

Invitation to take part in an interview for the THINC project

Dear [Name]

The National Institute for Health Research (NIHR) has recently commissioned a small scoping study of current practice in delivering therapy interventions to children with non-progressive neurodisabilities and perceived research needs on this topic from the perspectives of therapists, other practitioners and families. The purpose of the THINC project is to support and inform NIHR decision-making on the commissioning of future research. An information sheet about the project is attached. We would like to invite you to take part in this project.

We are contacting you because you have been identified as someone who is actively involved in research into therapy interventions for children with neurodisabilities. We would like to invite you to take part in a telephone interview from late July with a member of the research team. This will take place at a time convenient to you and will last around an hour. If you agree, we would like to audio-record the interview. The sort of topics we would like to cover in the interview include:

- Areas of research interest and reasons for focus on these topics
- The current state of evidence re intervention effectiveness
- What makes up a therapeutic intervention and what are the 'active ingredients' of the intervention.
- Outcomes and outcome measurement
- Research priorities, in terms of: intervention, population and service delivery issues
- The challenges and barriers to evaluating interventions, and potential solutions.

If you are interested in taking part in this project, please let me know by responding to this email or by telephone. Once we're in touch, I can explain a bit more about the project and make arrangements for an interview. If we have not heard from you in a week or so, a member of the research team will get in touch with you to check if you are interested in taking part. Your participation will provide us with valuable information that will help us to understand the key issues facing researchers in this field and to identify the high-priority research areas, so we hope you decide to take part.

Yours sincerely

(on behalf of the Research Team)

STUDY OVERVIEW



The THINC Project

Therapy Interventions for Children with neurodisability: A scoping study of current practice and perceived research needs

Background

A recent James Lind Alliance Childhood Disability Research Priority Setting Partnership conducted with respect to children with neurodisabilities (2015) identified ‘therapy interventions’ as the top research priority. Such interventions include physiotherapy, occupational therapy and speech and language therapy. A number of gaps in evidence were identified: the appropriate age to begin therapy, the choice of intervention approach, and the intensity and duration of the intervention. These accord with the findings of several recent reviews which have also called for research to determine optimal dosing and intensity of therapies in order to maximise outcomes, accurately cost services and offer family-friendly, achievable interventions.

To inform decisions regarding the future commissioning of research, NIHR are undertaking some preliminary work in this area. The THINC study has been commissioned by NIHR for two reasons. First, they want to understand more about current practice with respect to delivering therapy interventions to children with neurodisabilities. Second, they want to learn more about perceived research needs from the perspectives of therapists, other practitioners and families. NIHR have asked that the study focuses particularly on non-progressive neurodisabilities where physical/motor function is a predominant impairment.

Aims

- ❖ To identify current techniques, practices and approaches to delivering therapy interventions for children with non-progressive neurodisability where physical/motor function is a predominant impairment.
- ❖ To describe the factors which influence decisions regarding the approach taken and the delivery of the intervention.
- ❖ To investigate how professionals and families conceive therapy outcomes, and meaningfulness of 'participation' as a therapy outcome.
- ❖ To seek views of therapy practitioners, parents and children regarding the 'active ingredients' of a therapy session, and the other features of the session which may impact on effectiveness.
- ❖ To map NHS health professionals' parents' and children's views of the evidence gaps and research priorities.

Method

Group and individual interviews and an electronic survey will be used as appropriate to ascertain the views and experiences of different stakeholder groups:

- representatives of national professional bodies;
- therapy practitioners and assistant practitioners (based in a range of settings and organisations);
- clinical academics/researchers;
- community paediatricians and paediatric neurologists;
- parents;
- children and young people.

Study duration: The project started in May 2016 and will run for 10 months.

Project outputs

A report will be submitted to NIHR and individuals who have participated in the study will receive a summary of project findings.

The project team

The project is located within NIHR's Evidence Synthesis Centres at the Centre for Reviews and Dissemination at the University of York. It is being carried out by the University's Social Policy Research Unit (SPRU): a unit with a longstanding track record for health and care services research and user involvement in research. The research team is being led by Professor Bryony Beresford.

The THINC study

Therapy Interventions for Children with neurodisability: A scoping study of current practice and perceived research needs

Study Information Sheet for Professionals

What is the background to the study?

A recent James Lind Alliance Childhood Disability Research Priority Setting Partnership conducted with respect to children with neurodisabilities (2015) found that 'therapy interventions' was a top research priority. Such interventions include physiotherapy, occupational therapy and speech and language therapy. The Priority Setting Partnership identified a number of gaps in evidence including: the appropriate age to begin therapy, the choice of intervention approach, and the intensity and duration of the intervention. These accord with the findings of several recent reviews which have also called for research to determine optimal dosing and intensity of therapies in order to maximise outcomes, accurately cost services and offer family-friendly, achievable interventions.

What is the purpose of the study?

The THINC study has been commissioned by NIHR for two reasons. First, they want to understand more about current practice with respect to delivering therapy interventions to children with neurodisability. Second, they want to learn more about perceived research needs from the perspectives of therapists and other practitioners, clinical practitioners and families. NIHR 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?

The study is consulting with a wide range of stakeholders. Broad topic areas being covered in our work with different stakeholder groups will include:

- Current techniques, practices and approaches to therapy interventions with children with non-progressive neurodisability of which physical/motor function is the predominant impairment.
- Factors which influence decisions regarding the approach taken and the delivery of the intervention.
- Therapy outcomes and the meaningfulness of 'participation' as a therapy outcome.
- The 'active ingredients' in therapy and other features of the session that are responsible for effecting change (e.g. staff skills/qualification; physical environment; parent involvement).
- The evidence gaps for therapy services and research priorities.
- Challenges and barriers to conducting research in this area.

We are using focus group interviews to gain the views and experiences of children and young people, parents and from therapy practitioners/assistants based in various settings and organisations. Individual telephone interviews are being used to involve clinical academics and researchers as well as representatives from national/professional bodies. Finally, community paediatricians and paediatric neurologists will be invited to participate in the study via an online survey.

Are there any benefits or disadvantages to taking part in the THINC study?

There are no direct benefits to you if you take part in this research study. However, taking part will contribute to helping to inform and shape commissioning decisions about future research in the area of therapy interventions for children and young people with neurodisability. We hope you will decide to participate in the study but there is no obligation for you to do so.

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 located within NIHR's Evidence Synthesis Centres at the Centre for Reviews and Dissemination at the University of York. It is being carried out by the university's Social Policy Research Unit (SPRU): a unit with a longstanding track record for health and care services research and user involvement in research. The research team comprises the Chief Investigator, Professor Bryony Beresford; Researchers Jane Maddison and Susan Clarke; and Study Administrator Teresa Frank. For further information about any aspect of the research, please contact:



Social Policy Research Unit, University of York, Heslington, York, YO10 5DD

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

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

Consent Form for Professionals: The THINC study

Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in an interview for the study. After the interview 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 (Professionals - Version 1: 21.06.16.) and understand what taking part in an interview 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. If I withdraw from the study, I understand that any data collected before I withdraw will still be used.

I understand that, with my permission, the interview will 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 to inform the commissioning of research in the area of therapeutic interventions for children with non-progressive neurodisability.

I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written or presented about this research.

I understand that the information I provide is subject to the Data Protection Act.

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

Signature: _____ **Date:** _____

Name: _____