

# The THINC Study: Therapy Interventions for Children with neurodisability

## STUDY INFORMATION SHEET FOR PARENTS

You are being invited to take part in the THINC study. Please read the information below to help you decide whether or not you want to take part.

### What is the background to the study?

For children with neurodisabilities, the topic of ‘therapy interventions’ has been identified as a top research priority. Interventions include physiotherapy, occupational therapy and speech and language therapy. To help decide on the most appropriate research to carry out, the National Institute for Health Research (NIHR) has asked researchers at the University of York to undertake a preliminary study.

### What is the purpose of the study?

NIHR want to understand more about current practice with regard to therapy interventions for children with neurodisabilities, and to learn more about what needs to be researched. They have asked that the study focuses particularly on non-progressive neurodisabilities where physical/motor function is a predominant impairment.

### How is the research being carried out?

Researchers from the study team will be talking with a wide range of people involved with children with neurodisabilities, including therapy practitioners/assistants based in various settings and organisations, community paediatricians and paediatric neurologists, parents, children and young people. We are using focus group interviews to find out about the views and experiences of parents.

### What will taking part in a focus group discussion involve?

Taking part will involve joining an informal discussion group of up to eight parents who also have a child with a neurodisability. Key topics we would like to explore are:

- ❖ The sorts of therapy your children receive and the purpose of this therapy.
- ❖ The ways in which therapy improves the lives of your children and by what means this is achieved.
- ❖ Your experiences as ‘co-therapists’ and views with respect to assuming that role.
- ❖ Your views on the top priorities for future research.

We expect the meeting will last about an hour. With all parents’ permission, we would like to audio record the discussion. You will receive a £20 ‘thank you’ gift voucher for taking part and will be reimbursed for any travelling expenses you may incur.

### **Do I have to take part?**

Please be assured, you do not have to take part in the THINC study. Taking part, or not taking part, will not affect any support from any services your child receives. If you do decide to take part, you are free to withdraw from the study at any time, without giving a reason. The information you have provided up to that point will be retained.

### **How do I let you know whether I want to take part in the THINC study?**

Please indicate on the enclosed Study Response Form whether or not you would like to take part in a focus group with other parents to talk about your experiences and share your views. Please return the form to the research team using the pre-paid envelope provided.

### **Are there any benefits or disadvantages to take part in the THINC study?**

There are no direct benefits to you if you take part in the THINC study. However, taking part will contribute to helping understand current practice and research needs with regard to children with neurodisability.

### **A note about confidentiality**

All information will be kept strictly confidential in line with the Data Protection Act. All the information we collect during the study will be stored securely and will only be seen and used by the research team. We will not use your name, or include information which identifies you, in any of our study reports. Your involvement in the study and the information you provide will be kept confidential unless you tell us something that indicates someone is at risk of significant harm. We would discuss this with you before telling anyone else.

### **What will happen to the results of the study?**

When the THINC study is complete we will write a report for NIHR. All those who participated in the research will be informed of the key findings. The report and analysis will also be used to deliver presentations at professional/research conferences and to write up journal articles for publication.

### **The research team**

The THINC study is being carried out by researchers from the Social Policy Research Unit at the University of York. The research study is being led by Professor Bryony Beresford. The researchers carrying out the focus groups will be [REDACTED] and [REDACTED]. If you would like to speak to someone about this research, please contact one of the researchers below:

[REDACTED]  
[REDACTED]

**Social Policy Research Unit, University of York, Heslington, York YO105DD**

This study has been approved by the Ethics Committee of the Department for Social Policy and Social Work at the University of York.

# CONSENT FORM - PARENTS: The THINC study

## Therapy Interventions for Children with neurodisability: a scoping study of current practice and perceived research need

Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in a focus group discussion for the study. After the discussion the research team will send you a copy of this form for you to keep. ***For each statement, please put your initials in the box to indicate you agree with it:***

I have read and understood the Study Information Sheet (Version 2 – 25.07.16), and understand what taking part in a focus group discussion for the THINC Study involves.

I understand that my participation is entirely voluntary, and that I am free to withdraw from the research at any time without giving a reason.

I give my permission for the focus group discussion to be recorded using a digital voice recorder.

I understand that the results from the THINC Study will be used to write a report to NIHR who have commissioned this research.

I understand that all the information collected will be treated as confidential and that I will not be identifiable in anything written or presented about this research.

**I confirm I would like to take part in an interview with a member of the THINC study research team.**

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Name:** \_\_\_\_\_