



Quality in Organ Donation (QUOD)

Information Leaflet for Recipients of Livers from donors participating in QUOD

The purpose of the Quality in Organ Donation (QUOD) programme is to create and maintain a resource that can support research to improve outcomes of transplantation. This research looks at what factors influence success and failure of organ transplantation, and how injury to donated organs can be prevented. For this work, we need to study biological material from the organ donor.

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 ask the Specialist Nurse in organ donation.

Despite efforts by many, we still face a persistent donor organ shortage in the UK. 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.

There may be things that we can do prior to organ transplantation that will improve the quality of organs and help us to better understand how we can improve the function of a transplant. To help doctors learn more about this requires research on transplanted organs.

Why am I being informed about QUOD?

You are being informed because the donor whose liver has been offered to you may be included in the QUOD research programme. This means that the relatives of the donor have consented to participate in the QUOD programme. As such, they have allowed small samples of their relative's or loved one's organs to be used for this research.

What does taking part involve?

After agreement from the organ donor's relatives, the medical team have taken very small tissue samples of the kidneys, ureter, liver and spleen as well as some blood and urine samples. Some samples were taken in the intensive care unit (blood and urine) and the tissue samples were taken after the operation to remove the donor organs.

The tissue samples are approximately the size of a matchstick head and taking these samples will not affect the use or function of the organ after transplantation.

We will allow research groups to use these samples in order to understand how organs undergo changes during the donation process and whether it is possible to prevent damage, and repair improving how an organ will function after transplantation.

What are the additional risks or burdens from receiving a liver from a donor taking part in QUOD?

There is a very small additional risk at the time of transplantation of minor bleeding from the biopsy site during the retrieval procedure. Small tissue biopsies are nowadays standard in many transplant centres in the world to obtain a specimen for comparison if a question arises at later date. Your surgical team has been trained in this and takes tissue biopsies on a routine basis. Also, the risk is reduced as we can see the site where the biopsy is taken and if necessary, any required action can be taken straight away. If, at the time of the donor procedure there are any concerns, no research biopsy will be taken.

Any additional tests and biopsies required for research will be undertaken separately from the QUOD programme and you will be consulted and asked to give your consent for these.

Will my personal details be affected?

No. We do not require any personal details from you. We will however request anonymous clinical data relating to the outcome of the transplant to study the factors which influence the outcome after organ transplantation.

Will anyone make money from the samples or data?

The QUOD programme is funded by NHS Blood and Transplant. To cover a small amount of the cost for collection, storage and transportation, we charge researchers a small fee for access to the donated samples and data.

The donor family and recipient will not receive any financial reward from the results of the research, either now or in the future, and neither will the doctors and nurses involved in your care.

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

More information about QUOD is available at www.quod.org.uk

Results of the research projects which use QUOD samples will also be published there.

If you do not have access to the internet or if 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 QUOD Programme is funded by NHS Blood and Transplant and concerns a collaboration of the following institutions:

Institution:	Lead investigator:
University of Cambridge	Mr Gavin Pettigrew
University of Edinburgh	Mr Gabriel Oniscu
Kings College London	Mr Wayel Jassem
Newcastle University	Prof John Dark
University of Oxford (Lead)	Prof Rutger Ploeg
Oxford University Hospitals	Ms Isabel Quiroga
Royal Free London	Mr Neal Banga
University Hospitals Birmingham	Mr Hynek Mergental
Cardiff University	Mr Elijah Ablorsu
Leeds Teaching Hospitals	Mr Magdy Attia
Central Manchester University Hospitals	Mr Afshin Tavakoli

All transplant centres that are involved in the Advisory Groups of NHS Blood and Transplant are supportive of the programme and have confirmed the use of samples and the tissue biopsy.

Who has reviewed the study?

The study has been reviewed by the Research Ethics Committee (ref 13/NW/0017).

Principal Investigator:

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