HEALTH AND SPORT COMMITTEE
HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM NHS Blood and Transplant (NHSBT)

NHSBT is a special health authority supporting organ transplantation across the UK and blood transfusion in England and Wales. The Scottish National Blood Transfusion Service (SNBTS) and the Northern Ireland Blood Transfusion Service (NIBTS) support blood transfusion in Scotland and Northern Ireland respectively. NHSBT is funded by, and accountable to, the four Departments of Health in the UK government and devolved administrations.

The Organ Donation and Transplantation (ODT) directorate of NHS Blood and Transplant (NHSBT) supports transplantation in a number of ways. ODT supports and facilitates every organ donation that takes place across the UK through its 365 days a year and 24/7 specialist service. ODT receives referrals of potential organ donors, employs the Specialist Nurses in Organ Donation (SN-ODs), coordinates the matching and offering of organs for transplant to potential recipients, commissions the National Organ Retrieval Service and collects data on transplant outcomes for the National Transplant Database.

Our response to this consultation is focused on the operational implications of implementing an opt out legislation in Scotland. NHS Blood and Transplant is committed to working to maximise donation within whatever legislative framework the Scottish Government introduces.

The efficiency with which we can implement the changes to legislation across the different administrations in the UK will be increased if these legislative acts are consistent with each other. We would urge the different UK Governments to work together to develop legislations that are where possible complementary and consistent with each other, offering organ donation professionals and healthcare partners areas of uniform practice in Organ Donation and Transplantation across the UK.

1. What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

**Strengths**

The proposals are aligned closely with NHSBT’s current operational practices and as such do not represent a paradigm shift for those specialist staff currently involved in
progressing organ donation to transplantation. This should simplify the implementation process.

The National Conversation that the Bill stimulates, together with the planned communication strategy, will facilitate approach conversations by our specialist nurses as it will raise awareness of organ donation.

The Bill seeks to improve inclusiveness for children by allowing local authorities to consider authorisation for a child for whom it holds parental responsibilities and rights. We support working with anyone who has parental rights and responsibilities to obtain the best outcome for all those involved.

The addition of Quality Assurance as a category under ‘other purposes’ provides a clear intent that will support work which is critical to improving successful transplantation.

The Bill encourages advance confirmation of donation decisions which will ease decision making by families at a time of increased stress and emotion.

The Bill confers on Scottish Ministers the requirement to make arrangements for the establishment and maintenance of a register in Scotland. The ability to delegate this responsibility means that the existing informal arrangements will be formalised.

**Weaknesses**

Certain individuals may now feel forced to opt out because, whilst they are content to be donors, there is a misconception that their family will not be involved in the final decision at time of death. In the introduction of this legislation it is important that the involvement of the family during end of life decision making is clearly communicated.

Initial and ongoing increase in 'opt out' and removal of names from the Organ Donor Register may reduce the potential organ donor pool.

The Bill is being introduced at a time when similar legislative changes (e.g. Wales) have not been fully evaluated. Consequently, the evidence upon which the change in donor numbers is based has a large variance.

There are advantages in extending deemed authorisation to circumstances such as ‘other purposes’ beyond transplantation (for example research) as this would assist families in not having to make further decisions if their loved one had not opted-out.

There will be a need to provide the public with clear messages because of the differences in authorisation for children, with deemed authorisation from 15-16 years, yet self-authorisation from 12yrs.
2. What do you think are they key strengths and weaknesses of the plans for authorisation of pre-death procedures?

In the absence of a finalised list of tests, we cannot provide a final response to this question.

**Strengths**

NHSBT will meet the necessary legal requirements and ensure continuity of practice. Providing best practice information around tests undertaken is already part of the process carried out by our SN-ODs and the Bill will formalise this for some families.

**Weaknesses**

The 2006 Human Tissue (Scotland) Act affords Specialist Nurses the clinical autonomy to ensure families have information about the donation process and tests that is tailored to their needs. There has never been a family complaint about having been provided too little information since 2006. Indeed, families will often say they are receiving too much information. There remains a risk that formalising this process in the absence of public concern and without taking steps to evaluate the views of the public may make the authorisation process less efficient and overwhelming for families. The requirement to obtain authorisation for a list of tests will further lengthen the process. Evidence shows that lengthening the donation conversation has a negative impact and will potentially reduce authorisation rates.

We would ask that Type A procedures be organised according to allowable broad categories rather than appear as a long list of individual procedures. An example could be, blood tests to ascertain suitability for transplantation, rather than an exhaustive list of allowable blood tests. This reflects how the individual donor’s past medical history may require different blood tests and the need to rapidly respond to any newly identifiable transmissible risk.

3. Do you have any other comments to make on the Bill?

Donation conversations typically occur late in the evening and at a time when grieving families are shocked, exhausted and emotional. The SN-OD team in Scotland have expressed some concern that lengthening the donation conversation, alongside the requirement for families to comprehend more complex information around deemed authorisation, may have a negative impact upon family responses to the donation decision.

There is a need to educate NHS colleagues across the healthcare system about the proposed legislation. Consideration will need to be given to the resource implications around who will deliver this education, as any expectation that such training would be delivered by SN-ODs within their local resident hospitals may impact upon service delivery.
New legislation in the realm of organ donation, in 3 parts of the UK, is either in place or currently proposed. At present a resident in 1 UK country who dies in another UK country may be an exception to deemed authorisation or consent. Given that England and Scotland are moving towards opt out systems and Wales already has an opt out system in place, these continued exceptions cross countries become less understandable. Attention to this problem requires discussion across all UK legislatures.