

QUality in Organ Donation (QUOD)

Information Leaflet for Donor Families

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.

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

Why am I being asked to sign the consent / authorisation form for research?

You are being invited to consider allowing small samples to be used for this research because you have consented / authorised for organ donation. The supported research aims to understand characteristics of organ damage (for example the impact of the body's own immune system) during the organ donation process as well as understanding the processes leading to organ failure.

What does taking part involve?

If you agree, our medical team will take small tissue samples of the kidneys, ureter, liver, heart and spleen, as well as blood, urine and bronchoalveolar lavage (lung fluid) samples. Some samples will be taken in the intensive care unit (blood, urine) and others (tissue samples) will be taken during the organ donation process in theatre. The lung fluid sample may be taken either in intensive care or in theatre depending on circumstances. We will also attempt to retrieve blood samples from date of hospital admission to add to the biobank.

The tissue samples will be approximately the size of a match-stick head, except for samples of the spleen, which will be the size of a sugar cube.

The samples taken will not affect the use of the organs for transplantation.

We will use these samples in order to understand how organs undergo changes during the donation process and whether it is possible to predict and improve how an organ will function following transplantation.

Sometimes, even though you have given permission for organ donation, it may not be possible for us to collect samples due to unforeseen circumstances in the organ donation process which means we may then need to dispose of the samples.

What happens after the samples are taken?

The samples are processed and stored in a tissue bank ready for use by researchers. There will be a committee to review researcher requests and ensure that research projects will make good use of these samples. Researchers will be requested to pay a small cost recovery fee (around 10% of the cost of collection and samples storage). 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 don't want to take part?

If you decide not to take part in the research, no samples will be taken. This will not have any impact on your decision to donate your relative's organs. 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 in 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 is available on the QUOD website: www.quod.org.uk

A list of the research projects using the samples we collect will also be published there.

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 in 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:

Institution:

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

Lead investigator:

Mr Gavin Pettigrew
Mr Gabriel Oniscu
Mr Wayel Jassem
Prof John Dark / Prof James Shaw
Prof Rutger Ploeg/
Ms Isabel Quiroga
Mr Reza Motallebzadeh
Mr Hynek Mergental
Mr Elijah Ablorsu
Mr Shahid Farid
Mr Afshin Tavakoli

Who has reviewed the study?

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

Principal Investigator:

Professor Rutger J Ploeg
Professor of Transplant Biology
Honorary Consultant Transplant Surgeon
University of Oxford

Oxford Transplant Centre
Churchill Hospital
Headington
Oxford
OX3 7LE
Email: contact@quod.org.uk

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