for almost thirty years and am currently director of studies in medical ethics and law at Masters' level in a University College in the UK. Up until five years ago, I was strongly supportive of moving to a soft 'opt out' position on organ donation, but I now have increasing reservations about opt-out policies in general and about the National Assembly for Wales' proposed legislation in particular.

My concerns were particularly heightened in 2012 when lecturing to a group of healthcare practitioners and academics from Brazil at the University of Surrey.

In brief, there are three main points to which I wish to focus the Committee's attention.

1. Though there is some evidence that change to an opt-out system can result in an increase in organ donation, as in Belgium<sup>i</sup> and Austria<sup>ii</sup>, such a change does not in itself guarantee such an increase, as in Sweden where rates remain far lower than in the UK despite having a soft opt out since 1996.<sup>iii</sup> Whether the UK should adopt an opt out remains 'finely balanced'<sup>iv</sup> not a clear certainty.<sup>v</sup>
2. As one US blogger, observing this debate, shrewdly observes "Fears don't have to be well-founded to make the donation rate go down, they just have to be widespread."<sup>vi</sup> I have no doubt you will have had many submissions detailing the fears that may arise – some justified and others probably not, but 'perception is all' in regard to fear. Although the Assembly has indicated the Bill would propose a soft opt out, in fact it contains no provision providing next of kin with a right to object to the removal of organs when no consent was given by the deceased. Though this 'hard opt out' scenario has recently been advocated by Shaw<sup>vii</sup>, the Assembly should note that without exception, every online response<sup>viii</sup> to Shaw's article, including my own, indicated reservations or opposition to Shaw.
3. I was left in no doubt by the reaction of my Brazilian colleagues last year, that the Brazilian hard opt out system, which was a disaster<sup>ix</sup> and had to be rapidly reversed as donation rates there plummeted, is still a cause of national shame even 15 years later. The Assembly should certainly take heed the reasons for the failure of hard opt out in Brazil and ensure that Wales does not follow a similar course.

Dr Trevor Stammers BSc MA FRCGP DRCOG

Programme Director in Bioethics and Medical Law

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<sup>i</sup> Michielsen, P. (1996). "Presumed consent to organ donation: 10 years experience in Belgium." *Journal of The Royal Society of Medicine* 89: 663 - 666.

<sup>ii</sup> Rithalia, A., McDaid, C., Suekarran, S., Myers, L and Sowden. (2009) "Impact of Presumed consent for organ donation on donation rates: a systematic review". *BMJ* 338: from <http://www.bmj.com:a3162>  
doi:10.1136/bmj.a.3162

<sup>iii</sup> Organ Donation Taskforce (2008). The potential impact of an opt-out system for organ donation in the UK. London. <http://www.dh.gov.uk/>

<sup>iv</sup> Bramhall S. (2011) Presumed consent for organ donation: the case against *Ann R Coll Surg Engl.* 93(4): 270–272

<sup>v</sup> Coppen, R., Friele, R., Marquet, R. and Gevers, S. (2005). "Opting-out systems: no guarantee for higher donation rates." *Transplant International* 18: 1275-1279.

<sup>vi</sup> <http://crookedtimber.org/2010/05/05/presumed-consent-in-theory-and-practice/>

<sup>vii</sup> Shaw D 2012 We should not let families stop organ donation from their dead relatives *BMJ* 345:e5275

<sup>viii</sup> <http://www.bmj.com/content/345/bmj.e5275?tab=responses>

<sup>ix</sup> Bailey, E. (1998). Should the State Have Rights to Your Organs?- Dissecting Brazil's Mandatory Organ Donation Law. *U. Miami Inter-Am. L. Rev.*, 30, 707.