



STUDY INFORMATION SHEET FOR HEALTH PROFESSIONALS

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

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

What is the aim of the study?

We want to find out how health care professionals 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 will do this using an online survey to answer the following questions:

1. How do clinicians assess the bladder and bowel health of children and young people with neurodisability, their continence capabilities, and readiness for toilet training? Which clinicians are involved in assessments?
2. Which interventions do clinicians use or recommend to improve continence for children and young people with neurodisability? How are these individualised, evaluated and/or audited? Which clinicians are recommending, delivering or evaluating interventions?

Why do we want to hear from you?

We would like to hear from a range of health professionals that have experience of working with children and young people with toileting difficulties, and/or special educational needs and disability. This can include but is not exclusive to; nurses, paediatricians, psychiatrists, occupational therapists, physiotherapists, speech and language therapists, and surgeons.

We will monitor the types of participants that have responded to ensure that we gather a range of responses and experiences. As a professional working in health services in England, we would really like to hear your views.

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 from 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. 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 study?

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 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 their survey responses. Survey questions will mostly require a tick box responses, and will be focussed on the methods you have used to help children and young people with special educational needs or disability with toileting. You will not be required to provide specific patient information. We will also collect data regarding your professional role or speciality, your gender and the region in which you work. No other personal data will be recorded.

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 the study, 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**

