Healthcare Experiences After Transplant

Participant Information Sheet for Transplant Recipients

This Participant Information Sheet will help you to decide whether you would like to take part in the *Healthcare Experiences After Transplant* study. Taking part in this study is entirely **optional**, you are under no obligation to take part. If you decide you do not want to be interviewed the study team will not contact you again.

To help you to decide whether you would like to participate, it is important that you understand why the research is being carried out and what it will involve for you. Please take the time to read the following information carefully and discuss it with others if you wish. Please contact the study team if there is anything that is not clear or if you would like more information and we can arrange a call to talk through the information instead.

This study is being conducted by Ben Rimmer and Daisy Robinson, who are researchers at Newcastle University.

If, having read this Participant Information Sheet, you are interested in taking part, please email the study team, providing your name and contact details: ODT.experiences@newcastle.ac.uk

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Short definitions of some terms we use:

Transcript: a transcript is the written document that results from typing out the audio recording of an interview.

Anonymous: in its most basic form *anonymous* means not identified. So, when we talk about anonymised information, we mean information that has had all personal, identifiable details removed.

Confidential: when we say that something is *confidential*, we mean that this information would be private, accessible to a limited number of people. In the case of this research, the only people who would have access to confidential information would be the researchers who require access to this information to do this study.

1. What is the purpose of this study?

Organ transplantation saves lives. But life after transplant surgery is not always easy and can require long-term follow-up healthcare. This study follows on from the 'Experiences of Life After Transplant' study, which explored the healthcare experiences of solid organ transplant recipients. Those findings were used to inform the development of a Patient-Reported Experience Measure (PREM) to measure healthcare experiences in transplant recipients. PREMs are questionnaires that allow people to answer questions about their healthcare experiences.

We are now seeking to interview transplant recipients who **live in the United Kingdom**, are **aged 18 years or older** and have had a **kidney, liver, pancreas, heart, or lung transplant more than 12 months ago**, to get your thoughts on the draft PREM. This includes considering whether each question in the survey is relevant to transplant recipients; whether the survey includes all relevant healthcare aspects; and whether the survey and its instructions are easy to understand.

We hope the information gathered from the interviews will help us to refine the survey and address any issues with its completion. Speaking to people from a variety of backgrounds will help to reflect the wide range of experiences and views there may be across the population of transplant recipients in the UK.

It is hoped that a survey of healthcare experiences after transplant for transplant recipients will have multiple uses, for example, to indicate the quality of healthcare and identify areas where there are opportunities to improve healthcare services across different organisations.

2. Why have I been given this information sheet?

You have been given this information sheet because you have expressed an interest in hearing more about this study. This could have been through seeing the recruitment advert, finding out about the study from someone you know, or a conversation with

someone from the study team. It may also be that you expressed an interest in taking part in the 'Experiences of Life After Transplant' study and indicated that you were happy to be contacted about future opportunities. If you feel you have received this information sheet in error, please let us know – if you do not wish to be contacted again, we will respect this request.

3. Why have I been asked to complete an Expression of Interest form?

The population of transplant recipients in the UK is very diverse; it includes people of different ages and ethnicities, who live in different places, and have received different transplanted organs. The study team want to ensure that our research reflects this diversity. We are asking anyone who is interested in being part of the study to tell us a few details about themselves to help us ensure we talk to a varied group of people with different experiences.

You do not have to complete all the information in the form if you do not want to (it is entirely voluntary) but having this information will help us make sure we have participants from different backgrounds and regions across the UK.
All information you provide will only be seen by members of the study team and used to select participants to invite to interviews; we will destroy it at the end of the study if you are selected and take part in an interview.

If you are not selected for interview, we will let you know; if you do not wish to be contacted about further opportunities to be involved in the future, we will delete all your information.

4. Do I have to take part?

No. It is up to you to decide whether to take part in an interview. You can take some time to think over the contents of this information sheet and talk to others about it if you wish before you decide if taking part is right for you. Please feel free to contact the study team if you have any questions: ODT.experiences@newcastle.ac.uk

5. What will happen if I take part?

If you are happy to take part, please talk with a member of the study team to arrange a time for the interview that is convenient for you.

Interviews will last approximately 90 minutes although they may be slightly longer or shorter. They will be held either online, using Microsoft Teams, or over the telephone. This has the benefit of minimising travel and reducing risks to both participants and researchers. **If you are not sure about using Microsoft Teams, the interview can be held over the telephone, or a member of the study team can provide you with guidance on how to use this technology**.

Before the interview starts, we will ask you to complete a consent form which shows that you agree to take part and sign this with a simple e-signature in the form of a typed name. We will re-affirm your consent at the start of the interview.

Each interview will include a 'test' of the new healthcare experiences after transplant survey, to help us understand how the questions are working. The survey covers topics related to your experiences with access to information and support, interactions with your healthcare team, and attendance to follow-up appointments. You will be shown the questions and asked to answer each one, as you would in real life, but you will be asked to think aloud as you do so. For example, whether you think the question is easy to understand; asking about something important to transplant recipients; or has appropriate answer choices. There are no right or wrong answers and the interview is not a test of your knowledge. We are interested in your views and what *you* feel is important for us to know about the survey.

With your agreement, your interview will be audio-recorded. We record interviews so that the interviewer can truly listen to you without the distraction of notetaking. It also ensures that we have an accurate account of your views. These recordings will be transcribed (typed into written form) and the study team will securely store both the recording and transcription. We may use a professional transcription service provider. This service will adhere to General Data Protection Regulation (GDPR) and will have an established confidentiality/non-disclosure agreement with Newcastle University.

Audio recordings securely stored at Newcastle University will be deleted once we are certain of the transcript's accuracy. If a professional transcription service is used, they will have agreed to delete recordings upon the completion of the transcript. All data will be confidential, and all data will be anonymised - **that means that no-one will be able to identify you from anything that you have said.**

No interview participants will be personally named in any report or paper. Anything said by a participant will be treated with confidence.

6. What will happen if I do not want to take part, or I change my mind?

If you decide you do not want to be interviewed, we completely understand. We will destroy the personal information we have about you and will not contact you again. Just let a member of the study team know by emailing ODT.experiences@newcastle.ac.uk.

If you agree to take part but later wish to have your personal information withdrawn, this is okay too. You can request this at any time, without giving a reason and you will not be asked about it again. We will destroy your personal details. However, we will keep any anonymised data collected, such as the anonymised transcript from your interview.

7. Expenses and payments

The interviews are being held online or over the telephone. We will therefore not be able to pay any expenses. If the interview is by telephone, then the researcher will telephone you at our expense.

8. What are the possible disadvantages and risks of taking part in this study?

You may find talking about your experiences of transplantation during an interview upsetting. If you do become upset at any time you can choose to pause or stop the interview immediately. We will only continue with a paused interview if you are happy for us to do so. If you become upset during the interview, you will be able to talk about this with the researcher interviewing you. They will be fully trained and experienced in this kind of research and will listen. **However, they are not trained to provide mental health advice**. You can also discuss mental health concerns with a healthcare professional such as a GP.

9. Are there any possible benefits to taking part?

There are no direct benefits for you from taking part in this study, but it will help us to ensure that the survey is relevant, comprehensive, and easily understood by transplant recipients. This plays a very important part in helping us to achieve the study aims outlined above.

10. How will my information be used?

We will keep all information about you safe and secure, stored at Newcastle University. We are bound by a strict code of confidentiality. Storage and deletion of all personal or identifiable data, such as your email address, will comply with data protection legislation, such as GDPR, and local guidelines. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a study ID number instead. We will destroy your personal details at the end of the study. If you have requested to receive a short summary of the results and/or have stated that you would be happy to be contacted about future related work, we will keep your details to fulfil these requests before destroying them.

The information that the study team will use for analysis will all be anonymised, such as the anonymised transcript from your interview. Identifiable information, such as your name, will not be used as part of the analysis. We will write our reports in a way that no-one can work out that you took part in the study.

If you choose to be interviewed via Microsoft Teams, access to the interview will be restricted to keep the meeting secure. This will be done using the lobby system, where anyone requesting to join must be “admitted” by the host (in this case the researcher

conducting the interview). Teams has a recording function, where audio is recorded and stored within a secure network of servers and shared only with the host. Following interviews recorded using this function, the recording will be moved onto secure, password protected, Newcastle University computers. If you would like to be interviewed over Teams but would rather the recording function within this platform was not used, the interview can be audio-recorded using a Dictaphone instead. Microsoft Teams has their own privacy and security policy, which is available online: https://docs.microsoft.com/en-us/microsoftteams/security-compliance-overview

11. What will happen to the results of the study?

The results from this study will be published in scientific journals where the quality of the results will be assessed. In addition, results will be presented at national and international academic and research meetings. The results will also be reported to the Funder. We will write our reports in a way that no-one can work out that you took part in the study.

Fully anonymised interview transcripts may also be made available to other researchers or research students to help inform other research studies. **Your identity will always be protected**.

A summary of the findings of the study can be made available to you at the end of the study if you wish.

12. Who is organising and funding this study?

This work is part of the research taking place in the Newcastle and Cambridge Blood and Transplant Research Unit in Organ Donation and Transplantation. The Research Unit is funded by the National Institute for Health and Care Research and backed by NHS Blood and Transplant. You can find more information on the Unit's website: http://odt.btru.nihr.ac.uk/theme-6/.

This study is being led by Catherine Exley, Professor of Qualitative Health Research and Dean of Population Health Sciences Institute, Faculty of Medical Sciences, Newcastle University. The researchers who are conducting the interviews work directly with Catherine Exley at Newcastle University.

13. Who has reviewed this study?

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This Committee includes members who are internal to the Faculty. This study was reviewed by members of the Committee, who must provide impartial advice and avoid significant conflicts of interests. Reference number 63020/2023.

14. What if there is a problem?

We do not expect anything to go wrong as a result of you taking part. If you have a concern about this study or the behaviour of one of the researchers, you can seek advice from someone who is not working on this study by contacting sponsorship@newcastle.ac.uk and quoting the reference number 63020/2023 in your email.

If you have any concerns that you wish to discuss with Catherine Exley, the lead for this study, she can be contacted using the details below:

Catherine Exley
Professor of Qualitative Health Research
Dean of Population Health Sciences Institute
Faculty of Medical Sciences
Newcastle University
NE2 4HH
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Thank you for taking the time to read this information sheet.