



Department  
of Health &  
Social Care

# Quick read: government response to consultation on organ and tissue donation

# Introduction

Though great progress has been made in recent years, 3 people still die each day due to a lack of suitable organs and there are around 5,100 people waiting for an organ transplant in England.

The Government wants to change this so that we can give those people who are waiting for a transplant a better chance of receiving the organ they need.

## Our public consultation

In December 2017, we launched a 12-week consultation on proposals for a new approach to organ and tissue donation in England. We asked important questions on:

- ways to make it easier for people to register their decision on organ and tissue donation
- the potential impact proposals could have on people from certain religious groups or ethnic backgrounds
- how family members should be involved in confirming decisions in future
- exclusions and safeguards to the general rule of consent under the proposed new system

Key things that we heard were:

- Most people said there should be more ways to register their decision on whether they want to be an organ donor. But they also said that it's very important that this should be simple to do and that information about them should be kept safe.
- Strong support for a national media campaign to raise awareness of the changes and enable people to make an informed decision on organ donation.
- Some Jewish and Muslim respondents expressed concerns with the new arrangements. Overall, most respondents said that they did not think the change would have a negative impact.
- Mixed views on what should happen when someone has not opted out under the new system, though the largest proportion of people said that donation should always go ahead.
- Most people said that a decision to donate/not donate should always be respected.
- There was broad support to exclude children under 18, people ordinarily resident in England for less than 12 months and people lacking the capacity to understand the changes.

This document will set out how the Government will address the issues raised and wider changes to make the new system work.

## Proposed new system from spring 2020

### 1. Changing the default position

Under the new system, everyone in England will be considered as a potential organ donor unless they have said on the Register that they do not want to donate their organs or are in one of the excluded groups.

## 2. Making it easy to register your decision

We want as many people as possible to tell us their preferences. From December 2018, people in England will be able to record their organ donation decision on the Register via the new NHS app. From 2019, we will be developing further functionality so that users of the app can check and amend their registration details.

## 3. Telling people about the changes

There will be a 12-month transition period between the new law being passed and the arrangements coming into effect, to inform the public of the changes and encourage people to get talking about organ donation.

## 4. Recognising that faith is important to many

We will make it possible for people signing up to the Register to state that their faith is important to them and that their family and/or faith leader should be consulted in the discussions with nurses and doctors about the religious and cultural customs that need to be observed.

The faith training that is already available for specialist nurses on organ donation will be updated and extended to other healthcare staff working on organ donation.

We will be working on guidance for healthcare professionals setting out how the new arrangements will work in practice and detailing how religious and cultural considerations will form part of discussions with the family.

## 5. Family involvement at the time of donation

There will always be a personal discussion between the family, the specialist nurse and clinicians at the bedside before donation goes ahead, to also reflect faith and cultural considerations and the views of the family.

The family will be given the opportunity to provide information if their loved one would not have wanted to donate their organs or if their recorded decision was not the most recent.

## 6. People who will be excluded from the new arrangements

There will be exceptions. Children under 18, people who lack the mental capacity to understand the changes, and people not ordinarily resident in England for at least 12 months immediately before their death, will be excluded.