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17 September 2021

Dear Sir/Madam

**Re: Organ and Tissue Donation (Deemed Consent) Bill**

As Chief Executive of the Public Health Agency, I am pleased to provide our submission in response to the Health Committee's call for evidence on the Organ and Tissue donation (Deemed Consent) Bill.

The Public Health Agency (PHA) exists to protect and improve the health and social wellbeing of our population and reduce health inequalities through strong partnerships with individuals, communities and other key public, private and voluntary organisations.

In relation to the Organ and Tissue Donation (Deemed Consent) Bill, PHA has been working closely with colleagues in the Department of Health in Northern Ireland and NHS Blood and Transplant (NHSBT) since Health Minister Robin Swann announced a public consultation on the proposed law change in July 2020. This involved facilitating an extensive public consultation exercise to stimulate a comprehensive range of responses to inform the development of the Bill. PHA has also contributed to discussions from a clinical point of view through membership of the Clinical Advisory Group, whose recommendations were taken forward into the draft Bill and Explanatory and Financial Memorandum.

There is evidence of public support for the introduction of the Bill from the PHA Omnibus survey in November 2020 with 62% supporting a change to an opt-out system of consent; and from the public consultation with 90% of 1,917 responses indicating support.

**Comments on the Bill**

The Bill aligns closely to the Acts in effect in Wales and England. As such, the training and operational delivery will benefit from experience in those countries as well as seeing a consistent model for consent across England, Wales and Northern Ireland, all legislated under the Human Tissue Act 2004, which this Bill seeks to amend.

Evidence from Wales and early evidence from England indicates that the Bill can bring an increase in consent rate and subsequent life-saving transplants.



The Bill identifies important safeguards to protect certain Northern Ireland residents through the stated Exemptions.

As per feedback from the Clinical Advisory Group, the Explanatory and Financial Memorandum indicates the importance of a comprehensive marketing campaign to inform the general public of the upcoming changes, how it may affect them and how to record a donation decision (opt-in or opt-out). PHA supports this plan and recommends that a 12-month marketing campaign is delivered to ensure every opportunity is afforded to adequately inform the public. This is an essential component of the law change as it gives assurance that the law can be implemented safely knowing the general public have been provided with adequate opportunities to record a donation decision, or understand what happens if they don't record a decision.

### **Northern Ireland transplantation background**

There is a shortage of organs for transplantation in Northern Ireland. Quarterly figures to end June 2021 show 125 people waiting for a transplant. Contributing to this is the fact that while over half a million people die each year in the UK, only around 5,000 (1%) die in circumstances that mean that their organs could be considered for transplantation. Last year in Northern Ireland there were 51 deceased donors, resulting in 113 transplants throughout the UK. In total, 87 Northern Ireland residents received transplants.

The main policy objective of the move to an opt-out system for organ donation is to increase the current rate of consent in these small number of cases in which it is clinically possible for organ donation to proceed after a person's death. Doing so will increase the overall number of donors, and ultimately the number of lifesaving organs available for transplantation. Whilst a change in law will not increase the size of the UK donor pool, it has the potential to increase the consent rate in situations where a potential organ donor has been identified. In Northern Ireland, and in other UK regions until recently, this consent rate has remained at around two-thirds of potential donors. The consent rate in Northern Ireland is 64%, and has not increased significantly for several years despite consistently high levels of support for organ donation and consistent growth in registrations on the Organ Donor Register.

Since the introduction of an opt-out system in Wales, consent rates from deceased donors in have increased from 58% in 2015 to 70.7% in 2020. However, the international standard for world class performance is recognised to be an 80% consent rate. This is the target consent rate to which all UK regions have aspired within the current UK-wide strategy (2013-2020).

The Northern Ireland Organ Donation Services team (NIODST) is an NHSBT team of highly trained Specialist Nurses embedded in each of the HSC Trusts, and who manage organ donation discussions in a professional, sensitive and caring way. Data shows that family consent rates are higher if a Specialist Nurse is involved in the family approach. Northern Ireland performs well with a 96% referral rate to NIODST, and 95% of approaches having a Specialist Nurse present.

### **Research**

Prior to the public consultation which opened in December 2020, the PHA were asked to survey the general population in Northern Ireland to gain insights into current views about organ donation, donation behaviours, intentions and attitudes, and views about the opt-out



system. This was the fifth population-wide survey conducted by PHA with a focus on organ donation since 2013 and has provided the ability to track changes in the public's perceptions about aspects of organ donation over time.

The survey highlighted that there is widespread public support in Northern Ireland for organ donation, with 90% of people saying that they support organ donation. However, only 50% of people have recorded their decision on the Organ Donor Register. Support for a move to an opt-out system in Northern Ireland has grown with nearly two thirds (62%) being in favour of an opt-out system (growing from 56% in 2013). 72% said that if the system changed to opt-out, they would allow their consent to be presumed. Results also showed that nearly three quarters (73%) agreed that an opt-out system would maintain freedom of choice, and 70% agreed that an opt-out system would result in more lives being saved.

Opt-out legislation and supporting education and awareness will help to stimulate continued behavioural change and reduce the gap between intention (support for organ donation) and action (signing the ODR and sharing decisions).

Research will be planned at intervals to assess attitudes and behaviours on the change in legislation across the general public. Other metrics such as registrations to the Organ Donor Register, and consent rates will also be monitored and will support ongoing research studies.

### **Promotion, awareness and education to date**

Part 4 of the Health (Miscellaneous Provisions) Act (NI) 2016 placed a statutory duty on the Department of Health to promote organ transplantation by providing information and increasing awareness about donation. In 2018 the Department of Health released a Policy Guidance Statement on Promoting Human Organ Donation and Transplantation in Northern Ireland to provide guidance for implementing this statutory duty. Since July 2020, a dedicated resource has been embedded in the PHA to assist in delivering the commitments to promote organ donation in Northern Ireland through a coordinated, tailored and sustained approach to education and awareness. A rolling communications programme is now underway which has been focused on the following:

- Network development – partners, stakeholders and wider

Adopting a collaborative approach to amplifying organ donation messaging has been key to enhancing promotion.

Key partners such as Charities, Trusts and Local Councils are extremely supportive and proactive. Network development has also augmented promotion in other sectors such as community/voluntary, schools, further and higher education, and the business community. Community/voluntary partnership working allows us to reach a wide range of organisations, groups and target audiences at the grass roots of society, in particular Faith, BAME, young and older audiences.

Partner support is a key activity, particularly with our Charity partners to ensure their activities are facilitated and given additional exposure helping both the promotion of organ donation and the Charity in terms of helping them to sustain and grow their membership.

- Events and initiatives e.g. Organ Donation Week 2020

A co-ordinated programme of activity across all partners and stakeholders, as well as development of central plans to launch and promote the initiative.



- Schools resources

A working group has been established to develop age-appropriate resources for organ donation across the education journey from primary, to post-primary, through to 16+. The working group is comprised of teachers all of whom have personal experience of organ donation. Department of Education has been engaged with to support with review and advice.

- Opt-out legislation public consultation engagement

Comprehensive engagement activity for the period of the public consultation kept the topic of organ donation front of mind. A partnership approach was leveraged to ensure messaging around organ donation and the public consultation was cascaded widely..

- June promotion campaign

A public awareness campaign was delivered across the month of June. It was a re-run of the previously successful and powerful 'Wee Chat' campaign which delivered a high degree of exposure and awareness. Top line results show it was exposed over 13 million times to audiences on a range of channels across the month. There was a 12-fold increase to website visitors with 'registration complete' and 'talk to your family' pages in the top 5 pages visited. Registrations to the ODR saw an 8-fold increase.

### **Opt-out legislation promotion, awareness and education**

It is important to outline the key assumption around the promotion and education for legislation change:

- Opt-out legislation and promotion go hand in hand
- It is based on a 12 month campaign period to ensure adequate time for awareness and education

Planning for the promotion and education around opt-out legislation is underway to identify recommended activities, timetable, channels, and budget requirements. It outlines the importance of ensuring a wide range of messaging to include organs and tissue, deceased and living donation and transplantation. It will also include a range of perspectives from recipients, those awaiting a transplant, clinicians, and of utmost importance, donors and their families.

The aims of the promotion and awareness programme are stated below:

- Effectively communicate the change in law, the action required and encourage public support
- Raise awareness and educate audiences (widely & targeted)
- Motivate: stimulate and sustain behavioural change
- Be explicit: provide information, clearly communicate the choices
- Normalise donation conversations
- To encourage registrations to the Organ Donor Register

Messaging used in all promotion and education will address the following key components:

- The law is changing to opt-out
- What this means i.e. those who do not wish to donate are required to opt out
- How to do this (be explicit & clear)



- The time they have to make and record their decision (be explicit & clear)
- The importance of discussing a decision - consent rate is over 92% if the family know that their loved one had recorded a decision to donate on the Organ Donor Register
- Emphasise it is a personal choice, it remains 'your' decision
- Why organ donation is important / how it benefits others

The 'gift' of organ donation and acknowledgement of the selfless act of donors and their families will be central to messaging.

The objectives for education and awareness messaging can be outlined as:

- To be clear, consistent, accurate, and tailored
- To continue to develop a pool of ambassadors and advocates
- To use of real-life people and messaging throughout
- To mobilise key audiences such as young people
- To deliver ongoing activity and initiatives across a range of channels
- Which will be supported by mass awareness campaign at key intervals
- To use collaboration, partnership working and co-ordination of activity to roll-out and amplify the messaging

The programme of education and awareness around legislation change will comprise of 2 main phases, these are detailed below:

1. Primary approval & Royal Assent – early 2022
  - Announcement and explanation: 'The law is changing...'
  - Regular promotion and awareness throughout the implementation period (12 months)
  - Gradual build-up of activity towards a concentrated focus from November 2022 onwards
2. Legislation go-live – early 2023
  - Announcement and reminder: 'The law has changed...'
  - Messaging to reinforce options and drive action, encourage an informed decision via the ODR and conversation

While education and awareness is required at a general level across Northern Ireland, there are also a number of target audiences which will form part of the programme. Engaging with children and young people will be an important approach, therefore the completion and launch of the schools resources will be a key vehicle to help embed the information and stimulate discussions. A range of other outreach and engagement work will work with older audiences, faith and BAME audiences, as well as working with the community and voluntary sector to reach the grassroots of society. This approach is will ensure specific audiences are reached and engaged with in the most appropriate manner, so increasing the levels of engagement and understanding.

The majority of this work will continue as part of the rolling programme for promotion of organ donation, and much of it is achieved at little or no cost due to the current co-ordinated and collaborative partnership working approach. It will however be necessary to support this activity by evidence-based and user-tested public awareness campaigns to ensure there is the necessary weight and breakthrough to deliver the messaging to as wide an audience as possible. Campaign activity will examine the use of above-the-line channels including TV, radio, and out of home, as well as targeted social and digital channels, direct mail, and



media or commercial partnerships with the aim of reaching target audiences at multiple touch-points across their day.

Campaign concepts and messaging will be developed and tested with a cross-section of society to ensure messaging engages effectively in general and with target audiences. Ongoing research will examine attitudes and behaviours at regular intervals to inform the awareness campaigns allowing opportunity to tweak and evolve plans if needed.

### **Reassurance regarding the organ donation process**

NHSBT has provided reassurances regarding current and future organ donation processes. In preparation for legislation changes in other UK countries, NHSBT worked closely with faith representatives, patient groups and clinical teams to seek views on what changes might be needed to implement the new legislation, should the Bill be successful. Feedback from the public consultation will also be taken into consideration and reassurance given on the following:

- The role of the family

The family should be involved in the discussion regarding organ donation and the next of kin of potential donors will always be approached to discuss the option of donation.

- Faith or beliefs

The family will also always be asked for their views on whether there should be any special considerations to support the donation process, such as whether their loved one had any faith or beliefs that should be taken in to account and whether they would like to speak to a faith leader or counsellor.

- Safeguarding

NHS Blood and Transplant has safeguards in place to ensure that no organs or tissues are removed for any purpose without consent. There are strict policies and protocols in place, with many checks throughout the donation, retrieval and transplant process. The consent is checked on multiple occasions, by several different medical, nursing and support teams. NHS Blood and Transplant is audited and inspected on this aspect by the Human Tissue Authority.

### **Organ Donation Clinical Advisory Group**

The Organ Donation Clinical Advisory Group (ODCAG) exists as a forum for engagement with local and national clinical experts on the development and implementation of a Bill. Engagement has taken place with the group and their recommendation to include a provision to promote and report on legislation change has been written into the Explanatory and Financial memorandum, which seeks to enhance the Department's existing statutory duties to promote and report on organ donation and transplantation.

### **Human Tissue Authority**

The Human Tissue Authority has been engaged with independently and as part of the Clinical Advisory Group to ensure provision around writing (or amending) a code of practice for clinicians which will cover a range of scenarios which the clinical teams may encounter.



## Financial considerations

All implementation and recurring costs have been considered as part of the planning process for the Bill. NHSBT have provided operational projections, and promotion and education projected costs have also been examined.

Public education and awareness costs will stem primarily from mass awareness campaign intervals in support of the ongoing programme of outreach and engagement. There will also be other costs associated with engagement and awareness activity that will direct the public to the Organ Donor Register website, and the National Contact Centre for inbound queries which are public-facing services provided by NHSBT.

It will be important for the promotion and awareness programme to be cost-efficient and make the most of available resources and employ a collaborative approach to reduce required expenditure.

## Conclusion

PHA has worked closely and collaboratively with the Department of Health, NHSBT and the HSCNI family through the public consultation process, and in support of the passage of the Bill to date. We will continue to provide support and expertise as the Bill continues through the Assembly, and stand ready to deliver the work required for a new consent system in Northern Ireland, if Royal Assent is provided.

PHA can confirm it is comfortable for this written evidence submission to be made publicly available by the Assembly Committee.

Yours sincerely



**Aidan Dawson**

**Chief Executive  
Public Health Agency**

