



## Organ and Tissue Donation and Transplantation - a consultation on increasing numbers of successful donations

Deadline: Tuesday 14<sup>th</sup> March 2017

### Question 1: What do you think of the principle of a soft opt out system for Scotland?

Proposals for a soft opt-out system for organ and tissue donation in Scotland engage a range of children's UNCRC rights, including article 3 (best interests), 5 (evolving capacities), 6 (right to life), 12 (right to be heard), 13 (right to information), 16 (right to privacy) and 23 (support for children with a disability)<sup>1</sup>.

Under Part 1 duties of the Children and Young People (Scotland) 2014 Act<sup>2</sup>, Scottish Ministers are required to give due consideration to ways in which the UNCRC can be better implemented and to take account of the views of children and young people. Together recommends that a full Child Rights and Wellbeing Impact Assessment (CRWIA)<sup>3</sup> is carried out to inform the development of the Bill as it passes through Parliament. This will ensure that any negative impact on children's rights are identified and mitigated, and opportunities to further children's rights are progressed. A full CRWIA would ensure that the new system of organ donation would secure an appropriate balance between protecting children, enabling them to express their wishes regarding organ donation, and helping children that need transplanted organs.

Article 12 of the UNCRC ensures the right of children to have their voices heard on matters that impact on them. Together strongly recommends that any further work on proposals to change the system of organ and tissue donation include meaningful engagement with children, including through the CRWIA, which can further benefit the legislation by ensuring there are no gaps in provision.

If the soft opt-out system is to be introduced, the following considerations must be taken into account to respect, protect and fulfil children's UNCRC rights:

- Children should be aware of and understand why Scotland has a soft opt-out system and how the system works in practice. Their awareness should include a sensitive and age-appropriate understanding of potential family members' roles in organ donation.
- Young people should understand their rights in relation to the soft opt-out system in advance of reaching their 16<sup>th</sup> birthday when it starts to apply to them.

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<sup>1</sup> See <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>

<sup>2</sup> Children and Young People (Scotland) Act 2014, Part 1.  
<http://www.legislation.gov.uk/asp/2014/8/part/1/enacted>

<sup>3</sup> See <http://www.gov.scot/Topics/People/Young-People/families/rights/child-rights-wellbeing-impact-assessment>

- Parents and carers should understand the rights of children and young people in relation to the soft opt out system, and be given appropriate support and advice to talk to their children about options and implications.
- Information relating to children who register their wishes should be held securely and with complete confidentiality.

These considerations could be taken into account through:

- Public awareness campaigns targeted specifically at children, young people, parents, carers and professionals through schools, youthwork activities, public health activities and the media. Awareness campaigns should use a range of sensitive, accessible and age-appropriate communication methods that are fully inclusive of children who require additional support for learning.

**Question 3: where someone has joined the Organ Donor Register (ODR) or indicated in another way that they wish to donate, what do you think should happen if the potential donor's family opposes the donation?**

Consent to organ donation over the age of 12 is currently covered under the Human Tissue (Scotland) Act 2006<sup>4</sup> which provides that a child over the age of 12 can consent to organ donation without parental consent and, if in writing, this cannot be vetoed by family members.

Under the new proposals, children aged 12-15 will still be able to register their wish to become, or not become, an organ donor. In practice, if a child dies in circumstances where donation becomes a possibility, then their stated wish to consent, or not consent, to organ donation takes precedence and families should be sensitively encouraged to accept their decision. It would be normal practice for a person with parental responsibility to be consulted.

This echoes the principles of Article 5 of the UNCRC, which introduces the idea that children should be able to exercise their rights as they acquire the competence to do so. The UNCRC is clear that parental guidance must be geared towards supporting children to exercise their rights and make their own decisions, respecting the extent to which children can do this for themselves. In other words, as children mature, they should be allowed greater freedom of choice and respect for their ability to fully exercise their rights, including decisions to become an organ donor in the case of their death.

The intention is that publicity and educational campaigns will make more children aware of the opportunity to register whether they wish to donate or not donate organs and tissue if they die, and have a conversation with their family about it. If the child then dies, the family would be more confident that they could follow their wishes and more families would consent to donation. In respect of children's Article 12 rights, the child's wishes should as far as possible be carried out.

To facilitate these discussions, medical staff should receive training on children's rights under the UNCRC before engaging in consultation with families, in order to ensure that article 3 (best interests)

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<sup>4</sup> See Part 1, Section 8 <http://www.legislation.gov.uk/asp/2006/4/contents>

and article 12 (right to be heard) are carried out and in order to understand the rights of both parents / carers and child.

**Question 6: If there was a soft opt out system, what do you think about the categories of people set out above for whom explicit authorisation would still be needed from the person themselves or family member?**

*“A child under a certain age – we would still view it as appropriate for children of 12 years old or over to be able to self-authorise their own donation if they wish, but it may not be appropriate for someone’s authorisation to be “deemed” unless they are at least 16 years old.” – page 15 of the consultation paper.*

The principle of authorisation of a child not being ‘deemed’ unless they have indicated whether they wish to opt in or opt out is similar to measures included in the Human Transplantation (Wales) Act 2013.<sup>5</sup> In Wales authorisation will not be ‘deemed’ until a child reaches 18 years-old, whereas the proposal in Scotland is 16 years-old, which is in line with the views of members of the Scottish Youth Parliament<sup>6</sup> and other age-limits applied in Scotland.<sup>7</sup>

As such, for younger children under the age of 12, if the child has been provided with adequate information and is able to make an informed decision to opt-in consent, then this should be sufficient to authorise a donation in compliance with both article 5 (right to be heard) and article 12 (right to be heard), alongside sensitive encouragement of families and appropriate safeguarding.

Effective public awareness campaigns must work with schools and other avenues of engaging with younger children to communicate messages on opting in or out of the organ donor register, consistent with evolving capacities and having their voices heard. Children with additional support needs must be supported through various methods of participative communication to ensure any consent given is fully informed in line with article 23. The same principle would apply as above, that if a child had not indicated consent to opt in or opt out of the donor system, then authorisation would not be ‘deemed’ until the age of 16.

**Question 8 – under what age do you think children should only be donors with explicit authorisation?**

See response to Question 6.

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<sup>5</sup> See [http://www.legislation.gov.uk/anaw/2013/5/pdfs/anaw\\_20130005\\_en.pdf](http://www.legislation.gov.uk/anaw/2013/5/pdfs/anaw_20130005_en.pdf)

<sup>6</sup> See [http://www.parliament.scot/S4\\_MembersBills/Bookmarked\\_Organ\\_Donation\\_Consultation\\_Document.pdf](http://www.parliament.scot/S4_MembersBills/Bookmarked_Organ_Donation_Consultation_Document.pdf)

<sup>7</sup> Such as the right to vote which was extended to 16 and 17 year olds in the Scottish Referendum.

**Question 9 – for children who are in care, what are your views on allowing a local authority which has parental responsibilities and rights for the child to authorise donation for the child if no parent is available?**

If a child who is looked after has been supported to make an informed decision, and subsequently chosen to expressly opt in or out of the organ donor register, these wishes should be respected in the case where a possibility to donate arises, as in previous answers. As with all children over the age of 12, consent to organ donation is currently covered under the Human Tissue (Scotland) Act 2006 as above.

In situations in which the child has not given express consent and they are below the age of 16, the inclusion of Corporate Parenting roles in decision-making regarding organ donation must be scrutinised through a full CRWIA to ensure any proposals are underpinned by the UNCRC.

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