

# Improving toileting for children and young people with special educational needs and disability

## What is this study about?



This research study is about managing toileting for children and young people with a disability.

It may be more difficult for a child with special educational needs and disability to learn to go to the toilet by themselves. We want to find out how health professionals and families assess the capability for a young person to be toilet trained, and what kind of methods they use to help them manage toileting.

## Why have I been asked to take part?



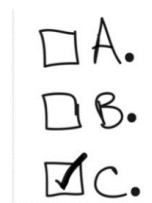
We are asking young people up to the age of 25 years for their views and experiences about how they manage toileting and the support they have received. We are doing this in an online survey.

We want to hear from young people with a range of different conditions, for example, Cerebral Palsy, Down Syndrome or Autism.

## What would I have to do?



Young people up to the age of 25, are invited to answer questions in an online survey. They may ask someone to help them. The questions will be short and mostly involve tick box answers.



## What happens to the information I give?

The information the young person provides to us will only be looked at by researchers. We do not share any personal contact details with any other organisation.

## Do I have to take part?



No. Taking part is the young person's choice. If they choose not to take part it will not affect their care in any way.

They can also change their mind at any point. So if they complete the survey, but change their mind later, let us know and we can remove all the information they have given us.

## How will I find out the results of the study?

We can send a summary of the results at the end of the study. This will be in 2020. We can do this if the young person gives us permission to keep their contact details. This option is on the survey.

## Will I be asked to take part in any further research?

No, we will not contact them again for any further research.

## Who is doing this study?

The study is run by the PenCRU research team at the University of Exeter Medical School. The National Institute of Health Research (NIHR), part of the NHS, have provided money for the University of Exeter to run the research.

## Can I talk to someone before taking part?



Yes. If you or the young person would like to talk about taking part, you can contact the ICoN team by phone or email;

Telephone – 01392 722923

Email – [icon@exeter.ac.uk](mailto:icon@exeter.ac.uk)



## What if I have concerns or a complaint?

If the young person has any concerns about the study you can contact:

- Helen Eke at the ICoN study on the contact details above
- Or Ruth Garside who is the Chair of the University Ethics Committee who make sure the research is carried out correctly. Ruth can be contacted at [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk).