ICoN
improving continence for children and young people with neurodisability

Improving toileting for children and young people with special education needs and disabilities (SEND) – ICoN study

Photo by Ben White on Unsplash

A protocol is an essential part of a research project. It describes in detail how the research will be carried out. This is important so that people can check whether what was done in a study was what the researchers said they would do, making the research more trustworthy. This "plain language protocol summary" aims to explain the steps that we will go through to carry out this research. It will help anyone interested in our research to understand the project without all the details necessary in a full protocol.

Where will this information be available?

This plain language protocol summary (along with the published academic protocol) is on our research group website, on the National Institute for Health Research (NIHR) website, and on the International Prospective Register for Systematic Reviews (CRD42018100572).

Why is this research project important?

Learning to manage going to the toilet is an important stage in growing up. This is known as becoming continent.

Being continent involves:

- knowing you need to go,
- delaying until an appropriate time and place can be found and getting to that place
- weeing and/or pooing in the appropriate place;
- cleaning up afterwards, washing hands, redressing and returning to the previous activity.

Children and young people with SEND (special educational needs and disabilities) may be slower to learn the skills they need to become continent, or they may need extra help. Professionals recommend various different actions to improve continence. These actions are known as interventions.

Many children and young people with SEND can become continent using appropriate interventions. These may include toilet training programmes, products and special equipment, communication aids, medicines and surgery. It is uncertain which are the best ways to assess and treat children and young people with SEND who are not yet continent.

In this research study, we want to find out for children and young people, aged 25 and under, with SEND –

i) How effective the interventions available are at improving continence,

ii) Whether the interventions used to improve continence are good value for money,

iii) Which factors influence how well these interventions improve continence and how easy they are to deliver, and

iv) What children and young people, their families, their healthcare professionals and others involved in their care feel about delivering and receiving such interventions.

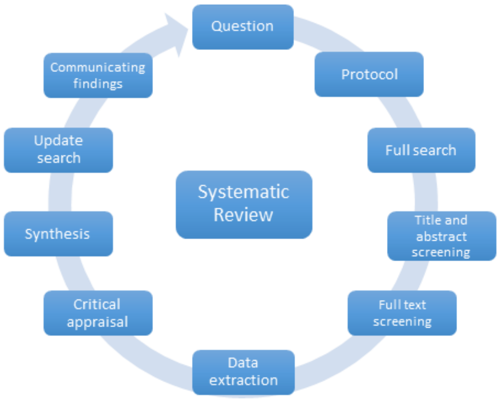
Who is carrying out the research?

The core team of researchers are from the University of Exeter Medical School. They are helped by specialists in bladder and bowel care for children and young people. We have also have a wider group of health professionals with an interest in this topic (our Professional Advisory Group) and a group of families and carers (our Family Faculty working group) to provide further advice.

How will the research be done?

The research we are doing is called a 'systematic review'. This brings together all the best research evidence that has already been done on continence in children and young people aged 25 and under with SEND. The stages of a systematic review are described below and illustrated in Figure 1.

FIGURE 1. STAGES OF A SYSTEMATIC REVIEW



The protocol is the plan for how the systematic review will be carried out, and is produced before the research begins. This plain language protocol summary will be part of the research protocol.

Full search - Our information specialist (Morwenna) will identify the words that relate to continence problems in children and young people with SEND with help from the Professional Advisory Group and Family Faculty working group. These words will then be combined to search in databases of published studies to find relevant evidence. These studies will then enter the 'title and abstract screening' phase of the project.

Title and abstract screening - The research team (Harriet, Jo, Morwenna, Becky and Helen) will read all the titles and abstracts (summaries) of the studies found in the full search to decide whether they are relevant to our project or not, and compare answers. Each title and abstract will be read by at least two people so that relevant studies are less likely to be missed. The full papers of the included studies will then be obtained

Full text screening - we will read the whole paper for each of the studies that looks like it might be relevant. The decision about whether it is relevant will be made using the same process as for screening the title and summary – two people will make a decision about whether a study should be included in the review, then compare answers and discuss any disagreements. A third researcher will help make a final decision if the first two cannot agree.

We may also ask members of the Professional Advisory Group and Family Faculty public involvement working group if we are unsure.

Data extraction - involves recording information from all the included papers and studies. We will design a form to do this in a logical way. This makes it easier to compare studies, to see similarities and differences, and makes it more straightforward to find important information. Harriet will extract the data and one of the other members of the team (Morwenna, Jo, Becky or Helen) will check that all the data has been extracted correctly.

Critical appraisal is a process of judging the quality of the evidence in each included study. Each study will be examined by assessing how the research was done, and what methods were used. We will use recognised checklists judged to be good by other systematic reviewers. Judging the quality of each study will help us prioritise evidence from the most robust (best) studies.

Synthesis - is bringing together the findings from all the studies. We expect to find:

- studies in which the effects of interventions to improve continence have been measured (quantitative research) and
- studies in which researchers have interviewed children and young people with SEND, their families, their healthcare professionals and others involved in their care about their experiences (qualitative research).

Findings will be described, compared, and – where it makes sense to do so – combined.

Through this process, we will integrate evidence for interventions that are being used and make recommendations for research and clinical practice that will improve continence for children and young people with neurodisability.

Our clinical team, members of the Professional Advisory Group and the Family Faculty will play a central role in this stage of the research, drawing on their experiences of caring for children and young people with SEND and continence problems. We will hold workshops to discuss the synthesis and the interpretation of the findings.

THE TEAM IN ACTION: INTRODUCTORY WORKSHOP

Communicating findings

Once the research is finished we will write about the study for publication. We will work with our clinical team, the Professional Advisory Group and the Family Faculty to identify the main messages, who needs to know about those messages and the best way to reach them. We will hold a special event to share the findings with people who work with children and young people with SEND, families who have disabled children, relevant charities and NHS commissioners (the NHS commissioners are the people who decide what services are going to be available from the NHS).

THE TEAM AT THE UNIVERSITY OF EXETER

(From L to R: Jo Thompson Coon, June Rogers, Harriet Hunt, Nicholas Madden, Morwenna Rogers, Katherine Fitzpatrick, Sue Ball, Davinia Richardson, Claire Lindsay, Rob Anderson, Julia Melluish, Helen Eke, Stuart Logan, Annette Allinson, Eve Hutton, Anne Wright, Juliette Randall, Chris Morris)

How to get in touch and find out more

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FUNDED BY NIHR | National Institute for Health Research