

QUality in Organ Donation (QUOD) Relative Information Leaflet

It is estimated that one in three people on the transplant waiting list either die or become too unwell to receive a life saving organ transplant. This is due to a shortage of suitable organs for transplantation.

There may be things that doctors can do prior to organ transplantation that will improve the quality of organs. To help doctors learn more about this requires research on transplant organs.

The purpose of Quality in Organ Donation (QUOD) is to set up a resource that can support research intended to improve outcomes for transplant patients. This research will look at what factors influence the success and failure of organ transplantation and how injury to donor organs can be prevented. This will include studying biological material and the best way for it to be treated in the course of transplant. In rare cases samples may be provided to improve outcomes for other health related purposes.

Please take the time to read the following information carefully, and discuss it with others if you wish. If anything is not clear, or you would like more information, please discuss this with the Specialist Nurse - Organ Donation.

What am I being asked?

You are being invited to consider allowing small samples of your relative's blood, urine and organs/tissues to be taken and used for this research because you have agreed to organ donation.

As your relative is unable to decide for themselves whether they would want to take part in a research study, we would ask that you put your own views about research aside and consider the past and present wishes and feelings of your relative, had they been able to decide for themselves.

What does taking part involve?

In the case of blood and urine samples:

As part of this study, blood and urine samples will be taken in the intensive care unit before your relative is transferred to theatre for the organ donation operation. We will also attempt to access the blood samples from the date of your relative's hospital admission.

In the case of organs accepted for transplantation:

If you agree, during the organ donation operation in theatre our medical team will take small tissue samples of the kidneys, ureter, liver, heart and spleen, as well as bronchoalveolar lavage samples (lung fluid collected during lung assessment). The liver sample will be approximately the size of a match-stick head, the kidney samples the size of a grain of rice and the spleen sample the size of a sugar cube.

In the case of organs that have been declined for transplantation:

Sample and organ collection/use will be in accordance to what you have agreed with your Specialist Nurse - Organ Donation during your conversation. If you have agreed to donate your relative's organs for research, should an organ be found unsuitable for transplantation **after** it has been removed, the organ may be allocated to a research project via QUOD. In the case of an organ being found unsuitable for transplantation **before** it has been removed for transplantation, the medical team will follow the usual retrieval procedure to remove the organ so it can be made available for research.

Occasionally, we may not be able to receive samples/organs due to unforeseen circumstances in the organ donation process; rarely, we may need to dispose of samples/organs after they have been taken due to problems with the suitability of the samples/organs themselves or unexpected delays in making them suitable for storage. This can therefore mean that, although you have agreed to the research, we are unfortunately not able to guarantee participation.

What happens after the samples are received by QUOD?

The samples are processed and stored in the QUOD biobank ready for use by researchers. A committee will review researcher requests and ensure that research projects will make good use of these samples by checking these have the necessary regulatory approvals. Researchers will be requested to pay a small fee to

cover a portion of the costs needed to maintain the biobank. Anonymised samples may be sent to researchers working in industry or in other countries. Research involving animals or relating to termination of pregnancy are not supported by the QUOD ethics and will not be allocated samples from the biobank.

What if I decide not to take part?

If you decide your relative would not want to take part in QUOD research, no samples will be taken for the purpose of QUOD and your relative's organs will not be allocated to QUOD. This will not have any impact on your decision to donate your relative's organs for transplantation. Your decision will not change the care provided to your relative.

Will my relative's personal details be protected?

Yes. The samples will be labelled using a unique number that will allow us to track and trace the samples while keeping them anonymous. No names or addresses will be used to identify the samples.

What if I change my mind at a later date?

If you change your mind, please contact your Specialist Nurse - Organ Donation to let them know. We will then no longer use any data recorded and will destroy the samples. However, samples and data which have already been used up to that point cannot be withdrawn.

How can I find out about the results of the research project?

More information about QUOD, including details of research projects using the collected samples, is available on the QUOD website: www.quod.org.uk

If you do not have access to the internet and you would like to receive further information or provide feedback on your personal experience of the QUOD programme, please contact your Specialist Nurse - Organ Donation.

Who is funding and organising the study?

The study is being funded by NHS Blood and Transplant and the Medical Research Council (UK). It is a collaboration of the following institutions:

University of Cambridge	University of Edinburgh	Kings College London
Newcastle University	Cardiff University	University Hospitals Birmingham
Royal Free London	Leeds Teaching Hospitals	Central Manchester University Hospitals
Oxford University Hospitals	University of Oxford (Lead)	

Who has reviewed the study?

The study has been reviewed by the North West – Greater Manchester Central Research Ethics Committee (ref 18/NW/0187).

Contact the Principal Investigator / QUOD Team

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Thank you for taking the time to consider taking part in the QUOD initiative