

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

Information pack



What is organ donation?

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.

The consultation

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

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'.

Why change to an opt-out system for organ donation?

In short, Organ and Tissue donation saves and transforms lives.

One donor has the potential to save 9 lives. Last year in Northern Ireland there were 51 donors, resulting in 113 transplants throughout the UK. In total, 87 Northern Ireland residents received transplants.

However there are still 115 people in Northern Ireland on the waiting list and each year around 10-15 people in die while awaiting an organ transplant.

Whilst over 80% of the population supports organ donation, only 48% have recorded this decision on the NHS Organ Donor Register. This means that the NHS Organ Donor Register is not truly representative of Northern Ireland's population's willingness to donate their organs and tissue after their death, as 53% of people have not formally record a decision.

To address this, a number of other countries have an "opt-out" system of consent to better reflect the public support which exists for organ donation.

The objective of the proposed change in legislation is to increase the current rate of consent for organ donation, thereby increasing the number of donors and ultimately the number of lifesaving organs available for transplantation. Consent rate is the percentage of families giving their agreement for organ donation to go ahead.

Since the introduction of the opt-out system in Wales and the corresponding information campaigns, there has been an increase in both consent rate and donation rate.

What will change?

Currently in Northern Ireland there is an 'opt-in' framework for consent for organ donation. 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 NHS Organ Donor Register and / or the family supports the donation proceeding. In the absence of an Organ Donor



Registration or the family are unaware if the patient wanted to be a donor, the family are asked to make a decision on behalf of the patient.

Instead of requesting that everyone who supports organ donation 'opts-in' and records their decision on the NHS Organ Donor Register, it is considered that everyone would be willing to donate their organs unless they have formally opted out on the NHS Organ Donor Register; expressed an objection that they do not want to be a donor after their death, or are in one of the excluded groups (see below).

It is important to note that the decision about donation after death remains with you, the individual. Individuals still have a choice and families will still be consulted if organ donation becomes a possibility.

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

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

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.

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. 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.

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.

In the case of a child 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 where there may be concerns about their ability to make a decision and fully understand the consequences of recording a decision on the NHS Organ Donor Register. It is necessary to decide whether the law should be applied to the following groups of people:

- Children
- Adults who lack capacity



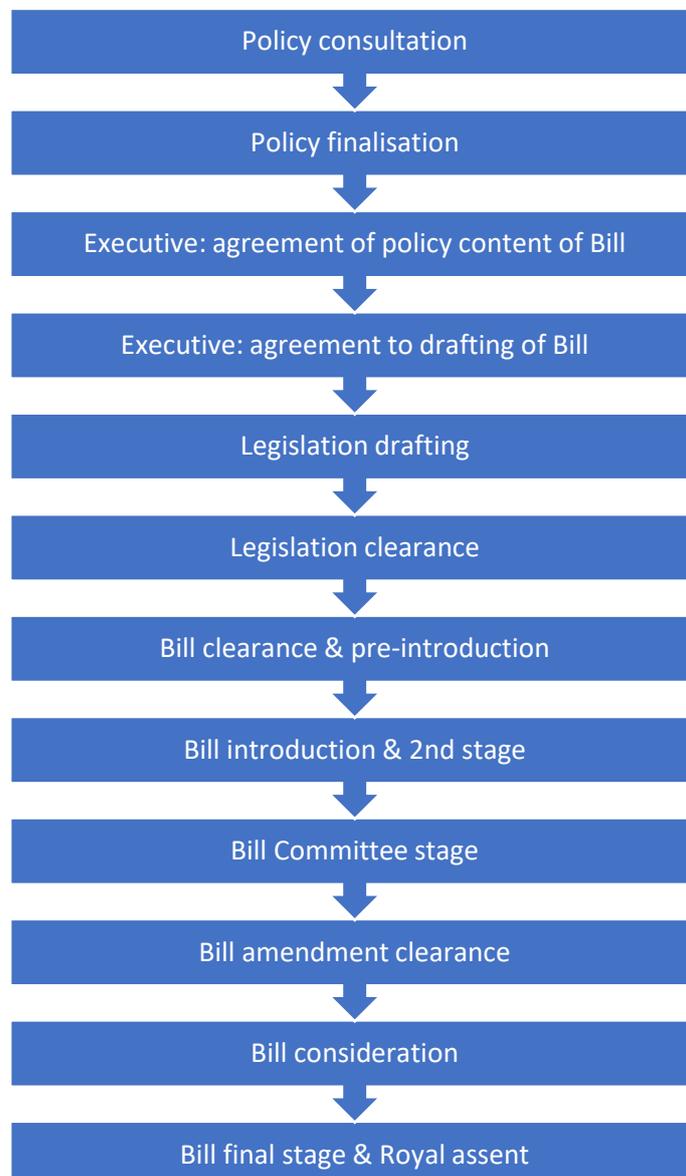
- Visitors to Northern Ireland
- People who are temporarily resident in Northern Ireland
- Prisoners
- People whose identity is unknown

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.

The legislative process

Below is an outline of the legislative process that would apply:



Additional information:

Coronavirus

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.

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.

What now?

The consultation will run for 10 weeks, closing at 5pm on 19 February 2021.

Everyone is encouraged to submit a response in any of the following ways:

- Submit to us online at: www.health-ni.gov.uk/consultations/organ-donation
- Download this form and email us at: organdonation@health-ni.gov.uk
- Download, print and post to:

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

Enquiries can be directed to: organdonation@health-ni.gov.uk

More information on organ donation can be found at: www.organdonationni.info

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



Testimonials

The objective of the legislation change is to increase the consent rate for organ donation and hence the number of lifesaving and life-transforming transplants. The need for an organ transplant can arrive at anyone's door at any minute and impacts not just the individual, but their family also. Here, we get a feel of the various perspectives that could affect any of us at any time...

A transplant recipient:

Erica Ferguson, from Carrickfergus, has had two lifesaving liver transplants.

"Prior to my liver transplant I was a busy Mum, working in a thriving retail environment. Like every working mum, I juggled work and family life. I was very fit and healthy. I worked out and enjoyed spending time with my family and socialising.

"After many tests I was told I had acute liver failure. I was told my only chance of survival was a lifesaving liver transplant. Soon after hearing this news my condition rapidly deteriorated and I was rushed into the Intensive Care Unit. My body had started to shut down as I had only approximately 48 hours to live without a lifesaving organ. I was then placed at the top of the International Organ Donor Register.

"I feel very fortunate to have been given this wonderful gift of life. I am very grateful to my life saving organ donors and their families and I think about them every day.

"I have been able see my daughter grow up, go to university and see her qualify as a teacher. I could be 17 years off this earth and my daughter, husband and family could be putting flowers on my grave. Instead, I am here living and loving life with my entire family, thanks to the generosity of two complete strangers who decided to say yes to organ donation.

"Life is precious and since I have been given a second chance I intend to put it to good use and enjoy every minute! I could never repay the generosity shown to me by my donors and their families, for giving me the gift of life.

"I live my life to its fullest for my two selfless organ donors and for myself. Organ donation has given me everything, which most of us take for granted! There is no greater gift than the gift of life. The need for organ donation is not selective – it can happen to anyone.

"Live life, then give life, as you will be giving someone like me the gift of life if you donate your organs."



A patient on the waiting list:

Kathryn Glover, 38, from Ballygowan, had a kidney transplant in 2009.

“In 2003, I found blood in my urine and, quite quickly after that, I was diagnosed with IgA nephropathy. I was then put on the transplant list.

“I also started dialysis. The type I was on was called ‘peritoneal dialysis’, which required me going onto a machine every night, for around eight hours. That had a huge impact on my life, but mainly on my sleep, and how tired I was. The next biggest impact would have been on my social life – I couldn’t go out in the evening, and I was constantly clock-watching.

“I was on dialysis for four years. It was a difficult four years trying to keep my job going. I just kept going as much as I could, because I was determined to not let dialysis get on top of me or my job.

“Looking back, I can remember in the first few weeks after being put on the transplant list thinking ‘the call could come any minute’ and every time the phone went I was checking. I then caught myself on and realised this is going to be a long wait.”

The family of someone waiting:

“Like most people, we had heard of the sensitive topic of organ donation. We knew how important it was but had never quite got around to discussing the subject. All that changed in 2006 when my brother-in-law, Richard, suddenly became very ill. After undergoing many tests, he was told that he had a rare genetic disease called Alpha-One Antitrypsin, there was no cure and he would need a liver transplant. When all the family were subsequently tested, my husband, Paul, was also diagnosed with the disease. Sadly, his brother Richard died in 2010 while he was still on the list, aged just 51.

Following his diagnosis in 2006, Paul had regular check-ups and, fortunately, showed no signs of being affected by the disease. However, in 2016, Paul’s health began to deteriorate and in 2018 he was put on the liver transplant list. It was a challenging time, full of fear about what lay ahead. I didn’t want to burden Paul with additional worry, so hid my fears or shared them with my 3 adult children and friends.

Eventually, Paul had to stop his work as a software engineer as he lacked the energy and concentration to do his job. His stomach had become quite bloated with excess fluid and most days he found it hard to take exercise or follow the prescribed diet. The smallest things were an effort.

As a registered childminder working from home, I was fortunate to be able to keep an eye on Paul. I was able to work right up to when we got the call from Kings Hospital, London, to say that a match had been found.

For me, waiting on a transplant was a challenging and humbling time. Paul’s brother, Richard, was unlucky not to receive the gift of an organ transplant, and that brought home to us the importance of having that delicate family conversation about organ donation. I think if people could see the daily impact on people’s lives, and knew the difference organ donation can make, they wouldn’t put off that all important conversation as we did.”



A donor family perspective:

Denise Carter sadly passed away in March 2009. Her husband Steve tells of his experience and why he is encouraging others to speak up and discuss their wishes.

“At the hospital I was approached by the organ donation specialist nurse. She asked if Denise was on the organ donor register or if we had ever discussed it? As we were both in our 30s and lived a healthy lifestyle, this topic was never raised. A topic, I wished we had.

“I was fortunate to have the tremendous support of Denise’s family with me at the time to help make a decision. Knowing that Denise was such a kind and loving person in life, she’d do all in her power to help anyone. I also wanted the children to remember their mum for both the wonderful things that she had done in life and in her passing. Considering all this, I agreed to donation.

“A couple of weeks after Denise’s passing, I received a letter from the organ donation team informing me that five different lives had been saved from Denise’s organ donation. A year on, I received another letter telling me that all five recipients were now living normal and healthy lives.

“It is very comforting to know that five strangers are now sharing their lives with their loved ones. Words cannot describe how proud I am of Denise, and the children are of their mum.

And most difficult of all, a perspective from those still waiting...

Dáithí Mac Gabhann is 4 years old and has been on the waiting list for the gift of a new heart for most of his short life.

Dáithí was born in 2016 with a condition called Hypoplastic Left Heart Syndrome, meaning he was born with half a working heart. He has had numerous open heart surgeries and was given less than a 10% chance of survival, before he was even one week old.

In January 2018, we were in London for what we thought was a routine check up to find out when Dáithí’s next stage heart surgery would be. Unfortunately, due to a severe leak in his tricuspid valve, he was ruled out of further surgery; meaning a heart transplant would be his only hope. Dáithí was placed on the routine waiting list for heart transplant in June 2018 and has remained on it since. That’s over 900 days, waiting for the phone to ring.

Nothing could have prepared us for hearing the words that a heart transplant would be Dáithí’s very last chance at life. No other options. Time and time again throughout his life, we’ve been faced with last chances, and it didn’t take us long to find out that Dáithí is a fighter. So much so that he inspires us to keep on fighting, keep on clinging on to hope that all will be okay. So we wait. And wait. And wait.

Emotions can only be described as a rollercoaster ride where hope and hopelessness can be felt in the same minute. And sometimes, all of a sudden, uncertainty of the future hits us, out of the blue, like a ton of bricks. As parents, we are helpless, with nowhere to turn to. Full time jobs are a thing of the past, as the fear of missing a life changing phone call takes priority. Well rested nights are few and far between.

