



Human Transplantation Bill (Northern Ireland)

Response from British Heart Foundation Northern Ireland

December 2015

British Heart Foundation Northern Ireland (BHF NI) is the country's leading heart charity. We are working to achieve our vision of a world in which people do not die prematurely or suffer from cardiovascular disease. Thanks to modern treatments built on our research, huge progress has been made in saving lives. Most babies born today with heart defects survive and 7 out of 10 people survive a heart attack. But cardiovascular disease still kills 1 in 4 people and affects 7 million people in the UK, so there is so much more to do. In the fight for every heartbeat we are the UK's largest funder of research in heart and circulatory disease and provide support and care to people living with cardiovascular disease and advocate for improvement.

For those with end stage heart failure, a heart transplant currently offers the only chance of long term survival. BHFNI therefore welcomes the introduction of the Human Transplantation Bill, as the BHF agree that a soft opt-out system of organ donation should be introduced across the UK. Our response below outlines overarching comments on the consistency of organ donation across the UK, age limit and our concerns regarding Clause 4, which we do not support in its current format.

BHFNI believe that system change is urgently needed to soft opt-out organ donation as the current system is failing to meet the demand for donor hearts: the demand for a heart has increased by 143% since 2006¹. Currently 263 people are waiting for a new heart in the UK² and in the last year alone 38 people died whilst waiting for a heart transplant and a further 47 were removed from the waiting list.³ In Northern Ireland, currently, there are 8 people waiting for a lifesaving heart.⁴

We also believe that moving to an opt-out system would better reflect the wishes of the public. We know that nine out of ten people support organ donation yet only three out of ten go on to sign the Organ Donor Register (ODR).⁵

It is important to add that to accompany any legislative change there needs to be investment in infrastructure and training of staff involved in organ donation to ensure a clinical system that can cope with an increase in transplantation activity. We also advocate the importance of discussing your wishes regarding organ donation with your loved ones as this would help make a difficult decision at a tragic time easier for families and helps to ensure your wishes are honoured.

¹ NHS Blood and Transplant (2014) 'Transplant Activity Report 2014/15'

http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/cardiothoracic_activity.pdf

² NHS Blood and Transplant (2015) https://nhsbtde.blob.core.windows.net/umbraco-assets/1062/weekly_stats.pdf

³ NHS Blood and Transplant (2014) 'Transplant Activity Report 2014/15'

http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/cardiothoracic_activity.pdf

⁴ As of 30 September 2015, NHS Blood and Transplant Quarterly Activity Data for Northern Ireland (2015)

https://nhsbtde.blob.core.windows.net/umbraco-assets/1069/northern_ireland.pdf

⁵ NHS Blood and Transplant (2013) 'organ donation infographics' <http://www.organdonation.nhs.uk/campaigns/campaign-materials.asp>

General comments

Consistency

Transplantation surpasses borders across the UK. Therefore whilst differing organ donation legislation is in practice across the UK, this Bill proposes to introduce a soft opt-out system largely like that currently active in Wales. Therefore to enable swift donation and clarity for clinicians and families BHFNI believe that this Bill should include a clause that considers those that qualify to have given deemed consent under Welsh organ donation legislation but die in Northern Ireland should have that deemed consent carry over to comply with NI organ donation.

Clause 4: Deemed consent: deceased adults

BHFNI believes that the aim of this legislation should be threefold:

1. To increase the number of organs available for donation
2. Maintain and respect the wishes of the deceased as paramount
3. Give families/qualifying person an important confirmation role at the point of donation.

However we believe Clause 4 (2) does not deliver on these aims. We believe in its current format that the legislation will make donation more difficult in deemed consent circumstances. If families are expected to affirm that the deceased would not have objected this could then place the wishes of the family/qualifying person above those of the deceased or make families reluctant to provide affirmation when they have absolute proof of this.

Whilst BHFNI firmly believe that the family or qualifying person of the deceased should play a role at the point of donation we support the Welsh legislation approach on this issue which gives families/qualifying persons the opportunity to object to donation based on the views of their loved ones, donation rather than asking them to 'affirm' in every case of donation that the deceased did not object.

This is important to consider as familial consent rates in the UK are one of the lowest in Europe and presents a serious barrier to increasing the number of organs available for donation. It is therefore paramount that any accompanying public awareness raising to this campaign should aim to encourage the public to have conversations with their loved ones about their wishes of organ donation.

Clause 6: Express consent: children

BHFNI would support the age of consent for donation being lowered to 16 years old to reflect the age that young people are legally deemed competent to make their own decisions. However, we believe that those under the age of consent should not be prohibited from becoming an organ donor if they want to do so. This would pull this bill into line with the Human Transplantation (Wales) Bill.

For more information regarding this response please contact Jayne Murray, Head of BHF Northern Ireland, murrayj@bhf.org.uk