

**Submission to the Health and Social Care Committee of the National
Assembly of Wales regarding
the *Human Transplantation (Wales) Bill***

At first, I was very encouraged when I read that Mark Drakeford A.M. Chairman of the Health and Social Care Committee had declared that this consultation on the Human Transplantation Bill was “an opportunity to look at it again with *fresh eyes*”. However, he also said, “The Welsh Govt. has already undertaken a significant consultation on this Bill before proposing it.”

It depends what you mean by a consultation. There are at least two choices:

- A. is the consultation open to the expression of differing opinions and are these opinions also taken on board, examined, discussed and answered?

- B. or is the consultation a deliberate attempt to ignore opposition and use any means to make it appear that the Govt.’s view is supported by the majority of respondents?

In **Options for Change May –August 2009 and the White Paper Consultation Nov. 2011 – Jan 2012**, the Govt. used every means from standard letters, petition style letters, identical e-mails to make it appear that there was majority support for the presumed consent policy. In the **final consultation on the Draft Bill June –Sept. 2012**, both standard letters and individual letters showed significant, not to say overwhelming opposition, to the Govt.’s policy, therefore, the consultation responses were ignored.

There was **NO** “significant consultation” previously, only a pretence at consulting the Welsh people. Respondent no 107 to the White Paper Consultation said, “**The State only pretends to consult the public on issues that impact directly on their lives.**” Then they take no notice.

Respondent No 863 said, “**You don’t listen to what people say and it doesn’t matter what the majority vote you will implement what you like. We are supposed to be a democracy not a dictatorship.**”

Many ordinary citizens had no idea that this issue of presumed consent was not only being discussed, but that decisions had been made to go ahead. Their comments show their anger and frustration that decisions had been taken to take away their control of their own bodies:

Responses to White Paper Consultation

No. 649 “ If my body is not my own then what is?”

No 54 (an organ donor) promised to opt out saying, “ I am not a farm animal”

No 110 “ A theft of a most hideous nature”

No 888 “ Habeas corpus has been an important legal instrument safeguarding individual freedom against arbitrary State action”

No 934 Welsh Intensive Care Society, “ Presumed consent is meaningless and under a soft opt-out system proposed organ donation would have to be acknowledged as being non consensual. Promoting presumed consent by comparing donation rates is disingenuous since there are many other confounding issues that all affect donation rates.”

The Welsh Intensive Care Society in its response to the Draft Bill consultation (no 221) stated that it was extremely disturbed by the way in the White Paper Consultation, their “ carefully analytical response seems to have been afforded the same weight as one of the pre-printed letter.”

The Minister had promised to consider carefully all submissions after the White Paper Consultation in her statement in March 2012. If she did, it was only to reject everything that did not agree with presumed consent even what supporters wanted: a longer residency period and a legal family veto.

All the power is on the side of the Government to manipulate processes, figures and invitations to respond. What power has the ordinary citizen –only the ability to band together and then be dismissed as a ‘campaign’. Since when did campaigns become illegal?

This Assembly HSC Committee is supposed to be looking at it with “fresh eyes”. And examining the principles underlying this Bill. I look forward to finding out what the principle is.

All that has been said so far which seems to serve as a principle, repeated endlessly like a mantra is: “ Presumed/deemed consent means more organs means more lives saved”.

Prof. Ceri Phillips disagrees and says that the Transplant service cannot cope with more organs as proved by the failure to remove the organs from the road traffic accident victim of whom I speak below.

I am very much afraid that this consultation will be like the Government’s consultations, debates and public meetings – a pretence. The time for written evidence was six weeks and

most of that time was taken up by the holiday period of Christmas. No different from the Welsh Government – their White Paper Consultation was over the Christmas period too.

I am opposed to presumed/deemed consent because it is wrong in principle to say that if you have not said 'No' than you must mean 'Yes' . It is twisting the meaning of the word consent.

If the Government is prepared to take up this immoral means of trying to increase the number of organs for transplantation why does it not follow Iran's example of wiping out the kidney waiting list by paying the donors to make a live donation? It seems to me that, at least, the 'donors' know what they are doing. I do not support that policy but one has to admit it works; which is more than the Health Minister now says about her policy "We know a 'soft' opt-out system alone won't increase organ donation rates" (on 4th Dec 2012).

There are several reasons for shortage of organs which may not be to do with shortage of donors:

- The NHSBT published the sad news that in the seventeen months till Sept 2012 eighty five (85) organs had been so badly damaged in the removing that they could not be used for transplants.
- A friend of mine told me of how her grandson had been badly injured in a road accident, his mother gave permission for his organs to be removed, he was put on a ventilator but two days later he was taken off the ventilator without the organs being removed because there was no specialist to do it. This cannot be an isolated incident.

These two points show that, as stated by Prof Matesanz, head of the Spanish transplant service, the most successful in the world, presumed consent is irrelevant to an increase in the numbers of organs; what is needed is more Intensive Care beds and better trained staff both doctors and nurses as well as transplant co-ordinators in every major hospital.

I know that following the recommendations of the U.K. Organ Donation Task Force there has been an almost 50 % increase in the figures for organ donations in Wales. Many Intensive Care staff are deeply unhappy about presumed/deemed consent as is evident in the many responses to the White Paper Consultation .

I am yet to be convinced that any one in the Welsh Government is listening to the views of the Welsh people. I had hoped that the Welsh Assembly might be ready to consider this

fundamental issue of fully informed consent before any medical procedure is carried out on somebody. I am still trying to be hopeful .

Listen to the Intensive Care staff who have written in; listen to Prof Matesanz of Spain; listen to Prof John Fabre, past president of the British Transplant Society; listen to the many ordinary people of Wales who took the trouble to write in and had their opinions ignored: as No 943 said, “ **Bodies do not belong to the State. Our organs should be given as a *gift* not a duty.**”

Janet Secluna Thomas
Dinas Powys
Vale of Glamorgan