Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill
Submission from the Scottish Youth Parliament

Introduction to the Scottish Youth Parliament

SYP represents all of Scotland’s young people. Our Vision for Scotland is of a nation that listens to and values the participation of children and young people. Our goal is to do our utmost to make this vision a reality. We see this as vital to ensuring Scotland is the best place in the world to grow up.

Our democratically elected members listen to and recognise the issues that are most important to young people, ensuring that their voices are heard by decision-makers. We provide a platform for young people to discuss issues that are important to them, and support them to campaign for the changes they wish to see at community, local and national levels.

As such, we are a fundamentally youth-led and rights-based organisation, and our mission and values are grounded in the United Nations Convention on the Rights of the Child (UNCRC), particularly, but not exclusively, Article 12.

Our Approach

The Scottish Youth Parliament, by its nature, is committed to a youth-led structure. As such, this response is based on direct consultation with young people through an online focus group; existing policy developed by the elected Members of the Scottish Youth Parliament (MSYPs); and “Change the Picture,” our youth manifesto, which is based on nearly 43,000 responses to a mass consultation exercise with young people.1

Therefore, our response is based on the genuine views of young people, and should be seen as a fair representation of the opinions of young people in Scotland.2

Do you support the Bill?

1 The online focus group was facilitated through SurveyMonkey, and contained nine questions based on the initial consultation document (September 2014). The questions were adapted to ensure they were conducive for consultation with young people. The Health and Wellbeing Subject Committee of the Scottish Youth Parliament facilitated the focus group. This is a group of elected Members of the Scottish Youth Parliament with a keen interest in issues of health and wellbeing in Scotland. The consultation exercise for “Change the Picture” received nearly 43,000 responses and can be accessed here:

2 For more information about the Scottish Youth Parliament, our structures, and our policy making procedures, visit www.syp.org.uk
The Scottish Youth Parliament welcomes the opportunity to respond to the call for evidence on the Transplantation (Authorisation of Removal of Organs) (Scotland) Bill and assist the Committee in its scrutiny of the Bill. Our engagement with young people suggests that this is an issue of importance to them.

- The Scottish Youth Parliament supports the introduction of a soft opt-out system of organ donation to replace the current opt-in system.

- The Scottish Youth Parliament supports provisions in the Bill that would allow an individual to appoint a proxy to make the final decision regarding transplant on their behalf.

- The Scottish Youth Parliament supports provisions that would limit the role of the family to being consulted on whether they are aware of any unregistered objection to organ donation by the deceased. We note that this limitation is particularly important for young people who do not have a ‘typical’ family life (e.g. looked after young people) and who might feel more comfortable appointing a proxy to make the final decision on what happens to their body after death.

- The Scottish Youth Parliament supports proposals that would allow all those aged 16 and over to be automatically opted-in as organ donors. We wish to make it clear that practice must reflect policy and treat those aged between 16 and 18 as adults according to the provisions of the Bill, particularly in regards to respecting this age group’s option to choose a proxy.

Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland?

Research has shown that although 90% of the UK population supports organ donation, only 40% of the Scottish population are on the Organ Donor Register.\(^3\) There is evidence to suggest that introducing an opt-out system would increase the numbers of organs available for transplantation by up to 30% in the UK.\(^4\) In light of this, in October 2014 the Membership of the Scottish Youth Parliament passed and has subsequently extended the following Members’ Motion to create official policy:

"Following similar moves in Wales to tackle a severe shortage of organ donors, the system for organ donation should be changed to an opt-out system rather than an opt-in system."

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\(^4\) Ibid.
Therefore the Scottish Youth Parliament is officially of the opinion that an opt-out system would increase the number of organs and tissue made available for transplantation in Scotland.

As previously stated, in keeping with our belief that young people should be included in decisions that affect them, we are supportive of proposals that would allow all those aged 16 and over to be automatically opted-in as organ donors. We believe that this increased involvement of young people will have a positive effect on the number of organs and tissue made available for transplantation in Scotland.

**Do you support the proposal of appointing a proxy?**

As an organisation, we strongly value Article 12 of the United Nations Convention on the Right of the Child (UNCRC) which states:\(^5\)

> “1. State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

Therefore the Scottish Youth Parliament supports the proposal of allowing an individual to appoint a proxy to make the final decision regarding transplant on their behalf as this allows young people aged 16 or over more freedom of choice in what happens to their body after death. A strong majority of respondents to the focus group indicated that they either agreed a little (10%) or completely agreed (70%) with the proposal to appoint a proxy.

One member of the focus group stated:

> “Young people should be given options. They would know best who should help make the final decision after their death, and it would be their decision to choose a proxy or not.”

We believe that the option to appoint a proxy is especially necessary for those aged 16-18 who are in care and may not feel comfortable for their nearest relative or legal guardian to make the final decision about what happens to their body after death.

In addition, we recommend that young-person-friendly information and materials about opting in to the donation system (for young people aged 12-15) and appointing a proxy (for young people aged 16-18) should be produced. An overwhelming 85% of focus group respondents completely agreed that young-person-friendly materials should be produced, and 10% agreed a little.

**Article 13 of the UNCRC states that**:\(^6\)

“1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice…”

Therefore, the Scottish Youth Parliament believes that young people should be able to receive information about the changes to the organ donation system that is understandable and comprehensive to allow them to make informed decisions.

Contacts

Roseanna Macdonald
Public Affairs Officer
Scottish Youth Parliament
Roseanna.M@syp.org.uk
0131 557 0452

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