

**Chief Executive**  
Dr Cathy Jack

**Chairman**  
Mr Peter McNaney, CBE

21 September 2021

Sent by Email: [committee.health\\_organodonationbill@niassembly.gov.uk](mailto:committee.health_organodonationbill@niassembly.gov.uk)

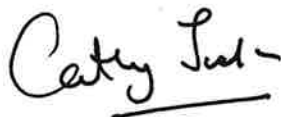
The Health Committee Clerk  
Room 419  
Parliament Buildings  
Ballymiscaw  
Stormont  
Belfast  
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Dear Sir/Madam

Further to the Committee for Health's email of 19 July 2021 seeking the Trust's views on the Organ and Tissue (Deemed Consent) Bill, I have attached the Trust's response.

Kind Regards

Yours sincerely



Dr Cathy Jack  
**Chief Executive**

Enc

## **Belfast Trust Response to Call for Evidence regarding upcoming Deemed Consent Bill for Northern Ireland**

The Belfast Health & Social Care Trust (BHSCT) is Northern Ireland's largest Health & Social Care Trust. The Royal Victoria, Belfast City, and Mater Infirmorum hospitals have been contributing to the NHS-wide deceased donor programme since its early development. We recognise that organ donation, and associated transplantation, is one of the most complex processes with which the modern-day NHS deals. The benefits to the organ recipient, their family, the NHS, and wider society are well documented. Over 100 patients in Northern Ireland are awaiting a life-saving organ transplant. Many of these patients are cared for by our Trust.

Organ donation also brings consolation to the donor family, knowing that the wishes of their deceased relative have been honoured. The BHSCT is one of the leading providers of deceased organ donors in the UK.

BHSCT has a functioning Organ Donation Committee (ODC) chaired by Dr Patrick Loughran (Non-Executive Director). Dr Dominic Trainor is the Clinical Lead for Organ Donation (CLOD) within the Trust. We also have a team of Specialist Nurses in Organ Donation (SNODs) embedded in each of our Intensive Care Units. The ODC is responsible for the governance of the organ donation process but is also involved in education and promotion of organ donation both within and outside BHSCT.

Our intensive care clinicians have extensive experience in both donation after brainstem death (DBD) and donation after circulatory death (DCD). We have well-established systems and processes across the Trust's Emergency Departments, Intensive Care Units, and Theatres for the identification of the potential deceased organ donor, referral to our specialist nurses, approaching the family of a potential organ donor, seeking of consent for organ retrieval and the organ retrieval process itself.

We welcome the development of this Bill for Northern Ireland and believe, in due course, more lives will be saved through its introduction. Northern Ireland contributes to the UK donation and transplantation pool, the governance of which lies with NHS Blood & Transplant. Our transplant recipient patients receive organs from anywhere in the UK. Similarly, our deceased donor organs may be transplanted in a patient anywhere in the UK. As such, we see the introduction of this Bill as bringing N.I. into line with the legislative frameworks in the other UK nations, as well as the Isle of Man, Jersey and Guernsey.

The experience gained through the introduction of Deemed Consent Bills in Wales, Scotland and England will be invaluable in assisting our staff through training and education in how to implement the Bill in practice. Furthermore, introduction of the Bill will ensure uniformity of practice across the UK. This is important when considering, for example, safeguarding issues around the Bill – the Bill will not apply to those under the age of 18, those who have not been resident in N.I. for over 12 months prior to their death and those lacking capacity to understand the Bill for a significant period prior to their death.

The explanatory and financial memorandum indicates the importance of a comprehensive marketing campaign to inform the general public of the upcoming change in the law. We believe this will be a vital component of the introduction of the Bill.

The general public must be safe in the knowledge they can opt-in, opt-out, or do nothing with regard to signing the Organ Donor Register (ODR). The deemed consent Bill will apply in those cases where the patient has chosen not to either opt-in or opt-out. Legislation should make explicitly clear those organs and tissues to which deemed consent applies.

### **The Role of the Family**

Through our extensive experience in deceased organ donation, we know the family have a crucial and irreplaceable role in facilitation of deceased organ donation. The family must always be central to the whole process. The new Bill will not change this.

When a potential deceased organ donor is identified, family members will always be approached in a collaborative and sensitive manner by our doctors and nurses. We will seek their views on whether their loved one would have wished to become an organ donor.

Our staff will inform them if their loved one has chosen to “Opt-in” on the ODR. It is known that when families are made aware that their loved one has signed up to the ODR, consent rates are over 90%.

Clear, simple, and accessible processes must allow those citizens wishing to record an “Opt-out” decision to do so easily. In cases where a person has chosen to “Opt-out,” it will be important to check if this was indeed the last known wish of that patient. If this is consistent with the patient’s last known wish then organ donation will not proceed.

In the event that someone has not indicated their wish regarding organ donation, deemed consent will apply. This will involve ascertaining from the family if the patient would not have wanted to donate. Data from Wales indicates that families in this situation may still override a deemed consent approach [between Jan 2016 and Dec 2018, families in Wales made a decision to override a deemed consent approach on 31 occasions (26% of all deemed consent approaches)].<sup>1</sup>

Organ donation will not, and cannot, take place without the family giving consent for donation to proceed. The role of faith and beliefs of the patient is central to the care of the deceased organ donor and the family will be consulted on how we can respect the patient’s faith and beliefs, including attendance of a religious minister or faith counsellor.

### **The Role of the Human Tissue Authority**

The Human Tissue Authority have produced Codes of Practice in Wales and England. We believe this is absolutely essential and will need to accompany the legislative change.

A Code of Practice for NI would give reassurance to our nurses and doctors involved in this complex and sensitive process. It would also help ensure there is no misinterpretation of the legislation which could potentially lead to unlawful actions.

### **Novel Organs and Research**

BHSCT agrees that secondary legislation is required for novel transplants. As in England and Wales, we agree that deemed consent should not apply to research. The public must have trust in the system, and to that end we feel express consent from family should be sought for both novel transplants and research.

### **Resource Implications of the Bill**

The desired effect of this Bill is to increase the number of organs available for transplantation. An increased number of deceased donor retrievals will increase demands on resources, including time spent in intensive care and operating time. This will require provision of additional service capacity to ensure that there is no detrimental impact on other services. Similarly, we must ensure the capacity is available so that organ donation can occur when a potential organ donor arises. To fully realise the benefit of this Bill for NI patients, adequate resources need to be made available to the renal transplant service.

### **Conclusion**

BHSCT supports the implementation of this Bill. We believe, in time, this Bill will result in a societal shift in attitudes such that organ donation becomes an expected part of end-of-life care throughout intensive care units in N.I. The Bill has identified that appropriate safeguards must be implemented to ensure public confidence in organ donation is maintained.

The implementation of this Bill needs to be accompanied by a widespread media and public awareness campaign, ensuring the public are kept abreast of the change to the legislation and the choices open to them. The public must have trust and confidence in the system.

BHSCT has extensive experience in all aspects of the deceased donation process. We have critical care experts with decades of experience. We recognise that the Committee may benefit from hearing from one or more of our experts. Should this be of interest then we can facilitate accordingly.

### **Reference**

1. Madden S, Collett D, Walton P et al. The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system. *Anaesthesia* 2020; **75(9):1146-1152**