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**Date: 4 December 2018 – Scottish Parliament – Health and Sport Committee**

**Consultation: *Human Tissue (Authorisation) (Scotland) Bill***

**Supplementary Evidence from the Scottish Council on Human Bioethics (SCHB):**

The SCHB very much supports, and is fully committed to, the possibility of donating lifesaving organs after death. However:

**1. Under the proposed Bill the organs from up to 970,000 Scots could be removed for transplantation against their will**

The November 2018 **Scottish Parliament Information Centre (SPICe)** report on the *Human Tissue (Authorisation)(Scotland) Bill* indicates (on page 32) that “*in the [Health and Sport] Committee's own survey, 29.3% of the respondents had not recorded their wishes anywhere.*”

Though this figure has not been confirmed in peer reviewed academic journals, it represents about 1.5 million people in Scotland (29% of the 5.3 million inhabitants in Scotland).

Moreover, the **SPICe** report indicates that “*Of these people, 65% did not wish to be an organ donor while 35% did*”, which means that up to 970.000 Scots (65% of 1.5 million) would be considered as donors even though they would be opposed to their organs be used for transplantation (because their wishes were unknown).

Moreover, according to SPICe, it is very unlikely that most people in Scotland would even know about the transplantation system in place. Already in Wales, 25% of residents, in June 2016, were unaware of the soft opt-out system that was legalised in December 2015.

In this regard, the SCHB is very concerned that such a situation could be considered as abusive and exploitative by the general public and give rise to serious scandals. Indeed, such controversy could eventually undermine trust in the system thereby reducing the number of organs available.

**2. An opt-out system already exists in Scotland alongside its opt-in system – with 4,774 Scots having already opted-out of the present ‘silence means authorisation’ system**

A lot of confusion exists concerning the **Health and Sport Committee's** public consultation especially with the message that the present Bill would legalise a soft opt opt-out system.

This is because a soft opt-out system already exists under the present *Human Tissue (Scotland) Act 2006* alongside the opt-in system. Indeed, it is already possible for people in Scotland to opt-out of the present system if they are opposed to their organs being removed for transplantation.

According to the SPICe report, **4,774 Scots have already opted-out** and registered their opposition to their organs being removed, which would be a completely meaningless decision if an opt-out system did not presently exist in Scotland.

Under the 2006 Act there is already an assumption that silence means authorisation (with the nearest relatives authorising the use of organs when they have no knowledge that the deceased was opposed to this happening – a form of soft opt-out system).

This also means that this new Bill is not likely to increase the number of organs for transplantation. It only incorporates the ‘deemed’ part in ‘deemed authorisation’ into the new legislation whereas, at present, the ‘deemed’ part is assumed in that everyone is ‘deemed’ to know the existing law.

### **3. At present individuals cannot opt-in or opt-out of the possibility of their organs being used for research and other uses on the NHS Blood and Transplant Register**

At present it is possible for individuals to opt-in or opt-out of donating their organs for transplantation after their death on the NHS Blood and Transplant Register. But there is no similar possibility for individuals to decide whether they want their organs to be used for research, education, training, audit and quality assurance on this Register.

Moreover, most individuals may not be aware that if they do not opt-in or opt-out then 'silence means authorisation' and their organs can be used for such purposes. This is because such a use of organs from the deceased is being left to nearest relatives to decide even though they may have no knowledge of the wishes of the deceased in this regard. Again, this may give rise to scandals and could eventually undermine trust in the system thereby reducing the number of organs available.

Furthermore, information should be made available to all individual in Scotland about the length of time for which such organs would be stored. They should also be told whether the material could be used for ethically sensitive research such as in the creation of reproductive cells (artificial sperm or eggs) or cloned embryos.

### **4. There is a significant amount of confusion surrounding this Bill which undermines the democratic process**

The definition of the soft opt-out system in (1) the SPICe report, (2) the Explanatory Notes and (3) the Policy Memorandum are not entirely the same which gives rise to confusion. Moreover, the SPICe report indicates (page 5) that Spain "*effectively operates an opt-in system*" but then indicates (page 28) that it is "*classified as operating a soft opt-out system and this is true in terms of the legislation*". Even the Health Minister, Joe FitzPatrick, indicated on the 27<sup>th</sup> of November 2018 that Spain had an opt-out system.

The SCHB is very concerned that such contradictions (and there are a significant number) lead to confusion. Because of this, it does not believe that the Scottish general public is being informed in an appropriate manner about the Bill, meaning that the democratic process is being undermined.

### **5. Confusion relating to the authorisation from deceased adult and his or her nearest relative**

Following the oral evidence which was given, on behalf of the SCHB on the 27<sup>th</sup> of November 2018 to the **Health and Sport Committee**, the SCHB would like to confirm that nearest relatives do indeed have the possibility under the present *Human Tissue (Scotland) Act 2006* to authorise the removal of organs from their deceased loved ones.

Indeed, in Section 7 of the 2006 Act (entitled '**Authorisation by adult's nearest relative**') it is very clear that if the nearest relatives do not have any knowledge that the deceased was unwilling for organs to be removed for transplantation then they could authorise such a removal.

Moreover, even if the deceased adult had left an authorisation under Section 6 of the 2006 Act (entitled '**Authorisation: adult**'), in practice, healthcare professionals would still ask for authorisation from the nearest relatives as well. This is why Scotland has a **soft** opt-out system.