P Donation of solid organs and tissue for transplantation



Guide for the general public to Code of Practice F Part two: Deceased organ and tissue donation



A guide for the public to the Human Tissue Authority Code of Practice F: Donation of solid organs and tissue for transplantation (Part two: deceased organ and tissue donation)

This guide to our regulation of organ and tissue donation is written to address 'you' as a potential donor who is interested in donating your organs and tissues after your death. It is based on the HTA's Code of Practice F (Part Two) Deceased organ and tissue donation, which is aimed at professionals working in organ donation and transplantation.

Part two was updated in 2020 to reflect the introduction of a new system (commonly referred to as an "opt-out" or "deemed consent" system) for deceased organ and tissue donation in England.

Wales has operated under a deemed consent system for deceased organ and tissue donation since 2015.

In Northern Ireland, deemed consent does not apply; consent must always be given expressly by the potential donor before their death, or by a nominated representative or a person in a qualifying relationship after their death (see <u>Appendix A</u> below).

The HTA does not have a role in regulating deceased organ and tissue donation in Scotland. You can read more about organ and tissue donation in Scotland on the Organ Donation Scotland website.

Not covered in this guide

- Body donation
- Organ and tissue donation for research

Commonly used terms

Organs

Where we use the term organ, or organs, in this guidance, it refers specifically to a whole solid organ, or organs, including:

- Kidney
- Liver
- Heart
- Pancreas
- Lung

The general definition of what constitutes an organ in this context is a body part which has a specific vital purpose.

Tissue

Where we use the term tissue, this refers to other various part/s of the human body formed by cells that are not whole solid organs.

Organs and tissue

When we refer to "organs and tissue", this is to make it clear there is a combination of both.

Deemed consent

In England and Wales, people aged 18 and over may be considered as potential organ and tissue donors after death, unless they make a decision that they do not want to be a donor. It is also possible to nominate a representative to make this decision on your behalf after death.

This won't apply if you are an "excepted adult" (see <u>Further information and resources</u> below for more information).

The role of the HTA

The HTA regulates the donation of organs, tissues and cells (excluding reproductive cells), and provides advice and guidance about the law.

A system of deemed consent for organ and tissue donation after death is operational in England and Wales. This does not affect the HTA's regulation of living organ donation.

Part 2 - Donating organs and tissue after death

This public guide **only** refers to donation after death of organs and tissues in England and Wales

In May 2020 the consent requirements for deceased organ and tissue donation in England changed to what is commonly referred to as an "opt-out" system. In Wales, this system has been in place since 2015.

What this means is that where no decision has been recorded to either opt-in or opt-out of organ and tissue donation, and a decision is not known, consent can be deemed (that is, it can be deemed that an individual would have agreed to donation). Organs and tissue may be used for transplantation after death in some circumstances. There will always be a conversation with the family and close friends of the person who has died (please see Appendix A - Qualifying Relationships below, for information on who this could be).



Opting in to organ and tissue donation

The HTA is responsible for providing guidance on what counts as lawful consent.

Consent must be in place to allow organ and tissue donation to happen lawfully, but it does not mean that where consent is in

place donation must happen. This is a clinical decision in which your family play a crucial role.

During your life, you can consent to donate in several ways:

- The most common way to do this is by registering your decision on the
 Organ Donor Register (ODR), which is run by NHS Blood and Transplant
 (NHSBT). This is checked in every case where organ and tissue donation is
 a possibility.
- Share your decision with your family and friends.

- You can also access the ODR to record your decision via the NHS App.
- You can <u>nominate a representative</u> to make a decision on your behalf after your death.

You can withdraw your consent at any time. **Please note -** consent cannot be deemed for purposes such as research; this is outside the scope of deemed consent. Express consent will always be sought.

What does my consent cover?

You can consent to donate all of your organs and tissue for donation after your death, or you can specify which organs and tissue you consent to donate.

You cannot specify a particular type of person that you wish to donate to. Sometimes, even when consent is in place, donation may not be possible. There are many reasons why this may be the case.



Opting out of organ and tissue donation

During your life, you can opt-out of donation in several ways:

- The most common way to do this is by registering your decision on the
 <u>Organ Donor Register</u> (ODR), which is run by <u>NHS Blood and Transplant</u>
 (NHSBT). This is checked in every case where organ and tissue donation is
 a possibility.
- Share your decision with your family and friends.
- You can also access the ODR to record your decision via the NHS App.
- You can <u>nominate a representative</u> to make a decision on your behalf after your death.

If you make it known that you do not consent to organ and tissue donation, then donation cannot go ahead.

Further information and resources

Organs not included under deemed consent

Consent cannot be deemed for some organs and tissues and express consent would need to be sought. You can see the list of <u>organs and tissue requiring</u> <u>express consent on the HTA website</u>.

Excepted groups (people whose consent cannot be deemed in England or Wales)

Consent cannot be deemed in the following circumstances:

- The person who has died is a child under 18 years old;
- The person who has died is an adult who had **not been ordinarily resident** for a period of at least 12 months immediately before dying; or
- The person who has died is an adult who **lacked the capacity** to understand the notion of deemed consent for a significant period before their death.

Faith and belief

Discussions with your family will take place before any donation goes ahead - even if you have recorded your decision to opt in to organ and tissue donation.

These discussions will take into account your faith and beliefs, be they cultural, spiritual, religious or non-religious. Hospitals may also have faith-trained co-ordinators, a chaplaincy service representing different faiths, or accredited non-religious pastoral carers, which help support families.

If you register your decision on the ODR, you can request that your family are spoken to about how organ and tissue donation can go ahead in line with your faith or beliefs.

You can find further information on <u>religious belief and faith in relation to organ and tissue donation</u> on NHSBT's website.

Appendix A - Qualifying relationships

The Human Tissue Act 2004 includes a list of 'qualifying' relationships, which are ranked.

The list is as follows:

- 1. Spouse or partner (including civil or same sex partner)
- 2. Parent or child
- 3. Brother or sister
- 4. Grandparent or grandchild
- 5. Niece or nephew
- 6. Stepfather or stepmother
- 7. Half-brother or half-sister
- 8. Friend of long standing

For these purposes, a person is considered a partner if they if live as partners in an enduring family relationship.