



A Response to the Consultation on the Organ and Tissue Donation (Scotland) Bill

Scottish Youth Parliament

September 2014

Background of the Scottish Youth Parliament

Our vision is of a stronger, more inclusive Scotland that empowers young people by truly involving them in the decision-making process.

The Scottish Youth Parliament (SYP) is the democratically elected voice of Scotland's young people. We listen to young people, recognise the issues that are most important to them, and ensure that their voices are heard.

In working towards our aims, we support the following values:

Democracy - All of our plans and activities are youth-led, and we are accountable to young people aged 14-25. Our democratic structure and the scale of direct participation across Scotland give us strength and set us apart from other organisations.

Inclusion - We are committed to being truly inclusive. The Scottish Youth Parliament believes that all young people have a right to a voice. It doesn't matter who we are or where we come from. We celebrate our diversity.

Political independence - We are independent from political parties. Only by working with all legitimate political parties can we make progress on the policies that are important to young people.

Passion - We believe that drive and energy are crucial to successful campaigning. We are passionate about the key issues and believe that young people are part of the solution, not the problem.



Executive Summary of Recommendations

- The Scottish Youth Parliament would be supportive of the introduction of a soft opt-out system of organ donation to replace the current opt-in system.
- The Scottish Youth Parliament would be supportive of 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.
- The Scottish Youth Parliament would be supportive of 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 would be supportive of proposals that would allow all those aged 16 and over to be automatically opted-in as organ donors. The Scottish Youth Parliament also believes that young people aged 12-15 should be able to opt-in as organ donors by giving their written consent, and that parents should be able to consent to the transplant of organs for children under the age of 12.
- The Scottish Youth Parliament believes that a six month campaign would be an appropriate amount of time to inform the public of the change to the organ donation system, and would be supportive of informational materials being produced to inform young people specifically about the change from the opt-in system to the soft opt-out system.
- The Scottish Youth Parliament believes that this Bill will have positive implications for equality, providing that children and young people are informed about the change from an opt-in system to a soft opt-out system.



Methodology

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 group¹; 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.²

Therefore, the response of the Scottish Youth Parliament 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.³

¹ The online focus group was facilitated through SurveyMonkey, and contained nine questions based on the consultation document. 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.

² The consultation exercise for “Change the Picture” received nearly 43,000 responses and can be accessed here:
<http://www.syp.org.uk/img/Youth%20Manifesto/Scottish%20Youth%20Parliament%20Youth%20Manifesto-%20Change%20the%20Picture.pdf>

³ For more information about the Scottish Youth Parliament, our structures, and our policy making procedures, visit www.syp.org.uk



Background and Policy Precedent

The Scottish Youth Parliament welcomes the opportunity to respond to the Organ and Tissue Donation (Scotland) Bill. As the democratically elected voice of Scotland's young people, the Scottish Youth Parliament actively pursues opportunities for young people to engage with local, national, and international decision-makers.

The Scottish Youth Parliament has existing policy that is directly relevant to this response. The following statement was endorsed by 85% of the responses to our "Change the Picture" youth manifesto:

"Young people are entitled to as much protection of their human rights as the law can give them. This means that the United Nations Convention on the Rights of the Child (UNCRC) should be given more force in Scots law."

Several of these articles relate directly to the proposals of this Bill, and will be addressed in more detail below.

In addition, 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."

These policy statements provide the Scottish Youth Parliament with the mandate to respond to this Bill, with a particular focus on the rights of children and young people.

In addition, this response does not directly address every provision contained within the consultation document; rather it focuses on the specific elements of particular importance for young people.



Scottish Youth Parliament Response: Research Findings

In addition to referencing policies of the Scottish Youth Parliament, this section provides the research findings from the online focus group session. Respondents were asked to choose the extent to which they agreed with each of the following statements ranging from: completely disagree; disagree a little; neither agree nor disagree; agree a little; and, completely agree. The young people were also given the opportunity to comment on the proposals.

The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move?

As previously stated, the MSYPs agreed to the following Members' Motion, creating official policy for the organisation:

“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.”

The MSYPs vote on behalf of the young people who elect them, giving significant weight to this policy statement. Therefore, the Scottish Youth Parliament is supportive creating a soft opt-out system of organ donation to replace the current opt-in system.

Recommendation: The Scottish Youth Parliament would be supportive of the introduction of a soft opt-out system of organ donation to replace the current opt-in system.
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I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree?

A significant number of participants agreed with this statement, with 20% saying they agreed a little, and 60% saying they completely agreed. Only 15% of respondents completely disagreed with the role of the family being limited in this way.



One participant stated:

“It should always be the decision of the deceased person rather than that of the family.”

Furthermore, as an organisation, we strongly value Article 12 of the United Nations Convention on the Right of the Child (UNCRC) which states:⁴

“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.

“2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.”

As such, we believe that the view of the young person should be respected in regards to organ donation. If a young person of the age stated in the Bill makes the decision to register as an organ donor, their family should not be able to overturn that choice.

Recommendation: The Scottish Youth Parliament would be supportive of 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.

Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf?

A strong majority of young people indicated that they either agreed a little (10%) or completely agreed (70%).

One member of the focus group stated:

⁴ UNICEF, *The United Nations Convention on the Rights of the Child*, http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf



“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.”

Recommendation: The Scottish Youth Parliament would be supportive of provisions in the Bill that would allow an individual to appoint a proxy to make the final decision regarding transplant on their behalf.

My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent, as they currently do. This approach is, I believe, the best way to safeguard children and young people. Do you agree?

Do you agree the age limit for an adult should be set at 16 years old? If you answered no, what would you consider a more appropriate age?

A majority of young people said that they either agreed a little (25%) or completely agreed (50%) that those aged 16 and over should be automatically opted-in to be an organ donor. The focus group participants largely believed that 16 was an appropriate age to be considered an adult for the purposes of organ donation, as this is also the age at which young people can consent to medical, surgical, and dental treatment.

One participant noted:

“All 16-year-olds entered into the scheme should be made aware in writing from their GP that they are now in the scheme and the process by which to opt-out if preferred.”

Additionally, 10% of the focus group members believed the age limit should be lowered to 12. One believed that 18 was a more appropriate age.

When asked if they believed that young people aged 12-15 should be able to register as potential organ donors by giving their written consent and opting-in to the system, 35% of respondents agreed a little, and 50% completely agreed.



One respondent stated:

“This still lets young people have a say in their future, even if they cannot make the same decisions 16-year-olds can.”

The participants were also asked if they agreed that children under the age of 12 should not be able to opt-in and register as organ donors, but that a parent could consent to the transplant of their organs after their death. A majority agreed with this, with 35% stating they agreed a little, and 45% stating they completely agreed.

One focus group member noted:

“The children should still be asked their opinion about the matter.”

Additionally, in respect to Article 12 of the UNCRC, the Scottish Youth Parliament welcomes the proposal to include young people aged over 16 in the soft opt-out scheme. We assert that young people should be included in decisions that affect them. Young people aged over 16 should be considered an adult for the purpose of this Bill, and the decision to opt-out of the system or not should be left to them.

Furthermore, we are also supportive of giving young people aged 12-15 the opportunity to opt-in and register as organ donors. This should also be their choice, and offers what we believe to be an appropriate amount of responsibility.

Furthermore, Article 5 of the UNCRC states that⁵:

“States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention. the responsibility

⁵ UNICEF, *The United Nations Convention on the Rights of the Child*,
http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf



to protect and assist families in fulfilling their essential role as nurturers of children.”

As such, we believe that families should be able to offer guidance to their children, and provide direction as appropriate for the maturity of the child. Therefore, we also support measures that would allow a parent to consent to the transplant of the organs of their child, if the child is under the age of 12 at the time of his/her death. The Scottish Youth Parliament recommends that parents keep their children as informed as possible, in line with their evolving understanding and capacity.

Recommendation: The Scottish Youth Parliament would be supportive of proposals that would allow all those aged 16 and over to be automatically opted-in as organ donors. The Scottish Youth Parliament also believes that young people aged 12-15 should be able to opt-in as organ donors by giving their written consent, and that parents should be able to consent to the transplant of organs for children under the age of 12.

Do you think six months is a long enough period to run a campaign prior to change over?

A majority of those who participated in the focus group believed that six months was an appropriate amount of time for an informational campaign, with 45% completely agreed, and 20% agreed a little. However, 25% believed that more time was needed to ensure everyone knew about the change.

Notable comments from the focus group included:

“The campaign should be continuous...”

“I feel that time is only one factor, and not the most important. The amount of information is vital - the more information given to people the better.”

As such, the participants also discussed if, in addition to producing informational materials in different languages, young-person-friendly materials should also be produced. An overwhelming 85% of participants completely agreed that young-person-friendly materials should be produced, and 10% agreed a little.



One participant also noted:

“Also not all young people have the same level of reading ability so other methods of information distribution should be used to convey the changes, and all methods should be in young person friendly language.”

Article 13 of the UNCRC states that⁶:

“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 change to a soft-out organ donation system that is understandable and comprehensive to allow them to make informed decisions.

Recommendation: The Scottish Youth Parliament believes that a six month campaign would be an appropriate amount of time to inform the public of the change to the organ donation system, and would be supportive of informational materials being produced to inform young people specifically about the change from the opt-in system to the soft opt-out system.

Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

Overall, the focus group believed that the Bill would have positive implications for equality.

Participants commented:

⁶ UNICEF, *The United Nations Convention on the Rights of the Child*,
http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf



“I believe this Bill will enhance the autonomy, independence, and control young people have over their own bodies.”

“Children and young people between the ages of 12 and 15 will have the opportunity to voice their opinion on their future in ways they did not before”.

“I believe that it will have a positive impact on the rights of children and young people in Scotland, as it gives them more responsibility; however, some parents may see it as them having too much responsibility.”

“I believe that allowing 12-to-15-year-olds to opt-in would empower them.”

It was also noted that children and young people must be kept informed the change from an opt-in system to a soft opt-out system, and that they should have an opportunity to discuss organ donation with medical professionals.

Recommendation: The Scottish Youth Parliament believes that this Bill will have positive implications for equality, providing that children and young people are informed about the change from an opt-in system to a soft opt-out system.

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