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PARTICIPANT INFORMATION SHEET

TAKING PART IN AN INTERVIEW - A STUDY OF EXPERIENCES OF PARENTS OF CHILDREN WITH NEONATAL SURGERY-RELATED COMPLEX CARE NEEDS AT HOME, NURSERY AND SCHOOL

Hello

My name is Karolina Kuberska. I am a medical anthropologist working with the Medical Sociology and Health Experiences Research Group at the University of Oxford. I am asking you to take part in research. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please read what I have to say carefully. Talk about it with friends, relatives or healthcare professionals caring for your child if you wish. Ask me if you have any other questions. Please take as much time as you like to decide. If you would like this information sheet in an accessible format please ask us.

Thanks for reading this.

What is the purpose of the study?

The aim of our research programme is to improve understanding of people's experiences of health, illness and healthcare, and provide resources to support people living with a wide variety of health conditions, their families, friends and the health professionals involved in their care. We collect video, audio and written interviews, which may be used in several ways:

- to find out what is important to parents or guardians of children with neonatal surgery-related complex care needs as their child is brought home, and goes to nursery and school
- to contribute to the www.healthtalk.org website which is run by the DIPEX charity
- to develop other support and information and training resources for people
- to train health and social care professionals

- to support quality improvement in healthcare
- to write research papers

www.healthtalk.org is a website that has:

- people's stories of health, illness and other health-related issues such as bereavement, ageing or parenting
- information about tests and treatments
- other information that may be useful to people going through similar experiences
- a teaching and learning area for health and social care staff and anyone involved in healthcare

The idea is that seeing and listening to other people's experiences on Healthtalk will provide people with additional help, emotional support and practical information.

Health and social care professionals, researchers and policy makers, who want to understand people's experiences can also visit the website.

Anyone who has access to the Internet is able to use Healthtalk.

The interviews we collect contribute to the information presented on the site, and extracts from many of them will be used to show what it is like for people facing illness or health issues. Your interview will not be used for advertising or purely commercial purposes.

As well as the website, we may use interviews to help create other information and support resources, such as DVDs or short films. These may for example be shown to people by health professionals as part of their care or they may appear on other websites approved by the University of Oxford

Interviews may also be used to develop other resources for members of the public, patients and families, for health and social care professionals and for clinical research staff, so they can learn from people's experiences and improve the care they provide. Training materials may be presented on the teaching and learning area of the www.healthtalk.org website, on other approved websites, and on DVDs.

All the interviews we collect also contribute to research articles and papers.

Why have I been chosen?

You have been contacted because I want to interview people who have had experience of health issues and decisions such as yours. I will be interviewing a range of people who have had such experiences. We are interested in talking with parents or guardians of children, currently aged between 4 and 8, who have neonatal surgery-related complex care needs as a result of a neonatal surgery for one of the following conditions:

- gastroschisis,
- Hirschsprung's Disease (HD),
- Congenital Diaphragmatic Hernia (CDH),
- Oesophageal Atresia/Tracheo-Oesophageal Fistula (OA/TOF),
- Necrotising Enterocolitis (NEC),

- Posterior Urethral Valves (PUV),

Your name has not been given to us at the Medical Sociology and Health Experiences Research Group, so I will only be able to contact you if you complete and return the 'reply slip' (in your information pack) and return it to us by post (using reply paid envelope) or by email to Karolina Kuberska (karolina.kuberska@thisinstitute.cam.ac.uk).

Do I have to take part?

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to complete a 'consent form'. If you decide to take part, you are still free to stop at any time without giving a reason. No questions will be asked if you stop. Deciding whether or not to take part in the study will not affect the standard of medical care you receive.

What will happen if I take part?

If you complete and send back the enclosed 'reply slip' to me by post or email, I will contact you to arrange an interview at a time and place that suits you. If this place is not your home, you will be paid for the cost of your travel. We can also interview by telephone or online.

I will try to answer any questions you may have about the interview or the Healthtalk project. Before the interview I can show you the Healthtalk website. You can see how clips from other people's interviews look in video, audio and written formats.

What would the interview be like?

I will ask you if you are willing to have the interview video or audio recorded. You will be given the 'consent form' if we meet face to face, or complete a verbal consent form if the interview is by phone or online. You only complete this form if you agree to take part in the interview. You will be given a copy of the consent form to keep.

The interview will be a little like a conversation, in which I will help you talk about yourself in your own words. I will ask you to talk about your experiences as parents or guardians of children with neonatal surgery-related complex care needs at home, nursery, and school. I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have got information, what you have done, and what have been the good and bad parts of the experience.

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, I can give everyone a list of useful contacts which can be used to get more help if you want.

How long would the interview take?

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

Expenses

Any travel costs/caring expenses incurred on the day of the interview will be reimbursed.

What if I decide to withdraw after the interview has taken place?

You are free to leave the study at any time. If you decide to leave after an interview has taken place, all video recordings, transcripts and typing of your interview would be destroyed. If you decide to leave after the website or other audio-visual resources have been finished, we would remove your contribution from all later versions, but we would not be able to destroy existing material, which other people could already have seen or copied.

What would happen after the interview?

I will label the interview recording with a code number and give it to a typist who will type out everything you said in the interview. The typist has signed an agreement to keep everything you say in the interview secret. The digital recording and the typed up record (transcript), identified only by the code number, would be kept in a secure place at the University of Cambridge.

I will send you a copy of the interview transcript to help you decide whether you want your interview to be made available to use for our research, including on Healthtalk and other audio-visual resources. A copy of the interview recording can also be provided if requested. You would be asked to read or listen to the interview and consider if there was anything you would like to change or remove, to keep anything secret or hide your identity, or to delete or change some of your interview. We can remove any sections that you do not want us to use. You can take as long as you need to do this. You can also choose how your interview will appear in any resources we produce (see below).

How would the researcher use the interview tape and transcript?

You will be asked to sign a form '**Further use of my interview**'. If you sign this form, you give copyright of the interview to the University of Oxford. It is very important that you take time to think about and discuss the copyright form before you sign it. You will be given a copy of this form to keep.

If you do decide to allow your interview to be used for the study, it would be used along with interviews from between 15 and 20 other people who have experiences of being parents or guardians of children with neonatal surgery-related complex care needs at home, nursery, and school. A summary of these interviews would be prepared for the Healthtalk website. People who use the site would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. All data use is strictly within the terms of the Data Protection Act (DPA)

2018). The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

Can I choose how my interview will appear?

You will have a choice about whether a video, audio or written version of your interview is included. If you want to be anonymous, you will be invited to use an alias for yourself and others, and you can keep out of the interview anything which might identify you. **You may wish to discuss this with members of your family, since they might possibly be connected to your appearance on the screen.**

If you are recognised on a website or a DVD, this would be a little like appearing on the TV. The material on the website is protected by copyright and people are not allowed to copy or record what they find there but it is possible that they could. If you have any doubts about how you want the interview to be included, talk to me, or I could find an independent adviser for you to talk to if you prefer.

What will happen to my data?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly.

We will use information you provide in order to undertake this study and will use the minimum personally-identifiable information possible. We will keep identifiable information about you (phone and contact details) for up to three years after the Healthtalk study has finished. With your permission we will archive the research data (interview recording and transcript) and the consent and copyright forms securely at the University of Oxford for up to 100 years after the end of the study.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at

<https://compliance.web.ox.ac.uk/individual-rights>

You can find out more about how we use your information by contacting ruth.sanders@phc.ox.ac.uk.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct by the Berkshire Ethics Committee.

Who is organising and funding the research?

Narratives of health and illness for Healthtalk
Participation Information sheet Generic adults V8 01.07.2022 12/SC/0495

The Medical Sociology and Health Experiences Research Group is based at the Nuffield Department of Primary Care Health Sciences, University of Oxford. The project “Children with neonatal surgery-related complex care needs at home, nursery, and school” is part of the Children’s Surgery Outcome Reporting (CSOR) programme and is being funded by NIHR (127844).

Contact for further information

I hope that this information sheet has told you what you need to know before deciding whether or not to take part. If you have any queries at all about the project or wish to make a complaint please telephone Karolina Kuberska on 01223 761 881 or Sue Ziebland of the Medical Sociology and Health Experiences Research team on 01865 289 302.

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by Berkshire Ethics Committee REC Ref 12/SC/0495

What if there is a problem

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part, However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Sue Ziebland of the Medical Sociology and Health Experiences Research team on 01865 289302 or the head of RGEA, email ctrng@admin.ox.ac.uk.

Many thanks for reading this information sheet.

Karolina Kuberska

The Healthtalk site is run by DIPEX, which is a registered charity number 1087019 and a company limited by guarantee, company number 04178865.