Y Pwyllgor Iechyd a Gofal Cymdeithasol

Bil Trawsblannu Dynol (Cymru)

Ymatebion i'r Ymgynghoriad
Rhan 2
Chwefror 2013

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Health and Social Care Committee

Human Transplantation (Wales) Bill

Consultation Responses
Part 2
February 2013

Bil Trawsblannu Dynol (Cymru)

Human Transplantation (Wales) Bill

Ymatebion i'r Ymgynghoriad

Consultation Responses

* Ar gael yn y Gymraeg/Available in Welsh

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HT(Ind)110	Diane Jones

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)1 – Theresa Ann Orford

Dear Sir/Madam

I read an article in a newspaper,that invited the public to contribute to a new consultation, on the above.

I am a retired qualified nurse, with many years of experience. I can understand an attempt to secure more organs for transplant, but presumed consent is absolutely not the way forward.

One only has to look at Wikipedia to discover ,the thoughts related to ownership of ones body.

"The philosophers William Rees-Mogg and James Dale Davison described those possessed of a mind conclusive to self ownership, as sovereign individuals, which have supreme authority and soveriegnity over their own decisions."

When looking at a persons human rights. Article 8 places limits on the extent to which a public authority can do things which invade a persons privacy in relation to their body without permission. This means it is unlawful for a public authority to act in a way that is incompatible with a convention right. The purpose of the Human Rights Act is to treat people with dignity, fairness, equality and respect.

I feel the lack of respect for peoples wishes by presuming consent before it is given, will alienate the public and have the reverse desired result, with fewer organs available.

Yours sincerely

Theresa Ann Orford
N.N.E.B. R.G.N.
R.M . Cert.Couns. Dip.Couns. M.A.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)2 – Emma Rees

To whom it may concern

I attended a discussion on the bill of human transplantation on the 11th of December with my college classmates. I am writing to share my opinion on the bill.

I do not think the bill on human transplants should be put into place . Although after discussing it with my classmates in the Senedd I think that there are positive aspects if the bill was to be put in place such as how it may decrease the waiting list for transplants which may save or increase the quality of many lives.

However I feel that the current system is much fairer as it is easy to opt in if you wish to be on the organ transplant list. I also think that the bill is a stepping stone towards taking away the choice of whether to donate or not. Also I do not agree that someone without the mental capacity to fully understand has their decision made by someone else as I feel this violates their human rights.

Yours faithfully

Emma Rees

For the attention of:

Mark Drakeford
Health and Social Committee
National Assembly
Cardiff Bay
CF99 1NA

Dear Mr Drakeford,

I see that the Welsh government has announced plans to introduce presumed consent, or deemed consent, for organ donation. The proposal appears to be that people living in Wales for a period of six months or more will be opted-in automatically as organ donors.

These proposals reminded me of an article on this subject that I saved about four years ago. I have attached it in the hope that it might be helpful in your deliberations be because I am sure that most people have no idea of what is involved in this process. So many things such as this are being pushed by politicians on to the general public who have no idea about the ramifications of what they are being asked to agree to. People are just thinking on a shallow, emotional level without any idea of the long-term consequences.

What I find quite scandalous is that politicians who are pushing this legislation of deemed consent are, in fact, telling the population that their bodies will belong to the state, and it is the state and the medical profession which will have primary control over a person's body when they die. Those who are pushing this legislation are telling people that they will commandeer their bodies when they die and pluck out what they want before returning the unwanted bits to the family for disposal. Without mincing words, this is the reality of what is being proposed. The individual and the family become of secondary importance (of no importance?) if the state wants a person's body. This is arrogance beyond belief and yet another example of the Godless state being imposed upon us. Where are all the Christians in the famous Welsh chapels to rise up against this? It is symptomatic of the eastern European communist states where the individual was unimportant and the state was all powerful. It is repugnant to the dignity of the body when someone approaches death, because it is when a person approaches death that the organs will be harvested, not when they are actually dead. Death occurs when the blood stops flowing in the veins. Any first year medical student will tell you this. But this is not acceptable for the removal of organs which must still have blood flowing through them; hence the person, quite clearly, is not 'dead'. 'Brain death' is not death, but a medically invented term to ensure that doctors get their hands on organs that are still living and viable.

If the government wishes to introduce presumed consent what is the situation regarding children under the age of 16? Will the state 'presume the consent' of youngsters who are under the legal age of consent? And what about people with mental illnesses who are unable to give presumed consent? Does the state intend to dismiss out of hand and ride roughshod the wishes of parents and legal guardians who oppose this legislation? This smacks of totalitarianism and is a scenario too horrific to contemplate. History shows that the Welsh people (and the Scots and Irish) quite rightly resented the centuries-old domination of the English where they had no control over their own destiny. Is it not ironic, now that the Welsh finally have their own assembly, that their own politicians want to treat their own people with even greater contempt and remove that most basic of freedoms – the right of control over one's own body? Save us from politicians who become exhilarated with power and forget that they are the elected servants of the people; not their masters.

If there are not enough voluntary donors to satisfy the desires of the medical profession then so be it; this is called the will of the people. If the medical profession cannot convince the population to fill in their consent forms then so be it; they must accept that the people are not convinced. But what I find most distasteful about this business is when people at a time of great emotional distress are pleading for a transplant to save their loved one. The reality is that they want someone else's loved one to die so that the doctors can pluck organs from the deceased (or not quite completely deceased) so that their loved one can live. Where is the charity in this?

Please do not continue with this bill.

Leo Darroch.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)3a – Lee Darroch - Annexe

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Debate Over Brain Death Continues

Book Release Highlights Lingering Questions

By Carrie Gress

ROME, MARCH 2, 2008 (Zenit.org).- While brain death has been accepted as death legally, from an ethical and ecclesial perspective, the debate is still open, says Professor Roberto de Mattei.

De Mattei affirmed this Wednesday during the release of the Italian edition of "Finis Vitae: Is Brain Death Still Life," a book he edited that compiles essays considering the issue of brain death from legal, medical, philosophical and sociological perspectives.

The book was published by the Council for Research, not an ecclesiastical body, but an Italian public organization focusing on the area of scientific research. They released the English edition in 2006.
While Bishop Fabian Bruskewitz of Lincoln, Nebraska, is a contributor, along with three members of the Pontifical Academy for Life, the Church has not yet made an official determination about brain death. There are others in the Church who argue that brain death is a licit criterion for death.

In addition to de Mattei, those attending the book release included Mercedes Wilson, of Family of the Americas; Dr. Paul Byrne, of St. Vincent's Medical Center, Ohio; Josef Seifert, of the International Academy of Philosophy of Lichtenstein; and Dr. Cicero Galli Coimbra, of the University of São Paulo, Brazil.

Really dead?

Byrne, a neonatologist who was invited by the Pontifical Academy of Sciences in February 2005 to speak on this issue, said: "Brain death is not true death. Brain death is a fiction concocted to get organs. After true death very few, if any, organs are suitable for transplantation."
"True death," Byrne explained, "is the body without life, when disintegration sets in. It is more than just non-functioning, which brain death revolves around."

"With true death," the American doctor continued, "there is no pulse, no movement. With brain death someone can be declared dead although the heart is beating, the skin is pink, the body is warm, they are growing, and wounds are healing. A pregnant woman declared brain dead can still deliver a healthy baby and her body will produce milk.

"Many think that brain death means flat brain waves, when in fact some criteria do not include even the recording of brain waves in their evaluation, much less the demand for no electrical activity.

"Every set of criteria for brain death includes an apnea test -- apnea means the absence of breathing. This test, which has no benefit for the comatose patient, and in fact aggravates the patient's already compromised condition, is done without the knowledge or informed consent of family members."

"The sole purpose of the apnea test is to determine the patient's ability/inability to breathe on his own in order to declare the individual brain dead. Without the apnea test," Byrne summarized, "the diagnosis of brain death is impossible, and without the diagnosis of brain death, transplantation of unimpaired vital organs is not permissible."

He added, "A living person can give blood and bone marrow to another person. A living person might give one of their two kidneys, a part of their liver, or one lobe of a lung to another person. The word 'might' is purposely used to alert potential donors that as long as such donation does not cause death or disabling mutilation to the donor, it is acceptable."

Source

De Mattei discussed the provenance of the notion of brain death. In 1967, after the first heart transplant was successfully performed in South Africa, questions were raised about how to ethically acquire organs for transplant given the short window of time in which they must be transplanted.

"The problem arose that if a person near death, but not yet dead, was killed for their organs, it would be killing an innocent person," explained de Mattei. "So there were two options: change the moral law making it licit to kill the innocent, or change the criteria for ascertaining death."

"The second option was chosen with a utilitarian justification: that many lives would be saved," de Mattei added. "So brain death is a social construction developed to meet the needs of transplanters during the procedure's development stages."

Byrne explained that: "The first article on brain death was in the Journal of the American Medical Association in 1968. The title was 'A Definition of Irreversible Coma.'

"There were no basic science studies and no patient data in the article. It was put together by a committee at Harvard Medical School in Boston, Massachusetts.

"The largest study in the literature is the collaborative study. They reported on 503 patients; of these 44 did not die. Of those who did die, 10% had no pathology in the brain."

Bishop Bruskewitz mentions in "Finis Vitae," and Byrne said on Wednesday, there is no established or universal criteria to determine brain death. What used to be a two-day observational stage to establish if a patient has signs of brain death, in some places, has now been reduced to 30 to 60 seconds.

Mercedes Wilson, the last speaker at the event, said: "If our reference point is Catholic social doctrine, which has always affirmed the sacredness of life from conception to the total separation of the soul from the body, then death happens only in this instance. It is not necessary to be a doctor to understand this."
Until the Church makes an official statement about brain death, Byrne and others say they will continue to work to inform the public about the source and science behind brain death.

[Luca Marcolivio contributed to this report.]

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)4 – Kevin Harrington

Hi,

I would like to submit my views on the above Bill.

My views are straightforward.

We know that many people die each year because of a shortage of organ donators.

We all know that this doesn't neeed to happen, there is an infinite supply of organs available from the deceased.

All of us know that when we become deceased, we no longer have any use for our organs however there is a great shortage of donators.

There is something in us which makes us hold back from joining the organ donation register, but I believe that we need a little push to change this aspect of our culture.

I joined the register last year after watching the advert where a person goes from being healthy but not having time to join the register, to suffering organ failure and desperately needing one.

I don't relish the thought of having my organs cut out of my body, however this advert made an impression on me. I realised that I was a hypocrite because if I suffered organ failure I would expect the NHS to close its arms around me and go find an organ before I die.

However I was a little squemish about the thought of having my own organs removed. I still am, but that advert tilted me in the right direction, it made me think a little harder about this issue.

So I support the introduction of this Bill.

Regards,

Kevin Harrington
Penarth

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)5 – Ella Cartwright

Hello

I couldn’t agree more with the opt-out system and find it incredible that any right thinking adult would disagree.
It’s terrible that people are dying for the want of organs that are being burnt or buried.

Even the religious viewpoint doesn’t stand up as the spirit is supposed to leave the body.

I don’t agree with the current system where the relatives can veto the wishes of the deceased.
If a name is on the register then those wishes should be respected.

There could be more information about living donations to strangers, which organs and how to go about it.

Regards, Ella Cartwright.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)6 – John Gunn

Dear sirs,

I am in favour of opting out instead of the current opting in. If there is no record of saying no, take what you want/need to save a life, at once. They are dead and have no further use for it. I do not understand the who-har about samples kept, if it helps medicine do it, as a believer I know where I am going when the Lord calls and I don't want Him asking me why I didn't help when I had the chance.

I have carried an organ donor card as long as they have been around.

I am also a blood donor and apparently the record holder in this region.

May God speak well of you,
and wishing you all the blessings of Christmas and Blessed New Year.
John Gunn.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)7 – D. B. Webb

31 12 2012

Re: Consultation on the Human Transplantation (Wales) Bill

Dear Mr Drakeford,

Above all I want to emphasise the vital need to maximise organ donation. The concerns expressed below are entirely directed at the proposed bill which is unlikely to increase donation rates, a point now tacitly admitted by the minister concerned , and may well make matters worse. My intention is to avoid damage to the donation process which has seen a great advance in the last few years..

Although I am both the Chairman of the Abertawe Bro Morganwg Organ Donation Committee and Vice Chair of the Clinical Ethics Committee I am responding to the request for consultation in a personal capacity. I am doing this in part because of previous arithmetical arguments as to the level of support for the bill being based on the number of returns for and against. It was clear that if an organisation provided proforma letters to its members to sign individually those letters would be counted as individual submissions whereas the considered opinion of a large group with special expertise which provided one submission via its chairman would be counted as one submission.

1. a. The “elephant in the room” which continues to be ignored is that both presumed and deemed consent are oxymorons. Consent can only be legally and ethically meaningful if it is contemporaneously informed. However much publicity is given informed consent can never be assumed for an individual. This bill is in fact proposing non consensual donation. The name of the process is therefore mendacious and manipulative. It sets out to mislead the public from the outset and therefore cannot have public confidence except by way of ignorance.

   b. The notion that government can proceed by deemed or presumed consent is very dangerous ; for instance why not presume if a voter does not attend a ballot then it be assumed that they accept the status quo?

2. Contrary to that stated by Welsh Government there is not robust data to support the concept of presumed consent as a route to increased donation. Indeed in their own publications they refer to robust data in the same paper as that giving different levels of expected benefit. This is an intrinsic contradiction inconsistent with “robust” data. There is an increasing appreciation that data the from the Spanish presumed consent process has been widely misquoted . The increase in donation rates in Spain occurred about ten years after the bill was introduced and followed extensive investment in the donation process. The demographics of the health service, ITU bed numbers and head injuries are very different in Spain and in fact vary across Europe. In this context it is essential to note that the UK has an appalling record in the number of ITU beds per head and as increased donor numbers will put extra pressure on those beds other patient categories will suffer. No allowance has been made for this need. It is all to easy to assume

post hoc propter hoc, and if this bill had been introduced in 2007 then the efforts of the organ donation taskforce in raising the donation rate by 48% in four years would have been ignored and the increase ascribed to the bill not to other more pertinent measures including increased publicity. This increase has taken up a lot of "slack in the system" and any further increase will be correspondingly more difficult to achieve.

3. NHSBT has identified areas within Wales where there is a significant failure to identify donors. If the money set aside for the Principality wide mechanism now proposed was concentrated in those areas the expected outcome would be reached sooner and more effectively.

4. There is an increasing swell of concerned public opinion about the bill's proposals with many anecdotes (some of which fall within my direct personal experience) that potential donors are withdrawing from the organ donation register. NHSBT organ donation register data on this are difficult to interpret as the reporting process altered about the time of the bill's announcement but they can be interpreted as supporting this anxiety . There is understandable concern that what was previously considered as a gift similar to blood transfusion has now, at the state's behest, become a right of the state to take not a choice of the donor to give. A major part of the increase in donation rates is due to the inception of donation after cardiac death. This process only applies in 4 countries of the EU and is illegal in many . It has been difficult enough to ensure that clinical staff understand and support the concept . When the general public become more aware of it , especially in the context of assumed consent , disquiet will be become still stronger. Although some organisations notably the BMA have been seen to support the bill nationally there is clear evidence that within Wales that support is not shared and an informal poll of 18 renal specialists in Wales revealed only one in favour. It is unfortunate that it was at the national BMA meeting held in Cardiff when the supporting vote was proposed by a Welsh doctor and then announced. This gave a spurious validity to positive feeling amongst Welsh doctors.

5. The Human Transplantation (Wales) Bill includes the following provision at its sub-clause 5(3) in respect of an 'excepted adult', i.e. a deceased person to whose mortal remains the law, if enacted, will not apply:

'(b) an adult who has died and who for a significant period before dying lacked capacity to understand the notion that consent to transplantation activities can be deemed to be given; and for this purpose a significant period means a sufficiently long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed to be given'

A rational adult being, by virtue of their rationality, unable to understand the notion of an oxymoron such as "deemed consent" (except as an intellectually invalid abstraction) the bodies of the majority of potential 'donors' would automatically be made unavailable for transplantation purposes by the wording quoted. My own body would certainly be unavailable under such wording.

6 The estimated costs of the scheme have varied depending on what is included, but do not include the costs of inevitable challenges all the way to the Supreme Court. The sequential subjectivity of the definition of ‘excepted adult’ that is quoted above is itself remarkable, quite unusually vague, and open to challenge accordingly in almost all conceivable circumstances. We fear that, as a consequence only the lawyers will benefit.

In summary the bill is defective in many ways, it is the consequence of political initiative in the face of professional and public disquiet. There is little evidence that it will increase donation rates and the strong negative publicity it has already attracted gives cause to expect the opposite. There are also better and cheaper ways to go forward.

D.B. Webb
Cowbridge

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)8 – Jeana Hall

Dear Sir

I am strictly against organ transplantation without having the agreement of the donator upon their death. If you do decide to continue with this Human Transplantation (Wales) Bill, then I and all my family will opt-out.

Yours sincerely Jeana Hall

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)9 – John L Birkin

Your proposals raise serious ethical problems. Presumed consent is NO consent. Organ donation should be voluntary, not an obligation.

John L Birkin
Caerphilly

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)10 – C. M. Wood

Dear Sir/Madam,

I refer to the proposals to change the way in which organ donation is organised and want to state that these proposals raise serious ethical problems for me since presumed consent in effect equals no consent and organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation.

Therefore if the proposals are passed I will immediately cease carrying a voluntary donor card and rescind any actual or assumed consent for my organs to be donated or used in any way. Further in concert with an already existing group I will raise the issue within the European Court of Human Rights and will seek blocking activities in conjunction with the ICO to ensure that those opting out will then receive a written confirmation from the people/organisation responsible for managing such a scheme and that such persons must be able to contact without the need of a computer or any cost to the individual (freepost) with the clear intent of costing more revenue than could otherwise be supported within given budgets of yet another intrusive entity governing every instance of my life developed by the loony left New Labour or amatuer house in Cardiff.

Additionally being a practising Christian I am aware that the proposals will exclude sections of society based upon ethnicity and religious grounds thus I would argue that the scheme itself is racist explicitly by it's designed intent and governance because it would include myself because I am white and my Christianity would not even be taken to account.

Lastly my current participation is currently based upon my explicit consent in that my body belongs to me not the State of Wales and I do not and will not trust the likes of Jane Hutt my area AM to be socially or intellectually capable in making any decision without my consent in addition to my total mistrust of the medical profession not to steal or utilise body parts without the proper consents being given!

KEEP YOU HANDS OFF MY BODY PARTS!!!!!

Yours,

Mr C M Wood,
Barry

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)11 – Ron Enticott

Dear Sirs

I learn with great concern the proposal to make a presumption of consent to donate organs when one dies. I am a live kidney donor who chose to donate and to be on the register. I do however respect the view of many of my friends that they nor their close relations would want body parts taken without specific consent.

It seems to me that it would be incredibly difficult to maintain a register of those who have expressly said they do not want to donate with the real risk that the official person accessing the register to check, misses the name of the deceased person due to similarities in names or for other reasons. How could one access it to ensure that one's name was on there. There are many people who move around or have no fixed abode and they may not have been aware or able to refuse. It is sacrilegious that a doctor or surgeon can remove parts of anyone's body without their consent whilst they were alive.

Ron Enticott
Surrey

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)12 – Michael J Holt

To whomsoever is concerned!

I just want to register my complete oposition to organ donation by presumed consent.

All those, like myself, who have not been asked for their permission or agreement, need to live our lives in the confidence that the body we have belongs to us and will not be subject to state theft the moment we cease to breathe.

Based on confidences shared with me by NHS nursing sisters with experience in operating theatres I have absolutely no confidence that a person's end will not be hastened by the need to harvest organs for "use" elsewhere. I could give concrete situations when such things have happened, but, obviously, I have no intention of mentioning them.
Further to this, may I point out that the "presumed consent" argument assumes that human beings always operate in honest and transparent ways - that this is patently not the case is, to my mind, conclusive proof that the thesis is fundamentally flawed.

Very sincerely,

Michael J Holt - [Former teacher.]

To whom it may concern.

I understand that the Welsh Government is consulting the general public as to whether to introduce a new scheme whereby all citizens in Wales will be presumed to have consented to organ donation unless they file a formal refusal prior to their death.

These proposals raise serious ethical problems since presumed consent in effect equals no consent and organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation. I would like to respond to the consultation to say NO to this presumption.
I would not wish my organs to be donated after my death, and would prefer to opt into the scheme if I was persuaded rather than be dragged in if I fail to remember to address the issue before I expire.

John Milton
Mathern, Nr Chepstow

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)14 – Lynda Osborne

Dear Sir or Madam

I object to organs being automatically donated, unless the deceased person has objected before they died. Presumed consent in effect equals no consent.

It is not right to presume people would not mind their organs being donated, if they haven't registered objection before they died. It could also be very distressing for the relatives. I do not think it is the answer to more organs being donated.

Yours faithfully
Lynda Osborne.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)15 – Tony McNicholl

I wish to register my opposition to the proposal to introduce organ donation by ‘presumed consent’.

These proposals raise serious ethical problems since presumed consent in effect equals no consent and organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation.

I can envisage that the pressure to remove organs while they are still ‘fresh’ within the dead body will result in there being no time available to check whether or not the person concerned had opted out of the proposed default scheme. There is also the danger that when someone is dying that death will be hastened so that the organs can be harvested, especially if the person has no relatives at hand.

Please acknowledge receipt of my objection.

Tony McNicholl
Trearddur Bay

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)16 – Rod Sharp

Dear Sir,

I understand it is proposed to introduce a bill presuming consent to organ donation.

Whilst I understand there is a laudable motive of increasing organ donation behind this, I nevertheless think it is a bad move and urge that the bill be dropped.

This is because the proposals raise serious ethical problems since presumed consent in effect equals no consent.
Organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation.
The families of donors (and donors themselves) need to be congratulated for such decisions, rather than being grouped together with and treated as those who choose not to donate.

Yours,

Rod Sharp
Kent

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)17 – Dr Hefin Jones

Dear HSCCommittee

I write, again, in response to the Consultation on Presumed Organ Donation and as someone who has carried an Organ Donation Card since 1979, to register my deep concern regarding this legislation.

Firstly, I do so as a practising Christian and without repeating his words, highlight the thoughtful response of the Archbishop of Wales on this matter. I also note that a large number of my Islamic (Muslim) friends share very similar and strong concerns regarding this proposed legislation.
I also seriously question, the ethical justification for the fundamental correctness of the assumption that consent can be presumed. I would argue that p*resumed consent in effect equals no consent,* unless there is an extensive public information programme, which would need to capture *the entire adult population* including those on the margins of society. Only this would ensure that those who do not opt out of donation have made an explicit choice, rather than doing so by default, by ignorance or by a lack of knowledge or understanding. This, to me, makes the whole concept of 'presumed', or 'deemed', consent ethically problematic, as well as complex, and very costly, to administer. There is, as you will be aware, considerable evidence in peer-reviewed literature that it is not even the most effective way to increase organ donor numbers.

I have read the various documentation associated with this debate and unless I am totally mistaken it appears to me that it has been said all along that 'soft' opt-out legislation will be introduced, allowing the family of the deceased a role in the final decision, **the Bill as it stands does not in fact allow for this**. While provision is made on page 20 of the draft memorandum, there is, again as far as I can determine, no provision in the Bill itself for providing distressed relatives with a right to object to the removal of organs when no consent was given by the deceased.

I again register my deep concerns and inability to support this legislation.

Yours sincerely

Hefin Jones (Dr)

I understand that this Bill will make organ donation compulsory, unless each individual signs a document to say that they do not wish to donate their organs when they die.

There is very likely to be a good proportion of Welsh residents that do not understand, or are not made aware of, the need to sign to say they do not want to donate their organs. Just the implication that you consent to donating organs when you may not in fact agree to that is very wrong, and surely impinges on Human Rights.
It is also wrong on moral grounds, I believe.

Consequently I am against this proposed Bill, even though I do not live in Wales. I would oppose it if it was proposed for English residents.

C Moss

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)19 – Nicholas Betts-Green

Sir,

I wish to register my objection to your plan to take organs for re-use without the donors' specific consent.

To 'assume it has been given' or 'would have been given if asked' is morally wrong. [And probably illegal].

E.g. I am passing your house. I see in the garden a plant lying on the ground, apparently discarded. I pick it up and take it away. I justify this by saying "Well, the owner probably doesn't want it, so he won't mind me taking it and putting it to good use." Legally this is theft.

A person's body automatically becomes part of that person's estate at the moment of death. The body is OWNED by the next of kin. You cannot steal from it at will. One hopes that if the deceased has not given permission for organ removal, then the next of kin might do so, and your problem is solved.

But please, have the decency to seek permission first before you loot for organs.

My best wishes for a successful 2013.

Nicholas Betts-Green

5 Jan 2013

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)20 – Deb Smith

with regard to your proposed idea of making organ donation compulsory in Wales i feel it should still be something people can make their own choice before God about .thanks Miss Smith

I wish to register my opposition to the presumption of consent in organ donation.

Firstly, organs will in effect become the property of the state, until and unless there is an opt-out.

Secondly, family and relatives have no say in the blocking of the taking of an organ, as the proposed legislation now stands.

Thirdly, there can no longer be an act of free voluntary donation when a context of obligation is introduced.

Fourthly, it is not explained how the whole population can be fully informed of the new presumption short of a comprehensive public information programme.

Yours sincerely,

C Elston

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)22 – Christina Aston

Dear Sirs,
I am appalled at this prospect: it is barbaric and makes a nonsense of the respect for the body of a dead person which is a hallmark of a civilised society. This change in the law would make the State party to the desecration of the dead.

Yours faithfully
Christina Aston (Mrs)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)23 – Helen Smith

I do not agree with the plans you have to introduce a new scheme whereby all citizens in Wales will be presumed to have consented to organ donation unless they file a formal refusal prior to their death. Organ donation should stay as it is now - we donate if we want to.

These proposals raise serious ethical problems since presumed consent in effect equals no consent and organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation.

You are totally wrong to try and bring this legislation in

Helen Smith

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)24 – Daphne McBreaty

Dear Sir/Madam,

May I state that the Human Tissue Authority pointed out that "for consent to be valid. it must be given voluntarily by an appropriately informed person who has the capacity to agree."

In your consultations this aspect has been ignored.

Yours faithfully,

Daphne McBreaty (Mrs.)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)25 – Ann Farmer

I wish to comment on the above because of deep concerns about the effects on the human right to bodily integrity of introducing a scheme of presumed consent to organ donation.

The most basic concern is the idea of the state owning the bodies of citizens and taking their organs for transplant.

It is emphasized that people can opt out of such a scheme, however given the chaotic state of hospitals and lack of emphasis on consulting patients even about putting them on the Liverpool Care Pathway, itself a matter of life and death, it does not inspire confidence that individuals' wishes will be respected even when clearly stated in writing.

This being the case, the anticipated effect on unforced donations - that they will decline - we will go further and further down the path of compulsory organ-snatching.

The campaign for an 'opt out' system has continued for many years, but has always raised the same questions, none of which has been adequately answered; there is a clear danger that a managed consultation in Wales will be used to promote the idea in other parts of the UK.

With an ageing population and younger generations compromised by heaving drinking clearly there is a problem in obtaining healthy organs for transplant; however, a better approach would be to discourage heavy drinking and cease the official programme of state-sponsored mass abortion of future citizens.

Yours faithfully,

Ann Farmer (Mrs)
Essex

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)26 – M Thomas

Dear Sir/Madam

I would like to register my vote on the above with a definite 'NO'. as I don't believe this is necessarily a good thing.

M Thomas

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)27 – S. English

I am writing to express my strong opposition to the proposed automatic organ donation being considered in Wales. Assumed consent is equal to no consent in my opinion and this ignores the moral and religious views of the general public. Apart from that experience has apparently shown that this change does not result in more organs becoming available for transplant.

Please let well alone and leave things as they stand whereby people can state that they wish their organs to be used for transplant following their death but do not presume that they wish to automatically.

Sincerely

Mrs S English
Essex

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)28 – Gervase Markham

"The Health and Social Care Committee is undertaking an inquiry into the general principles of the Human Transplantation (Wales) Bill."

I am glad to have an opportunity to respond, on my own behalf, to the general principles of this Bill.

At the heart of this debate is the question: who owns your body? You the individual, or the state?

If the individual own their body, then no form of presumed consent can be acceptable. After an individual dies, their ownership claims to objects and property do not lapse, but are dealt with according to the terms of their will - their express wishes. If they have not made a will, it is only rarely the case that the state assumes ownership of their assets In the common case, the intestacy rules benefit their next of kin, not the state.

If the state owns an individual's body, then that principle would have significant consequences when logically applied to other areas of life.
For example, the state could order an individual to treat their body in a certain way, even if they did not wish to.

I urge you to reject the principle of "presumed consent", and put your efforts into other initiatives to increase the amount of organ donation (a very worthy cause).

With best wishes,

Gervase Markham

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)29 – Mary Rees

TO WHOM IT MAY CONCERN

At the moment I am a registered donor and have been for many years. However if this bill is passed I will be opting out asap. I am totally in favour of organ transplantation but it is my choice to give as a gift. My body is not owned by the government and they have no right to take it upon themselves to assume consent.

Yours faithfully

Mary Rees

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)30 – Joseph Biddulph

I feel I ought to get in contact once again, before the Assembly makes a big mistake. Compulsory donation of organs for transplant does not seem to be an effective answer, and offends many people's dignity and sense of self-worth. Voluntary donation, opting-in, has none of these problems, and would suit .e.g. cornea transplant operations, where they are unable to use material without the express consent of the donor. Pushing ahead with the legislation would seem to be a prime example of the exercise of power for its own sake, and for the sake of making Wales look "progressive" - whereas what would really be progressive (and somewhat out of step with recent political thinking) would be reforms in the interest of ordinary people struggling to make a living and live their lives without undue official interference. And as long as legalised abortion remains on the statute book in Wales (and positively encouraged by health authorities) some of us will find it very hard to believe that our own human rights are of fundamental concern to our elected representatives - at the moment, it looks as if organ seizure seems perfectly okay to pro-abortion-up-to-birth politicians (or at least those who fail to express disgust at the prospect of pre-birth children being legally killed up to the day of birth, as under present law), as one might begin to suspect. However, it isn't okay with the population at large, and I still hope that sufficient AMs will feel at least a little ordinary oldfashioned shame at offering this further insult to the people of Wales. Or are we supposed to be so hardened by decades of anti-human-life practices that we no longer feel any misgivings
on such subjects?

Yr eiddoch yn gywir,
Joseph Biddulph

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)31 – B. M. Rooney

For the attention of the Chairman and the Clerk,
I understand that you are inviting comments on the proposal to bring in legislation for "Presumed Consent" to the removal of human organs for transplantation. I would like to register my profound objection to the proposal. My body belongs to me, not to the Welsh (or any other) Government and it is my responsibility to decide how it should be used. This is a disgraceful proposal and its advocates should be thoroughly ashamed of themselves. Of course organ donation may be desirable, and it is reasonable to encourage a high donation rate, but for any government to attempt what amounts to coercion, if only by default, is to go down the road followed by some of the most viciously authoritarian regimes of recent years.
Quite apart from the ethical aspect, there must be serious doubt whether legislation would improve the donation rate, which in Wales is already high by international standards - indeed it is possible that many existing voluntary donors would withdraw their consent. You must be aware of the furore after the Alder Hey scandal, and of the findings of the subsequent Redfern report. You will also know that responsible expert and professional authorities have advised against presumed consent. And it is highly likely that the arrangement would seriously undermine confidence in the medical profession.
In summary, the introduction of presumed consent legislation would be morally questionable, damaging to professional reputations and probably ineffective, and the proposal should be rejected.
I attach for your information a copy of a letter I sent some months ago to my AM
Yours faithfully, B.M.Rooney

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)32 – Rev D and S. Wilson

Dear Sirs, My husband and I would be very concerned about the proposed change in organ donation. We understand the need for more donors, but there are huge ethical concerns about changing from a choice to donate and mandatory donation, and we are very much against the latter. We foresee great opportunities for unscrupulous people if this goes ahead.
Yours

Rev D and Mrs S Wilson

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)33 – Peter Dutton

Dear Madam/Sir

Although I live in England, I wish (if I may) to record my opposition to these proposals as they stand.

They raise serious ethical problems since presumed consent is often taken to equal no consent. Organ donation should, in fact, be treated as a voluntary gift characterised by free will - not an obligation. Evidence from other countries suggest that readily available abuses of such a system lead to considerable misuse.

This certainly goes against my Christian beliefs.

Yours faithfully

Mr Peter Dutton

Date: January 9th 2013

From: Dr Iain J Robbé
BSc, MSc (PHM), MSc (MEd, distinction), MB, BS, MRCS, LRCP, MFPHM
[redacted]

Re: Consultation on the Human Transplantation (Wales) Bill 2013

Submission to: National Assembly for Wales Health and Social Care Committee
<HSCCommittee@wales.gov.uk>

Pre-amble

The principles underlying the Bill are deeply flawed for two reasons. Firstly the principle of autonomy is being ignored. It is a lie to claim that deemed consent is a valid form of consent. Deemed consent is a fictitious phrase that ignores international conventions around valid consent.

Secondly the principle of involving families/persons in a qualifying relationship in a soft opt-out system is being ignored. It is a lie to claim that the system in the Bill will involve families because families will have no right to veto donation which is a core issue in a soft opt-out system.

Section 2: to promote transplantation

36% of the Welsh population are on the Organ Donation Register (McGlade, 2011) and an extensive study of more than 46,000 UK hospital deaths found that 59% of families will agree to the removal of organs and tissues from potential donors (Barber, 2006).

Furthermore the rate of deceased organ donations per million population is higher in Wales than in the rest of Scotland and Northern Ireland and in some recent years the rate has been higher than England (McGlade, 2011). Crucially, overall in the UK the donation rates are increasing (European Union, 2007, Organ Donation Taskforce, 2011, Organ Donation Taskforce, 2012). International comparisons have identified a range of factors that influence donation rates including introducing systems of opt-in, prompted choice, mandated choice and opt-out (Barber, 2006, European Union, 2007, McGlade, 2011, Wellesley, 2011). Other influences include altering the organisation and infrastructure of the existing transplant system particularly the approaches to relatives, taking decisions about different priorities for investment in health care, and running campaigns to influence underlying public attitudes and awareness (Nuffield Council on Bioethics, 2011, Organ Donation Taskforce, 2008, Rithalia, 2009, Simpkin, 2009).

The weight of evidence supports improving the opt-in system (National Institute for Health and Clinical Excellence, 2011). Instead of moving to an opt-out system the Welsh Assembly Government should have made a policy decision to improve the opt-in system based on sound ethical principles, respecting Human Rights, and showing consistency with the expertise of the UK Organ Donation Taskforce (Organ Donation Taskforce, 2008).

Sections 3 to 8: authorisation of transplantation activities and consent

Deemed consent and presumed consent (Erin, 1999) are equally fictitious phrases and the Welsh Assembly Government has no right to presume it can disregard an individual's autonomy, ignore the law surrounding valid consent, and take an individual's organs and tissues without express consent.

The safeguard that families/people in qualifying relationships could provide information that the deceased did not consent is meaningless when the deemed consent process is spurious. Also, clinical staff under pressure from managers will be able to ignore the families' information and wishes by citing the law created by the Welsh Assembly Government. In the Bill there is no right by a person in a qualifying relationship to veto donation which is a core issue in a soft opt-out system (Nuffield Council on Bioethics, 2011).

Barriers to implementation and unintended consequences of the Act

Barrier to implementation from fear of breaching Human Rights legislation: patients admitted to hospital expect doctors and other health care staff to respect the ethical principles of autonomy and beneficence. Also, the European Convention on Human Rights, Article 8, states that everyone has the right to respect for their private life so taking their organs and tissues without explicit consent would breach that Human Right.

Barrier to implementation from errors in identifying that a person has opted-out: even in an organisation as committed to helping people as the NHS, mistakes can occur, for example, prescribing errors including the wrong drug, wrong dose and wrong patient (Dornan, 2009), and wrong patient and wrong site errors for procedures carried out by physician and surgeons (Stahel, 2010). Telephoning the duty officer at the NHS Blood and Transplant service (Explanatory Memorandum paragraph 185) is highly inadequate for exchanging such important information. It is therefore likely that although a person has opted-out, a mistake would be made and their body would be used for the removal of "any relevant material" (Bill section 3). Consequently there would be legal claims for compensation and criminal prosecutions of clinicians and other health care staff.

Unintended consequence due to adverse publicity arising from removing organs and other materials from a person who had opted-out: it would have a significant detrimental effect on the willingness of any Welsh resident to donate voluntarily before death e.g. blood, platelets, bone marrow, as well as after death with a huge increase in people opting-out as has happened in other countries following this type of error (Wellesley, 2011).

Unintended consequence amongst the public: the use of deemed consent is highly likely to provoke anxiety and fear amongst individuals and their families about admission to hospital and perceptions that their organs will be "taken" (Monaghan, 2012) would lead to feelings of resentment. Overall a reduction in voluntary donations through informed, expressed consent is likely to occur.

Unintended consequence amongst health care professionals: hospital staff under pressure from management will face psychological trauma through taking brain stem deceased patients for organ removal surgery without the support of the patients' families (Dominic Bell, 2012).

Unintended consequence through changes in patient care: it might be the intention that there will be no official changes in the way patients are cared for, the ways in which death is confirmed, or the clinical decision making about transplants.

However there are no guarantees that changes will not occur in the new culture of deemed consent and not respecting the views of the family of a deceased person. Welsh residents would be viewed on admission to hospital as both patients and deemed consenters as providers of organs and tissues, clinical teams would experience pressures to give less consideration to the patient's wishes and the families' wishes and more consideration to the need for organs and tissues. There could be improved access to intensive care facilities enabling more admissions of brain stem dead or cardiovascular dead patients whose organs and tissues could be removed.

Conclusion

If the Bill is enacted then it will represents a costly and dangerous experiment by the Welsh Assembly Government using Welsh residents as the subjects in that experiment.

The policy is deeply flawed in ethical terms and in terms of the weaknesses of the evidence to support it.

There is a high risk that the current progress in donation rates will be halted or reversed due to resentment against unethical government interference, failure to obtain informed consent, ignoring the wishes of families/people in qualifying relationships, and forcing health care professionals to consider people under their care as both patients and potential sources of organs.

Wales might be able to rely on donations of blood, organs, and other relevant materials from genuine donors in England, Scotland and Northern Ireland but there will be delays and supply problems and it will be poor compensation for the damage that will have been caused.

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Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)35 – Sandra Adshead

As a member of pro-life, SPUC., and for their Campaigns, I wish to ask you to STOP, any legislation for PRESUMED CONSENT, of any Organ Doning; for anyone. Where a person has decided and arranged themselves, that is their own choice, and even then, I would suggest that details are checked , and that it is viable.

Yours sincerely,

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)36 – Anonymous

Dear Sirs

I understand that in an effort to improve **organ donation** rates, the Welsh Government plans to introduce a system of presumed, or deemed, consent to Wales. If a person fails to make a decision about donating their organs after death, the state will presume that consent has been given.

The Christian Medical Fellowship has on a number of occasions expressed concern with the principles underpinning this Bill; I am adding my concerns and my family's concerns to theirs.

Responses to the initial public consultation and the subsequent draft Bill reflects **significant opposition** with both the **concept of introducing presumed consent** and the wording and **operation** of the draft Bill itself, from Christians both Catholic and Protestant and also the Muslim community.

Although the Welsh government has said all along that it will introduce 'soft' opt-out legislation, allowing the family of the deceased a role in the final decision, the Bill as it stands does not in fact allow for this.

While provision is made in the draft memorandum (p20), there is no provision in the Bill itself for providing distressed relatives with a right to object to the removal of organs when no consent was given by the deceased. I am voicing my objection to this bill

To whom it may concern

I wish to register my opposition to the introduction of 'presumed consent' in organ donation. Presumed consent is not another form of consent, as it involves no actual consent at all on the part of the potential donor, who cannot be termed a donor either, as the organ/s would be harvested without any prior agreement on their part. It would hand too much power to the state and override the rights of the family. I already have grave misgivings about the use of brain-stem death as the criterion for deciding when organs may be removed, and I can only foresee the ethical questions becoming more confused as a result of a policy which appears to be pushing the harvesting of organs above all other considerations.

Yours faithfully

Janet Turner (Mrs)

London

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)38 – Dominie Stemp

Please halt the presumed consent on organ donation. This would open a minefield and dying and living people could have their organs removed before they die. It paves the way for abuses.

Dominie Stemp

HT(Ind)39 – Judith Summerfield

Dear Sir/Madam,

I'm concerned about the proposals to presume the consent of a deceased person and their relatives to donate their organs on death.

While I understand that there is currently a shortage of donated organs I don't believe it is ethical to presume consent.

I myself carry a donor card and my relatives are aware of my views on this, but I also need to be comfortable that their wishes will also be respected on the event of my death.

I understand that the present legislation does not allow for relatives to object. It should.

So there are two problems for me with this legislation –

a) Consent should not be presumed.
b) Relatives should be able to object.

Yours sincerely

Judith Summerfield

Concerned individual

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)40 – Veronica Heald

Dear Sirs,

I wish to add my name to those who are deeply unhappy that presumed consent for organ donation may be made legal in Wales. My reasons for being against this move are:-

Ignorance of such a law may lead to organs being taken without the knowledge of the deceased and his/her family, thereby causing distress. Not everyone is comfortable with having their freshly departed loved one whisked away before they have had an opportunity to spend a few more precious moments with them.
Organ donation is a laudable wish but should be treated as a gift not as a practiioner's right to receive.
It may deter organ donation if people are unhappy about the methods employed, ie over-eager attempts to gain organs from their bodies. Many more people may decide to opt out rather than leave anything to chance.
It would effectively make a person's body state property.
Many people are concerned that the definition of death may be blurred in a hasty attempt to 'harvest' organs.
Presumed consent could very likely then be extended to other areas of medicine.
I hope that these concerns and those of others will be taken very seriously and this whole programme halted.
Yours faithfully,
Veronica Heald

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)41 – Vincent Lewis

Dear Sir/Madam

I wish to register my objection to the notion that a person's body when dead can be cut up, have parts removed, stored in jars, donated to science or another person without the direct and personal consent of the person involved and their family.

The human body is sacred and not the servant of medicine, it should be assumed that this is the case unless a person gives their express permission otherwise.

Yours faithfully,

Vincent Lewis

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)42 – Christopher G. Ross

I am writing on behalf of St Bernadette's Catholic Parish, Larbert, Stirlingshire (1400 strong) in response to the Welsh Assembly Consultation on this issue.

We oppose the concept, indeed the oxymoron, of "presumed consent". Consent has to be informed and freely given for it to be consent at all. "Presumed consent" is an extremely dangerous concept, and wide open to abuse in this and other areas.

Voluntary organ donation we would not oppose, but it is absolutely vital that the donor is actually truly dead, and not just deemed to be brain dead. Otherwise the removal of the vital organs for donation is murder of the donor.

The correct approach if you wish to increase organ donations is to develop and enforce very strict guidelines on definition of death, which then provides reasuurance to voluntary donors.

If you cannot do this, or are unwilling to, or do not think that rules of this nature would be respected and followed in both spirit and letter, then you may well have a major problem with attitudes in the Health Service and in the Assembly, and maybe society itself.

It is not right for the state to claim this automatic power over people's bodies, after or even before death, and to override the family and next of kin. It is also very wrong for all the agencies of the state to pressurise and overbear on potential donors when they are at their most vulnerable, ie almost at the point of death.

This Bill then goes on to attempt enshrine itself permanently in Welsh Law by imposing a duty on the Welsh Ministers to promote organ transplantation including presumed consent. This would have the effect of making it legally difficult for a future Minister who might be opposed to the Bill, to organise a repeal of it. As I have pointed out, the whole concept is wrong headed, and is likely to have other unintended consequences.

Our Parish of St Bernadette's here in Scotland is taking part in your consultation because as Catholics and people of conscience we are duty bound to speak out in defence of life, from conception to natural death. We take a friendly and supportive interest in all the countries of the UK. Besides, proposals made in the Welsh Assembly tend to be copied by the Scottish and UK Governments and vice versa, and so it will affect us directly.

Much Obliged,

Christopher G Ross

Stirlingshire

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)43– Jacky Mattam

Dear All

I am not in favour of the Presumed Consent for organ donation.

a.The Bill provides for organ harvesting, not organ donation, driven by a desire to acquire more organs to meet the perceived demand

b. Deemed consent is not consent. Consent is the “express willingness or agreement” to a particular procedure. To assume that someone has consented to something without any evidence that the person has so consented is to subordinate the wishes of the weak and the vulnerable to those of the strong.

c. The Bill supposes that some people have a right to the organs of others

d. The Bill assumes that the State has a prior right of access to the bodies of the deceased (who may not always in fact be deceased - see section 6 below). Such an assumption by the State is arrogant, wrong-headed, and indicative of an authoritarian and non-democratic regime.

This move;
Abolishes organ donation as a free gift
Makes the body the property of the state
Does not necessarily lead to more organs available for donation
Presumed consent could be extended into other areas of medicine
Ignores serious concerns about current definitions and practices concerning death i.e. brain death, beating heart donors
Families will have no or a very reduced say in what happens to their loved one

Such a change would make the assumption that everyone is equally informed.

I understand that anesthetising is not always carried out when organs are removed, and that it is possible that the 'donors' are not really 'dead' and are possibly still able to feel pain.

Regard

Jacky Mattam

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)44 – Graham Johnson

Please note that I am very concerned about the Welsh Government's ideas on introducing a new scheme whereby all citizens in Wales will be presumed to have consented to organ donation unless they file a formal refusal prior to their death.
This is quite unacceptable in terms of the rights of the individual.

Graham Johnson
Caerffili

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)45 Anonymous

Rather than complete the consultation, I would simply like to express my complete opposition to automatic organ donation. Presumed consent actually amounts to no consent and I consider this is completely wrong.

Yours,

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)46 – Philip Barnett

To: Welsh Government Health and Social Care Committee

Re: Consultation on the Human Transplantation (Wales) Bill

Sirs,

I am writing as an interested individual in response to the proposed legislation on presumed consent for organ donation.

Firstly let me confirm I wholly support organ donation and am aware of the tremendous good this does for individuals who benefit from transplanted organs. However I am deeply troubled by the proposal In Wales for presumed consent. I am not clear why such a term should be used because in reality "presumed consent" is a misnomer - it is not consent

Secondly I am concerned about the potential problems that could transpire between doctors, patients and their families due to potential conflicts. I appreciate there is a need to increase the number of organs available but presumed consent is not the right way. Perhaps better publicity should be considered to encourage more individuals to sign up to being donors. The important thing to me is that organ donation should remain the freewill choice of individuals and not the state. Patients and their families should be able to trust doctors but there is a danger with the proposed legislation that this trust, which underpins healthcare in the UK, could be broken. The Welsh Government is on dangerous ground here and my fear is that a precedent is set for the rest of the UK to follow. I am aware of the fact that some presumed consent legislation nations have low organ availability rates, so the legislation may not be the "success" it is expected to be and may not deliver the desired outcome. Has sufficient research been done on this?

Thirdly, given that the Welsh Government has now committed itself to this legislation, I would ask that assurance should be included in the drafting such that if the surviving family objected, organs would not be taken. This would demonstrate respect for the views of the surviving family and I understand other countries with similar legislation include such assurance.

I trust you will be able to take these points into account as part of your consultation.

Yours faithfully,

Philip Barnett
Crawley

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)47 – Philip Barnett

To: Welsh Government Health and Social Care Committee

Re: Consultation on the Human Transplantation (Wales) Bill

Sirs,

I am writing as an interested individual in response to the proposed legislation on presumed consent for organ donation.

Firstly let me confirm I wholly support organ donation and am aware of the tremendous good this does for individuals who benefit from transplanted organs. However I am deeply troubled by the proposal In Wales for presumed consent. I am not clear why such a term should be used because in reality "presumed consent" is a misnomer - it is not consent

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I trust you will be able to take these points into account as part of your consultation.

Yours faithfully,

Philip Barnett
Crawley

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)48 – Revd Brendan Gerard

Dear Committee Members,

As an overseas UK voter, I wish to make the following comments on the proposed legislation for an opt-out system of organ donation in Wales, which could set a precedent for developments elsewhere in the UK and abroad.

It is principle, a laudable act to allow the removal of organs, including unpaired vital organs, in the event that one's death has been verified.

However, respect for the human person (and for the human body after death) requires that this be a free decision on the part of the donor. To safeguard that freedom, a system of presumed consent is not adequate. One must be at liberty to opt in, not obliged to opt out.

That freedom is all the more essential since "brain stem death" is (to say the least) a doubtful criterion for verifying death. Even the more stringent criterion of "brain death," adopted in other countries, is disputed.

There are people who, if properly informed, would not be happy about the removal of their vital organs under those conditions. If they should meet with a fatal accident without having opted out of the system (for whatever reason) the removal of their organs would be an abuse.

An opt-out system could also encourage a certain tendency to treat the human body as a commodity falling under the power of the state.

Given the magnitude of this question, I would also respectfully urge you to extend the consultation period before any draft legislation whatsoever on this subject goes any further.

Yours faithfully

Brendan Gerard

Revd Brendan Gerard
Opfenbach

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)49 – Sharon Morgan

Good evening,

I saw the poster inviting comments about the consultation on this draft bill in Carmarthen library, and I would like to express my views on this matter if this is acceptable.

I am in favour of automatic consent and believe that those who do not agree should opt-out in writing if this is what they desire.

27 years ago I gave consent to switch off the ventilator that was keeping our 3 day old daughter alive. Her lungs had not developed during the pregnancy and there was no way that she could survive on her own. We were not asked whether her organs could be used for others, however had we been asked I would have given permission in an instant.

You see, had there been the slightest possibility of Haf's life being saved by a lung transplant I would have begged the doctors to do this. And if you are willing to save a loved one's life by accepting organ donation then surely you must be prepared to save another person's life by donating organs should the opportunity arise. I am just sad that the opportunity to perhaps improve some other child's quality of life was lost but at the time I did not even think about this possibility. In how many cases is the opportunity lost because the next of kin and the medical staff are too upset to broach the subject, even when consent would be given if asked for? Deemed consent would go some way towards avoiding this type of scenario.

Anyway, these are my views.

Sharon Morgan

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[i] and Austria[ii], 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.[iii] Whether the UK should adopt an opt out remains 'finely balanced'[iv] not a clear certainty. [v]
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." [vi] 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 oft 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[vii], the Assembly should note that without exception, every online response[viii] 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[ix] 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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[i] Michielsen, P. (1996). "Presumed consent to organ donation: 10 years experience in Belgium." *Journal of The Royal Society of Medicine* 89: 663 - 666.

[ii] 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 dio:10.1136/bmj.a.3162

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

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

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

[vi] http://crookedtimber.org/2010/05/05/presumed-consent-in-theory-and-practice/

[vii] Shaw D 2012 We should not let families stop organ donation from their dead relatives *BMJ* 345:e5275

[viii] http://www.bmj.com/content/345/bmj.e5275?tab=responses

[ix] 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.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)51 – Dr John Warburton

Organ Donation Procedures

Dear Sirs,

I wish to protest against the idea that the donation of organs after death should be on the basis of presumed (or deemed: I'm unsure as to why you think there is a practical difference) consent. Leaving aside the obvious; that it is then no longer a donation but a seizure, I have carried a donor card for longer than I can remember and have been a blood donor since 1969, so it is clear that I do not object to the giving process. What I most strongly disagree with is the presumption that the Welsh Assembly has the right to decide what to do with my corpse unless I tell it otherwise. This is a qualitative, not a quantitative, change and seems to me to cross a rather sinister threshold. It is an age-old custom that the immediate family has the right to decide on the disposal of the body, in the absence of instructions from the deceased. If they have the strong conviction that they wish their nearest to go to the grave entire, exactly what moral right have you or the Assembly to say otherwise? We have recently had scandals; eg Alderhey, because the medical profession assumed that it had the right to take bits of dead bodies without consent even though it was expressly against the law. So, if it has a history of ignoring the law, what credence can be placed on the pious words of politicians that "the nearest will be consulted" when they are too timid even to include it in the Bill?

Secondly, I am unconvinced by the legality of the proceedings: the Welsh Assembly is not the final arbiter of Human Rights. Do you seriously think that, if a family pushed the matter to the European Court of Human Rights, that your stance would prevail? I suspect that you do not expect anyone to take such action, rather than that the legal groundwork is sound.

We are told that presumed consent is used in Spain and that the donor rates are higher. This is only partly true: my information is that, in the event of what might be termed a re-usable death, the relatives are always asked for permission and that no removal has taken place without either their permission or the prior written consent of the deceased. Given that their operating practice is fundamentally the same as ours, the differences are presumably related to culture, the differing profiles of the state of the recently deceased or the better co-ordination of the various parts of the Spanish health system. Having spent time in Spain and having witnessed the system in action when my wife suffered a heart attack, all three reasons seem entirely possible.

Clearly it is for the best that those in need of organs can have access to them. A better rate of donor card carrying would be preferable and I would suggest that GPs could be more active in this respect. What is not acceptable is the attitude that you should form legislation based on the notion that you are a better judge of what people should do, when what they might wish to do is neither illegal nor harming others.

Yours Sincerely
Dr John Warburton
Penarth

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)52 – Anonymous

Dear Sirs

Thank you for the opportunity to respond to the above consultation.

Although the proposed legislation appears, on the surface, to be an ingenious and attractive solution to the problem of inadequate donor supply - unfortunately, I believe it to be a seriously misguided and unnecessarily draconian response to that issue and indeed, that it raises more fundamental and far-reaching concerns than those that it may seek to address.

The principle of *informed* patient consent is fundamental to the position of trust between clinician and patient (and indeed, with regard to the status of the person, between the patient and the State). The principle of deemed consent, in the form that underpins the draft legislation, is anything but that. It is not consent at all, even if it may be couched in those terms by way of legal fiction or in media-friendly terms such as a 'soft opt-in'.

It seems to me that the potential effect of deemed consent in the legislation is that, inter alia, the State in effect owns a person's body after death, regardless of that person's individual wishes or convictions (religious or otherwise), with the very real risk that a citizen may simply be regarded as a 'resource' - and that the dignity of that person, and indeed all citizens, is eroded. This seriously undermines what many would regard to be a fundamental human right - that donation should, as now, be a gift freely given. A State should not assume the rights or freedom of conscience of its citizens if it is to call itself democratic nor should it dictate, as it seems to in this draft legislation, that ministers be propagandists for transplantation in this form (and therefore the questionable ideology behind it) irrespective of their personal views or those of the citizens that they are democratically charged to represent. The imposition of a 'duty' upon ministers to promote transplantation in this way is a dangerous legal precedent in general terms and, more specifically, could also suppress objective and necessary review of these policies in future - for fear of breach of duty. In particular, it may suppress any sensible debate about any other alternatives to, or means of, increasing the donor pool in an ethical, democratic and clinically beneficial way.

The draft legislation also raises the issue of consent more generally. I query whether those who are generous enough to consent to organ/tissue donation, even now, are aware of what precisely they are consenting to upon their death. Many will not know that the bar for determining death for the purposes of organ and tissue donation is, I understand, set much lower than perhaps they would understand. Many, perhaps most, are not aware of the significant concerns that exist within the medical community whether, say, brain-stem death is actual death, and that potentially a donor could have organs removed in circumstances when their heart is still beating and when they could give birth or feel pain/be deemed to require anaesthesia, i.e. when most of us might consider ourselves still to be alive. This raises serious ethical issues, which I do not believe are addressed.

I would urge, therefore, that the proposed legislation be rejected for the reasons stated, and that time be devoted towards other solutions to clinical need based on real informed patient consent - not least as I am particularly concerned that such legislation might be regarded as some form of 'pilot' for the wider UK.

Please acknowledge safe receipt.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)53 – Keith Rigg

Consultation on the Human Transplantation (Wales) Bill

I am responding as a Consultant Transplant Surgeon in Nottingham who has been involved in transplantation for 25 years. I am a member of the Human Tissue Authority, Past-President of the British Transplantation and Chair of Transplant 2013, but I respond with my own personal view.

1. The individual provisions set out in the Bill

Section 2, relating to the promotion of transplantation

Whilst it is important for Welsh Ministers to promote the benefits of transplantation, it would seem more important under 2(b) and 2(c) for Ministers to specifically provide information and increased awareness about organ and tissue donation, as this is what is actually required. I recognize that organ and tissue donation are included under the umbrella term of transplantation activities for the benefit of this Bill under section 3(2), but I still feel it important that organ and tissue donation are specifically mentioned at this point of the Bill.

Section 3, relating to lawful transplantation activities

Could section 3(3) (and 9(2)(b) be taken to read that primary consent was not required when transplantable material was removed outside Wales? I'm sure this is not what is intended and may just be the way the Bill is worded, but should be considered at this stage to ensure.

Sections 4-8, relating to consent

No comments

Sections 9-11, relating to offences

No comments

Sections 12-20, which make general provision

Can I suggest that 17(2) includes aunt and uncle (particularly as niece and nephews are included), as this seems to have been omitted from the Human Tissue Act 2004?

2. Any potential barriers to the implementation of these provisions and whether the Bill takes account of them.

Currently the rate of relative refusal when an individual is not on the Organ Donor Register across the UK is of the order of 56%. Whilst the approach to families under the proposed system of deemed consent will be different, there is no evidence to show whether families will be more likely to give consent if they didn't actively know what their loved one would have wished. So whilst individuals may have been deemed to have given consent if a) they had not registered an objection or b) previously registered on the Organ Donor Register – in reality despite any communication plan many individuals will not have had a conversation with the family in life about their wishes after death and therefore consent will not have been given and families may still refuse to give consent to similar rates as at present.

3. Whether there are any unintended consequences arising from the Bill.

See comments under 1 above about potential unintended consequences namely:
i) the need to express clearly the responsibility of Welsh Ministers to promote both organ/tissue donation and transplantation
ii) to ensure that primary consent is given under the Human Tissue Act 2004 or Human Tissue (Scotland) Act 2006 for tissue removed and stored outside Wales and then imported into Wales.

It is still unclear to me as to how much public support there is within Wales for these changes. It appears that two public opinion polls have been skewed by organized campaigns – one in favour and one against, so the real view of the people of Wales may not be as clear. Whilst opting out/presumed consent legislation has been accepted in Europe, the effect in Brazil and Chile has been to reduce organ donation rates and legislation has subsequently been repealed. The European countries with the highest organ donation rates are Spain, Coatia and Portugal and it is changes in the infrastructure that have resulted in these improvements. Even though Spain has an opt-out law they do not attribute their high organ donation rate to it – see Fabre J, Murphy P, Matesanz R. Presumed consent is unnecessary. BMJ 2010; 341: 922.

4. The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the Bill).

No comment

5. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Part 1, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).

No comment

Keith Rigg

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)54 – Courtney Brown

Dear Sir/Madam,
I would like you to to take note of my concern regarding persumed organ transportation based on a system where people will need to actively out out rather than opt in. I feel that this presumption could erode an individuals human rights or those of their family.
I am also concerned that this could prove to be a development that would make a body the property of the state. Where the body could be seen chiefly as a source of spare parts.

I hope you will give due consideration to my concerns.

Yours sincerely,

Courtney Brown (Mr)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)55 – M. Griffiths

Dear Sir/Madam,

I was visiting my local library today and I saw a poster regarding the above-mentioned subject.

It stated that people were invited to express evidence/opinion if they so desired.

I have no evidence to submit, but I feel very strongly that the sponsors of this Bill are on the right lines.

It is a great tragedy that people are dying while waiting for organs to become available for transplantation, and in my humble opinion anything that has the slightest chance of increasing their chances is to be applauded.

I would go even further and remove the veto that is available to family members who, for whatever reason, cannot bring themselves to sanction organ donation.

I have told my family that under no circumstances are they to go against my wishes in this regard, should the situation arise.

I sincerely hope that this Bill makes it into law, and wish it's supporters every success.

Best regards,

Mr. M Griffiths

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)56 – Gloria Owens

15th January 2013.

Response to the Health and Social Care Committee's Inquiry into the Human Transplantation Bill (Wales)

I am writing to support the general principles of the above Bill and to recognise that this legislation will increase the number of organs and tissue donations in Wales and the UK. There is no doubt that there is a shortage of organs for transplantation. The waiting list for a transplant is nearly 400 and in Wales, and approximately 7,000 in the UK as a whole. People die every day needlessly whilst waiting for a suitable organ that will save their lives.

I had a successful renal transplant in February 1982, which still functions today. I have had renal illness since 1964, during all this time, there have been numerous campaigns to raise awareness of the need for more people to join the organ donor register. These have had a measure of success, but people still die waiting for an organ transplant.

Recent international evidence supports earlier studies that the introduction of an opt out system is associated with an increase in organ donation rates. This is obviously not the only factor involved. Clearly the necessary infrastructure has to be in place and public attitudes and understanding of the organ donation process need to be addressed. Studies have also shown that the family's wishes play a key role in organ donation rates. The UK family refusal rate being quite high. A review of evidence into the reason why next of kin refuse permission is a largely due to a lack of knowledge of their loved one's wishes.

In response to the main points raised by this Inquiry, I should like to add the following:-

1.

Section 2 The Welsh Assembly has consulted with the Welsh people at every step of the process of introducing the soft opt out law. I agree with the provision in the Bill that Ministers must promote transplantation as a means of improving health. It is essential that people are informed of what transplantation entails, and in particular, the meaning of express consent and deemed consent. The method by which any person who wants to opt out must be clear and readily available.

Section 3 All transplant surgery in the Wales and the UK has been legally carried out under the present system and this Bill will ensure that all future transplant surgery will continue to be legal. There is no place for illegal transplantation surgery under any system or any law in the UK or anywhere in the world

Section 4-8. Consent is the most important part of every organ donation system. This Bill will involve the next of kin in the organ donation process, as they are now under the current system. In addition the Welsh Government have already launched the "Heart to Heart" campaign to encourage families and friends to talk about their attitudes and wishes regarding whether they wish to be considered organ donors after death.

The Welsh Government is committed to raising awareness among the Welsh people leading up to and after the Bill becomes law. This Bill provides for children and those lacking capacity and makes clear the role that the next of kin or the person's representative has in the organ donation process.

Section 9-11 It is essential that the Bill makes clear what account as offences in activities relating to transplantation are. Offences are already legislated for under the present UK law. This will continue in the future under this Bill.

Section 12-20 I have no particular comment on these sections which appear to support the current legislation but make the necessary amendments for the Human Transplantation Bill (Wales)

2.
There is at present an excellent new kidney transplant unit in Wales which is well equipped to cope with any extra organs that will become available following the Bill becoming law. In addition there is such an acute shortage of organs on a UK wide basis that all organs that become available will be used. I see no potential barriers to the implementation of the provisions of this Bill, the main aim of which is to improve the health of people and promote organ transplantation

3. There has been much debate about this Bill and some people have indicated that they will remove themselves from the Organ Donor Register. The Welsh Government is aware of this as these views have been voiced both at public debates and through the media. The predicted increase in organ donors that the soft opt out system brings will negate that consequence.

4. There is no doubt that transplantation is cost effective. The savings to the NHS in treatment for patients, who would otherwise require years of expensive treatment, will be of huge benefit to the NHS which is currently under immense financial strain. In addition those people made well by transplantation will be able to contribute financially to the country.

5. Health has devolved to the Welsh Assembly. The referendum for more law making powers in Wales showed public support. Wales has passed its first law. I see no reason why Welsh Minister have not got power to make the subordinate legislation necessary to passing this Bill

I trust that the HSScommittee will take the above views into consideration when coming to a conclusion on this very important issue that I believe will benefit the people of Wales and the UK.

Yours sincerely,

Gloria Owens(Mrs)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)57 – Robert Strinati

[redacted]

RECEIVED

[illegible] 2013

Whilst I support human organ transplantation in principle, I write to register my opposition to the draft bill of the Welsh Government on "deemed" consent in the removal of organs without the explicit consent of the "donor" and ask you to consider the following points. Deemed consent is no consent at all and has major implications for other legislation. It ignores the essence of donation which is that of a free gift, to say nothing of the "ownership" and "autonomy" of the human body – even in death. We are not the property of any government. Organ donation should be a free gift, not a legal obligation.

The word "deemed" is deliberately confusing. Relatives will have little or no say about the integrity and well-being of their deceased relations. The consultation document on the draft bill reads: "In deemed consent cases (people close to the deceased) ... are not required to give their consent to the donation". Is the general public aware of this ?

Spain is often cited as a country where 'presumed consent' has been successful. Professor Rafael Matesanz (founder of the transplantation service) in his article in the British Medical Journal 2010, entitled Presumed consent: a distraction in the quest for increasing rates of organ donation said "in fact what Spain has shown is that the highest levels of organ donation can be obtained while respecting the autonomy of the individual and family, and without presumed consent." Informed consent has led to the donation rate in Wales increasing by 50% in recent years. Wales is second only to Spain in it's donation rate of 27.7 per million of the population which compares favourably to that of Spain with 34 donors per million of the population.

Working parties such as the U.K. Organ Donation Taskforce and the Wales Organ Donation Implementation Group have come out against presumed or deemed consent. Why has the consultation in Wales since December 2011 been so rushed with so little desire to inform and receive the considered views of the population at large?

RStrinati

Robert Strinati

[redacted]

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)58 – Simone Strinati

[redacted]

RECEIVED
11 JAN 2013

Whilst I support human organ transplantation in principle, I write to register my opposition to the draft bill of the Welsh Government on "deemed" consent in the removal of organs without the explicit consent of the "donor" and ask you to consider the following points. Deemed consent is no consent at all and has major implications for other legislation. It ignores the essence of donation which is that of a free gift, to say nothing of the "ownership" and "autonomy" of the human body – even in death. We are not the property of any government. Organ donation should be a free gift, not a legal obligation.

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Working parties such as the U.K. Organ Donation Taskforce and the Wales Organ Donation Implementation Group have come out against presumed or deemed consent. Why has the consultation in Wales since December 2011 been so rushed with so little desire to inform and receive the considered views of the population at large?

A Strinati

SIMONE STRINATI (Mrs)

[redacted]

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)59 – Rev Dr Gareth Leyshon

Dear Health and Social Care Committee members,

I write in connection with the Welsh Government's proposed legislation on deemed consent for organ donation.

I am a registered organ donor, a science graduate (PhD from the University of Wales) and a Roman Catholic Parish Priest.

While I recognise that the proposed legislation would increase the availability of donor organs in Wales, I am deeply concerned that it violates a significant point of principle – that a human being's rights over their own body are so intrinsic that they cannot be appropriated by the state without explicit consent.

The public outcry over the retention of children's organs without consent some years ago indicated that human beings have a deep instinct about body parts being precious. That instinct should be recognised by acknowledging that explicit consent is required for parts of that body to be used even for the most altruistic purpose.

Surely the same outcome could be achieved by a "Required Request" scheme whereby every resident in Wales was explicitly required to state their desire to be a donor or not. This would not override the intrinsic dignity of the persons concerned.

I would also like to see the rights of immediate family members strengthened in the final legislation, to the extent that next-of-kin have the right of veto.

Yours Sincerely

Rev Dr Gareth Leyshon

Address – [redacted]

Date – 14/1/13

Mr Mark Drakeford, A.M. Chairman,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay,
CARDIFF CF99 1NA

Re: Consultation – Human Transplantation Bill

Dear Mr Drakeford,

Just to say that I oppose the so called Presumed Consent/Deemed Consent of taking human organs at a person's death. It is simply body snatching and should be no part of a democratic Government's legislation.

My body does not belong to you, or the Government of any country, and even worse that a lonely person, a person living rough, a person old and lacking family and friends should be treated with such disregard, is an absolute disgrace.

Taking peoples organs without consent is not the way forward. Wales is already doing well with regard to democratic and voluntary organ donations – just increase the opportunities for people to sign up, but make sure they are told the truth about what they are signing up to.

The State does not own me now and neither must they own me when I am dead.

Yours truly,

M. Brice (Mrs).

Address – [redacted]

Date – 15/1/13

Mr Mark Drakeford, A.M. Chairman,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay,
CARDIFF CF99 1NA

Re: Consultation – Human Transplantation Bill

Dear Mr Drakeford,

Just to say that I oppose the so called Presumed Consent/Deemed Consent of taking human organs at a person's death. It is simply body snatching and should be no part of a democratic Government's legislation.

My body does not belong to you, or the Government of any country, and even worse that a lonely person, a person living rough, a person old and lacking family and friends should be treated with such disregard, is an absolute disgrace.

Taking peoples organs without consent is not the way forward. Wales is already doing well with regard to democratic and voluntary organ donations – just increase the opportunities for people to sign up, but make sure they are told the truth about what they are signing up to.

The State does not own me now and neither must they own me when I am dead.

Yours truly,

C. M. Daly.

[redacted]

12th January 2013

Dear Mr Drakeford,

Thank you for your invitation to respond to the Assembly's plans to change the law, or make a new law concerning Human Organ Transplantation.

We have been involved in the debate about the possible change in the law to allow the taking of Human Organs without the consent of the person deceased and without the consent of living relatives. We are seriously concerned at this attitude of our Government which is more in line with extreme left wing (communist) or extreme right wing parties – really state control. How can politicians be so bereft of the natural instinct of what is just.

States and Governments do not own people, even children are not owned by their parents who are their first teachers. It is shocking that we hear the Minister Lesley Griffiths state on television that relatives will have no right to say No to organs beings taken from their loved ones, if they cannot prove that the deceased relative said No while alive. This is beyond reason and belief.

Perhaps if and when a decision is made at someone's death, the person to receive the organ should be told that permission was not given by the deceased, or the family, for the organ(s) to be used – Why not ? We would if in this position want to know this and would reject the organ(s) under these circumstances.

But the real issue is that of 'presumed consent', what a nonsense. Typical political jargon and because the people understand that this is in actual fact not consent but stealing, we get the less understandable, but better sounding 'deemed consent'.

It is our honest opinion that the Assembly Government are not listening. We are not their servants, but they are the servants of the people, that is if we are a democratic society.

Under this Bill trust in Health Professionals will go out the window. Trust in Politicians who vote for this Bill will certainly disappear.

Yours faithfully

Paul Botto
D Botto

Paul & Diane Botto

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)63 – M C Dwyer

Address – [redacted]

Date – 14/1/13

Mr Mark Drakeford, A.M. Chairman,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay,
CARDIFF CF99 1NA

Re: Consultation – Human Transplantation Bill

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Yours truly, M C Dwyer

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)64 – Ann Savoury

Address – [redacted]

Date –
14·01·013.

Mr Mark Drakeford, A.M. Chairman,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay,
CARDIFF CF99 1NA

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The State does not own me now and neither must they own me when I am dead.

Yours truly,

Anne Savoury.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)65 – Mary F Galbraith

[redacted]

Wed. 15th Jan 2013

Mark Drakeford
Health & Social Committee
National Assembly
Cardiff Bay,
CF 99 1NA

Dear Mark Drakeford

Presumed Consent for Organ Donation

I have only found out today about the above and I wish to register my dismay at the shortage of time allocated to the public consultation for "presumed consent" for organ donations.

This Bill could impact not only on the people of Wales (who, I am sure, will not welcome this improperly timed and unfair form of consultation) but will also affect other parts of the U.K. and beyond.

It is arrogant to presume that because people have not "opted out" that they will be deemed to have "opted in" when the majority of people do not even know that this is being proposed. The truth is that if people have not given their consent then their organs should not be "up for grabs".

Therefore I ask that the subject of this consultation be well and truly publicised and the consultation period be extended until the public are well and truly informed.

Yours Sincerely
Mary F. Galbraith (MARY F. GALBRAITH)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)66 – Corinna Turner

[redacted]

Dear Ms Sargent,

I'm writing to register my opposition to introducing planned consent for organ donation in Wales or any other part of the United Kingdom. This would be an extremely serious development, rendering organ donation no longer in any way 'voluntary' and overturning the idea of organ donation as a free gift.

In practical terms, it would make the body the property of the state, not the individual. This, especially when taken in conjunction with the increasingly serious concerns about the current definition of death, is extremely disturbing. At what medical stage might the state in future find it expedient to consider a person 'dead'? Already, as David W Evans MD, FRCP has noted:

> "the basis upon which a mortally sick patient is declared "deceased" – for the purpose of acquiring his or her organs for transplantation without legal difficulties – is very different from the basis upon which death is ordinarily diagnosed and certified and that highly relevant fact is not fully and generally understood."

There is also evidence that presumed consent does not necessarily result in more organs available for transplantation, whilst it does fundamentally alter the meaning of the word 'consent'.

The proposed bill will also give families little or no say in what happens to their loved ones and amounts to the legal imposition of State ideology. The drastic reduction in family involvement is especially horrifying considering the growing controversy over the definition of death. Will families have to allow their - in their eyes - living relative to be wheeled away, paralysed with drugs, anaesthetised and dismembered?

The immediate and future consequences of bringing in implied consent are so morally dubious and fraught with ethical danger that the government should concentrate on promoting genuinely voluntary organ donation, with appropriate engagement - and transparency - about the ethical demands surrounding the definition of death.

I hope you will oppose this bill in its entirety.

Your Sincerely,

Corinna Turner

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)67 – Pauline Gately

Submission to the Welsh Assembly Health and Social Care Committee Consultation on Presumed Consent to Organ Donation

1 Introduction

This submission is concerned primarily with the general principles underlying the proposed legislation. Brief comment is also offered on the constraints imposed by the terms of reference of this consultation and two specific aspects of the proposals.

2 The terms of reference of your consultation

2.1 The terms of reference for your consultation seem to require you to start by accepting the premise that there is a need for legislation "to increase the number of organ and tissues available for transplantation by introducing a soft opt out system ..". This premise is challengeable since evidence suggests that such a proposal would not necessarily have the effect of increasing the number of such organs and tissues available (see below). The terms of reference therefore inhibit your consultation from offering a fully objective assessment of the proposed legislation. This is contrary to the public interest.

3 The general principles

3.1 The proposal to move to a system of "deemed consent" should be rejected on the following grounds:

1) It is objectionable in principle.

2) There is a lack of evidence that it will achieve the desired result.

3) It compounds an existing and serious wrong.

4) There is potential for significant and adverse unintended consequences.

It is objectionable in principle

3.2 The principle of informed consent underpins good medical practice. This is central to respect for the individual and his personal autonomy. It must not be compromised.

3.3 In keeping with this and while recognising the real and significant benefits of organ donation it is an important point of principle that organs should never be removed without clear evidence of the fully informed consent of the person from whom they are taken. Without this there is no donation, merely harvesting. 'Deemed' consent is no consent at all in the absence of absolute certainty that the person's failure to opt out was both intentional and fully informed. It is for those who support this proposal to demonstrate how this can be achieved.

There is a lack of evidence that it will achieve the desired result

3.4 This was the conclusion of the UK Organ Donation Taskforce following their 2008 Inquiry on this matter[1].

It compounds an existing and serious wrong: brain death is not death

3.5 It is clearly fundamental to public understanding and acceptance of vital organ donation that such organs are only harvested after the death of the patient. The 'dead donor rule' was adopted in principle from the early days of vital organ donation and potential donors are offered this assurance. It is on this understanding that the donor system is accepted, trusted and supported. Yet the criteria used to establish death in the context of organ donation are characteristically different from those used traditionally and in other contexts..

The whole brain criterion:

3.6 On the previously widely-accepted definition of death as 'cessation of the functioning of the body as an integrated whole'[2] the death of the whole brain does not mark but rather heralds death in the absence of further interventions. Outside the context of organ donation a certain diagnosis of brain death may reasonably justify the removal of life support. On this definition, however, the person does not die until after the life support is removed since it is only subsequently that the body ceases to function as an integrated whole. This is well understood by those who will keep vigil at the bedside until the point of subsequent 'clinical death'.

3.7 The use of the death of the whole brain as marking the point of death has been subject to serious and strong evidence-based challenge in other jurisdictions since it evidently fails to mark the moment of death on this definition. Even following diagnosis of the death of the whole brain patients may still have beating hearts, maintain integrative bodily functions with limited support, heal wounds, pass through puberty or gestate a baby. The start of the process of harvesting in such patients may prompt a rise in blood pressure and an increase in heart rate.

3.8 In the light of this and other, more technical, challenges some argue that organ retrieval on this basis should stop.

3.9 For others, however, the continued retrieval of vital organs from those now tacitly acknowledged not to be dead encourages a widening of the criteria to encompass other non-dead donors[3].

3.10 Yet others argue that death itself should be re-defined to encompass some not previously regarded as dead[4].

3.11 There is honest disagreement as to whether the concern regarding the use of whole brain death as a valid criterion for death is one of principle or of unreliable diagnosis. Nonetheless it is clearly the case that the principle of informed consent requires that the potential donor should fully understand and accept the implications as a condition of his consent. The failure to provide this information prior to consent has prompted considerable concern and challenge[5].

The UK 'brain stem' criterion:

> ***"Conceptually suspect and clinically dangerous"***
>
> The US President's Council on Bioethics in December 2008[6]

3.12 While the death of the whole brain as a valid criterion for death is increasingly challenged and prompted calls for a higher standard of information to validate consent, the weaker criterion of the death of the brain stem alone is almost universally rejected and in most jurisdictions harvesting on this criteria would be a serious criminal offence.

3.13 In the UK, however, the brain stem criterion is used without warning to potential donors or their relations of the implications: In distributed leaflets they are invited to "Register now" simply on the basis that the organs will be taken after 'death' without elaboration or qualification. On the organ donation website the information provided is highly challengeable and, in failing to acknowledge this controversy, misleading[7]. In observing, for example, that "when the ventilator is switched off the heart will stop beating" a prognosis is presented as if it were a diagnosis without offering any philosophical basis for this approach or acknowledging its controversial nature. This is a grievous, ongoing abuse which, regardless of the current proposal, is long overdue for challenge and review.

3.14 There is nothing in the proposed legislation which obliges those responsible to ensure that all Welsh citizens are given full knowledge of the criteria used to establish death for the purpose of harvesting organs, the challenges to this, the difference between the UK in this regard and other countries and the implications of this for the process of harvesting. Without this the Assembly cannot reasonably claim that 'consent', whether 'deemed' or actual, has any validity and any attempt to do so amounts to state-sanctioned deceit.

There is potential for significant and adverse unintended consequences.

3.15 After examining the 'opt out' proposal in 2008 the Organ Donation Task Force observed that "such a system has the potential to undermine the concept of donation as a gift, to undermine trust in doctors and negatively impact on organ donation numbers".

3.16 This must be particularly so in the absence of full prior knowledge of the death criterion issues already outlined[8].

3.17 The potential for real and ongoing distress to grieving relations who find out too late about the state of the 'donor' at the point of harvesting must be recognised and taken into account in considering this proposal. It is also possible under the terms of this legislation that relations are aware of this, wish to prevent the removal of organs but are over-ruled by the doctors. The psychological implications of both these scenarios must be considered.

4 Comment on specific aspects of this proposal

4.1 Over and above these matters of principle there are two aspects of the proposed legislation which also cause concern.

4.2 Under these proposals the relevant minister would be legally obliged to promote organ transplant on this basis, regardless of any future changes of view or policy arising from concerns such as expressed here or others and despite the misleading presentation arising from the use of the term ‘consent’ where consent is not evident. It is wrong in principle to so constrain any Minister.

4.2 Under the proposed system the family are no longer permitted to veto the harvesting of their relation’s organs. The prior rights of the family are thus usurped. Is it really anticipated that support for organ donation will continue once such a regime is up and running and reports begin to emerge from aggrieved families? It is therefore suggested that the presumption should always be against harvesting in the absence of clear evidence of the fully informed consent of the potential donor and their next of kin.

5 A personal perspective

5.1 I have lost a close friend to kidney failure. I understand the desire to save those who need new organs and would support organ donation in principle. But this must be done both ethically and with due regard for potential donors and their families. My late friend shared this view throughout.

6 Conclusion

6.1 These proposals should be rejected as wrong in principle: The state for the first time takes ownership of its citizens mortal remains. The presumption in favour of protecting the potential donor and respecting their wishes is radically weakened. The term ‘deemed consent’ is clearly misleading since no consent is involved. The proposal is potentially counter-productive since it radically erodes the basis on which vital organ donation has hitherto enjoyed public support.

6.2 Given that a Government’s first duty is to protect its citizens the Assembly should take steps to ensure that organs are not harvested in the absence of clear evidence that the potential organ donor has provided fully informed consent and that such information includes a full understanding of the implications of the criteria used to establish ‘death’.

6.3 The information offered here regarding the criteria used to establish ‘death’ is essential for informed public debate on these proposals. Without this the public interest is not served and the proposed legislation cannot be regarded as enjoying true public support.

Pauline Gately MA (Bioethics)

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[1] See Taskforce Report, for example §§ 1.5, 1.9, 1.13 and 1.14.

[2] First formulated by Bernat, Culver and Gert and widely adopted subsequently.
Bernat, J. L., Culver C. M. and Gert B. 1981 “On the Definition and Criterion of Death”, *Annals of Internal Medicine*, 94, 1981 pp. 389-394
Whole brain death was initially justified on the basis that it satisfied this definition but this was subsequently challenged. In response Bernat reformulated the definition to one which, he argued, better fitted the whole brain criterion. This was also challenged.

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[3] For example, writing in the prestigious New England Journal of Medicine Drs. Truog and Miller review relevant research and acknowledge that *"The uncomfortable conclusion to be drawn from this literature is that although it may be perfectly ethical to remove vital organs for transplantation from patients who satisfy the diagnostic criteria of brain death, the reason it is ethical cannot be that we are convinced they are really dead."* They go on to argue that, this being the case, we should abandon the "dead donor rule" and permit potential donors to sanction the removal of their vital organs should they succumb to specified, seriously disabling conditions.

Truog, R D and Miller F G, 2008 "The Dead Donor Rule and Organ Transplantation" New England Journal of Medicine Vol. 359:674-675.
http://www.nejm.org/doi/full/10.1056/NEJMp0804474

[4] An editorial in the influential science journal Nature, for example, argued that the criteria for death should be widened. To support this proposal they observe that *"In practice, unfortunately, physicians know that when they declare that someone on life support is dead, they are usually obeying the spirit, but not the letter, of this law. And many are feeling increasingly uncomfortable about it"*.

They conclude that: *"concerns about the legal details of declaring death in someone who will never again be the person he or she was should be weighed against the value of giving a full and healthy life to someone who will die without a transplant."* They thus imply that death should be redefined to encompass those with a permanent loss of significant prior mental faculties (however that may be defined or determined) apparently regardless of physical prognosis.

"Delimiting death". Nature Vol. 461 1 October 2009.
http://www.nature.com/nature/journal/v461/n7264/full/461570a.html

[5] Dr Alan Shewmon writes:
"Just as cigarette ads are required are required to contain a footnote warning of health risks, ads promoting organ donation should contain a footnote along these lines: "Warning: It remains controversial whether you will actually be dead at the time of the removal of your organs...." Similarly, in conversations with families of patients in total brain failure, representatives of organ procurement organisations should frankly disclose the existence of ongoing controversies over whether their loved one is dead or in a deep, irreversible coma. Of course such information is never given, neither to the public nor to individuals, because it would likely decrease the number of donated organs."
See "Brain Death: Can it be Resuscitated" *Hastings Centre Report* 39.2 (2009): 18-24

[6] The US President's Council on Bioethics in December 2008, while accepting the "whole brain" criterion, was highly critical of the UK "brain stem death" criterion which it described as *"conceptually suspect and clinically dangerous"*.
Washington, D.C.: President's Council on Bioethics, 2008 Pages 66/67
http://bioethics.georgetown.edu/pcbe/reports/death/Controversies%20in%20the%20Determination%20of%20Death%20for%20the%20Web%20%282%29.pdf

[7] See http://www.organdonation.nhs.uk/how_to_become_a_donor/questions/ in particular questions 11 and 12.

[8] Consider one bereaved mother's observations: *" .. I as an individual, an intelligent, articulate mother, did not consider the diagnosis of brain stem death to be final expiration of my son, when in 1987, I offered my son's organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But, despite asking to be present when the ventilator was switched off, I was not aware, nor made aware, that my son would still be ventilated when his organs...his heart, his liver, his kidneys, were removed from his body. Moreover, having discussed organ donation with him, I know that he also was completely unaware of this information."*
Letter to Mr David T.C. Davies MP, Chair, Welsh Affairs Committee from Mrs Eileen Rowlands
http://www.publications.parliament.uk/pa/cm201011/cmselect/cmwelaf/896/896vw23.htm

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)68 – Ben Biddulph

I am writing to you concerning this matter, as I am seriously worried about the implications of this policy were it to be introduced. Presumed consent essentially means that organs can be harvested from people who have not expressed any wish for this to happen. It should be a free gift, otherwise the concept of "donation" is meaningless. This effectively gives the state power it has no authority to wield, in effect making the bodies of those who happen to die in Wales the property of the state. If Government believes it is there to serve the people, then it would not cross their minds to act with such presumption. What they are implying by such a move is that they are the "masters" and the function of the rest of us is to serve their needs. From a philosophical standpoint it appears to reveal the arrogance of those that govern us, especially as this plan is made public only as a *fait accompli* , with consultation seemingly only being sought on the way this is to be implemented. I wish to express my extreme anger at this entire proposal, and would also question the legality of something that would appear to exceed the Assembly's remit.

Ben Biddulph

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)69 – Heather Scammell

In 2009, I donated my husband's organs. It is unquestionably one of the best things I have ever done, it gave him a dignity and purpose in death and was, and remains, a source of great comfort to me. Paradoxically, it was through this experience that I developed a profound unease with regard to the whole notion of presumed consent, which I had previously considered a 'no brainer.' This is partly because of what is necessarily a part of the process; that of being taken to one side to answer questions which are of a deeply personal nature. Unless you are completely committed to the principle and are able to in some way come to terms with the imminent demise of your loved one, this could be deemed to be intrusive and in some cases could adversely affect the grieving process. One only has to look at the furore surrounding the tissue collection at Alder Hey to appreciate some of the deeply held sensitivities about organs.

Of greater significance to me was the realisation that it really did matter to me that my husband's organs were a gift, freely given to others in need. This is what I have tried (and failed) to communicate at the two meetings I have attended about this bill. I have also been increasingly concerned about the vocabulary that is used in support of proponents of the bill. My husband was turned down for a lung transplant shortly before his death, so we had been aware that, had he been accepted we would have had to come to terms with the fact that someone would have had to die to facilitate that. Whilst I appreciate that most people would move Heaven and Earth to secure an organ for a loved one, the argument that '*They'* have *'got' t*o give him an organ is missing the point - it would be fantastic if someone did, but there is no obligation to do so. My husband's liver went to King's during the time that the hospital was later shown to have been selling theatre space to overseas recipients. I have no idea whether his liver was one of those involved, but I have never received any thanks from any of the seven recipients of his organs and tissue - which I don't actually mind,- but it did occur to me that had I paid several thousand pounds towards the cost of an operation, I would be less appreciative of the human costs of any organ I received. Similarly, once it becomes a matter of state policy, the significance of the donor is somehow devalued. Additionally, although I cannot imagine any of the wonderful team who dealt with us being guilty of any coercion, I can envisage situations in which that may be perceived to be the case, which would be a shame.

The bill was launched with the expressed intention to ‘make’ Wales altruistic. Unfortunately, this is inherently flawed; by definition ‘altruism ceases to be altruistic once it is enshrined in legislation. I am passionately committed to increasing the number of donors, but do not believe that this bill is an appropriate vehicle to facilitate this.I do not think there has been anything like enough attention given to the needs of donor families and feel that the current shortage of organs has more to do with modern society's attitude towards death - well beyond the scope of this bill!

Heather Scammell

Dear Deputy Clerk,

I wish to submit the following comments on the proposed Bill to introduce ‘deemed consent’ to organ donation in Wales:

The ethical basis of organ donation is just that – it is a gift freely given, with the informed consent of the donor. This Bill would replace donation by organ harvesting, in order to acquire more organs to meet the perceived demand. It arrogates to the State the right of access to the bodies of the deceased without any evidence of such informed consent.

Current law and associated code of practice requires either the donor to consent while alive, or a nominated representative or next of kin to give express consent after the person’s death. The Bill would replace this with an untrammelled right by transplant teams to the deceased person’s organs, casuistically called ‘deemed consent’. The person has not consented, has not said one way or the other what their views are, but the State will take the organs anyway.

The provision for family members to give evidence that the deceased would have objected to the taking of his or her organs, is meaningless, since if the doctor decides to reject the evidence proffered, the family cannot veto the harvesting of their loved one’s organs. The prior rights of the family are to be usurped by the State.

Moreover, the Bill imposes a “duty on the Welsh Ministers to promote transplantation”. And that duty is defined in section 2 of the Bill as follows:

The Welsh Ministers must—

(a) promote transplantation as a means of improving the health of the people of Wales,

(b) provide information and increase awareness about transplantation, and

(c) inform the public of the circumstances in which consent to transplantation activities is deemed to have been given in the absence of express consent.

This removes the freedom of conscience and action from a Minister who may disagree either with the principle of organ donation of with the spurious notion of deemed consent, and some authorities take the view that it would make it very difficult to modify in the future. The Bill is authoritarian, and does not respect fundamental human rights.

The Welsh Parliament is being asked to pass an authoritarian and anti-democratic Bill, which is based upon a fiction, that “deemed consent” is the same as ”consent”, and which:

1. allows the State to claim ownership of a person’s body after death (a form of ‘grave robbing’) – and possibly even before death, since there are serious scientific concerns as to whether brain-stem death is actual death with all the fundamental ethical issues that follow from that;
2. permits the State to make assumptions about a person’s beliefs and wishes which no one is entitled to make;
3. imposes on the community a set of values at odds with the traditional practice of medicine;
4. deprives Ministers of their right to freedom of conscience; and
5. imposes a “duty on the Welsh Ministers to promote transplantation” as understood by this Bill and the ideology of deceit which underpins it.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)71 – A. F. & B. Lewis

Health and Social care Committee

Welsh Assembly

Dear Sir,

We wish to register our concern about the proposed move to' presumed consent' legislation being brought before the Welsh Assembly.

It seems odd that politicians should engage in legislation about presumed consent when the medical profession are not yet able to agree on death, as in brain stem death or whole brain death or persistant vegetative state, especially when patients are still showing, on occasion that they are able to recover or show improvement when suffering from PVS or some similar illness.

Surely a more proactive push of the donor card system would be more likely to increase levels of consenting donors, especially when research has shown that presumed consent does not significantly increase the amount of organs for transplant.

A.F. & B Lewis

Heckmondwike

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)72 – Janice Proctor

I fully support the idea of a soft opt-out system of organ and tissue donation in Wales.
Janice Proctor
Barry

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)73 – Mo Lacey

I do not agree with the proposal to introduce a scheme whereby all citizens in Wales will be presumed to have consented to organ donation unless they file a formal refusal prior to their deaths. Organ donation should be voluntary and this scheme may cause unncessessary stress on relatives who know of their deceased relative's objection before they had had chance to object. This to me seems like getting organs via the back door and people should have chance before death to volunteer their organs.
Yours Faithfully
Mo Lacey

Whilst I support human organ transplant in priciple I wish to register my opposition to the draft bill of the Welsh Government on deemed consent in the removal of organs without the explicit consent of the "donor" and ask you to consider the following points.

1. Deemed consent is no consent at all and has major implications on other legislation.
2. It ignores the essence of donation which is that of a free gift to say nothing of "ownership" and "autonomy" of the human body, even in death.
3.We are not the property of any Government.
4. Organ donation should be a free gift and not a legal obligation.
5 In the extreme one could be put on the Liverpool Care Pathway, killed and then butchered for one's body parts so very similar to an abattoir without one's consent. In other words treating human beings like animals. How very National Socialist.

Sincerely,
Geoffrey Robinson,
Newport

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)75– Anonymous

Dear Mr Drakeford,

I am writing to engage with the latest round of consultation on the Human Transplantation (Wales) Bill. I do so despite the response of the Welsh Government (WG) to previous consultations to which I have submitted evidence, where the WG has consistently failed to acknowledge the level of disquiet about this bill. While the transplant community in Wales has made great progress in increasing the level of donation over the past two years, assisted no doubt by the controversy over this bill, the case for changing the law has not been made.

In the face of opposition the WG has turned to evidence ostensibly showing that an opt-out system will increase donation, and to opinion polls showing support for the legislation. However the very report the WG cites states explicitly that “it cannot be inferred that this association means that presumed consent *causes* increased organ donation” (emphasis in the original). At the same time support for the legislation has declined over the period of engagement with the public and has now fallen below 50%. The results of the most recent consultation showed more opposition than support from those who engaged, not only from identical submissions (which generally reflect campaigns for or against legislation) but from those, such as myself, who took trouble to write individual responses. It is also very evident that the process of engagement has significantly alienated certain minorities within Wales. This opposition also seems to have increased over the period of engagement with the public. “Consultation” without listening generates frustration and anger.

My greatest concern about this bill remains the key idea that someone who has never expressed any view can be “deemed” to give consent. This act of deeming is a legal fiction which perhaps does no harm when the relatives are also supportive, but where relatives object, there is the prospect of the body being effectively confiscated by the state on the basis of a legal fiction. Even where someone has signed the donor register there is no way to assess if this consent is informed or if it is consent to donate in the face of serious opposition from close relatives. No donor is ever asked if they consent to use of organs *in these circumstances* (which they may do, but it may be that they would not wish to upset the people they leave behind and have not considered the possibility of such opposition).

Clearly the best case is where people think about this issue and discuss it while they are alive (as I have discussed it with my wife, as well as signing the register) but in the absence of such *knowledge of the actual wishes of the deceased*, some consideration must be given to the feelings of the bereaved. People have a right to bury their wives, husbands, parents and siblings, and to give to them the respect due by the rites of their religion and tradition. This is quite compatible with a system of organ donation where it is voluntary and respects the feelings of those left behind. The greatest flaw in the draft bill is section 4 subsection (4) which includes no qualification of deemed consent ***in cases where there is no evidence of prior express consent and a person who stood in a qualifying relationship to the deceased has a strong objection to the removal of organs***. Not to include such a qualification is inhumane and risks undermining long term support for organ donation. Such a qualification is of course compatible with an opt-out system (as in Belgium).

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)76 – Tony Young

f.a.o. Mr. Mark Drakeford (Chair, Health and Social Care Committee, National Assembly for Wales)

Dear Sir,

I object in the strongest possible terms to the proposed change in the law, affecting human organ transplantation in Wales, that would be brought about if the Human Transplantation (Wales) Bill were to be passed into law.

My main objection is to the concept of 'presumed consent' (or 'deemed consent'). There is no such thing as 'presumed consent', because if you are in a position of 'presuming' that a person has consented, it is tantamount to an admission that the person has not actually consented. It is an absurd notion, dreamed up in the corridors of Cardiff Bay or Cathays Park.

The Bill would severely diminish the role of the family of the deceased person, and possibly eliminate it entirely, in deciding whether or not to donate an organ -- and I object strongly to that.

There is controversy over the definition of death, for the purpose of transplantation in the terms of this Bill. 'Brain stem death' is not actual death, as far as I am concerned.

The concept of 'presumed consent' or 'deemed consent' totally negates the concept of the freely expressed wish of the deceased, in life, to donate his/her organs in the event of death.

There is no conclusive evidence that the enactment and consequent operation of this particular Bill would increase the rate of organ donation in Wales. Experience in countries that have introduced similar legislation gives the lie to this idea.

Finally, I wish to state here and now that if this Bill ever becomes law, I for one will refuse to add my name to the Organ Donation Register.

Yours faithfully,
Tony Young

Swansea
17 -1 -2013

[redacted]

Sarah Sargent,
Deputy Clerk
Health and Social Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA.

HSCCommittee@wales.gov.uk

18 January 2013

Re: Consultation on the Human Transplantation (Wales) Bill

Dear Ms Sargent

I am grateful for the opportunity to reply to this consultation on the Human Transplantation (Wales) Bill[1] (the 'Bill'), and hope that my observations might be of some assistance to the Health and Social Committee in its deliberations on this important subject. In making my response I have read the Bill and its Explanatory Memorandum[2], and additionally examined the Summary of Responses[3] on the Draft Bill.

The stated purposes of the Bill[4] are to:

1. increase the number of organs donated in Wales;
2. to address the relatively low rate of consent to organ/ tissue ('organ') donation through "clarifying the wishes of more people" and by "effecting changes to public attitudes and awareness about the issue".

Nothing is stated in the Introduction to the Bill quoted above, concerning the introduction of 'deemed consent' for organ donation, though it quickly becomes clear that this is not only central to the proposed legislation, but has been a key concept informing the background to the Bill since 2008[5].

Specific points of uncertainty arising in my reading of the Bill are:

1. Section (S) 5 Subsection (ss) 3 - it is not clear whether this is a transitional arrangement applying only to the first years after the introduction of the Bill, and that following this period, 'deemed consent' will potentially apply to all those who lose capacity in Wales;
2. S 7 ss 10 part (b) - the nature of the proscription of certain persons as acting as a potential donor's representative is not clarified in the Bill, but is to be addressed in regulations if the

Bill is passed into law. The reason for giving such a power to the Welsh ministers is not explained though it seems remarkable;

3. S 8 ss 2 part (b) - the sole assumption in 'deeming consent' in this section is to present the person lacking capacity only as a donor of transplant material, but not as a recipient, though Equality legislation would surely require that a person lacking capacity should not be excluded by law from the potential benefits of transplantation. It is also highly debatable whether there are more than a handful of cases where the risks of what is normally major surgery and the loss of at least one major organ could reasonably be described as being in the donor's as opposed to the recipient's 'best interests';

4. S 9 ss 1 & 4 + S 10 - describe the punishments under this Bill for carrying out a transplantation activity unlawfully, for example without consent. Given that such activity is technically an assault, may seriously impair the mental &/ or physical health of the 'donor', or cause their death, the penalties seem remarkably lenient, being set at a fine &/ or a maximum term of 3 years imprisonment. This suggests to the world at large that such acts are not to be taken seriously;

5. S 12 - is there a limit to the time a body may be held in an institution after death while consent to transplantation is sought? Will there a limit to the length of time transplant activity is deferred while relatives or representatives of the potential donor are sought, and could some clarity be given to this issue before enactment proceeds?;

5. S 13 - might this mean in practice that if for instance the cause of a person's death is uncertain, and a Coroner's post-mortem might therefore be required, that this would effectively prevent the authority from holding the body (see S 12 ss 1) or using the body for donation at all?;

6. S14 ss 4 - it seems as if there is to be 'deemed authorisation' as well as 'deemed consent'. The employment of 'negative resolution', and the power to make subordinate legislation by regulation or order by to the Welsh ministers alone, suggests a lack of democratic oversight at the least.

It is clear that a lot of thought has gone into the drafting of this Bill. There are however some matters which are not addressed in the materials I have examined, some of these being fundamental. It might be clearer if these were set out in a list form:

(i) The Explanatory Memorandum presents the figures on the relatively low rate of consent to in the organ donation UK, and the summary of the University of York study[6] suggests that the impact of presumed consent on organ donation rates is complex and that good evidence in favour of presumed consent appears to be lacking at this time. Furthermore, the EU (2007) survey[7] suggested 63% of relatives in the UK would consent to organ donation from a deceased close family member, and the 'Organ Donation Task Force' (ODTF)[8] stated that about 60% of the UK population surveyed would accept a well-implemented opt-out system ie. a presumed consent system like the one proposed for Wales in this Bill. The figures are so close for the opt-in and opt-out schemes that one has to wonder why, if they are a key part of the evidence for this Bill, a move to a potentially very contentious system like 'deemed consent' has been preferred above efforts to improve the current opt-in system?;

(ii) infrastructure and healthcare costs are considerable, particularly for Heart and Lung transplants, as the initial surgery is so highly expensive. At a time when healthcare expenditure is being cut, and there is a widely publicised reluctance in central government to fund better care for the elderly in the UK for example, what is the opportunity cost for the healthcare system of this move to 'deemed consent'? Are the elderly going to receive better care in Wales in the future than elsewhere in the UK?;

(iii) transplantation is not a panacea. It is quite frequently fatal within the first year, and it introduces a different form of chronic health condition associated with immune suppression, drug-induced harm to the body and its own range of medical conditions. It is true that health and life expectancy are improved for many people through transplantation however;

(iv) it would seem that 'deemed' consent simply adds to the ethical and moral difficulties associated with transplantation. As has been widely noted, 'deemed consent' is an oxymoron - consent cannot be 'deemed', and can only be given or withheld. Moreover it creates a dangerous precedent for Medicine, and offers the state a still greater control of the citizen, even to the disposal of their body parts after 'death'.

(v) it is far from clear that the safety of those lacking mental capacity will be adequately protected by this Bill in its current form. The only unarguable application of 'best interests' to those lacking capacity is the receipt of a donor organ, not its donation. In the very rare cases in which donation from a person lacking capacity might be thought to be in their best interests, for instance to the family member who cares for them, application should be made to the courts in each case. The Bill as it stands gives excessive latitude to those who might be tempted to view those lacking consent as mere organ containers there to benefit others;

(vi) while it may be true that, solely because of the relative shortage of organs, age is no longer a bar to donation, few recipients would wish to receive organs from a person in their 60s or older. The organ too will be old, and the incidence of undiagnosed malignancies and other pathology is also likely greater than in a young person;

(vi) given that under the 'Human Tissue Act 2004', consent of a person in a 'qualifying relationship' (or of a representative), in the absence of 'express consent' on the part of the potential donor, is sufficient to permit organ donation to occur (or not to occur), the situation in Wales would be little altered under this Bill if relatives retained anything like the same authority. It is clear that the authority of the relatives of an 'unexcepted adult' will be significantly reduced under the new Bill, and that the burden of providing sufficient evidence such that a 'reasonable person' would agree that the potential donor would not have consented[9] - may become very hard indeed, particularly if targets for 'donation' are set, or if the Welsh ministers decide to make non-donation more difficult by regulation or order. This is a disturbing prospect, since taking organs from a body without the agreement of relatives, will not only be highly traumatic for them (what is left of their loved one's body may be little more than a shell when every organ and structure to be harvested has been removed), but in quite a short time may also significantly lessen the regard of the population for the law and for the Assembly;

(vii) the recipients of donated organs may be very uncomfortable with the reality of living with organs taken without the express consent of the deceased or their relatives. This seems likely to increase the risks and prevalence of psychological vulnerability in patients receiving organs in these circumstances;

(viii) the deeply serious, relevant and ongoing ethical concerns over transplantation are ignored in this Bill. There is in fact no agreement that 'Brain Death' truly represents death, and the profusion of tried and discarded definitions for it over the last 50 years strongly suggests that none is correct. Moreover the 'brain stem tests' or other tests used to diagnose 'brain death' are applied very early and before any brain recovery from its trauma could occur. This means that death cannot safely be diagnosed on 'Brain Death criteria'. This in turn means that many 'organ retrievals' are not the removal of organs from a deceased person, but from one still living, even if possibly dying. Unfortunately, since this is so, 'Donation after Circulatory Death' where circulatory arrest, the universally accepted definition of death, is induced in the operating theatre by clinicians themselves, must place the clinicians involved on very awkward legal and moral ground.

In conclusion I feel obliged to express deep reservations about this Bill. The body does not belong to the state, nor ought the state to assume a power of disposal over it, in any but the most extreme circumstances. Consent is not consent where it has to be 'deemed', nor is there a donation when the state assumes the right to take the person's organs. It is also the case that transplantation unfortunately cannot safely or morally employ such a changing and changeable criterion of 'death' as is offered by so-called 'Brain Death criteria'. These are facts which should be known to, and understood by legislators and the public.

Yours sincerely

Dr R J Clearkin

1 Human Transplantation (Wales) Bill: http://www.assemblywales.org/bus-home/bus-business-fourth-assembly-laid-docs/pri-ld9121-e.pdf?langoption=3&ttl=PRI-LD9121 - Human Transplantation (Wales) Bill (accessed 17 January 2013)

2 Welsh Government, Human Transplantation (Wales) Bill, Explanatory Memorandum: file:///C:/Users/Ronald/Documents/MyDocuments/Life/OrganDonationPresumedConsentWalesJan2013/Research%20Service%20PresumedConsentOrganDonationWales2013Bill%20Summary.pdf#Human Transplantation (Wales) Bill, Explanatory Memorandum (accessed 16 January 2013)

3 Welsh Government, http://wales.gov.uk/docs/dhss/consultation/121203responsesen.pdf (accessed 16 January 2013)

4 Welsh Government, Bill summary Human Transplantation (Wales) Bill January 2013 page 2

5 Welsh Government, Bill summary Human Transplantation (Wales) Bill January 2013 page 1

6 Welsh Government, Human Transplantation (Wales) Bill, Explanatory Memorandum: Part 2: Options; Evidence Base to Establish Impact of Proposed Legislation - Section 105 file:///C:/Users/Ronald/Documents/MyDocuments/Life/OrganDonationPresumedConsentWalesJan2013/Research%20Service%20PresumedConsentOrganDonationWales2013Bill%20Summary.pdf#Human Transplantation (Wales) Bill, Explanatory Memorandum (accessed 16 January 2013)

7 Welsh Government, Human Transplantation (Wales) Bill, Explanatory Memorandum: Part 2: Options; Evidence Base to Establish Impact of Proposed Legislation - Section 99 file:///C:/Users/Ronald/Documents/MyDocuments/Life/OrganDonationPresumedConsentWalesJan2013/Research%20Service%20PresumedConsentOrganDonationWales2013Bill%20Summary.pdf#Human Transplantation (Wales) Bill, Explanatory Memorandum (accessed 16 January 2013)

8 Welsh Government, Human Transplantation (Wales) Bill, Explanatory Memorandum: Part 2: Options; Evidence Base to Establish Impact of Proposed Legislation - Section 98 file:///C:/Users/Ronald/Documents/MyDocuments/Life/OrganDonationPresumedConsentWalesJan2013/Research%20Service%20PresumedConsentOrganDonationWales2013Bill%20Summary.pdf#Human Transplantation (Wales) Bill, Explanatory Memorandum (accessed 16 January 2013)

9 Human Transplantation (Wales) Bill: Section 4 Subsection 4 Part (b) http://www.assemblywales.org/bus-home/bus-business-fourth-assembly-laid-docs/pri-ld9121-e.pdf?langoption=3&ttl=PRI-LD9121 - Human Transplantation (Wales) Bill (accessed 17 January 2013)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)78 – Anonymous

I wish to register my opposition to the above bill. It is wrong in that it is unethical in failing to respect one 's right to autonomy over their body. Donation rates are increasing in Wales anyway as publicity has made people more aware of the importance of carrying a donor card , so that people who feel it is important and want to donate their organs can make that decision for themselves.

If the Bill is passed into an Act then I believe many people will actually fear admission to hospital.

Yours faithfully,

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)79 – John Mellor

Dear Sir/Madam,

23rd/24th October 2011, I lost my wife very suddenly because of a brain haemorrhage. My consent was sought for her organs to be used to save others & I & my family agreed.

I would have been grievously distressed if they had taken them without our consent. When they asked if they could have my wife's eyes I couldn't stand the thought of it & the NHS would have had another medical problem on their hands if they had taken them anyway - i.e., my health. It has been hard enough coming to terms with losing her.

I share the view that the idea proposed of 'assumed consent' is unethical. Consent to organ donation can no more be assumed than that if someone leaves a window open a burglar may assume consent to help himself to what is inside.

If this legislation goes through, GPs, psychiatrists et al - maybe the police, too - will find themselves treating a lot of cases they might not have. Of course, it will be hidden from view by the fact that GPs often do treat bereavement cases with drugs. How much better, though, for relatives to be asked for their consent & be encouraged by the help thus given to those in need of replacement organs? I have been informed that two of the three recipients of my wife's organs are doing very well & that is a great comfort to me. It would have meant nothing to me if they confiscated her organs without my & my family's consent.

I gather that it is unlikely to increase the availability of replacement organs. Please change your minds on this. I know that politicians consider that humility is anathema to their business, but many electors would be thrilled if you would reconsider on this occasion.

John Mellor
Flintshire

Mr Mark Drakeford,
Chair of the Health Committee,
The National Assembly for Wales.

17th January 2013.

Dear Mr Drakeford,

Re: Explanatory Memorandum for the Human Transplantation (Wales) Bill.

I would like to bring to your attention a crucially important factual error in the memorandum, as well as other important points in the Memorandum that the Welsh Government needs to address.

1. The factual error occurs in Clause 102, in the section entitled “Evidence Base to Establish Impact of Proposed Legislation”. It states “For example, an opt-out system is operated in Spain and it has the highest donation rate in the world with approximately 32 deceased donors per million of population”. *Spain does not operate a presumed consent system.* The Director of the Spanish Organ Donation Organisation (Organizacion Nacional de Trasplantes www.ont.es), Dr Rafael Matesanz, is on the public record several times making this point, most recently in an article published in the British Medical Journal on the 30th October 2010 (volume 341, pages 922-924). The authors of this article, listed on the last page, are myself, Paul Murphy (an intensive care physician), and Rafael Matesanz. I attach a copy of this article. If you read the middle column of the first page you will see “Crucially, Spain does not have an opt-out register for those who do not wish to become organ donors. Not a penny is spent on recording objections to organ donation by Spanish citizens, nor on public awareness of the 1979 legislation. Clearly, the presumed consent law in Spain is dormant, and it pre-dates key policy changes made in 1989. In these circumstances, Spain’s outstanding deceased organ donor rate cannot reasonably be attributed to its presumed consent laws”.

If you have any doubt on this point, you should contact Dr Matesanz on [redacted] or [redacted]. Linking this factual error, about Spain and presumed consent, with the true fact that Spain has the best deceased donation rate in the world, in a section on the evidence base for the proposed legislation, is clearly and quite outrageously misleading. Any expert adviser will know that Spain does not operate a presumed consent system.

The Welsh Government must issue to Assembly Members and the Public a corrective statement along the lines of “The Welsh Government regrets that the statement in Clause 102 of the Explanatory Memorandum for the Human Transplantation (Wales) Bill is incorrect. Spain does not operate a presumed consent system, as stated in Clause 102, although it does have the highest rate of deceased organ donation in the world. Spain’s 1979 presumed consent legislation predates the key policy changes made in 1989. Spain does not have, and never has had, an opt-out register or other means of registering objections to organ donation by Spanish citizens. Spain does not spend any resources whatsoever to publicise the 1979 legislation”. It would be a scandal if the Bill were passed by Assembly Members given a manifestly misleading statement by the Government of Wales.

If the Welsh Government believes that the mere presence of the legislation in Spain somehow subliminally influences donation, then it should emulate Spain and pass the legislation but without a donor register and without spending resources on publicity.

2. There is an additional point that will also mislead Assembly Members and the public. It concerns the 2006 study by Abadie and Gay, comparing organ donation rates in countries with and without presumed consent systems. This is prominently quoted in Clause 21 and Clause 103 as the basis for expecting a 25% to 30% increase in donation rates after the introduction of presumed consent. As correctly explained in Clause 104, the Abadie and Gay study was one of 4 methodologically sound "between country" comparisons identified in a review of the literature on presumed consent by the University of York. This review was commissioned by the Department of Health's Organ Donation Taskforce. The University of York also identified 5 methodologically sound "before and after" studies, comparing donation rates before and after the introduction of presumed consent legislation.

However, even with the best methodology, the quality of the conclusions is entirely dependent on the quality of the data analysed. The study by Abadie and Gay made a critical error, which should have been noted by the Welsh Government – it included Spain as a presumed consent (opt-out) country. It is worth noting that another of the 4 between country studies identified by the University of York, that by Gimbel et al published in 2003, correctly classified Spain as an opt-in country. This error in the Abadie and Gay would inevitably bias its findings in favour of presumed consent , and therefore invalidate its conclusions.

The Explanatory Memorandum is also selective in its quoting of the University of York's report. The University of York's negative comments are omitted. For example, in paragraph 1 of page 28, the University of York states regarding the Abadie and Gay study that "Countries were selected from an initial panel of 36, with some being excluded because of low transplantation rates, many of which were presumed consent countries. Thus it is possible that the impact of the presumed consent law was overestimated".

The Welsh Government appears not to have asked itself why the Department of Health's Taskforce found against presumed consent in November 2008. This Taskforce is known to consist of a large group of knowledgeable specialists in many fields. In January 2008, prior to its November 2008 report on presumed consent, this same Taskforce made another report which has led to the spectacular increase in deceased organ donation in the UK, as noted in the Memorandum. After stagnating or falling since a peak in 1989/1990, the deceased organ donation rate in the UK has risen from 809 donors in 2008 year-on-year to 900, 959, 1010 and 1088, and is on schedule for another big increase in the year to April 2013, probably to ~1150. The credentials of this Taskforce are excellent.

Going through the details of the 4 "between country" studies and the 5 "before and after" studies is tedious for non-specialist audiences. However methodologically sound these papers might be, they are poor quality papers, some extremely poor, and hardly a basis for policy. I mentioned above the Gimbel et al study, and that it had correctly assigned Spain as an opt-in country. However, oddly, it excluded Spain from the analysis, as an outlier. The University of York states on page 28 "If Spain had been included, the magnitude of the impact of presumed consent would have been lower". There were 2 other between country papers. The paper by Healy et al, published in 2005, analysed 17 of 30 OECD countries. The University of York comments on this paper (page 29) "As with Abadie et al, it is not clear whether the choice of countries may have affected the results of this study. There was no rationale provided". In any case, the results of Healy et al were not statistically significant. The last paper, by Neto et al, was published in 2007. The University of York had concerns about the statistical analyses, which are outside my expertise.

The 5 "before and after" studies all involved 3 countries - Singapore, Austria and Belgium. One of these concerned secondary legislation in Singapore for liver donation, and is not directly relevant. The other 4 were brief, 1 to 2 page meeting reports, rather than full-length, peer-reviewed papers, and they were published more than 20 years ago. At the time, Austria and Singapore were using hard presumed consent. In all 3 countries, numerous additional initiatives were introduced with the legislation, and it is impossible to ascribe any role to the presumed consent legislation.

Perhaps the Welsh Assembly should organise a public, expert discussion of these papers.

3. Other points.

a. The presumed consent legislation fundamentally aims to move the decision about donation from the family to the hypothetical wishes of the donor. It is claimed that this will better accord with the potential donor's wishes. However, failure to register an objection on an opt-out register, ie the absence of an objection, is hardly the best way to ascertain a person's wishes. It defies common sense to say so. *There is in fact no good way of ascertaining the wishes of a potential donor who has neither opted in nor opted out, or discussed the issue with family.* If establishing the wishes of the potential donor was paramount in the mind of the Welsh Government, an opt-out register without presumed consent legislation would achieve it as effectively as with legislation, at a much lower cost. It is worth remembering that in Spain, which has the world's highest deceased donation rate, and more importantly for the current discussion, the world's lowest refusal rate (currently only 10%), the decision about donation rests with the potential donor's family (see BMJ article).

b. The bureaucratic intimidation described in clause 44 is unnecessary.

c. I do not think that 50% or 60% support for contentious legislation that will affect the rights of all the citizens of Wales is nearly enough to proceed.

d. The Memorandum states that there is no alternative to presumed consent legislation. That is a remarkable comment for the Welsh Government to make. One alternative, now that transplant coordination is being developed so effectively following the January 2008 Taskforce recommendations, is to aim for an acceptance rate of 90% over the next 5 years, as has been achieved in Spain. Not by presumed consent legislation, but as the Spanish have done, by excellent public relations and public education (see BMJ article), which should be possible in Wales.

e. I think it is worth noting that if we look around the world today, we see that Spain and the USA have excellent deceased organ donation rates without presumed consent. Spain has an outstanding acceptance rate, without presumed consent. By contrast, Sweden, which operates a presumed consent system, has a donation rate substantially lower than the UK's. The case for presumed consent is weak, and it will be costly. The money can be spent much more effectively to achieve the improvement in donation rates which it is our duty to achieve.

Yours sincerely,

Professor John Fabre
Professor Emeritus
Kings College London

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)81 – Jonathan Cundill

Dear Sir/Madam,

One of the arguments put forward for moving to an opt-out organ donation system is that most people are in favour of organ donation even though they do not get around to joining the ODR.

My own experience is that it is already too *easy* to become a registered organ donor without realising quite what you have let yourself in for. I learnt relatively recently that I had been registered as an organ donor for over 10 years as a result of information provided by my GP's surgery from when I registered with them. I recall ticking a number of boxes indicating that I would be willing to donate several of my organs for transplantation **after my death** (emphasis mine).

I had no idea then that this would be taken to indicate my consent to the removal of my organs in the event that I was diagnosed with brainstem death. I had taken 'death' to mean death in the commonly understood sense, implying a complete cessation of all bodily activity. Not knowing much about how organ donation really works, I did not realise how difficult (and in the case of most organs, impossible) it is to obtain transplantable organs from a real corpse. And I certainly had no idea that organs could be removed whilst the donor's heart is still beating and his/her body still warm, ventilated and (without muscle-paralysing drugs or anaesthesia) possibly reactive to trauma.

As none of these things were made clear to me, there is obviously something seriously wrong with the current system for indicating consent to organ donation after 'death'.

Unfortunately, nothing I see in the system being proposed for Wales makes me think that this problem of consent from ignorance / misinformation is to be addressed. Placing ministers under an obligation to promote transplantation will make it more difficult for them to be truthful and transparent about organ donation and provide potential donors with the kind of information they should be given when considering whether or not to opt out – information like the state their body would be in at the time of organ harvesting and the fact that immunosuppressant drugs would be needed to prevent their organ(s) being rejected by another person's body (unless donor and recipient are identical twins).

The Explanatory Memorandum of the Human Transplantation (Wales) Bill claims that a soft opt-out system is being proposed – even though it has been made clear that families will have no legal veto over their loved-ones' organs being harvested. Page 10 of the document describes soft opt-out systems as being 'where organs would become available for donation after death if the deceased had not opted out, but where families would retain full involvement in the process.' Given families' lack of a veto under the proposed system, it is difficult to see how they would 'retain full involvement in the process' and therefore how the system can truthfully be described as 'soft'. Being consulted on their relative's lifestyle / medical history – in order to help assess how suitable their organs are for transplant – hardly means retaining full involvement in the process.

Presuming consent to organ donation from silence and, quite probably, ignorance / misinformation and potentially in opposition to relatives' wishes appears to be a recipe for making a bad system worse.

Reference is often made to Spain in advocating an opt-out system – even though their change of system was made back in 1979 and did not in itself make much difference to donation rates (see http://www.ont.es/publicaciones/Documents/Articulos/2010/BMJ%20Analysis%20on%20presumed%20consent.pdf). However, the much more recent example of switching to an opt-out system provided by Brazil in 1997-98 should also be noted when considering whether the Bill could have any unintended consequences.

Two letters to the Western Mail from medical experts describing the state of a donor's body during transplantation are appended for your consideration.

Yours faithfully,
Jonathan Cundill

Letter 1: The truth about organ donation (Saturday, July 2 2011)

http://www.walesonline.co.uk/news/letters-to-the-editor/western-mail-letters/2011/07/02/saturday-july-2-2011-91466-28980625/

SIR – I read that Wales intends to adopt the "opt out" (presumed consent) system governing the procurement of organs for transplantation ("Presumed-consent organ donation still BMA policy", June 29).

I therefore feel obliged to do what I can to alert the good people of the land of my birth to the full implications of that change – and, perhaps, of registration on the NHS Organ Donor Register under the present "opt in" system.

To take the latter point first, all those who have so registered must clearly understand that they are deemed to have agreed thereby to the removal of their organs while their bodies are still very much alive.

As a moment's thought should indicate, it is not possible to obtain healthy complex organs, which can be expected to function efficiently for years in another person's body, from someone who is truly dead in the commonly understood sense, ie an unresponsive cadaver whose heartbeat and breathing have long ceased.

Hearts for transplantation are taken from donors in whom they have been maintaining the blood circulation up to the time of their removal, oxygenation of their blood being maintained by continuing mechanical ventilation.

By virtue of that continuing life-support after the diagnosis and certification of death, donors' bodies remain reactive and may have to be paralysed with drugs to facilitate the organ procurement surgery. Some attending anaesthetists may give general anaesthesia also.

The diagnosis of death for that purpose will have been made on a very different basis from that used for the diagnosis of death in more than 99% of cases worldwide.

In the UK that diagnosis is made for transplantation purposes on criteria considered inadequate in most parts of the world and recently rejected by the US President's Council on Bioethics. They require only simple bedside testing of some functions of the brain stem – the stalk which connects the spinal cord to the cerebellum (the "little brain") and to the major part of the brain (the massive cerebral hemispheres).

It is alleged that these tests ensure there can never again be any form of consciousness, but there is no sound scientific evidence to support that claim. There is, however, evidence suggesting persisting function in brain stems pronounced "dead" by the UK criteria.

If there are some on the NHS Organ Donor Register who did not understand that the words "after my death" on the application forms (and Donor Cards) do not mean after death in the commonly understood sense – no heartbeat or breathing for long enough to ensure irrecoverability of any responsiveness or awareness – they may feel they "signed up" on a false premise.

They may even feel they were to some extent deceived by the wording and emotional appeals to register without being given a full and fair explanation of the nature of the offer sought. In such cases, their offers cannot be considered valid and they may wish to seek means of removal of their names or modification of their offer by imposing conditions such as a request for anaesthesia to cover the explantation surgery.

Turning to "presumed consent", it will be assumed that people diagnosed "dead" by the UK Code of Practice criteria governing that diagnosis for transplant purposes have agreed – "consented" – to the removal of their organs while in that state unless they have registered prior objection.

The absurdity of that presumption – given the lack of certainty that everyone is fully apprised of the organ procurement procedure and has considered it while of sound mind – has been pointed out in submissions to the House of Commons Welsh Affairs Committee earlier this year (available online).

My plea is for the public to be fully informed about the procurement of organs for transplant – hitherto quietly concealed behind propaganda emphasising the plight of those hoping to acquire organs.

It is high time the truth was made generally known. The responsibility to make it known rests heavily and specially upon those who wish to impose an "opt out" system on the woefully uninformed, or misinformed, public.

They must also ensure that, when the public is so informed, there is a ready mechanism to hand for those who want to register their objection to being used as organ donors, as they are currently treated when only notionally dead.

DAVID W EVANS

Sometime consultant cardiologist at Papworth Hospital

Letter 2: Death and donors (Saturday, August 29 2011)

http://www.walesonline.co.uk/news/letters-to-the-editor/western-mail-letters/2011/08/29/western-mail-letters-monday-29-august-2011-91466-29319355/

SIR – Dr Paul G Murphy (Letters, Aug 13) infers that Dr David W Evans' anxieties on organ donation (Letters, July 2), that organ donors are not "dead" in the generally accepted sense, is only a personal view. Far from it!

If he searches the literature, as indeed he should, he will find many international authors in ethical and philosophical, as well as medical, journals, supporting his view. That is in spite of some editors choosing not to publish such information.

His statement that "The UK guidelines for the diagnosis of brain-stem death, prepared by the country's most senior medical bodies [with a strong transplant interest – I would add], have been used for more than 30 years and have never been demonstrated to be incorrect" is only evidence of a self-fulfilling prophecy.

These tests, introduced to establish irrecoverability were used either to withdraw further treatment and allow the patient to die, or else to harvest organs for transplantation. In either case, death supervenes and complaints would be few.

A patient diagnosed as dead for transplant purposes will have all major organs continuing to function (or they would be of no use for transplantation). Characteristics of life remain – respiration (exchange of gases), heartbeat and circulation, metabolism and excretion, reproduction (with IVF, and the maintenance of existing pregnancy), and response to the environment.

This last includes responses to the trauma of operation, similar to those involved in any major operation, such that muscle-paralysing drugs and some form of anaesthesia are required when the surgery is performed.

Dr Murphy should be (and probably is) aware of this, but that information has never been part of the consent procedure on Donor Card or Register, and I have been unable to establish from UK Transplant any guarantee that a potential donor will in fact be given anaesthesia.

Some anaesthetist colleagues withhold anaesthesia on the grounds that it cannot be needed for a “dead” patient, in spite of visible reactions.

The majority (I am pleased to say) do give anaesthesia, “just in case” and to allay the anxieties of other staff in the operating theatre. Before giving their consent, patients might care to know of this.

More than four centuries ago, in Romeo and Juliet, Shakespeare used Friar Laurence to describe (apparent) death in a way that most people would recognise today:

No pulse

Shall keep his native progress, but surcease:

No warmth, no breath shall testify thou livest;

The roses in thy lips and cheeks shall fade

To pearly ashes; thy eyes’ windows fall

Like death when he shuts up the day of life;

Each part depriv’d of supple government

Shall, stiff and stark and pale, appear like death.

(Romeo & Juliet. Act 4, Scene 1)

An organ donor will be warm, pink, supple, have pulse and circulation and be reactive. Surely those being asked to give consent, or if consent is to be presumed, should be allowed to know of the difference.

DR DAVID J HILL

Retired consultant anaesthetist, Huntingdon, Cambridgeshire

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)82 – Janet Secluna Thomas

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

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)83 - Sue Jamieson

Dear Ms Sarah Sargent,

I am opposed to presumed consent to organ donation for the following reasons:-

Presumed consent rules out the organ donation as a free gift and makes it compulsary for te donor's relatives let doctors have the organ(s).
In effect if no opposition to donation can be found the body becomes the the property of the state with which to do as it likes.
Presumed consent will not necessarily lead to more organs available for donation
Presumed consent may well be extended into other areas of medicine for example, removal of feeding tube without permission.
Takes no notice of serious concerns about current definitions and practices concerning death, are donors proven to be brain dead, or will donors have their organs removed while their hearts are still beating?
Families will have no or very little say in what happens to their loved ones' organs. II mean they could end up being stored or frozen for some future grisly use.
In short, *don't like the idea of Presumed Consent* and I don't want it legalised.

Yours sincerely,
Mrs Sue Jamieson,,
Basildon.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)84 - Jill Hutchinson

Dear Sir or Madam

I am writing as a private individual, who works as an accredited counsellor. Whilst I personally would be glad to donate any of my organs to assist with research or for transplants, I believe that the proposed legislations amounts to no consent, as it will be impossible to guarantee that every member of the public is informed of the law and the procedures for opting out.

As a counsellor I have some experience of the distress experienced by bereaved individuals, whose loved-ones have not been treated at or after death in what they consider a respectful way. Again, it would not be against my personal beliefs had one or more organs been removed from a close friend or relative, but I think for many people it would be extremely upsetting.

I would therefore urge you to reconsider your proposals and not to proceed with the introduction of this legislation.

Yours truly

Jill Hutchinson

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)85 - Annette Turner

18 January 2013

Opposition to ‘Presumed Consent’

Dear Ms. Sargent,

I am writing to oppose ‘presumed consent’ with regard to organ donation. In my view this very wording is misleading and the proposal should more accurately be called ‘compulsory donation’. My reasons are:

- It is an absolutely basic human right that people own their own organs and, once death is established, responsibility passes to their next of kin.
- Unless the patient is already carrying a donor card, it is more reasonable and likely to assume that they would ***not*** wish to donate their organs
- It appears to disregard the views of the patient’s family
- There is already concern that the need for organs may influence the treatment given to patients
- It is not appropriate and possibly not even fair, that a doctor should have to make this decision
- It would be impossible to isolate these decisions from pressure to reduce the organ waiting list
- Over time there is a risk of ‘parameter creep’ where a laxer and laxer standard is applied to establishing death
- This measure would potentially reduce the number of organs available for donation as people will protect themselves by carrying ‘anti-donor’ cards.
- This would materially erode the trust between the medical profession and patients, even as the ‘Liverpool Pathway’ is doing
- The recent and ongoing controversy regarding ‘sex selection abortion’ suggests what an appalling arena this proposal could open up for the exercise of prejudice and corruption.

I believe that this is a very bad proposal which no ‘safeguards’ could make safe or moral.

Yours sincerely,

Annette Turner
CHELTENHAM, GLOUCESTERSHIRE

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)86 - Stephen Keay

Dear Sir, Madam,

I would like to inform you of my disagreement with the potential policy to be passed in Wales regarding the presumed consent for organ donation.

Organ donation is a positive action, a gift from one person to another. Presumed consent is theft,pure and simple. When I lose the right over what to do with my body I have lost the last thing I have. I am a blood donor beacuse I want to give however if this legislation is passed along with a formal document to refuse my organs being taken from me I will also withdraw my blood donations.

Yours faithfully

Stephen Keay

Dear Committee Members,

I am very concerned to hear that there are proposals for organ donation to change from being Opt-in, to Opt-out as this would actually have the unintended consequence of meaning that people's bodies would effectively become the property of the State, and for the State to determine the future of, rather than, as at present, each individual being responsible for their own body; including having passed such responsibility to nearest and dearest at the appropriate time.

This proposal alarmingly also has the feeling of coercion trying to force people to do something against their will. It smacks of China's one child per couple type of dictatorial State interference.

I believe that there is also potentially a fundamental deceit going on here, as I understand that for organ donation to work, often organs are taken at the point where a person's life is no longer viable, so that they may have effectively died but actually haven't, since I understand the organs have to have been adequately recently alive in order to be viable as potential transplants.

Any scheme whereby citizens will be presumed to have consented to organ donation unless they file a formal refusal prior to their death raise serious ethical problems since presumed consent in effect equals no consent. Organ donation should, in fact, be treated as a voluntary gift characterised by free will by the owner - not a statutory obligation/State takeover.

In conclusion, I say NO.

Yours sincerely,

David G. Meacock.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)88– Iris Raile

I hereby want to voice my vote and say "NO" to automatic organ donation. It should be my right and choice and not predetermined by somebody else!

Iris Raile

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)89 – Godfrey Harverson

As a doctor, I fully agree with the importance of organ donation.
I am concerned that absence of stated consent should be taken as presumptive evidence of agreement.
Agreement of closest relatives is vital if no opinion has been recorded. It would be far better to encourage statements of consent during life, by increasing news coverage and highlighting this need in doctors' surgeries.
Legislating can only undermine the doctor-patient relationship and lead to a lack of trust by the electorate in those who govern.
Yours sincerely
Godfrey Harverson
Retired consultant radiologist

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)90 – Dr John R. Ling

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.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)91 – R. Winward

Hello,

I am writing because I am extremely concerned about your proposal to make organ donation automatic unless people opt out.

If you presume consent you are failing to ensure actual consent. Unless there is an extensive public information programme, which would need to capture *the entire adult population* including those on the margins of society, presumed consent in effect will be equivalent to no consent.

It is not clear how people will be able to ‘opt out’ and how this information will be readily available at time of death. Will people have to be tattooed with the information or have to carry special opt out identification cards at all times?

I also understand that there is no provision in the Bill itself for providing distressed relatives with a right to object to the removal of organs when no consent was given by the deceased. This goes completely against any idea of care for family and friends and the hope of a ‘good’ death.

This legislation will take Wales back into an uncivilised era where people are seen merely as body parts for recycling instead of unique human beings made in the image of God.

One of the very important rights we have as human beings is protection from torture and mistreatment. The Human Rights Act defines torture in the following terms; “Torture occurs when someone acting in an official capacity (for example a police officer or soldier) deliberately causes serious pain or suffering (physical or mental) to another person. This might be to punish someone, or to intimidate or obtain information from them.” In my view extracting body parts from someone without the consent of those who love them, at a time of distress, could easily be construed as torture.

This is a very dangerous and unwelcome proposed change to the current legislation, which is unlikely to achieve the desired objective of more organs for transplantation, and it should be abandoned now.

Thank you for giving us this opportunity to respond. Please listen to those who object and not only to those in favour.

With best wishes

R Winward

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)92 – Sheila Watters

I respectfully submit my grave reservations at this proposal.

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 versus15% 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 **<u>WAG's Recent Research Review to Update the Univ York Review of 2008.</u>** 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. **<u>Financial Estimates.</u>**

4.1 **<u>The QALY</u>** 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 **<u>Litigation.</u>** 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 **<u>Waste.</u>** 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,
[redacted]

Tel [redacted].

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)94 – Rhoslyn Thomas

To the clerk of the HSC Committee,

Mark Drakeford said, on the 10th December 2012, that the HSCC would be looking at the principles of the Human Transplantation Bill.
Before doing this, I believe it is vital to acknowledge that the consultations carried out by the Welsh government, who are proposing the bill, were very poorly executed. Not only that, but when addressing the responses to the consultations, the Welsh government seemed either to ignore all opposition the bill or to acknowledge and then disregard it. Lesley Griffiths said of the White Paper consultation in January 2012,

"91% of the responses we received did indicate an overall view, with 52% (646) of respondents supporting the proposals and 39% (478) opposed"

Of the 646 letters in support of the bill, 485 were standard letters and 52 were identical e-mails. In contrast, of the 478 letters in opposition, 478 (that is, every single response in opposition) were individual responses. Yet, both the standard and individual responses were given equal weight by the Health minister. However, when the opposition decided to use standard letters, given that individual letters had been, unjustly, counted as equal to standard letters, Lesley Griffiths now decided that she preferred "carefully considered responses" as opposed to standard letters.

On the 19th of October, 2012, Lesley Griffiths said,

"We received an excellent response to the consultation, with 2,891 replies received before the deadline. The vast majority of the responses [2,601] were in the form of a standard letter which raised a number of specific issues. A smaller number of responses gave detailed and considered comments to the questions. We are grateful to all respondents for their contributions"

Double standards are not befitting of someone who is supposed to represent *all* Welsh citizens, both those who are for and against this bill.

If one considers the principles of presumed consent, it seems quite obvious that it is immoral and nonsensical to assume that someone has consented to giving a part of their body if they have not expressly said "no". In our society, consent is everything, especially regarding our bodies. Nowadays, rape is a subject of much concern. If a woman has not expressly said "no" to a man, does that mean she has said "yes"? Of course it doesn't. In the same way, the Welsh government cannot assume that because a Welsh citizen may not have expressly said that they are against the removal of their organs, that their organs may be taken.

The Welsh government is at risk of turning Welsh citizens against Organ Donation in any form if they continue with this totalitarian piece of legislation.

Yours Sincerely
Rhoslyn Thomas

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)95 – D. R. Davies

I do not agree that organ donation should be automatic after death. Presumed consent is wrong. The Welsh Government has no right to introduce this measure without a referendum.

Yours sincerely
D. R. Davies (Mrs)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)96 – **Bernie O'Hanlon**

Dear Sir,
I hope you will consider asking people first through voting how they feel about automatically donating their organs.
I think organ donation is a great idea and perhaps doctors could help in asking their patients if they would like to enroll on a list.
I think this would be better than going ahead without infringing on the human rights of the people of Wales.
It is this very action of automatically opting people in that annoys them because they havent been asked.
If asked, you may find that people would gladly offer their organs to help save another and perhaps offer even more such as the donation of their body to science.
I hope you will take my oponion into consideration vefore your next course of action.

Regards,

Bernie O' Hanlon.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)97 – Eve Gilkes

Dear Sir/Madame,
I am aware that the deadline has passed for any comments on 'whether to introduce a new scheme whereby all citizens in Wales will be presumed to have consented to organ donation unless they file a formal refusal prior to their death.'
I am very much against this.
Organ donation is a very deep emotional area.
Corneas and kidneys can be taken from a dead body and used, as well as other body parts …….. BUT ……. hearts are a different matter. A dead heart is no good to anyone, so has to be taken from a live body, albeit on 'a life support machine'
I have spoken to a Dr an anaesthetist who confirms my feelings by what he has in fact seen.
A donation is a gift, 'organ donation' it is called, but you are taking away the gift, it is no longer a gift, a free will offering, if you go down the route you are tentatively planning at his stage.
I hope you will think long and hard .... and pray about it.
Yours very concerned,
Eve Gilkes (Mrs)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)98 – Daniel Blackman

Written submission to the Health and Social care Committee regarding proposals to introduce "deemed" (presumed) consent for organ donation.

Organ donation can be seen as a generous and free gift, and should remain as such. This is premised on respect for the human dignity of the donor and the recipient, and the high regard we place on human life. Another vital premise is that of free and informed consent, so that the donation of an organ is respected as a free gift. For the sake of these important premises, I am opposed to the introduction of presumed consent for organ donation.

Before we even consider the issue of consent for organ donation, we need to address the deeply concerning issue of what definitions are being used to determine whether someone is dead. Is 'Brain-death' actual death, to our certain knowledge? As David W Evans MD, FRCP has noted:

> "The basis upon which a mortally sick patient is declared "deceased" – for the purpose of acquiring his or her organs for transplantation without legal difficulties – is very different from the basis upon which death is ordinarily diagnosed and certified and that highly relevant fact is not fully and generally understood."

The proposals ignore the facts concerning this area of scientific dispute, yet this is a question with enormous ethical implications. Most organ donors are unaware that their hearts may be beating when their organs are taken, and that they may be pink, warm, able to heal wounds, fight infections, respond to stimuli, etc. They are also unaware of common practices of paralysing and (sometimes) anaesthetising supposedly brain dead donors before their organs are taken. Simply signing a donor card does not in any way indicate that the prospective consenting donor understands what will be involved - and those who are merely 'presumed to consent' by the State are likely to know even less.

It is extraordinary that the issue of determination of death, which must govern consideration of so many other issues in organ donation, is so often ignored, in spite of the US President's Council findings and the growing scholarly literature on the question. That the public are not made aware of the controversy is deeply regrettable. Notions of informed consent, let alone presumed consent, are meaningless unless the facts of the matter are openly discussed and considered.

The evidence suggests that a system of presumed consent will not improve organ donation rates in Wales. As it stands, Wales already has one of the highest organ donation rates in Europe (27.7 per million). The UK's Organ Donation Taskforce in 2008 concluded:

> "...after examining the evidence, the Taskforce reached a clear consensus in recommending that an opt out system should not be introduced in the UK at the present time. The Taskforce concluded that such a system has the

> potential to undermine the concept of donation as a gift, to erode trust in NHS professionals and the Government, and negatively impact on organ donation numbers. It would distract attention away from essential improvements to systems and infrastructure and from the urgent need to improve public awareness and understanding of organ donation. Furthermore, it would be challenging and costly to implement successfully. Most compelling of all, we found no convincing evidence that it would deliver significant increases in the number of donated organs."

According to the Clinical Director of the *Organizacion Nacioanl de Trasplantes* in Madrid, Rafael Matesanz, the evidence for a positive impact of presumed consent is very thin.

> "It [an opt out system] contributes little or nothing to the improvement of organ donation rates and, on the debit side, diverts precious resources to imaginary rather than effective solutions."

Three further points should also be highlighted. First, the Welsh government must draw back from measures that could put added pressure and even soft forms of coercion upon the family of a deceased person, which could be the case if presumed consent is introduced.

Second, there is no respect for the right of conscientious objection for medical professionals and Welsh ministers, who will in different ways, be expected to comply with presumed consent as stated in the draft Bill. Conscientious objection is a vital right that must be protected.

The third point is that anyone living for 6 months or more in Wales will be opted-in. This is unfair and will pose a significant challenge when it comes to ensuring every single person is informed and allowed easy access to methods for opt-out, and also information on practices relating to definitions of death being used in medical practice.

For these reasons I hope that presumed consent for organ donation will not be introduced in Wales. Providing ethical standards are met regarding the determination of death, organ donation can be a praiseworthy practice. The evidence indicates that presumed consent is not ethical and practically ineffective.

Daniel Blackman
Emailed on 18th January 2013

15.01.13

Dear Ms Sargent,

I'm writing to register my opposition to introducing planned consent for organ donation in Wales or any other part of the United Kingdom. This would be an extremely serious development, rendering organ donation no longer in any way 'voluntary' and overturning the idea of organ donation as a free gift.
In practical terms, it would make the body the property of the state, not the individual. This, especially when taken in conjunction with the increasingly serious concerns about the current definition of death, is extremely disturbing. At what medical stage might the state in future find it expedient to consider a person 'dead'? Already, as David W Evans MD, FRCP has noted:

"the basis upon which a mortally sick patient is declared "deceased" – for the purpose of acquiring his or her organs for transplantation without legal difficulties – is very different from the basis upon which death is ordinarily diagnosed and certified and that highly relevant fact is not fully and generally understood."

There is also evidence that presumed consent does not necessarily result in more organs available for transplantation, whilst it does fundamentally alter the meaning of the word 'consent'.

The proposed bill will give families little or no say in what happens to their loved ones and amounts to the legal imposition of State ideology. The drastic reduction in family involvement is especially horrifying considering the growing controversy over the definition of death. Will families have to allow their - in their eyes - living relative to be wheeled away, paralysed with drugs, anaesthetised and dismembered?

The immediate and future consequences of bringing in implied consent are so morally dubious and fraught with ethical danger that the government should concentrate on promoting genuinely voluntary organ donation, with appropriate engagement - and transparency - about the ethical demands surrounding the definition of death.

I hope you will oppose this bill in its entirety.

Yours Sincerely,

Sarah Gardiner

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)100 – Ian and Rachel Bevington

My husband and I would like to say 'NO' to this draft bill of the Human Transplantation (Wales) Bill.
Presumed consent really equals no consent.
There needs to be a public information programme which reaches all, including those on the margins of society.
Such a bill makes the whole concept of 'presumed' or 'deemed' consent ethenically problematic. It would be expensive to administer.
The Bill, as it stands, does not allow for families to object or opt out. And there would be very many distressed relatives who have no legal right to stop removal of organs when no consent was given by the deceased.
If this Bill is to become legal it is essential that the views of surviving family members are respected within the legislation itself. The National Assembly for Wales should amend the Welsh Government's Bill to make this commitment clear.
Yours sincerely,
Ian and Rachel Bevington

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)101 – Brendan K. and Jennifer A. Cleary

MR MARK DRAKEFORD A.M. CHAIRMAN
HEALTH & SOCIAL CARE COMMITEE
NATIONAL ASSEMBLY FOR WALES
CARDIFF BAY
CARDIFF CF99 1NA

RE CONSULTATION – HUMAN TRANSPLANTATION BILL

Dear Mr Drakeford,

I oppose the so called Presumed Consent/Deemed Consent of taking human organs at a person's death. It is disingenuous to refer to those who do not objecte in writing as having an implied or presumed consent, when it is anything but consent!

How can you ensure that everyone in Wales knows that the criteria for removing organs has changed? We hear no reference to this. This is particularly relevant to short-term stay people such as students and those who move to Wales to work for the long term.

Increased availibility of viable organs could be obtained in other ways e.g. reduce the high rate of damage to organs during

removal from the donor, making them unusable
It seems strange that the Assembley does
not address this problem.

If this last point was addressed the
proposed Bill could become superfluous.

Yours faithfully

Brendan K. Cleary

Jennifer A Cleary

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)102 - John Griffin

[redacted]

Sarah Sargent,
Deputy Clerk,
Health and Social Committee,
National Assembly for Wales,
Cardiff.
CF99 1NA

Dear Sahra,

Human Transplant (Wales) Bill

I would appreciate if you would kindly place before the Committee my reasons for not supporting the introduction of proposed legislation, as listed below:-

1 At any time in the future, it will be most difficult or even impossible for Ministers to refrain from promoting transplantation. Does the Welsh nation want such an authoritarian imposition on their representatives? I certainly do not wish to see us ruled by dodgy ideology. (Section 2 of the Bill)

2 The whole subject of "deemed consent" is so convoluted and emotionally charged. This will result in unnecessary trauma being suffered by the next of kin, with the likelihood of expensive and lengthy legal proceedings. I believe that such costs should not be placed upon these people or the NHS.

3 Our forebears in their struggles to obtain democracy, would never have supported a situation where the Authorities could claim and help themselves to the organs of the deceased. In those days, our ancestors would have been well aware of the sufferings caused by such highhanded arrogance. So let's not put the clock back.

4 The medical experts are seriously divided on the certainty of "Brain Death". Until the profound misgivings associated with the whole concept are 100% resolved, it behoves us to not only to protect the dying donor but also to avoiding adding to the harrowing grief experienced by families who were not consulted,

5 There appears to be no clause in the draft Bill of allowing medical staff to refuse to participate in such operations on grounds of conscience. Another example of blinkered intolerance.

I appeal to the committee to abandon the whole project, thereby allowing our nation to be proud of its history of organ donations and to strive to increase the number of donors based upon ethical informed consent.

Yours truly,

John Griffin

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)103 – F & B Mabbs

Address – [redacted]

Date –

14 - 1 - 2013

Mr Mark Drakeford, A.M. Chairman,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay,
CARDIFF CF99 1NA

<u>Re: Consultation – Human Transplantation Bill</u>

Dear Mr Drakeford,

Firstly, may I encourage you to support a time extension to consultations re this Draft Organ Donation Bill. The Christmas period has eaten into the time allocated, who on earth would have the time, or even the inclination to respond while rushing around preparing for Christmas?

My main objection to the Bill is that of presumed consent, this phrase is simply a lie. There is, or can be no such thing as consent which is <u>presumed</u>, and my body is not the property of the State. It is beyond belief and frightening that in a so called democratic society any Government could take peoples organs without the deceased person's consent and under the terms of this Bill, without the consent of the their family.

Please reject this stealing of bodies Bill.

Yours sincerely,

F Mabbs
& B Mabbs.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)104 - Eileen Rowlands

Clerk to the Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF991 NA

[redacted]

January 22, 2013

Dear Sir,

Due to family commitments, I have only very recently been made aware that the National Assembly Committee opened a consultation on the Human Transplantation(Wales) Bill, which closed on 18th January, 2013.

Mark Drakefield AM, chair of the Health and Social Care Committee, states,
'The Welsh Government has already undertaken a significant consultation on this Bill before proposing it....'
I completely disagree with this statement. I have been involved with the issue of organ donation for twenty six years, and have attended all the public consultation meetings in the Swansea, Neath/ Port Talbot venues since January 2008. All of these meetings were poorly publicised and abysmally attended by the Welsh public.
January 2008 - Neath/Port Talbot - 5 attendees
November, 2011 Aberavon Beach Hotel- Approx. 15 attendees
January,2012 Brangwyn Hall Swansea-Approx. 20 attendees
July, 2012 Swansea University Approx 14 attendees

I have responded to the consultation documents and read all the responses. I would hope it is encumbent on all AMs and the First Minister to have read those responses too.

No AMs attended any of the public consultation meetings for the above areas and consequently could not gauge public feeling about the issue of legislation for a soft opt out organ procurement system. I have met with Edwina Hart, the former AM for Health and also Peter Black who seemed unaware of some facts relating to the procedures involved in organ donation.

Similarly, Dr. Chris Jones, Cardiologist, Medical Director of NHS Wales and presenter of two of the Consultation meetings, admitted at the Brangwyn Hall in January 2012, that he had only recently become familiar with the necessary procedures involved in organ retrieval. i.e. Potential organ donors are identified when admitted to ITUs with critical head injuries or traumas and subsequently diagnosed as brain stem dead NOT brain dead.

If representatives of the Welsh people in the Welsh Government are not adequately educated about all aspects of this issue, how can the public be given clear and transparent information on which to express true opinion and choice?

The consultation meetings I have attended have been biased by representatives of the Welsh Government in favour of legislation and were really only interested in gathering opinion and ideas on the implementation of the proposed legislation. No real public debate has been initiated by the Welsh Government where public opinion about all the issues surrounding legislation for a soft opt out system for organ RETRIEVAL has been welcomed and taken into account. Those opinions and concerns at these meetings were expressed despite organisers attempting to steer the dialogue to pre - arranged script ie. The consultation document with its pre-scribed ., specific questions.

The consultation meeting held at Swansea University in July, 2012, was again poorly attended. It seemed strange to me at the time that I appeared to be the only independent member of the public present. As other people began to arrive I became aware that they were present in a medical / professional capacity. I later learned, via the media , that Lesley Griffiths had issued invitations to 'stakeholders' for these consultation meetings, but relied on poorly publicised and short noticed information for Joe Public. I was appalled at the term ' stakeholder ' which infers someone with a particular or vested interest in the success of this legislation. It was evident to me that ordinary members of the public, without an invitation, were not expected to attend .

During that meeting, I brought up the requirement for clarity and transparency with regard to informing families about brain stem death diagnosis and the context in which organ retrieval would proceed. I was challenged by another attendee who suggested that the public should trust the medical profession implicitly and that discussion of the complexities of brain stem death would not be appropriate. A heated exchange ensued where I found it necessary to declare my personal experience in such a situation. Following the meeting, I was informed that this individual was an intensive care consultant. This is a professional who should have a duty of care to the patient's family; a family, who , if not fully informed pror to a tragedy occurring, should have ALL information when a potential ' deemed to have opted out ' scenario occurs.

The Welsh Government has made numerous misleading statements regarding public attitudes to a soft opt out RETRIEVAL{ not donation} legislation. They have massaged statistics in their favour and have badly managed and organised public information and meetings. They have also given misleading information regarding the success of an opt out system in other European countries.

The Welsh public are being hoodwinked by this vain and arrogant Welsh Government whose political and economic aims are being disguised as altruistic values.They want to be seen as leading the way on this highly provocative legislation....Metaphorically, exercising the Welsh Dragon's fire !

I am forwarding copies of my responses to the UK Parliament and the Welsh Governments consultation, together with letters and articles I have written to the press over a period of time.

Even though the period of response has ended, I hope that my letter and documents will be received and considered as a serious contribution to the National Assembly Committee's consultation.

I am not opposed to organ donation per se, providing it is based on a free and informed choice. Legislation should not replace goodwill.... It may even dispel goodwill and reduce organ donation rates. The Welsh Government is taking a huge risk and may rue the day this Bill was ever proposed.

There is no substitute for goodwill and no publicity more powerful than word of mouth.

Yours faithfully,

Eileen Rowlands (B. Ed. Hons.)

E. Rowlands.

[redacted]

29 January 2012

Organ Donation Bill Team
Medical Directorate
Cathays Park
Cardiff
CF10 3NQ

Re: Consultation on the Proposals for Legislation on Organ and Tissue Donation

I am unable to use the above Consultation response form as it does not accommodate any questions which have pertinence for my concerns and objections for its introduction and implementation.

I believe that legislation for organ donation should not be considered under any circumstances, but particularly when there is little transparency or clear information on what the actual process involves for potential donors and their families. There is a current lack of public information regarding the diagnosis of brain stem death and the process that is required for retrieval of viable organs for transplantation in the present "opt in" UK system. Many misconceptions exist amongst the general public regarding the perception of death for the purpose of organ donation. But, at least, individuals, who take that positive, proactive step to "opt in" would hopefully have sought some information and discussed it with their families, prior to a tragic event occurring.

The failure to opt out cannot possibly be interpreted, via legislation, as presumed consent or acquiescence. The probabilities that a person who has not "opted out" would have sought information about organ donation and discussed it with his/her family, would be very low or non existent. A soft opt out system where such families are approached and consulted about their relative's intention would be acting on guess work ; it would be taking advantage of a lack of pre informed choice, ignorance and apathy. Such a system would acquire donor organs and tissue by default through pressured persuasion from dedicated health personnel intent on meeting targets.

I am a parent of an eighteen year old donor who has suffered as a result of the lack of transparency of information and who has researched this issue for over twenty years. I did not consider the diagnosis of brain stem death to be the biological death of my son when I offered his organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But despite asking to be present when the ventilator was switched off, I was not aware, nor made aware that my son would still be ventilated when his organs… his heart, his liver (which was not used because a transplant team was unavailable to perform the transplant operation), and his kidneys were removed from his body. Moreover, having discussed organ donation with him I know that he also was completely unaware of this information. When I discovered, incidentally, some months later, that my son's heart had been removed whilst it still beat, I was devastated.

Over the years, I have expressed my intrinsic belief that my son had not biologically expired at the point of brain stem death diagnosis. Often I was not taken seriously and sometimes perceived with derision and animosity by some professionals with a vested interest in organ transplantation. However, in the last few years, after a great deal of research, those beliefs have been validated. One research study of patients who had been diagnosed as brain stem dead but not considered as organ donors, were observed not to have biologically expired over various periods of time and that the brain stem continued to control certain functions in the patient's body.

Then, at the time of my son's critical injuries, as now, the diagnosis of brain stem death through bedside tests, the futility of further treatment, and the lack of hope for recovery, does not mean complete biological death. Brain stem death is only a moment in the process of dying when viable organs may be retrieved for transplantation. In fact:

"There is no scientific basis for equating the state known as "brain stem death", as diagnosed by the UK Code, with the death of the person".

"A Code of Practice for the Diagnosis and Confirmation of Death"

Academy of Medical Royal Colleges (70 Wimpole St, London) October, 2008.

For some individuals that futility and lack of hope may be good enough reasons to allow their loved one to be used for organ and tissue retrieval. . For my family and many people I have spoken to they are not. To be compelled, by law, and not by choice, to opt out in order to uphold our belief , is a travesty.

With regard to the public Consultation meetings held in various venues in Wales, my husband and I have attended all those organised for the area between Carmarthen and Cardiff. The first, in January 2008, held at the Neath / Port Talbot civic buildings where only five members of the public attended. The second meeting held in November 2011 at the Aberavon Beach Hotel where only twelve members of the public attended, and recently, in January 2012, at the Brangwyn Hall , Swansea, where approximately twenty five members of the public attended. These numbers are hardly representative of the Welsh population in the South West region of Wales and indicate an enormous sense of disinterest, more important personal priorities, or even just plain apathy for the proposed legislation. (Especially when compared to some months earlier, when in May 2011, I stood outside the Brangwyn Hall amongst crowd of thousands celebrating the success of Swansea City Football Club.

Moreover, the inadequate prior notice and lack of publicity for these Consultation meetings, left a great deal to be desired from the Welsh Government and its intentions for healthy public debate. Additionally, the designated times for all these meetings were not conducive to the attendance of the working population in Swansea and outlying regions.

I am proud and privileged to live in Wales, but I am also a citizen of the United Kingdom. The evidence from the UK Parliament Task Force did not find it appropriate to introduce this legislation. Why does the Welsh Government arrogantly believe that it is appropriate for the Welsh nation to be the human salvage yard, via legislation, for the whole of the UK Transplant Service.

Should the Welsh Government surge ahead with its proposal for legislation, it may find that its misguided intentions will backfire , leading to many people opting out and a consequential drop in organ donor rates.

Eileen Rowlands (B.Ed. Hons.)

(David Davies M.P.).

[redacted]

David Davies MP.
The Grange,
16, Maryport St.,
Usk,
Monmouthshire,
NP15 1AB

7.3.2011

Dear Mr. Davies,

I am writing to you as a Welsh,United Kingdom citizen,in your capacity as Chair of theWelsh Affairs Select Committee in Parliament.I am extremely concerned about the Welsh Assembly's current proposal to introduce a law on organ donation, in favour of Presumed Consent.

I am aware that the matter has been referred to the Committee and Attorney General for further scrutiny and have listened to recent debates about the issue on BBC Wales television,in particular, Dragon's Eye, February 17. None of these debates have described how a person will possibly come to be considered as an organ donor or the procedures that will occur when retrieving organs. Very real issues which the general population should know when making vital decisions. In my experience, so few do!

I do not believe that the Assembly are competent enough to legislate on all matters that relate to Health and Health Services in Wales. I believe there is a conflict of interests in this area, especially since the Neurological Department at Morriston Hospital in Swansea has been transferred to Cardiff. Critically head_injured patients in Swansea and further west would have to be transported and treated there, and consequently might lose precious time in which injuries and their effects worsen.

I believe that the AM for Health has a responsibility to these patients, but by closing the critical neurological department at Morriston Hospital she has deprived them of the early intervention they require for optimum recovery.

Research stresses the importance of quick and professional treatment very soon after head injury. In many cases adequate treatment could minimize medical damage and lessen the mortality rate. The importance of getting a patient to a medical centre for appropriate treatment within the VERY FIRST HOUR from the moment of injury.....the ' Golden Hour ' cannot be stressed enough.

Quicker link_up with senior medical personnel, use of advanced technologies of location , diagnosis, monitoring and treatment from the very first moment of injury, should be initiated in order to improve the chances of survival and lessen the chance of death.

Perversely, these will be the patients (not yet cadavers) who will be considered as 'presumed donors'! Energy and resources should be directed in this area, rather than towards changing a system which already works, and introducing a law which will do little to improve the chances of potential organ recipients.

Early intervention for critically, brain injured patients could alleviate swelling of the brain and pressure on the brain stem... the main cause of ' brain stem death'. Brain stem death became a very convenient criteria for diagnosis of death in the UK, when the technology and requirement for human transplantation became more successful and demanding.

However, I, as an individual, an intelligent, articulate mother, did not consider the diagnosis of brain stem death to be final expiration of my son, when in 1987, I offered my sons organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But, despite asking to be present when the ventilator was switched off, I was not aware, nor made aware, that my son would still be ventilated when his organs...his heart, his liver, his kidneys, were removed from his body. Moreover,having discussed organ donation with him, I know that he also was completely unaware of this information.

The perception of death is a very personal one, but research has shown that even in someone who has been declared as brain stem dead, the brain still retains residual energy.

Most significantly, in their pursuance at any cost, of introducing legislation for Presumed Consent, AMs, Edwina Hart and Dai Lloyd must consider, that although clinical guidelines have been developed to define brain stem death, these have not been incorporated into legislation, which means the diagnosis is NOT A LEGAL DEFINITION OF DEATH.

I enclose several attachments for your perusal and consideration: A letter submitted to my local newspaper and printed as an article. Also enclosed is a copy of research I have discovered since writing this letter, with significant points highlighted for scrutiny.

I understand that Lord Dafydd Wigley plans to raise the issue in the UK Parliament's second chamber and this question is scheduled to be answered in the Lords on Wednesday, March 23

I trust you will read my letter and its contents and give them consideration in the scrutinization process. If the working parties for Parliament did not find it appropriate to introduce legislation for Presumed Consent for the rest of the UK, then it is not appropriate for Wales!

I look forward to your response.

Yours sincerely,

Mrs. Eileen Rowlands

[redacted]

January 25th 2011-01-24

Evening Post
Adelaide Street
Swansea

Dear Sir,

The Evening Post 'We Say' column,Friday,January14,2011,refers to the Welsh Assembly's proposed Legislation for 'Presumed Consent' regarding organ donation,as a 'small administrative change.'

I take issue with this statement since the proposal will devalue the positive altruistic process of giving willingly.The success of the legislation will depend to a great extent on the premise that many people will not take the deliberate and purposeful steps to 'opt out' of the donation process.

There are many areas of society where people,who may,through apathy,lack of knowledge on the issue,or more pertinently,have personal priorities such as homelessness,poverty,etc.,which override or obscure their concerns for other people.Whatever the reasons,these should be respected.

Legislation will not increase the number of donors.This will only occur if there is a rise in the number of people who receive critical head injuries through road or other accidents and traumas such as stroke or brain haemorrhage which renders the patient deeply unconscious,able to be ventilated and not dead on arrival at hospital.

Spain is often cited as a successful example of how Preumed Consent works.However,Spain and other European countries which operate this system have a less successful road safety history than the U.K.Consequently,there are more critically injured patients received into trauma units.Moreover, in the U.K.the risk of stroke has been reduced by the successful diagnosing,monitoring and treatment of hypertension and high cholesterol levels.

Recently,the Secretary of State for Wales informed the Assembly that the proposed law for Presumed Consent would be placed before the Attorney General and the pre-legislative committee In Central Government.Concerns were expressed that it would not be appropriate for the Assembly to undertake this legislation as it may contravene aspects of the Human Rights Act.

Edwina Hart AM ,Dai Lloyd AM and other members of the Assembly were surprised by this statement as it was delivered so close to the date for the Welsh referendum on its law making powers.Part of their response stated that Wales has been preparing for this change in the system to Presumed Consent for over two years.Part of this preparation was to place the debate in the public arena.

Two years ago,several public debates were held in a few areas of Wales,over a short period of time and with little notice or publicity.No meeting was organised for Swansea,the second city of Wales! The nearest meeting for the Swansea area and west towards Carmarthen was held in the Neath,Port Talbot Civic buildings on January 13 2009.

Five members of the public bothered to attend that meeting! My husband and I,parents of an eighteen year old son whose organs were donated for transplant; a female kidney recipient and an elderly couple with an altruistic interest in the issue.The three panel members ,a consultant urologist,a consultant anaesthetist and a transplant coordinator all had a biased interest in promoting Presumed Consent.An administrative representative from the Assembly conducted the meeting. There was no AM present!

The lack of interest from the general public on this occasion could not have been more indicative of what will probably occur if an 'opting out' system is introduced.

The Evening Post opinion 'We Say',and others who support this legislation at any cost refer to market research which allegedly indicates that 90% of people support organ donation.In my experience,over twenty years of speaking to many people,in all walks of life about their views, very few have sufficient information on which to make informed choices.

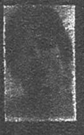
There are so many aspects of this issue to be taken into account before legislation should even be considered.Who will decide what organs a 'presumed donor' would be willing to donate? A heart, a liver.....a face! An arm. All body parts!.

To quote the Evening Post, 'over the years donation has become more common', but that should not lessen the perception that it is a gift. A gift does not require legislation. 'Presumed Consent' will reduce the altruistic act of organ donation to one of acquisition by default and at worse requisition.

Yours faithfully,

Mrs.Eileen Rowlands

Organ donation should still be a gift - not a regulation



By Eileen Rowlands, West Cross

THE Evening Post We Say column on Friday, January 14, referred to the Welsh Assembly's proposed legislation for "presumed consent" regarding organ donation as a 'small administrative change".

I take issue with this statement, since the proposal will devalue the positive altruistic process of giving willingly. The success of the legislation will depend to a great extent on the premise that many people will not take the deliberate and purposeful steps to "opt out" of the donation process.

There are many people who may, through apathy, lack of knowledge on the issue, or more pertinently, personal priorities such as homelessness or poverty, have over-riding issues that obscure their concerns for other people. Whatever the reasons, these should be respected.

Legislation will not increase the number of donors. This will only occur if there is a rise in the number of people who receive critical head injuries through road or other accidents and traumas such as stroke or brain haemorrhage, which renders the patient deeply unconscious, able to be ventilated and not dead on arrival at hospital.

Spain is often cited as a successful example of how presumed consent works. However, Spain and other European countries which operate this system have a less successful road safety history than the UK, and consequently there are more critically-injured patients received into trauma units. Moreover, in the UK the risk of stroke has been reduced by the successful diagnosing, monitoring and treatment of hypertension and high cholesterol levels.

Recently, the Secretary of State for Wales informed the Assembly that the proposed law for presumed consent would be placed before the Attorney General and the pre-legislative committee in central Government. Concerns were expressed that it would not be appropriate for the Assembly to undertake this legislation as it may contravene aspects of the Human Rights Act.

AMs Edwina Hart and Dai Lloyd, and other members of the Assembly, were surprised by this statement as it was delivered so close to the date for the Welsh referendum on its law-making powers. Part of their response stated that Wales had been preparing for this change in the system to presumed consent for more than two years. Part of this preparation was to place the debate in the public arena.

Two years ago, several public debates were held in a few areas of Wales, over a short period of time and with little notice or publicity. No meeting was organised for Swansea, the second city of Wales. The nearest meeting for the Swansea area and west towards Carmarthen was held in the Neath Port Talbot civic buildings on January 13, 2009.

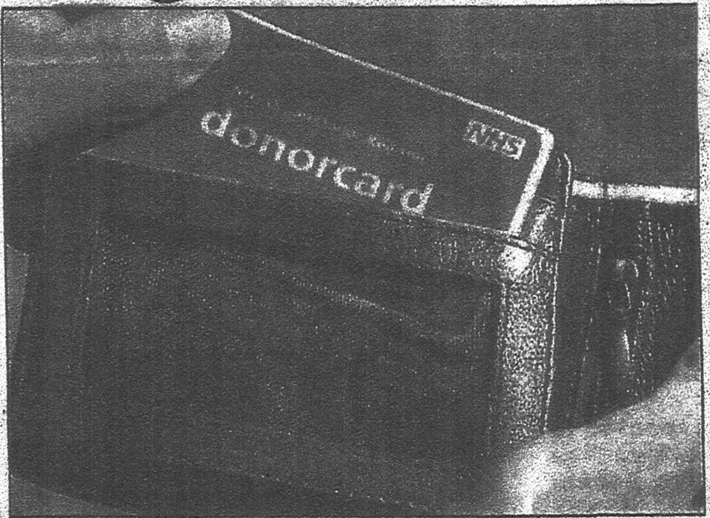
Five members of the public bothered to attend that meeting! My husband and I, parents of an 18-year-old son whose organs were donated for transplant, a female kidney recipient and an elderly couple with an altruistic interest in the issue. The panel — three members, a consultant urologist, a consultant anaesthetist and a transplant co-ordinator — all had a biased interest in promoting presumed consent. An administrative representative from the Assembly conducted the meeting. There was no AM present.

The lack of interest from the general public on this occasion could not have been more indicative of what will probably occur if an "opting out" system is introduced.

The Evening Post We Say column, and others who support this legislation at any cost, refer to market research which allegedly indicates that 90 per cent of people support organ donation. In my experience, after more than 20 years of speaking to many people, in all walks of life about their views, very few have sufficient information on which to make informed choices.

There are so many aspects of this issue to be taken into account before legislation should even be considered. Who will decide what organs a "presumed donor" would be willing to donate? A heart, a liver ... a face? All body parts.

To quote the Evening Post, "over the years donation has become more common", but that should not lessen the perception that it is a gift. A gift does not require legislation. Presumed consent will reduce the altruistic act of organ donation to one of acquisition by default and at worse requisition.



SPECIAL GIFT The Assembly is proposing new legislation on organ donation.

Duty Calls

SWANSEA Lord Mayor Richard Lewis will attend:
Tomorrow: No civic engagements
Monday: 9am Welcome assembly for International Inspiration Olympic 2012 Indonesian delegation, Gors Community School, Townhill, Swansea.
10.30am Welcome assembly for International Inspiration Olympic 2012 Indonesian delegation, Penyrheol Primary School, Gorseinon.
2pm Viewing of the Ugly Lovely Town exhibition, Swansea Museum.
7pm Valentine Evening in support of the Lord Mayor's charity, Mansion House, Swansea.

Neath Port Talbot Mayor Leila James will attend:
Tomorrow: No civic engagements
Monday: No civic engagements

Carmarthenshire chairwoman Tegwen Devichand will attend:
Tomorrow: No civic engagements
Monday: 10am Executive board meeting, County Hall, Carmarthen.

[redacted]

29 January 2012

Organ Donation Bill Team
Medical Directorate
Cathays Park
Cardiff
CF10 3NQ

Re: Consultation on the Proposals for Legislation on Organ and Tissue Donation

I am unable to use the above Consultation response form as it does not accommodate any questions which have pertinence for my concerns and objections for its introduction and implementation.

I believe that legislation for organ donation should not be considered under any circumstances, but particularly when there is little transparency or clear information on what the actual process involves for potential donors and their families. There is a current lack of public information regarding the diagnosis of brain stem death and the process that is required for retrieval of viable organs for transplantation in the present "opt in" UK system. Many misconceptions exist amongst the general public regarding the perception of death for the purpose of organ donation. But, at least, individuals, who take that positive, proactive step to "opt in" would hopefully have sought some information and discussed it with their families, prior to a tragic event occurring.

The failure to opt out cannot possibly be interpreted, via legislation, as presumed consent or acquiescence. The probabilities that a person who has not "opted out" would have sought information about organ donation and discussed it with his/her family, would be very low or non existent. A soft opt out system where such families are approached and consulted about their relative's intention would be acting on guess work ; it would be taking advantage of a lack of pre informed choice, ignorance and apathy. Such a system would acquire donor organs and tissue by default through pressured persuasion from dedicated health personnel intent on meeting targets.

I am a parent of an eighteen year old donor who has suffered as a result of the lack of transparency of information and who has researched this issue for over twenty years. I did not consider the diagnosis of brain stem death to be the biological death of my son when I offered his organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But despite asking to be present when the ventilator was switched off, I was not aware, nor made aware that my son would still be ventilated when his organs… his heart, his liver (which was not used because a transplant team was unavailable to perform the transplant operation), and his kidneys were removed from his body. Moreover, having discussed organ donation with him I know that he also was completely unaware of this information. When I discovered, incidentally, some months later, that my son's heart had been removed whilst it still beat, I was devastated.

Over the years, I have expressed my intrinsic belief that my son had not biologically expired at the point of brain stem death diagnosis. Often I was not taken seriously and sometimes perceived with derision and animosity by some professionals with a vested interest in organ transplantation. However, in the last few years, after a great deal of research, those beliefs have been validated. One research study of patients who had been diagnosed as brain stem dead but not considered as organ donors, were observed not to have biologically expired over various periods of time and that the brain stem continued to control certain functions in the patient's body.

Then, at the time of my son's critical injuries, as now, the diagnosis of brain stem death through bedside tests, the futility of further treatment, and the lack of hope for recovery, does not mean complete biological death. Brain stem death is only a moment in the process of dying when viable organs may be retrieved for transplantation. In fact:

> "There is no scientific basis for equating the state known as "brain stem death", as diagnosed by the UK Code, with the death of the person".
>
> "A Code of Practice for the Diagnosis and Confirmation of Death"

Academy of Medical Royal Colleges (70 Wimpole St, London) October, 2008.

For some individuals that futility and lack of hope may be good enough reasons to allow their loved one to be used for organ and tissue retrieval. . For my family and many people I have spoken to they are not. To be compelled, by law, and not by choice, to opt out in order to uphold our belief , is a travesty.

With regard to the public Consultation meetings held in various venues in Wales, my husband and I have attended all those organised for the area between Carmarthen and Cardiff. The first, in January 2008, held at the Neath / Port Talbot civic buildings where only five members of the public attended. The second meeting held in November 2011 at the Aberavon Beach Hotel where only twelve members of the public attended, and recently, in January 2012, at the Brangwyn Hall , Swansea, where approximately twenty five members of the public attended. These numbers are hardly representative of the Welsh population in the South West region of Wales and indicate an enormous sense of disinterest, more important personal priorities, or even just plain apathy for the proposed legislation. (Especially when compared to some months earlier, when in May 2011, I stood outside the Brangwyn Hall amongst crowd of thousands celebrating the success of Swansea City Football Club.

Moreover, the inadequate prior notice and lack of publicity for these Consultation meetings, left a great deal to be desired from the Welsh Government and its intentions for healthy public debate. Additionally, the designated times for all these meetings were not conducive to the attendance of the working population in Swansea and outlying regions.

I am proud and privileged to live in Wales, but I am also a citizen of the United Kingdom. The evidence from the UK Parliament Task Force did not find it appropriate to introduce this legislation. Why does the Welsh Government arrogantly believe that it is appropriate for the Welsh nation to be the human salvage yard, via legislation, for the whole of the UK Transplant Service.

Should the Welsh Government surge ahead with its proposal for legislation, it may find that its misguided intentions will backfire , leading to many people opting out and a consequential drop in organ donor rates.

Eileen Rowlands (B.Ed. Hons.)

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)105 - Dr Barker

[redacted]

16 January 2013

Miss/Mrs Sarah Sargent
Deputy Clerk Health and Social Committee
National Assembly for Wales,
CARDIFF
CF909 1NA.

Dear Miss/Mrs Sargent

Human Transplantation Bill

I have recently received a copy of a letter on this subject reference LG09022/12 dated January 2013 sent to Mrs Gwenda Thomas AM for Neath, by Lesley Griffiths AM Minister for Healtth and Social Services. I wish to make some observations on it,

Presumed consent in effect equals no consent unless there is very extensive publicity, to ensure that those who do not opt out of donation have made an explicit choice, rather than do so by doping so by default, by ignorance or by lack of knowledge or understanding. This makes the concept of "presumed" or "deemed" consent an ethical problem as well s being complex and expensive to administer.

The Welsh Government's letter says it has introduced "soft option" legislation allowing the family of the deceased a role in the final decision but the Bill as it stands does not allow for this, and there is no provision in it for providing. distressed relatives the right to object to the removal of organs. when no consent was given by the deceased.. I think it is essential that respect for the views of the surviving family are written in the legislation itself. The National Assembly for Wales is asked to consider amending the Welsh Government's Bill to make this commitment clear.

Yours sincerely

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)106 – L. J. C. Coventry

Dear Sir/Madam

Why is the Welsh Government putting so much time and money into changing the law instead of providing more resources?
Other people will die because "patients will be refused admission to the ITU because the bed is occupied by a potential doner" (Faculty of Intensive Care Medicine, London in its submission to January 2012 consultation.

Yours faithfully,

LJC Coventry

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)107 – Graham J. Bishop

Dear Sir or madam
I happened to notice a new policy of presuming consent for organ donation when someone dies unless the person specifically refuses.

I believe the donation of a particular person's organs is a voluntary personal decision which the person themselves may or may not consider. It is **not** the right or presumed property of the state to make such assumptions, hence I disagree with the proposed policy.

From Graham J. Bishop, Reading, Berkshire.

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)108 – Dean Price

Hello Sarah,

I wanted to highlight a very real life story (mine) of health adversity to now being a company owner just in the process of opening Motorsport venue in Wales. The purpose being to highlight a real reason in support of the bill.

In 2008 I suffered a condition called Budd Chari Syndrome (very rare) whilst on business in Scotland, I was 36 at the time. The outcome being more than 30 blood clots at once in my heart, liver, portal vein hepatic vein etc I had to be helicoptered into Kings College London for a Liver Transplant all of this happened within 12hours. I become the highest patient on the 'Super Urgent Transplant List'. My life was saved only because of a liver donor. Four years later I have an online business and we are opening our first outlet on March 1st. We are an employer and contributing to the community and the growth of Wales in addition my wife and I with the help of the London Women's Clinic on November 1st were overwhelmed to become parents to a beautiful little girl.

I'm the vice chair of the Liver Transplant Support Group and so wanted to highlight to you and councilor Lesley Griffiths AM my willingness to help both for the benefit of the bill and for our business.

Kind regards
Dean Price

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)109 – David Jones

FAO Sarah Sargent
Deputy Clerk
Health and Social Committee
National Assembly for Wales

18/01/2013

Dear Sarah,

RE: The Welsh Assembly Health and Social Care Committee consultation on presumed consent for organ donation.

Having looked at the proposals I would like to express my concerns as I can't find acceptable answers to a number of serious issues.

In my opinion the best course of action would be to undertake a concerted campaign to encourage organ donation and other voluntary activities thereby achieving the aims of this proposal and maintain the spirit in which they are offered.

If I understand it correctly the state would effectively have property over the body and this has chilling connotations. It is easy to see how this could be extended to making decisions based on “quality of life” and who is deemed fit to carry on living etc. This question can be raised about when to end someone’s life in the case of accident, terminal illness or life-support where their organs may, possibly, be of use to someone else. Who decides and how and by what authority? How are the wishes of the family taken into account and what priority is given to these? Are there any long-term guarantees?

I am not convivnced that more organs will become available because there are so many practical variables involved and would like to see more evidence of this and of how many organs will be used for experiment and investigation rather than for transplant.

It is also of concern that what is currently a conscious decision to try to do something to help others would now, effectively, be undertaken by the state on our behalf. Not only does this imply the state deciding how we must think but removes the ability to make what many consider to be a caring and compassionate choice. That is to say it removes from people the opportunity to act in accordance with their conscience to do something they believe to be beneficial to other members of the community and it prevents family members from choosing to keep the body of their loved-one intact. This has harmful consequences as it diminishes the value of conscience and may lead us to a mindset that we need not be concerned about anything unless instructed by the state.

yours sincerely

David Jones

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)110 – Diane Jones

Mr Mark Drakeford AM
Chairman
Health & Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Drakeford

I strongly oppose the taking of human organs at a person's death under what it pleases the Welsh Assembly Government to call "presumed consent/deemed consent". Wales has achieved a voluntary deceased organ donation rate of 27.7 per million people (pmp) which compares well with other European countries and the UK average rate of 16.3 pmp. The way forward is to build on the 27.7 pmp in a way that does not rob a person of autonomy over their own body, living or dead.

Masses of NHS money will be spent on this when there is so much progress that needs to be made in other areas of medicine, for example, cancer, dementia, macula degeneration, illnesses and diseases that blight the lives of millions of sufferers and their families. It is grossly unfair also that life-extending cancer drugs approved by NICE are being denied to patients by many hospitals and new treatments are not being prescribed for heart attacks, multiple sclerosis etc according to a recent report published by the Health and Social Care Information Centre. Where will the money come from to support what could be termed organ snatching?

Furthermore, I do not trust an 'opt-out' system in such an important matter. Will we be expected to carry an 'opt-out' card at all times? Really there has not been enough explanation and even when I attended a public meeting in City Hall (although missed the very beginning) I was no wiser at the end of the meeting about the 'opt-out' procedure.

I feel that with this proposed legislation the Welsh Assembly Government has taken to itself the power of unnecessary intrusion into people's lives and frankly based on this experience I worry about this government coming out with ideas in the future regarding issues of an ethical nature.

If you are serious about people's reactions at the very least would you please consider and take on board the following 2 suggestions:-

1. Put in hand arrangements for a proper inquiry to state and publish the principles of the Bill, before expecting the public to comment on them.

2. Ask the Business Committee to extend the deadline for written responses to March 31st; and for oral evidence to start at 1st April. This is only reasonable in view of the consultation from December 7th to January 18th. This period included busy Christmas preparations, 3 public holidays, a period when many organisations and businesses closed down and when norovirus and viral infections were rife, these problems have accentuated the shortage of time for many people to respond. I shouldn't think there could have been a more difficult time in the whole of the calendar for people to have their say. Without an extension there can be little doubt that the Stage 1 examination is cut short and inadequate. There seems little need for a hasty rush through this very important stage of the examination of the proposed Bill. The consequences of inadequate drafting will be with us for many years to come.

Yours sincerely

Diane Jones
Penarth
Vale of Glamorgan