



14 Park Grove,
Cardiff CF10 3BN
02920 382406

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Response of the British Heart Foundation to the *National Assembly of Wales Committee Inquiry – Presumed Consent for Organ Donation*

The British Heart Foundation (BHF) Cymru welcomes the opportunity to provide written evidence to the Health, Wellbeing and Local Government Committee Inquiry on presumed consent for organ donation. The BHF is the UK's leading heart charity, fighting to eradicate early death from heart and circulatory disease – the UK's biggest killer, causing 57,000 premature deaths in 2005¹. The BHF's aim is to play a leading role in the fight against disease of the heart and circulation so that it is no longer a major cause of disability and premature death.

Heart transplants offer the best chance of long term survival for critically ill heart failure patients. Unfortunately there is a shortage of donor hearts for use in transplantations across the UK. As the nation's heart charity, BHF has a role to play in increasing the rate of organ donation to make sure that those patients requiring new hearts have the best possible chance of survival.

Questions to consider in preparing evidence

Q1: Presumed consent is currently being considered by the UK Government and within the European Union. Should Wales move ahead on its own or should changes only be introduced on a wider basis? How problematic would it be to operate different systems of consent in different parts of the UK or the European Union?

The BHF Cymru supports measures to improve the Wales' rate of organ donation on a wider UK basis. These measures include consistent national promotion coupled with a strong infrastructure of organ retrieval and professional training. Whilst such measures will go a long way to improving donor organ availability, we believe that presumed consent should underpin organ transplantation in the UK. This change in legislation, in and of itself, should help increase public support for organ donation.

We believe that an opt out system will only gain public confidence if it is sufficiently robust to ensure that everyone who wishes to opt out has an opportunity to do so and there are safeguards to ensure that an individual's wish to opt out is respected and honoured. Furthermore, even in the absence of an explicit opt-out statement, close relatives should still be able to refuse permission at the time of request.

However, BHF Cymru believes if Wales was to implement a presumed consent system ahead of the rest of the UK legislators, safeguards need to be in place

¹ See www.heartstats.org

protecting non-Welsh people who die in Wales from being presumed to have consented to organ donation.

Further, BHF Cymru is concerned about how any logistical problems of having different organ donation systems within the UK should be addressed satisfactorily.

Q2: Systems of presumed consent are usually described as “weak” (where loved ones are able to object to or prevent the removal of organs) or “strong” (where the views of loved ones do not carry such weight). What are your views on the two systems?

BHF Cymru’s support for presumed consent is contingent on individuals and families knowing how they can opt-out (‘soft’ –system).

Once again, an opt-out system will only gain public confidence if it is sufficiently robust to ensure that everyone who wishes to opt out has an opportunity to do so and there are safeguards to ensure that an individual’s wish to opt out is respected and honoured. Furthermore, even in the absence of an explicit opt-out statement, BHF Cymru believes that close relatives should still be able to refuse permission at the time of request.

Q3: What arguments are there against introducing a system of presumed consent?

BHF Cymru believes that an argument against introducing a system of presumed consent is the issue of impracticality of having different organ donation systems across all four nations.

A presumed consent system needs to be supported by a robust, highly secure database which is readily accessible to ITU and transplant teams across Wales and can be updated by potential donors whenever they please.

Further, organ recipients report that the origin of the donor organ plays an important role. Knowing that that an organ was donated willingly can be crucial in helping the recipient come to terms with the circumstances of the donation – a reassurance that could be taken away if a presumed consent system was in place without strong safeguards to ensure people are able to opt out.

Q4: What evidence is there about the level of support among the general public in Wales for introducing presumed consent? Are there any minority views that need to be given particular consideration?

BHF Cymru acknowledges that a system of presumed consent could be a big issue for some individuals, such as those with mental illness or non English speaking immigrants, because of communication barriers on a complex issue.

The British Organ Donation Society, a support group for donor families, believes that the problem of low organ transplant rates is too complex to be addressed simply by introducing an opt-out system, because there is no evidence that opt-out alone increases organ donation.² It needs to be underpinned by a good system of transplant co-ordination, including specific training for intensive care staff on approaching relatives.³

² Gimbel R.W. et al. (2003), “Presumed consent and other predictors of cadaveric organ donation in Europe,” *Progress in transplantation* 13(1):17-23.

³ Martinez, J et al (2001): Organ donation and family decision-making within the Spanish donation system. In: *Social Science & Medicine* 53 (2001), 405-421

The Royal College of Nursing is also against presumed consent without public support, believing that this could lead to reduced rates of donation because of distrust of the system.

Q5: What changes would be needed to existing infrastructure, organisations and resources to ensure that a system of presumed consent is workable and successful?

In January 2008, the Organ Donation Taskforce released its first report⁴ on barriers and recommended actions. It included 14 recommendations on how to improve the current organ donation system in the UK, hoping to increase the rate of organ donation by 50% in five years.

BHF Cymru believes that the Taskforce's recommendations will be very effective at alleviating the current shortage of suitable organs for donation in Wales and the other three nations. They are based on international experience and we believe that, if successfully implemented, they will increase donation rates in Wales.

Q6: What mechanisms are needed to increase the number of organs donated?

BHF Cymru believes that a consistent national promotion coupled with a strong infrastructure of organ retrieval and professional training is fundamental to increase organ donation rate in Wales.

Further, we think that public confidence in the scheme is essential to its success and a presumed consent system will only work if everyone concerned has had the opportunity to opt out. This could be a big issue for some individuals, such as those with mental illness or non English speaking immigrants. These are issues that need to be incorporated into any public awareness campaigns and training for health professionals.

BHF Cymru welcomes the Health Minister's recent funding to run an awareness raising campaign among interested charities to increase the number of organ donors in Wales, and we are happy to play a role in implementing this campaign in Wales this spring, together with other leading charities and the Kidney Wales Foundation.

Q7: Does Wales have the capacity to meet a rising demand for transplants if more organs are available?

BHF Cymru is concerned that if there is a sudden major increase in donor organ availability the NHS will struggle in some specialities, particular heart transplantation, to ensure that all suitable organs are used.

Q8: What arrangements would need to be in place to ensure that patients in Wales continue to benefit from organs donated elsewhere in the UK? How would Wales contribute to the need for organs outside Wales?

Ideally, for the reasons outlined above in Q1, BHF Cymru believes that an organ donation system should be UK wide.

⁴ Organ Donation Taskforce (2008): Organs for Transplants: A report from the Organ Donation Taskforce.

Q9: Should presumed consent extend to all organs or should it be restricted to specific ones - for example, kidneys, hearts or lungs?

BHF Cymru sees no reason why presumed consent should be organ specific. A “restricted” scheme would add an additional level of administrative and IT/database complexity.

Q10: What alternatives might there be to presumed consent?

As mentioned in Q5, BHF Cymru believes that the Organ Donation Taskforce’s recommendations will be very effective at alleviating the current shortage of suitable organs for donation in Wales. In addition, rather than an alternative, presumed consent should underpin these recommendations.

Conclusion

BHF Cymru believes that while legislation in favour of presumed consent would not be a “magic bullet” to increase donor rates, a change in the law could help shift social norms and increase support for organ donation.⁵ We have seen similar progress in tobacco control where recent legislation outlawing smoking in enclosed public places has helped change the public’s view of the acceptability of smoking around non-smokers.⁶ A legislative change to presumed consent could have the same effect in Wales.

For further information please contact me, on 02920 382406, or email me at Lloyd@bhf.org.uk

Yours sincerely,



Delyth Lloyd
Communications & Public Affairs Manager
Rheolydd Cyfathrebu a Materion Cyhoeddus
BHF Cymru

⁵ Thaler, R.H.; Sunstein, C.R., (2003): Libertarian paternalism. In: American Economic Review (Papers and Proceedings) (93), 2, 175-179.

⁶ Tang, H et al (2003): Changes of attitudes and patronage behaviour in response to a smoke-free bar law. In: American Journal of Public Health, 93 (4), 611-617