QUality in Organ Donation (QUOD)

Information Leaflet for recipients of kidneys 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 your clinical team.

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 dies or becomes 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 kidney 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 that small samples of their relative’s or loved one’s organs can be used for this research.

What does taking part involve?

After agreement from the organ donor’s relatives, the medical team has taken very small tissue samples of the kidneys, ureter, liver, heart and spleen as well as some blood, urine and lung washing samples. Some samples were taken in the intensive care unit (blood and urine) and the tissue samples were taken after the donor operation when the donor organs are removed for transplantation.

The tissue samples are approximately the size of a grain of rice 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 improve organ function after transplantation.

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

There is a very small 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. However, 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.

If there are any additional tests and biopsies requested for research and separate from the QUOD programme, 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 success and failure of organ transplantation.

How can I find out about the results of the research projects?
More information about QUOD is available at [www.quod.org.uk](http://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 clinical team.

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:

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<tr>
<th>Institution</th>
<th>Lead investigator</th>
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<td>University of Oxford (Lead)</td>
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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 18/NW/0187).

Principal Investigator:

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