P Donation of solid organs and tissue for transplantation



Guide for the general public to Code of Practice F Part one: Living organ donation



A guide for the public to the HTA Code of Practice F: Donation of solid organs and tissue for transplantation (Part one: living organ donation)

This guide to our regulation of living organ donation is written to address 'you' as a potential donor.

This part one remains unchanged and applies to living donation in England, Wales, and Northern Ireland.

Part two was updated in 2020, following public consultation, to reflect the introduction of a new system for deceased organ and tissue donation in England. You can read part two here.

The HTA do not have a role in regulating organ and tissue donation in Scotland. You can read more about organ and tissue donation in Scotland on the <u>Organ Donation</u> Scotland website.

Part 1 – Living Organ Donation

Consent

You must give valid consent before you can donate an organ. We make sure that all donors give valid consent as part of our regulation. If you are a donor, this means that you have agreed to donate voluntarily and that you understand what you have agreed to. We do this through Independent Assessor (IA) interviews with all donors and recipients. After the interviews, the IA will send their report to us for a decision. Living organ donation cannot lawfully go ahead without our approval.

Limits to Consent

You have the right to give or refuse consent to donate all or any of your organs or tissue for transplantation. This applies both during your life and after your death. The most common kinds of limits to consent include giving consent to donate specific organs, or an organ to a particular person during their lifetime.

If there are conditions on consent, any donation must comply with these conditions to be lawful. Only the donor can remove these conditions.

You cannot use conditions to limit the type or types of recipients. For example, you can't exclude recipients based on gender, race, colour, language, religion or political opinions.

Types of living organ donation

There are several types of living organ donation. The information you will receive about your donation will vary depending on the type of donation.

Directed donation	This is organ donation to a specific person where donor and the recipient have a pre-existing genetic or emotional relationship. For example, siblings or close friends.
Directed altruistic donation	This is organ donation to a specific person where the donor and recipient do not have a pre-existing genetic or emotional relationship. These cases will normally involve a third party. For example, a social networking site for matching donors and recipients. We have published guidance on matching websites and social media.
Non-directed altruistic donation	 This is organ donation to an unknown person. In these cases, the donor and recipient are anonymous. This can be done either by donating: to a patient on the national transplant list, or into the paired / pooled scheme to create a 'chain' of transplants.
Non-directed altruistic donor chains (paired/pooled scheme)	This is also known as a paired / pooled donation. This is also organ donation to an unknown person. NHS Blood and Transplant (NHSBT) matches two or more donors and recipients so they can carry out a chain of operations. The remaining organ at the end of the chain is then donated to the best matched recipient on the national waiting list.

Please refer to our website for <u>further information on the different types of organ donations</u>.

Information you will receive

You should receive the information you need to reach a decision that is right for you. This information should be clear and suitable for your understanding about organ

donation. It should also include information on any material risks. Material means a risk which:

- you reasonably think is significant to making a decision; and
- your clinician would reasonably think you would consider significant.

Based on the information you receive, you should understand the particular risks and benefits in your circumstances, as well as in general.

The transplant team must also discuss the following with you:

- The medical procedure, including any material short or long-term risks and the risk of death.
- The donation is voluntary you should not be pressured into donating.
- The transplantation is not always successful you should be told the likelihood of success for the transplant, the health benefits for the recipient as well as any side effects or complications.
- That you have the right to withdraw your consent at any time you should also be told what this may mean for you and the person receiving your organ.
- That it is illegal to seek or receive payment or reward for donating organs for transplantation.
- You can be reimbursed for expenses resulting from your donation this might include travel costs or loss of earnings.

Additional information for non-directed altruistic or paired/pooled donors

If you are a non-directed altruistic or paired/pooled donor, you should receive further information about how these systems work. For example, how suitable matches or recipients are found.

In addition, for these types of donations, your identity and the identity of the recipient must remain confidential. You are not allowed to know who will receive your organ until after the transplantation. Similarly, the recipient will not know your identity.

HTA approval process

If you are assessed as a suitable donor, you will be referred to an Independent Assessor. A suitable donor is someone who is medically suitable to donate and who has given informed consent.

IAs act as a representative of the HTA. They will interview you and the recipient to check the requirements of the Act are met. In most cases, the donor and recipient

interviews are carried out together and separately. In non-directed cases, the donor and recipient will not be interviewed together. If you are a donor, the IA will first of all check you understand the medical procedure. This includes the risks involved. The IA will also check that you are aware that you can withdraw consent.

As part of your interview, the IA will check that:

- you are not being forced to do something against your wishes;
- you have not asked for, or been offered a reward; and
- you have made an informed decision.

Following the interviews, the IA will submit a report of their interviews to us to make a decision. If you are not happy with the decision, you can ask for a review.

Find out more about our approval process.

If you have any concerns about the services you've received, please contact the HTA on either 020 7269 1900 or by using our online form