|  |  |  |
| --- | --- | --- |
| **School of****Social Sciences****& Public Policy**Institute of Gerontology | King’s College LondonStrandLondon WC2R 2LSTel +44(0)20 7848 2735Fax +44(0)20 7848 1800gerontology@kcl.ac.uk  | **C:\Users\Chris\Documents\Work\Liver\KCL_no UoL_letterhead_32.5mm RGB.jpg** |

**Now grown up: Adults’ lives after childhood liver transplant**

**Adults’ Information Sheet**

**Introduction**

This sheet gives you further information about the study I am inviting you to take part in. You can discuss whether or not to join in with anyone you want to. You do not have to decide immediately.

You need not take part in this study if you do not want to. If you do decide to take part you may withdraw at any time and need give no reason for doing so. If you choose not to take part, or if you withdraw, your normal health care and treatment at Addenbrooke’s [King’s College Hospital] or anywhere else will not be affected.

**Participant Selection**

You have been invited to participate in this research because you had a liver transplant when you were a child about 15 years ago, or even longer, at Addenbrooke’s Hospital [King’s College Hospital]. We are writing to everyone from Addenbrooke’s [King’s College Hospital] who had a liver transplant as a child and is now an adult, to invite them to take part in this study.

**Purpose of the research**

As you may know, you were amongst the first group of children to ever have a liver transplant in the UK. It was a new operation and there was a lot for doctors to learn about how best to look after people like you. Now you are grown up there are more questions to ask. An important one is what is life like after liver transplant?

When I say ‘life after liver transplant’ I mean life away from medicine hospitals and doctors - life at home or work, for example. You could help us by talking about your liver transplant and what impact it has had on your relationships with family and friends, your work, social life and education. Knowing what you have experienced in your own words is interesting in its own right but could also help improve support to the next generation of children growing up after liver transplant and their parents too.

**What taking part involves**

Taking part in the research will involve you in one interview, possibly two, at a time and place that suits you. My colleague Dr Chris Hiley or I will ask about how it feels to grow up after a liver transplant and what it means to you – both the good and possibly not so good. We will not be asking about your medical history in any detail, though we may have to touch on it occasionally to clarify things that you might have said which we do not understand. We do not have access to your medical notes so we will not know any of your medical details. We will only know that you have had a liver transplant.

If possible, we would like to interview you in your own home, away from the distractions of the hospital or other public place. We can arrange to interview you elsewhere, if you prefer. If you would like to travel to King’s College London for your interview we will reimburse your travel costs.

Interviews will be recorded. This is so that what you say will be remembered accurately and the topics raised during the interview can be analysed carefully. The interviews will be saved to a password protected encrypted memory stick. This will either be hand delivered or posted, via Royal Mail Special Delivery, to an expert transcriber of confidential research interviews. She will have signed a confidentiality agreement prior to receiving them and will be told of the password by phone so she can access them. She will then type them up. Once she has finished we will then collect the transcripts as password-protected files on an encrypted memory stick.

After we have checked the transcription against the original recording, the *recording* will be deleted. The type written transcript is then the only record of what you said. Your name and any identifying comments will be removed and will not be reproduced in any report. Any direct quotes will be anonymised.

The interview is likely to take no longer than two hours. It can be split into two shorter interviews if you find the interview tiring or you simply want to stop. There is no obligation to persist with the second half of the interview, having completed the first half. You can also choose to have a second interview if you feel you have more to share with the researchers.

We are not testing your knowledge so there are no wrong answers. You do not have to discuss anything that you are not comfortable discussing. If you do not wish to answer any of the questions you may say so and the interviewer will simply move on to the next question. You can also end the interview at any time. No one else but the interviewer will be present, unless you would like someone else to be there.

The information recorded is confidential. Only Chris Hiley and I have access to what you said at interview.

The information that you provide will help us understand more about life after transplant and might help hospital staff plan patients’ long term care more effectively. It may also identify areas of concern or could improve communication between patients and hospital staff.

**What we are interested in**

We include a ‘topic guide’. This shows the kinds of question we will be asking. This may help you to decide whether or not to join in. It may also help you have a think about what you want to say beforehand, if you *do* decide to join in.

**About us**

It is important that you know we are not medical doctors. We are happy to answer any questions that you may have about the research but we cannot give health advice or answer medical questions nor act as intermediary for health queries you may have. Queries should always be directed to your usual GP, Addenbrooke’s [Kings College Hospital] or other health service. If in the course of an interview you tell us something that we suspect your doctors should know we will advise you to contact them about it. We will not do so ourselves.

**Risks**

You might share information with us that is very personal to you. We may touch on subjects that are sensitive or which you find upsetting. However, you do not have to answer any question if you do not wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. In the *very* unlikely event that medical professional malpractice becomes evident the researchers are obliged to report it.

**Benefits**

There will be no direct benefit to you in taking part in this research but you might find it personally interesting. Your participation is likely to increase understanding of how people on the cutting edge of medicine live their lives.

**Reimbursements**

You will not be provided with an incentive to take part in the research. However, we will give you £20 for your time.

**Confidentiality**

We do not share any information about you and what you may have said to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers can connect your number with your name and that information is kept securely. It will not be shared with anyone else.

**Sharing the Results**

Nothing you might say will be attributed to you personally. The knowledge that we get from this research will be shared with you before it is made widely available to the public. Each participant will receive a summary of the results. We will publish the results so that other interested people may learn from the research.

**Right to Refuse or Withdraw**

You do not have to take part in this research if you do not wish to do so. Having once agreed you may still stop participating at any time. You will have the opportunity to review your remarks at the end of the interview. You may modify or remove portions if, on reflection, you wish to do so. The sooner you point this out the easier it will be to do something about it. If you leave it too long it might not be possible.

This proposal has been reviewed and approved by the Ethics Committee in Cambridge. All good research is assessed by ethics committees. Their task it is to make sure that research participants are protected from harm. If you wish to find about more about them, contact [name, address, telephone number.] The study has also been reviewed by the Economic and Social Research Council which is funding it.

**If you wish to take part** email chris.hiley@kcl.ac.uk or karen.lowton@kcl.ac.uk

OR

Phone 020 7848 2566 – Karen’s direct line at King’s College London and leave a message *with your contact details.*