

Human Transplantation (Wales) Bill – Public Consultation Comments to the HSC Committee.

Dear Members of the HSC Committee,

Friday 18th January 2013

Here are a few comments for your consideration.

1. The Exchange of Organs to and from Elsewhere in the UK.

1.1 The Research Committee have stated that some Welsh Organs go to the rest of the UK. Since the whole service is a combined one, I presume that vice versa happens as well. The rest of the UK has about 19 times the population of Wales. England alone is about 17 times more populous than Wales. This means that just a 1% rise in the donation rate in the rest of the UK will provide as many organs as a 19% rise in Wales' rate. Even such a small 1% rise then, in the rest of the UK, should by the mutual sharing already in place provide all the organs that Wales needs. Depending on the proportion shared across boundaries the 1% might need to be 2 or 3 %, but it will be far less than the 15 to 20% WAG hopes to achieve. Therefore, please will you work this factor into your calculations and conclusions. Perhaps you could publish or let me see the results.

1.2 The Welsh Assembly Government (WAG) has repeatedly told the people of Wales that Wales' donation rate easily leads the UK. It has been stated that Wales' rate is second only to Spain, though this position might need updating. The UK's rate is only half Spain's. NB It is important to consider Wales' position in the comparison table of countries commonly published, not the UK's position which appears in it since that is dominated by England's rate. In a recent statement WAG takes pride that there has been a 49% rise in donation rate since 2008. The data for this has been published in the "Organ Donation and Transplantation Activity Data for 2008/9 to 2011/12 and two quarters of 2012/13". In that document the rise in the rest of the UK was about 12%. The UK is clearly a long way behind Wales. However, UK's rate is on the steep part of the curve which relates improvement to effort, whereas Wales' is near the top. Therefore it should be much easier for England to achieve a 1% rise than Wales, and hugely easier than for Wales to achieve 15%.

2. The Continuing Fall in Number of Patients Waiting for a Transplant.

Wales has performed so well over the last four years and previously over 15 years that the number of people on the transplant waiting list has fallen dramatically. This point has rarely been mentioned. However it is very clear from the Activity Data referred to above. The number on the list **fell** from 372 in 2008 to 237 in Sept 2012. If this rate of reduction continues the waiting list should be down to about 150 by the time the Bill comes into operation. It also shows clearly that the processes in force at the moment are already able to achieve the hoped for final situation of a zero waiting list. By extrapolation this zero would be achieved within about THREE years after the practical start of the Bill.

3. Potential Barriers to Implementation.

3.1 **In the written public responses**, 5% did not think the WAG would carry out an effective instruction of the Welsh population. Only 1% were convinced. When related to the 224-289 individual responses rather than the identical responses, these percentages become about 55% unconvinced versus 15% convinced, i.e. of those who thought about it for themselves. The recent documents also reveal that only a meagre 68 people attended the 7 public meetings arranged by WAG last year. Taken together, these two data items indicate the implementation will not be done well.

3.2 **Street Surveys.** These are inferior to the written responses, since they are too uncontrolled, e.g. they depend on the type of question asked, the way it is put, the bias involved, the emphasis of the researcher, the provision or rather omission of much relevant and precise data.

3.3 **WAG's Recent Research Review to Update the Univ York Review of 2008.** This update, together with the original review, uses data averaged over 20 or more countries. Some of the papers purport to extract the change in donation rate due to the change from true donation to deemed/presumed/(whatever adjective is used) donation, which is the main factor in the WAG Bill. NB first that the number of papers published can have a very misleading effect on a reader because the papers deal with nearly the same set of countries and same basic numbers. These are not independent reports, but more like the different emphases of the same event in different newspapers. NB second that averages are compared. This makes no allowance for the fact that Wales, like Spain, is not near the average, but instead is well above it. E.g. it is much harder for a world record to be improved. than the average of some club. Thus the results of these surveys should not be applied to Wales.

4. **Financial Estimates.**

4.1 **The QALY** figures used make the point that each transplant ultimately saves the country and the patient about £3 million. This is increased to £10 million per patient if 15 are done. Does this rise from 3 to 10 £million indicate there might be a problem with the method, or the scaling up, or the way the service is provided?

4.2 **Litigation.** It is clear from the responses to the public consultations that many people will be unclear of their position, of the meaning of the terms, of their loved ones wishes, of the family role. In these responses, it seems that the identical and standard responses were put to one side, or else the negative written response to the Bill would have been overwhelming at 90%. However if the 8-10% (224 – 289 respondents) who took the trouble to think things through individually are considered, it is clear that those who answered negatively still outweighed the positives, by about 2:1. Thus it is likely that mistakes will be made and possibly challenges made in the courts. Note, that this consideration swayed the mayor of New York to reverse his intention to introduce presumed (whatever similar adjective is used) consent. Has this scenario been considered in the financial assessments, and if so, how much will be set aside for it please?

4.3 **Waste.** In the light of the hard data and arguments set out above it seems a waste of public finance at this time of economic restraint to pursue what is a very faulty course. It could be deemed better to invest the money in an English programme and increase their donation rates, just by 1%, and relieve the Welsh people of all their hassle, or else, in the light of the falling waiting list, just employ a waiting policy.

Thank you for this opportunity to comment on this important issue.

Yours sincerely,

Dr C W Smith,

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