

Gathering Views on Organ and Tissue Donation and Transplantation

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Section 1: Executive Summary

- 1.1 The Scottish Government conducted a consultation exercise on Organ and Tissue Donation and Transplantation¹ which sought the views of the public and organisations on how to increase numbers of successful organ and tissue donations in Scotland. The consultation looked at two ways to potentially increase numbers of deceased organ and tissue donors – firstly, to increase numbers of referrals by clinical teams to specialist nurses for organ donation and secondly, to increase the number of times when donation is ‘authorised’ to proceed.
- 1.2 In particular, the consultation looked at a proposal to introduce what was described as a ‘soft opt out’ system of organ donation. This system works on the assumption that most adults can be a donor when they die unless they have specifically stated that they do not wish to donate. It normally allows for the person’s family to provide information about the person’s views about donation in some way.
- 1.3 Following the consultation, the Scottish Government decided to obtain further views on the ‘soft opt out’ system of organ donation. Whilst this report makes reference to organ donation, it should also be taken to mean organ and/or tissue donation.
- 1.4 The Scottish Health Council was asked for assistance to arrange and facilitate four discussion groups in four NHS Board areas in Scotland. In two of the Board areas (NHS Ayrshire and Arran and NHS Forth Valley) the discussion groups involved young people and in the remaining two areas (NHS Greater Glasgow and Clyde and NHS Fife) the participants consisted of adults with a learning difficulty. These groups were chosen as it was important to get feedback from people who might not ordinarily respond to written consultations or might be affected by a change in the current law.
- 1.5 During the course of the project, a further need emerged to gather views from looked after young people given the specific issues associated which organ donation could present for them. ‘Looked after’ is a term that refers to children who are subject to a supervision order and live at home or in ‘kinship care’ (care of children by relatives or, in some cases, close family friends). It includes children who live in foster care, residential units, residential schools and secure units. It also includes young people who are no longer in care but may continue to be supported by the local authority and a variety of other agencies and people up to the age of 26.

¹ <http://www.gov.scot/Publications/2016/12/3657/6>

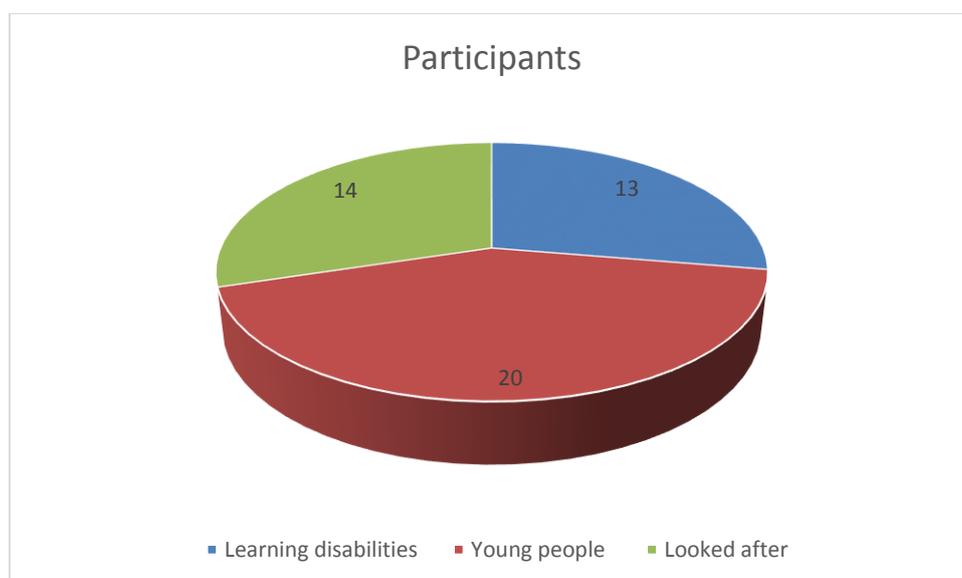
1.6 Scottish Health Council staff worked in conjunction with Barnardo's Scotland, a charity which cares for vulnerable children and young people, and organised a discussion group with looked after young people. An electronic online survey was also used to supplement the feedback received from the group discussion. Assistance was provided by Barnardo's staff to support the young people to take part in the discussion group and NHS staff supported young people to complete the online survey.

1.7 The discussion groups for people with learning difficulties and young people were arranged and facilitated by Scottish Health Council staff who worked closely with People First Scotland and Arran Youth Foundations. People First Scotland is an organisation which supports people with learning difficulties to have more choice and control over their lives. It provided assistance to the Scottish Health Council by identifying participants for two of the groups, sourcing suitably accessible venues and providing appropriate support to the participants to enable them to take part in the discussions.

Arran Youth Foundations is a registered charity that aims to engage young people in fun and meaningful work activities and which provided similar support to young people taking part in the discussion group.

1.8 A total of 47 people took part in the discussion groups and this was made up of:

- 13 people with learning difficulties in Fife and Greater Glasgow and Clyde, and
- 34 young people aged 12-22 in Ayrshire & Arran and Forth Valley (which included 12 looked after young people in Forth Valley).



1.9 Whilst participants in each group identified a number of issues around the 'soft opt out' proposal, in general they agreed that organ donation was positive and

worthwhile. They also felt that the 'soft opt out' option was a positive way forward as they thought that most people would be willing to be a donor; albeit that some may never get round to formally signing up. It was felt however that more should be done to increase awareness of organ donation to encourage conversations with families. Participants thought this could help ensure there were no 'difficult decisions' when someone died.

- 1.10 The groups of young people talked about what they thought the appropriate age of authorisation for organ donation should be and from what age deemed authorisation should start. This topic generated a lot of discussion with some saying that children aged 12 would be able to give authorisation whereas others felt 15-16 was more appropriate.
- 1.11 Similarly, the groups involving people with learning difficulties had good discussions around the issue of safeguards. One group highlighted the importance of "using the right words" to explain the process and advocated a need for support for people in the decision-making process. This group was also keen to ensure that, in cases where there were no family members, a close friend could be involved instead.
- 1.12 Across all groups participants said how important it was for people to be able to change their minds in relation to organ donation should they wish.
- 1.13 Participants recommended a range of ways to promote changes and information about organ donation. These ranged from advertising to social media and included suggestions such as formal letters and leaflets etc. They also gave some feedback on what they thought would not work such as YouTube and cinema advertising.
- 1.14 From the discussion groups, it was clear that participants found the subject of organ donation both positive and interesting; though at times felt that it was complex in terms of the processes involved. Participants could clearly see the benefits of the 'soft opt out' system, but said it was important that people could change their minds and come off the register in future if they wanted to. Some participants were keen that any changes to the current system should be closely monitored to see if it actually made a difference and increased the number of organ donations.
- 1.15 The group discussion with looked after young people showed that overall they had mixed emotions and strong opinions on organ and tissue donation and transplantation. Most of the group were not completely comfortable with the 'soft opt out' concept and had concerns about how it would work in practice if people did not know enough about it, or had not discussed their wishes with anyone.

As a group of looked after young people, they felt that it would be appropriate for local authority staff who knew them to give authorisation (or not if it was against the person's wishes) for organ donation, if they had parental rights and the person has no family, or no long term foster carer.

Section 2: Background

- 2.1 The Scottish Health Council was established in 2005 to promote Patient Focus and Public Involvement in the NHS in Scotland. We work to support the engagement of people and communities in the development of health and social care services. The Scottish Health Council is part of Healthcare Improvement Scotland, which seeks to drive improvements that support the highest possible quality of care for the people of Scotland.
- 2.2 Following the formal consultation the Scottish Government indicated its intention to bring forward legislation for a 'soft opt out' system of organ and tissue donation. At the time of this work, the law in Scotland allowed a person to give permission for their organs (heart, liver, kidneys, lungs etc) or tissues (eyes, tendons, heart valves, skin, etc) to be donated after their death and used to transplant into another person. This required the organ donor to have 'opted into' (signed up to) the Organ Donor Register Scheme or for authorisation to be given by a nearest relative after death. Where no such 'opt in' action had been taken, a specialist nurse for organ donation would discuss with the potential donors' nearest relatives whether or not there were any previous intentions or discussions around organ donation and whether permission for transplantation of organs could or would be given.
- 2.3 Organ donation is seen as a 'special gift' as it gives someone who is ill a chance to return to a more healthy life. A very small number of people (less than 1% who die in Scotland each year) can be an organ donor². This means that there are only a fairly small number of potential donors in Scotland in any one year.
- 2.4 In an effort to address this and help increase the number of people agreeing to donate their organs after death, consideration is being given to a change in the law to introduce a 'soft opt out' system. This change would mean that it is presumed that a person agrees to be a donor unless they have specifically indicated that this was not the case. It includes a wide range of safeguards which are intended to protect and respect an individual's wishes in relation to organ donation.
- 2.5 The Scottish Government carried out an engagement process to obtain feedback from the public on the new system. As a result of this, it identified a need to gather views on the 'soft opt out' proposal from adults with learning difficulties and young people. During the course of the project, it was also decided that it would be helpful to hear views from looked after young people

² Currently, it is only possible to donate if you die in a hospital – normally in a Critical Care area (for example an intensive care unit - and even then there may be a number of reasons why organ donation is not possible, such as medical reasons (if some or all of the organs are not functioning well) or for legal reasons (where there is an investigation into the cause of death and the Procurator Fiscal may not be able to allow some or all organs to be donated).

about another proposal in the consultation which would give local authorities the power in certain circumstances to authorise (or not) donation for children for whom they hold parental rights and responsibilities.

- 2.6 The Scottish Health Council was asked to arrange five discussion groups – two involving young people, two for people with learning difficulties and one with looked after young people to obtain their views on the proposed changes to the existing law to create a ‘soft opt out’ system. We also supplemented the discussion group with looked after young people with an online electronic survey. The aim was to explore what they thought was an appropriate age for authorisation and how they would prefer to receive information about organ donation.
- 2.7 The feedback we received has been reported to the Scottish Government to inform the process and the changes to Organ and Tissue Donation and Transplantation.

Section 3: Engagement Approaches

- 3.1 Our Voice is based on a vision where people who use health and social care services, carers and members of the public are enabled to engage purposefully with health and social care providers to continuously improve and transform services. People will be provided with feedback on the impact of their engagement or a demonstration of how their views have been considered.
- 3.2 A number of different organisations are key delivery partners for Our Voice including the Scottish Government, the Scottish Health Council, Healthcare Improvement Scotland, the Convention of Scottish Local Authorities (COSLA), and the Health and Social Care Alliance (the ALLIANCE).
- 3.3 The Scottish Health Council's Gathering Public Views methodology supports Our Voice by feeding public views into the heart of the development of policy and services. There are other examples of this available on the Scottish Health Council's website (www.scottishhealthcouncil.org).
- 3.4 This engagement activity on organ donation is intended to supplement that previously undertaken by the Scottish Government³. It is not formal research or public consultation.
- 3.5 The Scottish Health Council believes that gathering views via discussion with small groups of people as a particularly effective way of obtaining feedback. Our main consideration is about the quality of engagement as opposed to the quantity of people involved.

Discussion Groups

- 3.6 To gather views on organ donation, the Scottish Health Council organised five small discussion groups. They were held in Greater Glasgow and Clyde and Fife (for people with learning difficulties); Ayrshire and Arran and Forth Valley (for young people). A further session was held in Forth Valley for looked after young people.
- 3.7 The sessions were organised and run with the assistance and support of:
 - Arran Youth Foundations – which is a registered charity that aims to engage young people in fun and meaningful work activities.
 - Balfron High School (Forth Valley).

³ <https://consult.gov.scot/health-protection/organ-and-tissue-donation-and-transplantation/results/organ-and-tissue-donation-and-transplantation-analysis-of-responses.pdf>

- People First Scotland – which is a registered charity that supports people with learning difficulties to have more choice and control over their lives.
- Barnardo's Scotland (Forth Valley) – which is a registered charity that aims to support disadvantaged children, young people, families and communities to help ensure that every child has the best possible start in life.

3.8 A total of 47 people took part in the discussions and this was made up of:

- 13 people with learning difficulties in Fife and Greater Glasgow and Clyde, and
- 34 young people aged 12-22 in Ayrshire & Arran and Forth Valley (which included 12 looked after young people in Forth Valley).

In four of the sessions, the discussion was preceded by a short presentation which included two short video clips delivered by representatives from the Scottish Government. In the session involving looked after young people in Forth Valley, representatives were on hand to provide an informal overview of the planned changes and to answer any questions.

Electronic Online Survey

3.9 To supplement the group discussions with looked after children, the Scottish Health Council, in collaboration with Barnardo's Scotland, offered an opportunity for some looked after young people to share their views on organ donation through an online survey. Ten young people completed the survey.

Section 4: Feedback from the discussion groups

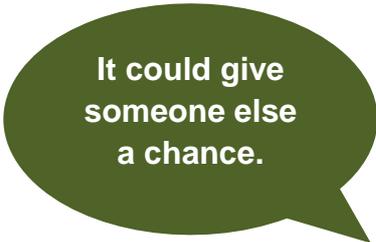
This section summarises the feedback from the five discussion groups. The quotes which appear in this section are from people who took part or are extracts from the discussions that took place.

4.1 Discussion group participants were first asked for their general views on organ donation

Generally, they all felt positive about organ donation and said it was “very important”. Everyone seemed to recognise and be enthusiastic about its benefits.



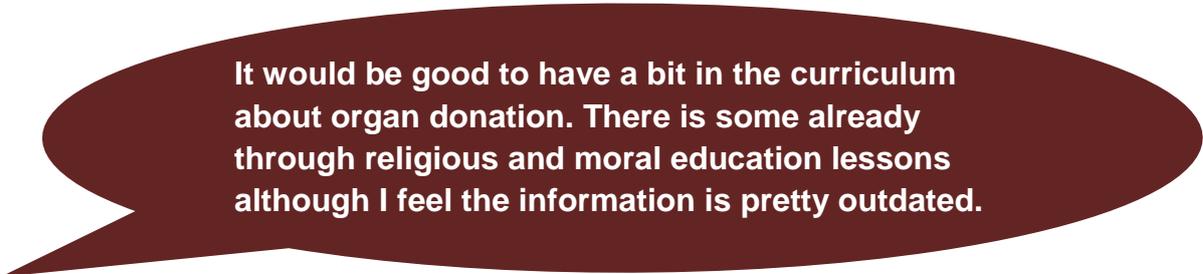
If everyone thought about it, it would be a good thing.



It could give someone else a chance.

However, some participants in the groups involving people with learning difficulties felt that the information and process was complex, especially in relation to donor suitability.

One of the young people in the Arran Youth Foundations Group said that:



It would be good to have a bit in the curriculum about organ donation. There is some already through religious and moral education lessons although I feel the information is pretty outdated.

4.2 We asked participants in the discussion groups what they thought of the proposals for a ‘soft opt out’ system for organ donation.

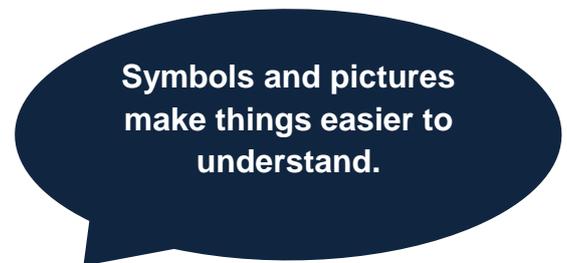
The general feeling across all of the discussion groups was that organ donation was necessary and it was “positive and worthwhile”. Participants also thought that most people would be happy to be a donor but acknowledged that there could be a number of individuals who may never get around to formally signing up to it, and this was seen as a missed opportunity.

It was agreed that, although they did not think many people would choose to opt out of being a donor, it was nonetheless seen as very important that there was an option to do so for those that wanted to opt out. Participants also felt

that it was important that individuals had the opportunity and right to change their mind about being a donor in the future and for whatever reason.

During discussion in one of the groups involving people with learning difficulties, there was a view that organ donation seemed like it was being imposed on people or as they described it “forced upon us if put into law”.

Additionally, in one of the groups involving people with learning difficulties, participants specifically highlighted the importance of “using the right words” to explain the organ donation process in a clear and concise way. In the same groups, the important issue of safeguards being in place was raised a few times, as was the need to inform and discuss preferences with family members. There was some further discussion, and anxieties raised, about what would happen in instances where there were no family members involved.



Making sure people understood the organ donation process was discussed by all groups and particularly in the groups involving people with learning difficulties. Participants suggested that use of symbols and pictures would be a helpful way to clearly show what organ donation meant and what was involved.

At one of the discussion groups involving people with learning difficulties, a series of pictures was used to tell a story based on a fictitious character called Molly who had a learning disability and had a supportive family and friends. The group then discussed Molly’s understanding of her decision to be an organ donor and whether her family thought she would be happy to donate, taking all the information into account to make an informed decision on her behalf after her death.

Using an example to illustrate the issues worked well in practice and participants felt reassured of the process and that necessary safeguards would be put in place.

They also said they would be happy to see supported decision making introduced to replace the existing arrangements, whereby only a parent or guardian could give permission for organ donation for a child under the age of 12.

4.3 We asked the discussion groups involving young people what age they thought the opt out system of organ donation should apply to. In other words, at what age should we be able to presume that children and young people are able to understand that they need to opt out if they did not want to be a donor? The young people also offered views on the age at which people should be able to authorise their own donation, or opt out of donation.

There was a mixed reaction to this question.

In one group, all participants thought that aged 12 was too young for the average young person to make that kind of decision. They shared that they did not think that organ and tissue donation and transplantation was a topic that young teens often (if ever) think about, and there is currently little information given to children and young people in that age group.



Organ donation
is not
something
young teens
think about.

In another group, there was discussion about maturity versus age with some young people suggesting that, rather than having a stipulated age, providing education on the subject on commencing first year at high school could be useful instead. It was thought in this group that the age a person could make a decision to opt out should be determined by whether or not young people were capable of making a decision. One person, who was aged 12, said “I think that I am mature enough to be able to decide”. Other participants agreed but acknowledged that not all 12-year-olds would have the same ability to make an informed decision about organ donation.

Others felt that 16 seemed like an appropriate age to provide authorisation for organ donation. Those participants who were aged 15 and 16 felt they had the knowledge, understanding and ability to make that choice (whether to actively sign up to the register, stay in the ‘soft opt out’ system, or choose to opt out completely) on their own at 16.

Some participants highlighted that at 15 young people were doing exams and making other life decisions, so should be capable of deciding on whether or not to be an organ donor. Some did acknowledge however that, regardless of age, it was important that the issue was discussed with parents where young people felt that was appropriate.

In summary, both groups involving young people felt that 15-16 was an appropriate age for deemed authorisation to begin from and all participants said it was very important for children and young people to learn about this

topic, to have discussions with their parents and to be able to state their wishes if they would like to be included on the register.

Some participants thought this to be even more important for children and young people living with long-term or terminal conditions.

4.4 We asked young people what they thought was the best way of keeping them informed of any changes to the organ donation system

They identified a range of methods such as use of social media (including Facebook, Twitter, Snapchat and Instagram) as well as television and radio advertising.

Participants also highlighted that, given the time young people spend at school, it should be possible to make more use of assembly and specialist classes such as Personal, Social and Environment (PSE) to promote and share information about organ donation and transplant.

Poster displays and leaflets were also highlighted as a good way of sharing information, providing they were located in obvious places such as toilets and dining areas (or other areas where people have to queue). Participants mentioned the importance of making any posters or leaflets “attention grabbing” in their appearance with the content being to the point and potentially containing “a real life story”.



Make posters and adverts eye catching and put them in obvious places.

Within the discussion at one high school it was suggested that young people be sent a formal letter or information pack when they received their National Insurance number from the Scottish Government when they reached 16 years of age. They said it could inform young people that they had now been included on the organ donor register and contain information about how to be removed from it if they wished.

It was also suggested that Young Scot could have a role in distributing information via its website. Others felt that sessions such as the Scottish Health Council Gathering Views discussion groups could be used to share information.



Do more sessions like today with groups – go out to where people are!

Section 5: Feedback from looked after young people

- 5.1** In response to a request from the Scottish Government for additional feedback, the Scottish Health Council worked with Barnardo's Scotland staff in Forth Valley and Scottish Government colleagues to gather feedback from looked after young people. A discussion group was organised at the premises of Barnardo's in Stirling and feedback was supplemented by online electronic survey. Four young people (aged between 17 and 22) took part in the discussion group and a further 10 people (aged 16-22) completed the survey.

Below is the feedback from the discussion session which was facilitated by Barnardo's staff.

Discussion group

- 5.2 We asked the young people what they currently knew about organ and tissue donation**

The group were generally aware of what organ and tissue donation and transplantation was and what it meant. Most of the participants were aware of and/or had experienced ways to sign up to the donor register (for example through their GP or when applying for a driving licence).

- 5.3 We asked them for their thoughts about organ and tissue donation**

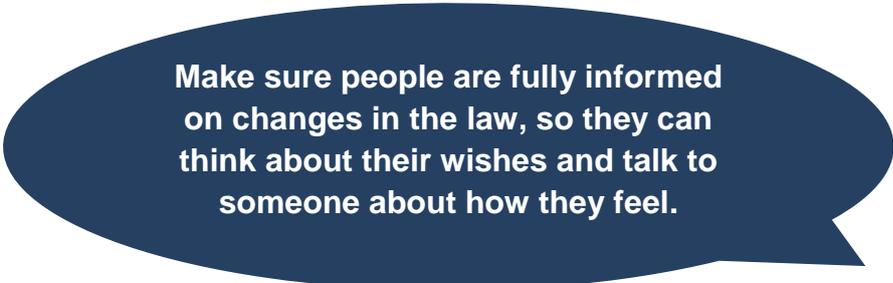
There were very mixed feelings about organ donation amongst participants. One felt very strongly that they were not comfortable with it and would not want their (or their loved ones) organs to be donated. Another person shared a concern that if someone signed up to the register and were really ill in hospital then that doctor may not try to save them so the organs could be taken (Scottish Government staff were able to provide reassurance that this would not happen).

Some participants felt however that organ donation was a positive thing and appreciated that it could save lives. One participant said that it would be a good feeling if it saved the life of someone who may have also died otherwise.

- 5.4 We asked looked after young people what they thought of the proposals for a 'soft opt out' system of organ donation**

At first the group, young people struggled with the term 'soft' as part of the proposed system and were very anxious as they thought it meant that if someone had not opted out your organs would just be taken for donation. Most participants described this as "so wrong". Once 'soft opt out' was explained in more detail, participants felt more reassured although there was still concern about the proposal. Participants said that organ donation was not

something that young people normally talked about. Some felt that there could be some who had never heard of organ donation and so may not talk about it with family, friends or support workers. This made a few participants worried that if you were not aware that you had to opt out, then you may not have told anyone your wishes either.



Make sure people are fully informed on changes in the law, so they can think about their wishes and talk to someone about how they feel.

5.5 We asked young people what they thought the age of authorisation for organ donation should be

They all felt that between 12 and 16 was too young for people to decide if they wanted to donate their organs or not. One participant was also worried about individuals (of any age) who may not understand how the system would work.

5.6 We asked looked after children whether the local authority should be able to give authorisation (on their behalf) to donate their organs instead of parents or family

One participant felt strongly that it should always be a family member (if the individual has family able to make that choice) and not the local authority who gave authorisation. It was acknowledged, however, that not all looked after young people had relatives. Some felt that if foster parents had known the person long enough, then they should be able to make the decision. If family or foster carers were not an option, young people agreed that local authority staff should be able to give authorisation (or deny authorisation if that was the person's wishes).

One person said they would be comfortable with a member of local authority staff (who was well known to the person) giving the final decision if they had parental rights.

5.7 We asked young people what they thought was the best way to keep young people informed of any changes to the organ donation system

The group shared their ideas on ways to promote the changes and keep young people informed. Some were thoughtful about including options that could maybe exclude people who did not have internet access or those who were homeless.

Suggestions included the following.

- A formal letter either from the Scottish Government or from the GP (as GPs currently send out letters for screening – although it was recognised that not everyone is registered with a GP practice).
- Information in schools – such as presentations in small classes (not large assemblies) and part of curriculum in a relevant class.
- Advertising and posters – on sides of buses, on the back of public toilet doors or on/in taxis, billboards in public places, on cups or boxes used at fast food restaurants and coffee shops (McDonalds, Costa, Greggs etc).
- Advertising in social work housing offices and other premises.
- Key workers sharing information or through the looked after care nurse (some young people though felt they would not be comfortable with this approach).
- Through social media – whilst one participant felt that they might pay attention to an advert on Facebook if it was short and engaging (for example easy to read, colourful and “not too boring”), others said they would scroll past without reading it.
- Set up a free telephone helpline where people could get more information (although advertising the number and accessibility was recognised as being challenges).

Whilst participants had a range of suggestions about how information could be shared about organ donation, they were also keen to provide feedback about what would not work for young people:



Online survey

With the support of staff from NHS Forth Valley, 10 young people (aged between 16 and 22) completed an online survey. Below is a summary of their feedback, thoughts and ideas.

5.8 What do you think of the proposal for a 'soft opt out' system of organ donation?

All 10 participants completed this question, with a mixed response.

- Six participants said they thought it was a good idea
- Three participants felt it was not a good idea, with one of these respondents saying 'it is okay to opt out'
- One person said they were not sure

5.9 What would be the best way to keep you up to date and informed of the changes to the organ donation system?

- Seven participants said the best way to keep them up to date was via social media
- Four people said that a personal letter would be a good way of informing them of any changes
- Other suggestions included radio, television (advertisements and news) and the internet

5.10 What do you think about allowing a local authority with parental rights and responsibilities for a child to authorise organ donation for the child if no parent is available?

- Eight people thought that they should be allowed
- One person said no they should not be allowed
- One participant was unsure

5.11 Should the local authority have to seek views from anybody else in reaching a decision on whether to authorise? (For example, family members)

- Five participants thought that the local authority should be able to seek views
- Four people said they should not.
- One person said they should only be able to seek views if the people in question knew the individual well enough

In summary, the feedback from looked after young people was that overall they had mixed emotions and strong opinions on organ and tissue donation and transplantation. Most of the participants were not completely comfortable with the 'soft opt out' concept and some people had concerns about how it would work in practice if people did not know enough about it or had not discussed their wishes with anyone.

As a group of looked after young people, they generally felt that it would be appropriate for local authority staff who knew them to give authorisation (or not if they knew the person's wishes) for organ donation, if they have parental rights and the person has no family, or no long term foster carer.

Section 6: Next steps and Acknowledgements

- 6.1 The feedback obtained from each of the discussion sessions and the online survey has been shared with the Scottish Government to help inform the decision-making process in relation to the proposed development of a 'soft opt out' organ donation system.
- 6.2 The Scottish Health Council would like to thank all the participants who shared their views on the proposed 'soft opt out' system relating to organ and tissue donation in Scotland. The feedback received has been extremely valuable in enabling the voices of people with learning difficulties, and young people, to be heard on this sensitive and important policy area.
- 6.3 We would also like to thank staff from People First Scotland, Barnardo's Scotland, Balfron High School and Arran Youth Foundations for their expert advice and support in gathering views. The Scottish Health Council is particularly grateful for the practical support we received to run the sessions and for assistance in making the engagement accessible and meaningful for all participants.
- 6.4 The Scottish Health Council will liaise with the Scottish Government in order to provide feedback to all participants about how their views and suggestions have been taken on board and what has changed as a result of their involvement.

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- अन्य भाषाओं में

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- Brailio raštu ir
- kitomis kalbomis.

Dostęp do tego dokumentu, a także możliwość jego pobrania, można uzyskać na naszej witrynie internetowej. Informacje można również otrzymać w następujących postaciach:

- wiadomość e-mail
 - wydruk z dużą czcionką
 - kaseeta audio lub płyta CD
 - zapis alfabetem Braille'a
 - zapis w innym języku
-

Вы можете прочитать и загрузить этот документ с нашего веб-сайта.
Информация также предоставляется следующим образом:

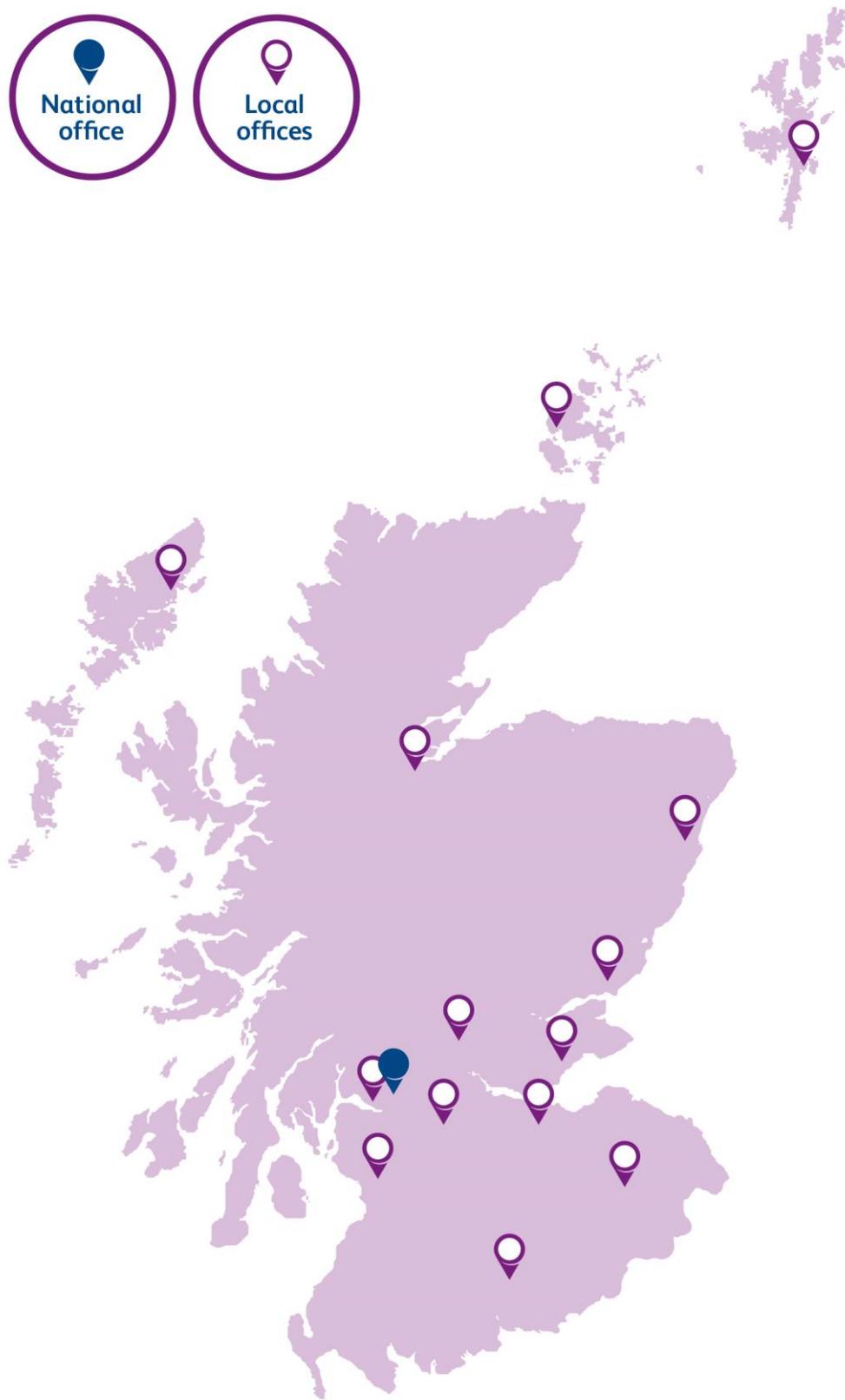
- по электронной почте
- крупным шрифтом
- на аудиокассете и компакт-диске
- шрифтом Брайля и
- на других языках

您可從我們的網站閱讀及下載本文件。我們亦透過以下方式提供此資訊：

- 電子郵件
- 大版面印刷
- 語音磁帶或 cd
- 盲文，以及
- 其他語言版本

آپ ہماری ویب سائٹ پر اس دستاویز کو پڑھ اور ڈاؤن لوڈ کر سکتے ہیں۔ ہم یہ معلومات درج ذیل کے ذریعہ بھی فراہم کر سکتے ہیں:

- بذریعہ ای میل
- چھاپے کے بڑے حروف میں
- آڈیو ٹیپ یا سی ڈی کی شکل میں
- بریل میں ، اور
- دیگر زبانوں میں



The Scottish Health Council has a national office in Glasgow and a local office in each NHS Board area. To find details of your nearest local office, visit our website at: www.scottishhealthcouncil.org/contact/local_offices.aspx

www.scottishhealthcouncil.org

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