

## Department of Health

# Public Consultation Document on the introduction of a statutory opt-out system for organ donation for Northern Ireland

**Date of issue: 11 December 2020**

**Responses to be returned by: 19 February 2021**

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## Foreword by the Minister for Health, Robin Swann MLA

***I believe that the time is now right for us to revisit the issue of consent for organ donation.***

*I am privileged as Health Minister to be able to speak about the positive attitudes of the people of Northern Ireland when it comes to organ donation, the selfless generosity of our donors and donor families, our fantastic intensive care clinicians and specialist nurses, and our world class kidney transplantation service.*



*With that said, I am ever mindful of the 11 people who died last year in Northern Ireland waiting on an organ transplant, and of the 115 people who are currently on a transplant waiting list.*

*Almost a million people (48%) in Northern Ireland have joined the NHS Organ Donor Register. Many more (over 80%) have said that they would consider donating an organ. However, when faced with the decision, we know that around a third of families will decide not to proceed with donation. Whilst this is fully understandable in these tragic circumstances, it is often because they do not know what their loved one would have wanted, or what decisions they have made.*

*Today, 11<sup>th</sup> December 2020, marks what has proudly become known as our day of discussion about organ donation in Northern Ireland. A day when we are all encouraged with the message to “tell your loved ones” about your organ donation decision. A decision and a discussion that can bring new life and new hope for up to nine others. That is why I am launching this public consultation today on proposals that I believe will encourage those discussions, and ultimately save more lives.*

*We must do everything we can to increase the rate of consent and, in so doing, the number of organs available for lifesaving transplantation. With many more people willing to consider donating an organ than are actually registered as donors, I am proposing a move to a soft opt-out system of consent to help to address the current shortage. Importantly, the decision on whether or not your organs are considered for donation remains with every individual, and families will always be consulted about this.*

*As very few of us will die in hospital, that is, in circumstances where donation may be clinically possible, it is vitally important that our decisions are known, and that is why the NHS Organ Donor Register will continue to play an important role.*

*In launching this consultation I want to pay tribute to all the people who have given the ultimate gift of life by donating their organs for the benefit of others. Words cannot truly express the difference they have made to countless people in Northern Ireland and further afield.*

*The changes I am proposing in this consultation will take several years to come into full effect, however it is more important than ever that we plan for the future healthcare needs of all our citizens. 2020 has been the most challenging year in the history of our Health and Social Care services. As it draws to a close I want to encourage families to take a moment to talk about organ donation, to read this document and to join this vital discussion.*

## Organ Donation – Key Information

- Organ donation is where a person, living or dead, donates their organs and tissues for transplant. A transplant can be life-saving, or improve the health and quality of life for patients suffering from chronic illness, and their families and carers, whilst also bringing great comfort to donors' families.
- One person's decision to donate their organs after they die is a gift that can save and improve the lives of up to nine other people.
- Living donations can include a kidney, part of a liver and some tissue.
- Donations after death can include kidneys, heart, liver, lungs, pancreas, small bowel, corneas and tissues.
- Currently in Northern Ireland, your organs and tissue will only be considered for donation after you die if you have given prior consent (e.g. by having joined the NHS Organ Donor Register, or ODR), or if a close friend or relative gives consent on your behalf after your death.
- The health service can also benefit through the reduced cost of treating patients, whose health has been improved through this altruistic act, by releasing resources to provide treatments for patients suffering from other ill-health conditions.
- Anyone can join the NHS Organ Donor Register. Children aged 14 and over in Northern Ireland can sign the register themselves and parents/guardians can sign their child on to the register regardless of the child's age - even at the time of birth.
- Further information about organ donation in Northern Ireland, including FAQs and 'mythbusters', is available at [www.organdonationni.info](http://www.organdonationni.info)
- The NHS Organ Donation Website contains further information, including links to the ODR – [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

## Organ Donation – Key Figures

- Currently in Northern Ireland, 913,224 people have signed the ODR, accounting for 48% of the population<sup>1</sup>.
- At present, around 115 people in Northern Ireland are on the transplant waiting list and every year around 10-15 people in Northern Ireland die waiting on an organ transplant.
- The majority of people in Northern Ireland are in favour of organ donation and would accept a donated organ if they needed one, however, much fewer have stated their intentions either by joining the ODR or by talking with family and friends.
- Only a small number of us, approximately 1%, will die in circumstances where organ donation after our death would be clinically possible. It is therefore important that when these circumstances do arise, the opportunity to help others is not lost.
- In 2019/20, the consent rate for donation to proceed after death in Northern Ireland was 64%. The current UK-wide strategy (2013-2020) sets a target consent rate of 80%.
- To understand how donation in Northern Ireland compares internationally, using data from 1 January 2019 - 31 December 2019, it can be seen that -
  - In 2019, Northern Ireland had 20.7 deceased donors per million of its population (pmp), compared to the UK average of 24.7 pmp (making the UK the world's eighth leading nation). The five leading countries were Spain (49.6 pmp), USA (36.1 pmp), Portugal (33.7 pmp), Croatia (32.0 pmp) and France (29.4 pmp).
  - In 2019, Northern Ireland had 38.3 living donors per million of its population (pmp), compared to the UK average of 15.6 pmp (making the UK the world's third leading nation). The five leading countries were Netherlands (30.6 pmp), USA (22.4 pmp), UK (15.6 pmp), Denmark (15.0 pmp) and Sweden (14.9 pmp).

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<sup>1</sup> Current to 30 November 2020 using ODR registration data and Office of National Statistics (ONS) 2019 midpoint population estimate data.

## Purpose of the Consultation

This document and questionnaire have been published by the Department of Health in order to consult the public about proposals to change the current system of consent for organ donation in Northern Ireland.

### What is the objective?

The objective of the proposed change is to increase the current rate of consent for organ donation to proceed after a person's death. Doing so will increase the overall number of donors, and ultimately the number of lifesaving organs available for transplantation.

This would require new legislation to change the current system in Northern Ireland, in which people can choose to 'opt in' or 'opt out' on the NHS Organ Donor Register (ODR), to a new statutory opt-out system. This is sometimes known as **deemed consent**.

A **soft opt-out system**, such as those now operating in Wales and England, incorporates additional safeguards and conditions which include seeking authorisation from the person's family or loved ones.

A **statutory soft opt-out system** therefore refers to the legislation that would introduce and underpin a new soft opt-out system of consent.

### What is being proposed?

In brief, it is proposed that a statutory opt-out system for organ donation would function as follows:

- It will be considered that everyone living in Northern Ireland agrees to donate their organs when they die, unless they have confirmed otherwise, or they are from one of the excluded groups (those under the age of 18; people who lack the mental capacity; visitors to Northern Ireland and temporary residents);
- Individuals will still have the choice about whether or not they want to become a donor;
- Families will continue to be consulted (this is known as **soft opt-out**); and,
- Decisions based on faith and belief will continue to be respected.

### What information is required?

The consultation seeks the public's views on how to introduce an 'opt-out' framework for consent for organ donation in Northern Ireland, including the following:

- Your current intentions or decisions about donating your organs/tissue after you die;
- Whether you have shared this decision with your loved ones;
- Whether a move to a statutory opt-out system would change your decision;
- The groups of people who should be exempt from the proposed changes;
- The role that your family and loved ones should play;

- The scenarios in which deemed consent should not be applied, e.g. donation for research purposes, or for novel and rare types of transplants; and,
- How we should engage with the public to raise public awareness of the proposed changes in the law, and the focus for future communications.

To assist people in completing the consultation questionnaire, information is provided below to explain the current system for organ donation, to describe the rationale for the proposed changes, and how these would work in practice. Links are provided to external sources of additional information where appropriate, to assist people in forming their responses.

#### What will happen next?

The views expressed in this consultation will inform the development of a draft Bill for consideration by the Northern Ireland Assembly, in order to enshrine the proposed changes in law. The first step will be to secure the approval of the Executive to introduce the draft Bill. Thereafter, any change to the current system will be subject to economic appraisal and available resources.

It is therefore important that the transplant community, the wider public, clinicians, patient representatives and other stakeholders take the opportunity to inform this process by contributing their views through this consultation exercise.

#### Living Organ Donation

It should be noted that this consultation, and the proposed changes in the law, do not relate to living organ donation (kidneys, part of the liver, and tissue). Northern Ireland has a world class living donor kidney transplantation programme, which will not be impacted by the proposals outlined in this consultation. The proposals relate only to the system of consent for organ donation to proceed after a person has died.

#### Additional information

To help set the context for the proposals under consideration, it is necessary to provide clarification on the following current issues:

- COVID-19

The proposals set out in this document will require a change in the law which will take several years to progress through the Assembly and come into effect. By then, it is envisaged that the coronavirus pandemic will have ended, and that COVID-19 will be managed through ongoing global monitoring and vaccination.

In the meantime, it should be noted that organ donation cannot proceed where the potential donor has, or is suspected of having, COVID-19. In addition, transplant recipients have to be immunosuppressed and many will require intensive care. Therefore, for the duration of the pandemic, i.e. within the current system for organ donation and transplantation, transplant clinicians and patients will continue to carefully assess any risk from COVID-19 when deciding whether

it is clinically appropriate to proceed with a transplant operation. Detailed clinical guidelines have been developed to assist clinicians with these decisions.

- EU Exit

The transition period for the UK's exit from the European Union is set to end on 31 December 2020. At the time of publication of this consultation document, the UK and EU remain in negotiations with a view to agreeing the arrangements for the post transition period. Regardless of the outcome of these negotiations, the Department of Health does not envisage any impact on UK transplant services or on the proposed changes outlined in this consultation.



## Organ Donation and Transplantation in Northern Ireland

Organ and Tissue donation saves and improves many lives each year and one donor has the potential to save 9 lives. Last year in Northern Ireland there were 51 deceased donors, resulting in 113 transplants throughout the UK. In total, 87 Northern Ireland residents received transplants.

Northern Ireland, along with England, Scotland and Wales, is part of an equitable UK organ sharing scheme. This means that Northern Ireland citizens benefit from being part of the UK 'pool', in which organs from donors anywhere in the UK are transplanted into individuals with the greatest need and the best chance of success. The system, including the [NHS Organ Donor Register](#)<sup>2</sup>, is operated by [NHS Blood and Transplant](#)<sup>3</sup> (NHSBT) on behalf of all regions of the UK.

Northern Ireland patients who need a heart, lung, liver, pancreas, or small bowel transplant are required to travel to specialist hospitals in the UK to have their operations and the same is true for some tissue transplants. The specialty of renal surgery and transplantation means kidney transplants, from both living and deceased kidney donors are normally provided at Belfast City Hospital.

### The current 'opt-in' system

Currently in Northern Ireland there is an 'opt-in' framework for consent for organ donation to proceed after a person's death. This means that donation will only ever proceed if a person had given their express consent for organ donation, usually by signing on to the ODR and / or the person's family supports the donation proceeding. In the absence of a decision being recorded on the ODR, or the family are unaware of their loved one's donation intentions, they are asked to make a decision on their behalf.

Only a small proportion of people (around 1%) die in circumstances where it may be possible for their organs to be donated. Usually this will be in a hospital intensive care setting, and in these circumstances families are given the option of consenting to organ donation on behalf of their loved one. They are usually referred to a *Specialist Nurse - Organ Donation* (SNOD) working within the intensive care unit and equipped with the specialist knowledge and skills to discuss organ donation and, if known, their loved one's intentions or decisions.

Whilst over 80% of the population supports organ donation, only 48% have recorded this decision on the ODR. Although this figure has increased steadily from 30% since 2013 through local and national awareness-raising campaigns, the ODR is not yet truly representative of the Northern Ireland population's willingness to donate their organs and tissue after their death, as 52% of people have not formally recorded a decision.

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<sup>2</sup> <https://www.organdonation.nhs.uk/register-your-decision/>

<sup>3</sup> <https://www.nhsbt.nhs.uk/>

### Why move to an opt-out system?

A number of other countries have adopted an 'opt-out' system of consent as a means of increasing the number of organs available for transplantation, and better reflecting the levels of public support for organ donation. Instead of requesting that everyone who supports organ donation should 'opt in' and record their decision on the ODR, it is considered that everyone – with the exception of certain exempt groups – would be willing to donate their organs unless they have formally opted out on the ODR, or expressed an objection to a close friend or relative during their lifetime that they do not want to be a donor after their death. This is sometimes referred to as 'deemed consent'.

Since 2015, when Wales introduced a statutory opt-out system for organ donation, all residents of the UK have been able to record a decision not to be an organ donor. In Northern Ireland, approximately 2000 people (0.1% of the population) have used the ODR to formally record a decision not to donate.

### Improving the Consent Rate for Organ Donation in Northern Ireland

The 'consent rate' is an internationally used measure to indicate the number of potential donors for whom consent to proceed with donation is confirmed. It is measured by the number of families who agree to support donation going ahead divided by the number of potential donor families approached for donation. The consent rate is always higher in cases where families already know their loved one's intentions.

The international standard for world class performance is recognised to be an 80% consent rate. This is the target consent rate to which all UK regions have aspired within the current UK-wide strategy (2013-2020). However the current overall consent rate across the UK (for the year 2019/20) is around 70%. The consent rate in Northern Ireland is 64%, and has not increased significantly for several years despite consistently high levels of support for organ donation and consistent growth in registrations on the ODR.

This means that each year, almost four out of ten families in Northern Ireland, when faced with the decision, did not give their consent for donation to proceed, sometimes against the known intentions of their loved one. Understanding and addressing the reasons for their refusal in these difficult circumstances is key to improving the consent rate.

### Comparing Consent Rates across the UK

Consent rates for the year 1 April 2019 - 31 March 2020 in each region of the UK are summarised in the table below:

Nation	Deceased Organ Donors (per million population)	Consent Rate (%)
England	23.5	68.3
Northern Ireland	26.1	64
Scotland	18.4	64.8
Wales	27.1	70.7

Since the introduction of the opt-out system in Wales in 2015 and the corresponding information campaigns, there has been an increase in both consent rate and donation rate. The consent rate increased from 58% in 2015 to 70.7% in 2020, although the impact was not immediate and took several years to take effect, following an extensive media promotion and information campaign by the Welsh government<sup>4</sup>.

In England, a new opt-out system came into effect from 20 May 2020, however it is too soon to analyse any impact on consent rates. Scotland's opt-out system will come into effect from 26 March 2021.

In Northern Ireland, it is proposed that the introduction of opt-out legislation could contribute towards an increase in the consent rate over time, similar to Wales, which will mean:

- If you want to be a donor, you can still register to be a donor (opt in) on the NHS Organ Donor Register and inform those close to you of this decision;
- If you don't record a decision to be a donor or let those close to you know your donation decision, you will be considered as having no objection to becoming a donor (i.e. 'deemed consent');
- If you do not want to be a donor, you must either register not to be a donor (opt out) on the ODR, or otherwise make your decision known to those close to you; and,
- You can also nominate a representative to make the decision for you after your death.

It is important to note that the proposed move to an opt-out system for Northern Ireland would not change the fact that individuals remain responsible for decisions about what happens to their organs after they die.

#### Promoting Organ Donation in Northern Ireland

It is acknowledged that legislative change alone will not achieve an organ donation consent rate of 80% or above. Rather, it is seen as a potential enabler of further progress towards this target, if combined with increased public awareness. Countries with mature opt-out systems and high rates of consent, e.g. Spain, tend to also have high levels of public support and understanding around the benefits of organ donation and transplantation. Any move to an opt-out system for Northern Ireland must therefore be combined with appropriate public education and communication for the maximum benefit to be realised.

<sup>4</sup> <https://associationofanaesthetists-publications.onlinelibrary.wiley.com/doi/full/10.1111/anae.15055>

The Department of Health in Northern Ireland already has a statutory duty<sup>5</sup> to promote organ donation, and in 2018 published a [policy statement](#)<sup>6</sup> outlining its key commitments to deliver this. The overall objective of the policy is, and remains, to promote a positive, cultural, long term change in attitudes and behaviours in relation to organ donation. The Department is working with the Health and Social Care (HSC) system, the public sector (including local government and the education system), and wider society, to promote organ donation through a coordinated and sustained programme of communication. These commitments are not impacted by the proposed move to a statutory opt-out system, and will remain in place during and after implementation of any new system.

#### Further Information

For further information including Frequently Asked Questions (FAQs) and mythbusting facts about organ donation and opt-out legislation, please visit [www.organdonationni.info](http://www.organdonationni.info)

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<sup>5</sup> Part 4 of the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016

<sup>6</sup> <https://www.health-ni.gov.uk/sites/default/files/consultations/health/organ-donation-policy-statement.pdf>

## How to provide your views

Written responses should be provided by 5:00pm on 19 February 2021.

You can submit your views in the following ways:

- Submit your responses using our online questionnaire through the link available at: [www.health-ni.gov.uk/consultations/organ-donation](http://www.health-ni.gov.uk/consultations/organ-donation)
- Download this form and email it to us at: [\*\*organdonation@health-ni.gov.uk\*\*](mailto:organdonation@health-ni.gov.uk)
- Download, print and post this form to:

**Organ Donation Consultation  
Department of Health  
Room 1 Annexe 1  
Castle Buildings  
Stormont Estate  
Belfast BT4 3SQ**

Due to the COVID-19 pandemic, we will not be holding face to face stakeholder events; however, a series of virtual events will be taking place. Details will be published in due course at <https://www.health-ni.gov.uk/consultations/organ-donation> and publicised on the Department and Public Health Agency's social media channels.

This document is also available in alternative formats on request. Please contact the Department, at the address above, to make your request.

## CONSULTATION RESPONSE FORM

### Public Consultation on the introduction of a statutory opt-out system for organ donation for Northern Ireland

I am responding:

As an individual

\_\_\_\_\_

As a health and social care professional

\_\_\_\_\_

On behalf of an organisation

\_\_\_\_\_

(please tick one option)

About you or your organisation:

Name:

--

Job Title:

--

Organisation:

--

Address:

--

Tel:

--

E-mail:

--

## Your Organ Donation Decision

The majority of people in Northern Ireland are in favour of organ donation and would accept a donated organ if they needed one.

The following questions will help us to understand the starting views and intentions of those who are responding to the consultation in relation to organ donation and the proposed change to an opt-out system.

### Q1. Would you be willing to donate your organs and / or tissue after your death [under the current legal system of consent in Northern Ireland]?

- Yes – all organs and tissue
- Partly - Some organs / tissue
- No – I would not like to donate any organs or tissue
- Not made a decision

### Q2. Have you already recorded your donation decision, e.g. by joining the NHS Organ Donor Register or otherwise?

- Yes
- No
- Don't know

### Q3. If you answered 'yes' to the above, have you shared your decision with your loved ones? Please tick all that apply

- Face to face conversation
- Social media platform (e.g. WhatsApp, Facebook)
- In written form (text, email, as part of a Will)
- Other
- I have not shared my decision

### Q4. Would a move to a statutory opt-out system change your decision regarding organ donation?

- No - It would make no difference
- Yes - It would make me want to become an organ donor after my death.
- Yes - It would make me no longer want to become an organ donor after my death.

## Exemptions to Opt-out Legislation

All residents of Northern Ireland are encouraged to make a decision about donation, record that decision on the NHS Organ Donor Register and make sure that their family know what they would like to happen. To support this, the Department of Health has a responsibility to promote awareness of organ donation.

In a statutory opt-out system, it will be considered that everyone living in Northern Ireland agrees to donate their organs when they die, unless they have confirmed otherwise by opting out, or they are from one of the excluded groups.

In the case of a child or young person under the age of 18, the family will be informed if there is a decision recorded on the NHS Organ Donor Register, so that they can take this in to consideration. There are several other groups for whom it is proposed that opt-out legislation should not apply, for example, where there may be concerns about a person's ability to make a decision and fully understand the consequences of recording a decision on the NHS Organ Donor Register.

It will therefore be necessary for the Assembly to decide whether the law should be applied to the following groups of people:

- Children and young people under the age of 18
- Adults who lack capacity to understand the new system, for example, an adult with advanced dementia or severe learning difficulties
- Visitors to Northern Ireland – for example, tourists, cross-border workers who reside in the Republic of Ireland (RoI)
- People who are temporarily resident in the Northern Ireland – for example students, overseas Armed Forces personnel temporarily based in Northern Ireland, people on work placements from overseas or the RoI.
- People whose identity is unknown
- Prisoners who may be placed in any prison in Northern Ireland

**Q5. To what extent do you agree that opt-out legislation should NOT apply to children (those under 18 years) and that the donation decision should be made by those with parental responsibility? Rate your agreement with this statement.**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree



**Q6. Do you think that any of the following people should be exempt from deemed consent for organ donation and the family should provide that consent? (please tick all those that apply)**

- Adults who lack capacity
- Visitors, including cross-border workers from ROI & tourists to Northern Ireland
- People who are only temporarily resident in Northern Ireland (e.g. students from overseas or ROI, overseas Armed Forces personnel), people on work placements from overseas or ROI
- Prisoners
- People whose identity is unknown
- Others – Please specify

## The Role of the Family and Loved Ones

Currently, people in Northern Ireland are encouraged to record a decision on the NHS Organ Donor Register and tell their family and loved ones whether they want to be a donor after their death. It is the responsibility of the individual to ensure that people know their decision. Knowing a loved one's decision greatly reduces the burden on the next of kin at the time of donation.

If an individual has recorded a decision to donate on the NHS Organ Donor Register, the family are informed of this decision. If there is no decision on the NHS Organ Donor Register the family are asked at the time that donation is a possibility, to inform the Specialist Nurse if their loved one had ever told them about whether they would have wanted to donate. If there had never been a discussion, the family are asked to decide on behalf of their loved one, based on their knowledge of the values and beliefs of their loved one.

Under opt-out legislation, it is proposed that the family would continue to be consulted about donation. This is for two important reasons. First, to determine the last known decision of their loved one (which may be different to a decision recorded on the NHS Organ Donor Register). Second, in cases where there was a known decision to donate, the family need to provide advice about past health and lifestyle (e.g. trips abroad, recent illness etc), to help determine whether organs would be safe to transplant.

**Q7. To what extent do you agree that, in situations where there is a known decision to donate recorded on the NHS Organ Donor Register, the family should always be asked about the last known organ donation decision of their loved one, to ensure it's still accurate?**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

There are around 100 cases every year in the UK where the family over-rules a decision to donate on the NHS Organ Donor Register. The most common reason given is that the family were not aware that their loved one had signed on to the NHS Organ Donor Register and they do not know what their loved one would have wanted.

The new legislation seeks to improve individual autonomy through placing the emphasis on whether the individual would have wanted to donate, rather than whether the family want donation to proceed.

**Q8. To what extent do you agree that, in situations where there is no known organ donation decision, the family should always be asked about whether their loved one would have objected to organ donation?**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

It is proposed that, under new opt-out legislation, it will not be possible to proceed with organ donation if there is an opt-out decision recorded on the NHS Organ Donor Register, or if there is a known decision not to donate.

**Q9. Which of the following statements best summarises how the introduction of opt-out legislation would influence your support for donation of a loved one's organs and/ or tissues?**

- I currently support organ donation and would continue to do so.
- I currently do not support organ donation and would continue to not support
- It would make me more likely to support organ donation
- It would make me less likely to support organ donation

## Novel and Rare Transplants

When recording a decision on the NHS Organ Donor Register to donate, it is possible to choose which organs or tissue you are willing to donate after your death. For example, you can state that you are only willing to donate your kidneys, liver, bowel and pancreas and The NHS Organ Donor Register is checked to determine which (if any) organs and tissues you choose to donate.

The number and type of organs and tissues that can be donated has changed over time, as clinical practice improves and new forms of transplantation are developed. These types of transplantation fall into two categories; novel and rare transplants. Face and uterine transplants would be examples of novel transplants. There have been no face or uterine donations in the UK, although there is work ongoing within the NHS to explore whether this might be possible. Limb transplants do happen in the UK but are rare. Currently, limb donation is only possible in England and since 2012, there have been 6 limb transplants in the UK.

It is proposed that under the new legislation, novel and rare types of donation should be excluded from deemed consent. This would mean that, in the unusual event that such a type of donation might be possible, the family would always be asked about this potential and their explicit consent would be required before donation could proceed.

**Q10. To what extent do you agree that organs and tissues that could be used for rare or novel types of transplantation (e.g. limb or face) should be excluded from opt-out legislation?**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

## Research

Where consent is given for donation, every effort is made to ensure that all organs are transplanted whenever it is safe to do so. Prior to retrieving any organs, there is always an examination to determine whether the organs would be suitable for transplantation (for example, looking for visible signs of disease). There are some situations where an organ may not be safe to transplant (for example due to a tumour being found). In these cases, it is possible that the organ could be used for research purposes instead.

Organs removed during the donation operation may be entered into a healthcare research programme if all of the following are in place:

- It is confirmed that the organ cannot be safely transplanted.
- The family has given consent for any organs that could not be transplanted to be donated for research.
- The research project has been reviewed by NHS Blood and Transplant and is on their approved list of research projects.

There is no function available on the NHS Organ Donor Register to formally record a decision to donate for research, if transplantation is not possible. Instead, the option of research is discussed with the family, who decide whether or not to consent to research. More information about how Organ Donation research is governed can be seen on NHSBT's YouTube channel here: [https://youtu.be/yHxSA2\\_g\\_WY](https://youtu.be/yHxSA2_g_WY)

It is proposed that the current consent process for donating organs and/ or tissues for research purposes should not be changed. Therefore, opt out would not apply for donation for research purposes and the family would continue to be approached for express consent.

**Q11. To what extent do you agree that the donation of organs and tissues for research purposes should be excluded from statutory opt-out and the family approached for express consent?**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

## Faith and Beliefs

The families of potential organ donors are always asked if their loved one had any faith or beliefs that would need to be taken into consideration as part of the donation discussion. The family is also asked if they would like a faith or belief leader present to support them. Whilst all the major UK religions support organ donation, there are some factors that need to be considered, such as final rites, where a faith/ belief leader can provide advice.

Recently, a new voluntary declaration on the NHS Organ Donor registration form was introduced to enable individuals to state whether they want faith/ beliefs taken into consideration as part of the donation discussion. After registration, people can also download a digital faith-specific organ donation card, which can help them to share donation decisions.

There are no plans to change the current commitment to honouring an individual's decision regarding faith/ beliefs and the support and advice available to families.

**Q12. To what extent do you agree that people's faith or beliefs should continue to be taken into consideration as part of the donation discussion after any move to an opt-out system?**

- Strongly Agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

## **Raising Awareness of the Change in Legislation**

Should opt-out be introduced, there will be a need to inform the public about the change in legislation.

A programme of communication and education would target all members of society. There will also be additional targeting of audiences who may be hard to reach or require additional support to raise awareness and understanding of organ donation.

This would include members of the BAME community, who are more likely to need a transplant, but significantly less likely to agree to donation proceeding and currently have to wait longer for a transplant, and for groups such as people with no permanent fixed place of residence, who may not be exposed to marketing campaigns and may therefore not be aware of any proposed change in the law, how it might affect them or have the opportunity to record a decision on the NHS Organ Donor Register.

### **Q13. What do you think is the most important and effective activity for raising awareness of the law change? (please select no more than 3)**

- TV, radio
- Social media adverts
- Out of home advertising (e.g. posters on public transport, bill boards etc)
- Adverts in print media (e.g. newspapers, magazines etc)
- Mail drop to all houses in N. Ireland
- GP surgeries
- Places of worship
- Local councils
- School / Curriculum resource
- Other – please specify

### **Q14. If you have any other comments or views you would like to express in relation to the proposed opt-out legislation, please comment below.**

**Q15. If you have comments or views you would like to express in relation to the Equality Screening, Disability Duties and Human Rights Assessment Template or Rural Screening Document that accompany this consultation document and can be found at <https://www.health-ni.gov.uk/consultations/organ-donation>, please comment below.**



## **Privacy, Confidentiality and Access to Consultation Responses**

For this consultation, we may publish all responses except for those where the respondent indicates that they are an individual acting in a private capacity (e.g. a member of the public). All responses from organisations and individuals responding in a professional capacity will be published. We will remove email addresses and telephone numbers from these responses; but apart from this, we will publish them in full. For more information about what we do with personal data please see our consultation [privacy notice](#)<sup>7</sup>.

Your response, and all other responses to this consultation, may also be disclosed on request in accordance with the Freedom of Information Act 2000 (FOIA) and the Environmental Information Regulations 2004 (EIR); however all disclosures will be in line with the requirements of the Data Protection Act 2018 (DPA) and the General Data Protection Regulation (GDPR) (EU) 2016/679.

If you want the information that you provide to be treated as confidential it would be helpful if you could explain to us why you regard the information you have provided as confidential, so that this may be considered if the Department should receive a request for the information under the FOIA or EIR.

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<sup>7</sup> <https://www.health-ni.gov.uk/sites/default/files/publications/health/DoH-Privacy-Notice.pdf>