

CHESS Study: Further information for interested sites

WHAT HAPPENS IN THE TRIAL, IF WE GET INVOLVED?

The teams taking part will be allocated, at random, to either current practice or CHESS, so that half of the teams will provide CHESS and half will provide their usual self-care support. We will measure children's self-care, health, and quality of life, and parents' health and wellbeing. We will also measure how much parents and services spend on accessing and providing support. We will compare measures at 12 months to see whether CHESS improves self-care. To help the trial run smoothly, we will talk to parents and therapists at some of the sites using interviews and focus groups. We will closely monitor whether CHESS has any potential risks or harms for children or parents. If your team is allocated to current practice then you will carry on as you are now. If your team is allocated to CHESS then your team will receive a half-day training session locally, and be supported to use the materials included in CHESS with families. Your service will lead the decisions about how you use the materials; the research team will provide you support and help you figure things out. Your organisation will get compensation for your time for the actual trial participation for both the CHESS and usual care teams.

CAN INDIVIDUAL THERAPISTS AND FAMIILIES OPT-OUT?

Therapists and families are free to opt out of providing data to the research team, and this will not affect them in any way. In the teams randomly allocated to CHESS therapists and families have agency in the changes that will be implemented.

HOW MUCH WORK WILL THIS BE?

We need one key contact (a 'Principal Investigator') who will receive training and support from us and from the clinical trials unit. The Principal Investigator's time (around two hours per week) will be compensated at their usual hourly rate, back to their organisation. For the teams allocated to current care, there will be a training session on trial procedures. For the teams allocated to CHESS, the therapists will receive a half-day of training, delivered locally, and will be asked to use some of their current practice sessions with children differently. Using sessions differently will initially require some planning and effort, but this should settle after the initial change.

WHO WILL CARRY OUT THE RESEARCH?

Team includes researchers from Newcastle, Sheffield, Exeter, London and Bangor; the Clinical Trials Unit in Aberdeen; and a parent of a young person with neurodisability. We have substantial expertise in large trials in the NHS and social care, as well as expertise in self-care support for children with neurodisability.

HOW WILL THE RESULTS BE SHARED?

We will share the results through NHS and social care networks, academic journals, national and international conferences, the British Academy of Childhood Disability, professional bodies, national charities, parent carer forums, social media, and press releases. We will develop creative and meaningful ways to share the results with children.

HOW WILL PARENTS AND CHILDREN BE INVOLVED?

We will work with PenCRU (Peninsula Childhood Disability Research Unit), who are experts in involving families with disabled children in research through their Family Faculty group. We will also create new links with community groups specialising in supporting families with children under five years of age.

WHAT'S IN IT FOR US?

You will be part of the biggest formal evaluation of paediatric therapy interventions that has taken place in the UK. You will learn about what works best for children's and families, and how you can best help young children with neurodisability to grow their independence. Most importantly, you are helping families to answer a question that is really important to them

If you are an NHS site and interested in learning more about potentially becoming part of the CHESS trial, please contact us at CHESS@abdn.ac.uk