



STUDY INFORMATION SHEET FOR ADVOCATES OR SCRIBES

VERSION NUMBER [3.0] : DATE [17/04/2019]

Please read this information sheet carefully and discuss with the young person. Please ensure the young person understands what is required before they decide whether or not to take part in the study.

What is the aim of the project?

We want to find out how NHS staff assess and treat children with special educational needs and disability to help them manage toileting, and whether there is any evidence that the interventions that are used are effective.

We would like to hear from children and young people specifically about their experiences and the support they have received to help with managing toileting. We will do this using an online survey to answer the following questions:

1. How do families judge a child's readiness for toilet training, and the need for specialist assessment and/or interventions?
2. Which factors are influential to consider in the implementation of interventions to improve toileting, and what is the acceptability of recommended strategies to children and young people?

Why do we want to hear from you?

We would like to hear from a range of young people that have special educational needs and disability, and that may have (or had) difficulties with toileting. As a young person with a disability and/or toileting difficulties, they have first-hand experience of what it is like for them and their family. We would like to hear from children and young people up to the age of 25 years, whether they are able to manage using the toilet independently or not.

We will monitor the types of young people that have responded to ensure that we gather a range of responses and experiences from across England.

What will you be asked to do?

If the young person would like to take part in this study, they are invited to register their interest with us and provide us with some contact details. We will then send an electronic link to an online survey, via the contact details they give us. The questions in the survey will be short and mostly tick box responses. The survey link will be sent to all registered participants in the summer term of 2019.

Are there any possible disadvantages and risks of taking part?

No, we do not anticipate that there will be any potential harm or discomfort from taking part in the survey. In the event that the survey questions make the young person feel uncomfortable, they may decline to answer any particular question(s). They can also withdraw from the study at any stage for any reason, without any disadvantage to themselves of any kind.

How much of your time do we require?

The survey can be accessed online at a time that is convenient to the young person. We do not anticipate that the survey will take a long time to complete, but they may need help to understand or complete the questions accordingly. There is only one survey to complete and we will not contact them again for any further research.

Can participants change their mind and withdraw from the project?

The young person may withdraw from participation in the study at any time without any disadvantage to themselves of any kind. Please contact us directly if the young person wishes to withdraw their survey responses. Their responses and any data that we have recorded will be removed accordingly.

Please contact study team at icon@exeter.ac.uk if the young person has changed their mind and would like to withdraw from the study.

How will my information be kept confidential?

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. Your data will only be access and analysed by the ICoN research group and it will be stored anonymously and securely. Data will be physically held on encrypted hard drives in secure locations at the University of Exeter Medical School. Personal contact details (collected in order to share a link to the survey via email) will be stored securely and separately from the research data.

The University will endeavour to be transparent about how your personal data is used and this information sheet should provide a clear explanation of this. If you do have any queries about how we use your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing

dataprotection@exeter.ac.uk or visiting the university data protection webpage at www.exeter.ac.uk/dataprotection.

What data or information will be collected and what use will be made of it?

Each participant will be assigned a unique study identification number which will be used on their survey responses. Survey questions will mostly require a tick box responses, and will be focussed on the assessment and support that the young person has received to help with toileting. We will also collect data regarding your gender and the region in which you work. No other personal data will be recorded and you will not be required to provide specific information about the young person's care.

The data will be stored for five years after the completion of the study, as requested by the funding body, on the secure university IT network and any paper documents in a locked filing cabinet. After five years from study completion the electronic files containing personal information will be deleted, and all paper files will be disposed by shredding.

What if you have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Dr Chris Morris
Associate Professor
South Cloisters
St Luke's Campus
Exeter EX1 2LU
01392 722980

OR

Helen Eke
Research Fellow
South Cloisters
St Luke's Campus
Exeter EX1 2LU
01392 722923

Complaints

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD
Chair of the UEMS Research Ethics Committee
Email: uemsethics@exeter.ac.uk

**This project has been reviewed and approved by the
University of Exeter Medical School Research Ethics Committee
UEMS REC REFERENCE NUMBER: Apr19/B/199**

