



## **STUDY INFORMATION SHEET FOR PARENTS AND CARERS**

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

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to take part.

### **What is the aim of the project?**

We want to find out how NHS staff assess and treat children and young people 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 parents and carers about their experiences of using interventions to improve toileting for children and young people up to the age of 25 years with special educational needs and disability. We will do this using an online survey to answer the following questions:

1. How do parent/carers consider and judge their child's readiness for toilet training, and their 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?

### **Why do we want to hear from you?**

We would like to hear from a range of parent/carers that have experience of a child or young person with special educational needs and disability, and/or toileting difficulties. As a parent/carer, you have first-hand experience of what it is like to manage toileting if your child has a disability. We would also like to hear about the different methods that you and your child's health workers may have used to help your child to manage toileting better. We would like to hear from you, whether your child is able to use the toilet independently or not.

We will monitor the types of participants 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 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.

### **Are there any possible disadvantages and risks of taking part?**

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

### **How much of your time do we require?**

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 participants change their mind and withdraw from the project?**

You may withdraw from participation in the study at any time without any disadvantage to yourself of any kind. Please contact us directly if you wish to withdraw your survey responses. Your responses and any data that we have recorded about you will be removed accordingly.

Please contact study team at [icon@exeter.ac.uk](mailto:icon@exeter.ac.uk) if you have changed your 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](mailto:dataprotection@exeter.ac.uk) or visiting the university data protection webpage at [www.exeter.ac.uk/dataprotection](http://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. We will collect data regarding your gender and the region of England in which you live. 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. No other personal data will be recorded, and we do not collect personal information regarding your child(ren)'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](mailto: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**

