



Health and Social Care Committee inquiry on the Human Transplantation (Wales) Bill

Response from BHF Cymru
January 2012

British Heart Foundation (BHF) Cymru is the nation's leading heart charity. We are working to achieve our mission of a world in which no-one dies prematurely of heart disease. Heart and circulatory disease is Wales' biggest killer claiming over 9,000 lives each year, nearly a third of all deaths. We fund ground breaking medical research, provide support and care to people living with heart disease and advocate for change. We rely on donations from the public to fund our life saving work.

BHF Cymru warmly welcomes this consultation on the Human Transplantation (Wales) Bill. We strongly support the Welsh Government's introduction of a soft opt-out organ donation system and highlighted this in our response to last year's White Paper consultation. BHF Cymru would welcome the opportunity to provide oral evidence alongside this submission.

Currently, heart transplants offer the best chance of long term survival for those patients with severe heart failure. Although the British Heart Foundation's work includes research into regenerative medicine, success of which would render the need for transplants obsolete, for now a heart transplant remains the only hope for survival for patients with severe heart failure.

Unfortunately the current organ donation system does not provide enough organs. Statistics show a continued disparity between levels of support and donation with research showing 65% of the population support organ donation, yet only 25% are signed up to the organ donation register.¹ Until this disparity is resolved, 3 people a month continue to die in Wales whilst waiting for a transplant. Similarly, a number of patients will also deteriorate beyond the point of donation whilst waiting for an organ. Real figures of those in need of transplant are likely to be higher, given that some patients are not placed on the register as their chances of receiving a transplant in time, under the current system, are slim.² In the UK in 2011/2, 508 patients died while on the active waiting list for their transplant and a further 819 were removed from the transplant list.³

BHF Cymru recognise that soft opt-out legislation in itself is not a 'magic bullet' but rather a key facilitator which must be introduced alongside an organised infrastructure and increased public awareness for a soft opt-out system to succeed.

Cost effective

BHF Cymru agrees with the Explanatory Memorandum that organ donation is a cost effective measure. Even with a small increase in donors the cost of implementing a soft opt-out system will be balanced by the savings made by reducing medical management of

¹Organ Donation Task Force. (2008) *The potential impact of an opt-out system for organ donation in the UK*. Department of Health website: pg. 8

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312]

²Ibid, pg. 6

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312]

³NHS Blood and Transplant. (2012) *Organ Donation and Transplantation Activity Report 2011/12*. Pg. 2.

[http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf]

conditions, as more donors become available. It is estimated that over a ten year period there would be a net benefit of £2.4million per transplant.⁴

Additional to financial benefits, those who receive donor hearts can see their life expectancy increase from only 1.5 years on medical management, to 18 years.⁵ No other form of medical intervention can provide this result. Alongside these financial benefits, there will also be significant psychological gains for patients that no longer have to receive on-going medical management and have the peace of mind of longer term survival.

International Comparisons

In the UK, Wales has the highest organ donation rate with 28 per million population (pmp).⁶ However, compared internationally this figure is low and heart failure patients are still dying unnecessarily. International data shows that an opt-out system is associated with higher donation rates and several studies suggest that it would increase the numbers of organs available for transplantation by up to 30% in the UK.⁷ This means that Wales could possibly project an increase of between 14 and 54 donors over a 3-5 year period after the introduction of opt out legislation. Spain, who adopted a soft opt-out system in 1979 now has the highest rate of donation in Europe at 35.3%.

Although caution should always be exercised when comparing health services internationally due to the range of influencing factors including social norms, there nevertheless remain some factors that we can draw comparisons with in Wales such as the importance of infrastructure and public awareness, both of which are highlighted below.

Promotion

BHF Cymru expressly supports the Welsh Government's inclusion of a sustained, wide reaching public awareness campaign. We also back the Welsh Government's aim to engage all cultural groups within Wales, especially within the Black and Minority Ethnic (BME) community which has significantly low levels of donation, representing just 4% of the organ donation register and a high refusal rate of deceased families with 75% BME families likely to refuse donation.⁸ A number of reasons are responsible for this, including religious beliefs, a reluctance to discuss with family and lack of information about donation. The Welsh Government must work hard to ensure they reach out to this community.

BHF Cymru believes that the public awareness campaign also needs to address the issue of family refusal. The main reason for this refusal is that the family did not know the wishes of their deceased. NHS Blood and Transplant (NHSBT) cite that 45% of family refusal is due to families not discussing their wishes.⁹ Therefore an important part of the awareness campaign should be encouraging families to make their wishes known before they die.

Additionally, part of the Post Implementation Review, as outlined in the Explanatory Memorandum, must ensure that the necessary steps and infrastructure are in place so that

⁴ Welsh Government (2012) Human Transplantation (Wales) Bill Regulatory Impact Assessment

⁵ Department of Health figures included in Explanatory Memorandum. Pg. 48.

⁶ NHS Blood and Transplant. (2012) *Organ Donation and Transplantation Activity Report 2011/12*. Pg.10.

[http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf]

⁷ Abadie A and Gay S. (2006). 'The Impact of Presumed Consent on Cadaveric Organ Donation: A Cross Journal Study.' *Journal of Health Economics*; 25. Pp. 599-620.

⁸ Sims, J et al. (2012). 'Overcoming barriers to registering as an organ donor among minority ethnic groups.' *Race Equality Foundation*. Pg.3. [<http://www.better-health.org.uk/briefings/overcoming-barriers-registering-organ-donor-among-minority-ethnic-groups>]

⁹ NHS Blood and Transplant. (9/07/12). Press Release: *Family support for organ donation doubles when wishes are known- Pass it On*. [<http://www.nhsbt.nhs.uk/news/2012/newsrelease090712.html>]

the continuing transient population of Wales, including students and new residents are aware that an opt-out system is in place once the public awareness campaign has stopped.

Consent

BHF Cymru agrees with the definition of ‘deemed’ and ‘express’ consent put forward within the Bill. We feel that the exceptions are clearly worded and agree with a soft opt-out system that, where known, prioritises the wishes of the deceased. We also believe there is appropriate involvement of the family, or next of kin, where the deceased wishes are not known.

Infrastructure and training

BHF Cymru believes that the Welsh Government should provide further detail on the infrastructure in place to ensure a successful transition to the opt-out system. This should include investment in on-going training in implementing and operating in a soft opt-out system for health care professionals particularly for transplant co-ordinators and staff working in intensive care and emergency departments. There needs to be an effective management pathway for donors – donor identification and organ retrieval must become a routine part of hospital practice.¹⁰ The Welsh Government should also ensure that the right financial incentives are in place for a successful move to opt-out. Increasing intensive care beds should be a priority of the Welsh Government before this legislation is implemented.

Organ Donation Register and relationship with NHS Blood and Transplant

BHF Cymru believes it is not yet clear how the Welsh Government will work in practice alongside NHSBT to ensure a smooth transition between the current organ donor register to a new Wales only register.

An opt-out system should be seen by both the Welsh Government and NHSBT as complementary to reaching their united goal of increased occurrence of transplantation. Internationally there is evidence to suggest that the existence of a core central agency overseeing organ donation in opt-out systems is key to its success.

Conclusion

To conclude, BHF Cymru supports the Welsh Government’s introduction of a soft opt-out system through this Bill and agrees with the key definitions proposed. Research shows the benefits of quality of life improvements and reduction in cost of medical management highlights that opt-out is a long term cost effective option.

BHF Cymru is pleased to see plans for a public awareness campaign included within the proposals, particularly the emphasis on engaging hard-to-reach communities. Moreover, we feel that appropriate evaluation needs to be included in this plan to ensure high levels of understanding and on-going training before the Welsh Government ends the campaign.

Similarly, BHF Cymru calls upon the Welsh Government to ensure the appropriate training for hospital staff and donor co-coordinators, in addition to investment in infrastructure such as critical care beds, is made to ensure the success of the system to become an everyday part of hospital life.

¹⁰ Gelder F, Roey, J et al. (2008). ‘What Is the Limiting Factor for Organ Procurement in Belgium.’ *Acta chir belg.* 108. Pg. 27-30.

Leading on from this, the correct infrastructure and funding needs to be in place to ensure that the formulation of a new register within NHSBT is efficient and robust, so that the public trust in its accuracy. BHF Cymru would like to see greater clarity on the relationship between the Welsh Government and NHSBT to ensure there is no needless confusion surrounding the establishment of a Welsh register and a simultaneous UK wide register. It is crucial that the Welsh Government and NHSBT work together on this introduction.

The UK active transplant waiting list for hearts increased 23.7% in the last year.¹¹ Alongside this an aging population, and increasing rates of chronic conditions are further exacerbating the shortage of organs. The Welsh Government needs to introduce this legislation quickly and efficiently by 2015.

As the only hope for those with chronic heart disease the Welsh Government are leading the way on organ donation, we hope as an example to the other Governments of the UK.

For more information related to this response, please contact Delyth Lloyd, Public Affairs and Communications Manager, at Lloyd@bhf.org.uk or on 02920 38 24 06.

¹¹ NHS Blood and Transplant. *Weekly Statistic Report*. (11/01/13)
[http://www.organdonation.nhs.uk/statistics/downloads/weekly_stats.pdf].