

**Response to the Consultation on *Proposals for  
Legislation on Organ and Tissue Donation:  
A Welsh Government White Paper.***

**I wish to register my opposition to the Welsh Government's proposals to introduce an opt-out scheme of posthumous organ and tissue donation.**

While I am not entirely opposed to either the concept or the practice of organ donation, I do have several severe reservations about both its ethics and practice. The White Paper contains scant reflection on either of these fundamental bioethical issues. This is regrettable because these Welsh Government proposals represent a radical shift in current UK medical policy. Instead the Consultation's principal concern is merely organ donation numbers and how to increase them. This is too simplistic an approach to the complexities of the organ donation and transplantation enterprise.

This one-dimensional approach is reflected in the Consultation Questions (p. 18). They are far too narrow and imply that a soft opt-out system is already a *fait accompli*. My response is broader and is submitted under the Consultation's invitation '... to provide additional comments and evidence on the proposal as a whole' and to record '...any related issues which have not been specifically addressed ...' My chief concerns are outlined in the following ten statements.

**1]** The Consultation makes no attempt to address the definition of the human body, or, perhaps more appositely, that of the human cadaver. Indeed, it may be argued that such considerations are beyond the Consultation's remit. However, such definition is crucial. What is the nature and status of the entity from which organs are to be removed? Is it, on the one hand 'the temple of the Holy Spirit', or is it simply a source of spare human parts? The very practice of organ donation tends to view the human body as the latter, namely, in a pragmatic and mechanistic manner, but such a view still raises the thorny questions of what kind of treatment is appropriate and what sort of respect is due to cadavers.

**2]** There is an emerging global debate, but particularly among medical authorities in North America, about the definition of death. For organ transplantation to be successful, organs must be taken 'in the pink'. Many would concede that the definition of death has changed from the traditional cessation of heart-lung function to that of brainstem death, solely to benefit the practice of organ donation.

**3]** There is also a growing concern about the diagnosis of death. While this raises little anxiety in general medical practice, it becomes crucial in organ donation. The doctrine of organ retrieval has always been based on the 'dead donor rule'. This principle has been complicated by intensive care unit

procedures that allow organ retrieval from heart-beating donors (brain function may have ceased, but cardiac activity is continuing) as opposed to non-heart beating donors (cardiac activity has ceased, but neurological function has not, so the criterion of brain death has not been met). In response to the latter dilemma, protocols have been developed to test repeatedly for pulselessness and apnoea, say every five minutes, until death can be safely pronounced. There are now calls, especially from the USA, to reduce this time period. These developments prompt a series of fundamental questions: is the 'dead donor rule' in jeopardy, are organ donors really dead, is organ retrieval the real cause of death? Organ removal before death is an unspeakable procedure.

**4]** None of the above is to object to proper, ethical progress in the medical sciences. But it must be recognised that such profound changes to traditional medical practice can only cause unease among the general public. People will, with good reason, question whether transplant teams are being encouraged to act too quickly to retrieve viable organs.

**5]** The concept of donation, in whatever sphere of human activity, has always been linked to the principles of a freely-given gift, generosity, altruism and so on. These notions have been largely reflected in the opt-in system of organ donation. Moreover, the key legal principle underlying all donations is that of consent. And consent in human medicine must be both fully informed and autonomous.

**6]** The proposed scheme of opt-out donation is entirely different. It abrogates these principles because there is no such free donation and no such proper consent. The former has always entailed 'giving', rather than the proposed 'taking'. The latter has always been signified by explicit agreement, rather than by silent default.

**7]** Furthermore, the proposed opt-out donation scheme would make Welsh human organs the virtual property of the State. Such a pronouncement by the State, with this aspect of implicit ownership, risks undermining the whole aim of increasing donations. People value their autonomy, freedoms and rights, and they will challenge the State if it removes, or even appears to remove, them. There is therefore the distinct possibility that the proposed scheme will lead to a counterproductive loss of respect for medical services, as well as a decline in the traditional doctor-patient relationship of trust.

**8]** Perhaps above all, proof that any opt-out scheme, whether of the hard or soft variety, would result in more donations, is lacking. Evidence, especially from the much-admired example of Spain, shows that other, less drastic, mechanisms, such as increasing the numbers of donation coordinators, early identification of potential donors, family discussions, more widespread publicity and so forth, have been the true drivers of success. Moreover, this argument is echoed in the recently-increased donation rate in Wales – publicity is a powerful motivator. The stringency of a legally-enforceable opt-out scheme is far too radical and quite unnecessary.

**9]** The costs of implementing, and continuing, a Welsh opt-out scheme have yet to be quantified (Section 87). If the Organ Donation Taskforce estimated in 2008 that the set-up costs for a UK-wide scheme would amount to some £55m, then the Consultation's guesstimate of £3m must be a huge underestimate. Of course, inflation and on-going costs would substantially increase this base figure. This, at a time when governments and the NHS are facing financial meltdown, does not appear to be a wise use of scarce resources. Again, there is no evidence that any cost benefits would flow from an opt-out scheme. However, other proven, medical services would certainly suffer financially if the proposed scheme were to be implemented.

**10]** And there would be additional logistical problems, some of which are highlighted in Section 47. These alone would create a bureaucratic tangle of unprecedented proportions. Furthermore, if an opt-out scheme were to be introduced in Wales, what would be the exact procedure to register opposition? How would people's change of mind be logged? Would hospitals be sufficiently aware of those who had opted-out? Would this be effective across the Principality? It is one thing to raise such questions, it is quite another to ensure that such registrations would be 'robust and secure'. The loss and misappropriation of computer data by government agencies has not had a happy recent history.

**In conclusion, if the Welsh Government is determined to increase the number of organs available for transplantation, then this could be achieved by simply enhancing current measures, such as public awareness campaigns, transplant coordinators, better end-of-life care and so on. There is no need to introduce an opt-out scheme. It is ethically unsound, dubiously beneficial, logistically uncertain and extremely costly. The proposed legislation is too blunt an instrument to achieve the Welsh Government's aim. Wales and its people deserve better.**