



STUDY INFORMATION SHEET FOR CHILDREN AND YOUNG PEOPLE

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

Thank you for your interest in this study. Please read this information sheet carefully before deciding whether or not to take part. Please ask a parent or carer to help you if you are unsure or do not understand anything.

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 going to the toilet, and whether there is any evidence that the interventions that are used are effective.

We would like to hear from children and young people up to the age of 25 years, about your experiences and the support you have received to help you with 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 their need for specialist assessment and/or treatment?
2. Which factors affect the use of different methods to assess and support young people to improve toileting, and how acceptable are the recommended strategies for children and young people?

Why do we want to hear from you?

We would like to hear from a wide range of children and young people up to the age of 25 years who have special educational needs or disability, and who may have (or had) difficulties with toileting. As a young person with a disability and/or toileting difficulties, you have first-hand experience of what it is like for you. Whether you are able to manage using the toilet on your own or not, we would like to hear from you.

What will you be asked to do?

If you would like to take part in this study, you will be invited to register your interest with us and provide us with some contact details. We will then send you an electronic link to an online

survey, via the contact details you 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.

You are allowed to have a parent or carer to help you with the registration process and the survey if you do not feel able to complete it by yourself.

Are there any possible disadvantages and risks of taking part?

No, we do not believe that there is any potential harm or discomfort for taking part in the survey.

If any of the survey questions make you feel uncomfortable, you do not have to answer those question(s). You can also choose not to take part in the study at any stage for any reason. There will not be any disadvantage to yourself if you choose not to take part.

How much of your time will the online survey take?

The survey can be accessed online at a time that is convenient to you. We do not anticipate that the survey will take a long time to complete, and someone can help you complete it if necessary. There is only one survey to complete and we will not contact you again for any further research.

Can you change your mind and withdraw from the study?

You may withdraw from taking part in the study at any time without any disadvantage to you of any kind. You or your parent or carer can contact us directly if you wish to withdraw your survey responses. Your responses and any data that we have recorded about you will be deleted accordingly.

Please contact study team at icon@exeter.ac.uk if you have changed your mind and would like to withdraw from the study.

How will your 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 your survey responses. Survey questions will mostly require a tick box responses, and will be focussed on the assessment and support you have received to help with toileting. We will collect data regarding your gender and the region of England in which you live. No other personal data will be recorded and you will not be required to provide specific information about your 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**

