

Topic guide for individual interviews with Clinical Academics and Researchers

“What therapy interventions are, could and should be offered to children with neurodisability to help improve participation outcomes?”

Preliminaries (3 mins)

- *Thanks for agreeing to take part*
- *Outline overall research*
- *Explain your own research background*
- *Explain confidentiality/ how going to use information*
- *Explain would like to record with consent*
- *Ask if any questions*
- *Check time they have available*
- *Ask for formal consent (briefly record consent)*

Introduction (5 mins)

Your paid post(s):

- what positions do you hold currently & what is your role within these posts?
(check whether involved in any teaching)
- any relevant previous (but recent) paid posts?

Your involvement in research: *(excluding your own undergraduate/ Masters research, ie we're interested in your work as PI &/or member of research team and/or delivering intervention under research)*

- Can you tell me a bit about your particular research interest and the topic of your current project(s)?
- What research qualifications do you have?

Your involvement with national professional therapy body *[The College of Occupational Therapists / The Chartered Society of Physiotherapy / The Royal College of Speech & Language Therapists]:*

- Are you are a member of any specialist interest groups?
- Do you have any voluntary roles within this body?

[Text for researcher to introduce the scoping study]

Now to remind you about the focus of this research. NIHR have commissioned this research for two reasons. Firstly to find out about current approaches and practices in delivering therapy interventions for children with non-progressive neurodisabilities, and secondly to explore perceived research needs from the perspectives of different stakeholder groups. They have asked that the study concentrates particularly on non-progressive neurological conditions that predominantly impact on motor function and motor skills, with varying levels of impairment from mild to severe. (For example, cerebral palsy, spina bifida, acquired brain injury, developmental coordination disorder, as well as those not with a formal diagnosis). The findings from this piece of work will be used by NIHR to inform decisions about what research they commission on this topic.

Current state of evidence re intervention effectiveness (10 mins)

The James Lind Research Priority Setting Exercise for Children with ND identified evidence on the effectiveness of therapy interventions as the top research priority. Does this surprise you?

We're interested to know your overall view on how good current research evidence is on the effectiveness of therapy interventions for children with ND. *[Note to researcher: wait for response before using prompts below]*

- Choice of intervention approach to manage presenting clinical need or functional impairment (including evidence which compares different approaches)
- Diagnostic groups *[include those without a diagnosis]*
- Those with simple vs complex needs
- The age of the child
- The setting
- Who delivers the intervention (therapists, their assistants, teaching assistants at school, parents)

Views on why this is the state of the evidence: eg imbalance / patchy evidence, why certain groups / types of impairment/ types of intervention approach have received more or less attention.

If there are areas of strength/good evidence, to what extent do you think this informs current practice by therapy teams?

What (other) factors currently inform or guide the approach taken by a therapist to the management of a case? *[Note to researcher: we might possibly expect them to raise issues here around the quality/resources available to NHS services; 'inherited practice']*.

- Are any therapeutic approaches now discouraged or no longer funded? If so, why?

Outcomes and outcome measurement (10 min)

In working with a child with ND, what key outcomes would you say therapists are working towards?

NIHR has identified 'participation' as a core outcome for research evaluating therapy interventions? What do you understand by this term?

[Note for researcher: the domains captured by this concept include participation in: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community, social and civic life].

Do you think participation is meaningful or relevant as a therapy outcome? If not, why not? If yes, why?

Do you think this concept of participation is routinely operationalised in practice? *[If involved in teaching:]* and in student training? If used in practice, is it shared with families?

To what extent is it possible to monitor this sort of outcome?

How therapy interventions make a difference (10 mins)

Can you describe to me your view of how a therapy impacts on outcomes for a child with ND?

Where the therapist is working directly with the child, what is it within a therapy session that is making a difference to the child's outcomes (eg...is it just the 'intervention' (eg massage, working on a particular task with the child, teaching the child a skill), or is it something else (eg the interaction/quality of the therapist-child relationship)?

- Do you think it's possible to capture and measure these different components of a therapy intervention? What are the challenges / barriers?
- Are you aware of any studies that demonstrate how this can be done?

Similarly, in terms of the provision of equipment (for example, a standing frame, postural sleep system, communication boards, hoists etc.), is it possible to break this down into different components (or the so-called 'active' ingredients) which, together, contribute to impact on the child's outcomes?

- Do you think it's possible to capture and measure these different components of a therapy intervention? What are the challenges / barriers?
- Are you aware of any studies that demonstrate how this can be done?

The challenges to evaluating interventions (10 mins).

The findings from this study, will contribute to and inform decision-making by NIHR regarding the commissioning of new research in this area. What messages would you want to convey to them about the challenges associated with evaluating research on this topic?

[Note to researcher: we are looking for spontaneous responses but this list may be useful if people are reticent or if you need to give some examples to illustrate the meaning of the question]:

- Are there issues around research capacity?
- Are there issues around practitioners/therapists accepting the need for research and engaging with it?
- To what extent does a standard 'protocol' exist in the delivery of a particular therapeutic intervention? And to what extent are therapists consistent in the way they deliver such interventions? Any ethical issues?
- Are there issues related to research designs: are randomised control trials possible? What would be the comparison?
- Are there issues regarding implementing research into routine/everyday practice?
- Are there issues regarding parents/families' willingness to participate in research?

Research priorities (5 mins)

You have already talked about the areas which you believe are key gaps in research evidence. Before we conclude the interview, can I ask you to specify your top research priorities in terms of developing the evidence base on therapy interventions for children with ND (and specifically, non-progressive ND which predominantly impacts on motor

function and functional skills)? This might be with respect to the management of a particular functional impairment, or diagnostic group, or age group or be concerned with the evaluation of a particular intervention.

- For each research priority identified, ask:
 - What (more) do we need to understand about this topic or issue?
 - *[If not covered above]* What are the key research questions?
 - *[If relevant/appropriate]* Are there any promising approaches in this area?

Anything else? (5 mins)

Is there anything else you would like to add before we close?

CLOSE (2 mins)

- Thank respondent
- Confirm confidentiality
- Explain that once the project has finished (in Spring 2017), we will send all those who participated in the research a summary of the key findings.

- In the study we'd like to include some small group discussions with practising therapists. Is this something you might be able to help us with, for example, by mentioning this request to any local service team leads who you know? We could then follow that up. If you might be able to help us in this way, perhaps I could ring you in a few days to see how we might take that forward?

Topic guide for individual interviews with Representatives of National Professional Bodies

Preamble

- *Thanks for agreeing to take part & check time available*
- *Brief recap of study*
- *Explain SPRU's expertise re scoping study (we are not therapists)*
- *Explain confidentiality/ how going to use information*
- *Any questions?*
- *Check OK to record consent & interview? TURN ON RECORDER*
- *Record Consent Form responses*

About you and your professional body

Your paid post(s):

- what positions do you hold currently & what is your role within these posts?
(if relevant, check whether involved in any teaching)
- any relevant previous (but recent) paid posts?

Any involvement in research?

- Research topics? When (current? recent?)? Extent of involvement?
- Any research qualifications?

[for reps in a voluntary role] Your work with your professional body

[The College of Occupational Therapists / The Chartered Society of Physiotherapy / The Royal College of Speech & Language Therapists]:

- including any specialist interest groups?

Your professional body

- Membership: do all practising therapists have to be a member? *Any sub-group for therapists working with children with ND?*
- What are its key functions?
- What are the current key challenges for [prof body]?

[Text for researcher to introduce the scoping study]

A reminder about the study. NIHR have commissioned the study for two reasons. Firstly to find out about current approaches and practice in delivering therapy interventions for children up to school leaving age who have non-progressive neurodisabilities, and secondly to explore perceived research needs from the perspectives of different stakeholder groups. NIHR has asked that the study focuses on **children with non-progressive neurological conditions that predominantly impact on motor function and motor skills, with varying levels of impairment from mild to severe**. Examples include cerebral palsy, spina bifida, acquired brain injury, developmental coordination disorder, as well as children without a formal diagnosis. The findings will be used by NIHR to inform decisions about research to commission on this topic.

Reminder: in this interview we include questions about the views of your professional body, as you have been nominated to speak on its behalf.

Current therapy practice

Are there distinct approaches/schools of thought re therapy for children with ND? *If so:*
what are these?

- does the [prof body] endorse or discourage any specific approaches? *Why (not)?*
- have there been any significant shifts in preferred approach over the past ten or so years? *If so, what has driven these?*
- are there any promising new/emerging approaches in this country or elsewhere?

Do any standard 'protocols'/ guidance exist in the delivery of interventions for children with ND? If so, role of professional body in:

- *developing protocols?*
- *assessing/ designating competence of therapists?*
- *addressing any adherence issues?*

Can you give me an overview of the different settings in which therapy for children with ND is delivered? (*eg specialist assessment centres, clinic, school, home*) and by whom other than therapists themselves? (*eg therapy assistants, special school TAs, parents*)

- Are there any particular groups of children with ND who would use therapists in private practice? In what ways might this therapy be different?

The current state of evidence on the effectiveness of interventions

Does it surprise [the prof body] that evidence on the effectiveness of therapy interventions has emerged as a top research priority? *Explain.*

Does [prof body] agree with this focus of attention?

What is the [prof body] view on how good current research evidence is on the effectiveness of therapy interventions for children with ND? In what areas is the evidence strongest?

Weakest? *Possible prompts:*

- *Choice of approach to manage presenting clinical need or functional impairment (including evidence which compares different approaches)*
- *Diagnostic groups [include those without a diagnosis]*
- *Those with simple vs complex needs*
- *The age of the child*
- *The setting*
- *Who delivers the intervention (therapists, their assistants, teaching assistants at school, parents)*

Views on why this is the state of the evidence: eg imbalance / patchy evidence, why certain groups / types of impairment/ types of intervention approach have received more or less attention.

What does [prof body] see as the challenges to implementing EBP? What can be done to overcome these? *Possible prompts re challenges:*

- *lack of research understanding/acceptance by therapists?*
- *lack of influence of prof body's work on therapy teams?*

Building and promoting evidence-based practice

What is the role of [professional body] with regard to building the evidence base on the effectiveness of therapy interventions? What is the organisation currently doing in this respect? Is there work going on to build research capacity?

Does [prof body] actively promote evidence-based practice? If so, how? *Possible prompts:*

- *encouraging therapists to be more research-aware (eg influencing content of accredited student programmes; training events for qualified therapists)?*
- *access to relevant information: collating/ disseminating research findings*

To what extent does evidence inform current practice by therapy teams? What other factors do therapists use to inform or guide their management of a case [*eg resources available to NHS services; 'inherited practice'*]?

Key therapy outcomes

What does [prof body] see as the key outcomes therapists are working towards with children with ND? *Any priorities?*

NIHR has identified 'participation' as a core outcome for research evaluating therapy interventions. [*Note for researcher: Participation domains include - learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community, social and civic life*].

- What does the [prof body] understand by this term?
- Does [prof body] regard participation as a meaningful/ relevant therapy outcome for this group of children? *Why (not)?*
- Is the concept of participation as an outcome routinely operationalised by therapists in practice? Shared with families?
- Does the [prof body] issue any advice on monitoring participation outcomes?

Current work being led by [prof body] on outcomes and/or their measurement?

Challenges/barriers to research

The findings from this study will contribute to and inform decision-making by NIHR regarding the commissioning of new research in this area for children with ND. What messages would [professional body] want to convey to NIHR about the likely challenges in researching this area? *Possible prompts:*

- *Any issues around therapists accepting the need for research and engaging with it?*
- *Any inconsistency in interpretation/delivery of any 'standard' interventions?*
- *Any ethical issues?*
- *Any research design issues: eg are randomised control trials possible? What would be the control?*
- *Are there issues regarding parents'/families' willingness to participate in research?*

Does [prof body] see any potential risks/negative aspects for the profession from new research in this area?

Advice on key research priorities to develop the evidence base

What are [prof body's] top research priorities in terms of developing the evidence base on therapy interventions for children with ND (and specifically, non-progressive ND which predominantly impacts on motor function and functional skills)?

This might be with respect to the management of a particular functional impairment, or diagnostic group, or age group or be concerned with the evaluation of a particular intervention.

For each research priority identified, ask:

- What (more) do we need to understand about this topic or issue?
- *[If not covered above]* What are the key research questions?

Anything else?

Is there anything else you would like to add?

CLOSE

- Thank respondent and confirm confidentiality
- We'll send all participants a summary of the key findings after the project ends (Spring 2017)
- ASK: *[say who else we are interviewing, if anyone]* in your view is there anyone else in the prof body we should ask for interview to as to be sure we cover both the **research** and **practice** perspective?
- ASK: to help our general understanding, is it possible for the research team to have a copy of the Professional Handbook?

Topic guide for individual interviews with paediatricians

“What therapy interventions are, could and should be offered to children with neurodisability to help improve participation outcomes?”

Preliminaries (3 mins)

- Thanks for agreeing to take part
- Outline overall research
- Explain your own research background
- Explain confidentiality/ how going to use information
- Explain would like to record with consent
- Ask if any questions
- Check time they have available
- Ask for formal consent (briefly record consent)

Introduction (5 mins)

Your NHS post(s):

- what positions do you hold currently & what is your role within these posts?
- are there particular groups of children (in terms of diagnosis, age) you care for?

Check re info we have re national / advisory roles (see info in invitation email)

Your involvement in research

- Have you had any involvement in research – that may be as an investigator or as a clinician delivering the intervention under investigation?
- [If appropriate] Do you have any research qualifications?

[Text for researcher to introduce the scoping study]

Now to remind you about the focus of this research. NIHR have commissioned this research for two reasons. Firstly to find out about current approaches and practices in delivering therapy interventions for children with non-progressive neurodisabilities, and secondly to explore perceived research needs from the perspectives of different stakeholder groups. They have asked that the study concentrates particularly on non-progressive neurological conditions that predominantly impact on motor function and motor skills, with varying levels of impairment from mild to severe. (For example, cerebral palsy, spina bifida, acquired brain injury, developmental coordination disorder, as well as those not with a formal diagnosis). The findings from this piece of work will be used by NIHR to inform decisions about what research they commission on this topic.

The role/place of therapies within the care and management of children with neurodisabilities on interviewee’s caseload (5-8 mins)

In terms of the children under your care, how do you/your team/clinic work with the different therapists?

What is your view on the role they play in supporting/achieving positive outcomes for children with ND,

What outcomes do you particularly identify as being the role/priority of the therapists?
Check: outcomes for the child and whether any outcomes for the parent.

Participation as a therapy outcome (5-8 mins)

NIHR has identified 'participation' as a core outcome for research evaluating therapy interventions? What do you understand by this term?

[Note for researcher: the domains captured by this concept include participation in: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community, social and civic life].

Do you think participation is meaningful or relevant as a therapy outcome? If not, why not? If yes, why?

Is it a concept which is used/relevant to your involvement with the care of a child? If not, why not? If yes, why?

Current state of evidence re therapy interventions for children with ND (10 mins)

The James Lind Research Priority Setting Exercise for Children with ND identified evidence on the effectiveness of therapy interventions as the top research priority. Does this surprise you?

Views on why this is the state of the evidence: eg imbalance / patchy evidence, why certain groups / types of impairment/ types of intervention approach have received more or less attention.

If there are areas of strength/good evidence, to what extent do you think this informs current practice by therapy teams **and/or** the way services are organised or delivered?

In your view, what are/might be the barriers/challenges to implementing research evidence regarding therapy interventions for children with ND?

.....and have you observed/experienced anything which has supported evidence-informed practice or service organisation?

The challenges to evaluating therapy interventions (5-10 mins).

The findings from this study, will contribute to and inform decision-making by NIHR regarding the commissioning of new research in this area. What messages would you want to convey to them about the challenges associated with evaluating research on this topic?

[Note to researcher: we are looking for spontaneous responses but this list may be useful if people are reticent or if you need to give some examples to illustrate the meaning of the question]:

- Are there issues around research capacity?
- Are there issues around practitioners/therapists accepting the need for research and engaging with it?
- To what extent does a standard 'protocol' exist in the delivery of a particular therapeutic intervention? And to what extent are therapists consistent in the way they deliver such interventions? Any ethical issues?
- Are there issues related to research designs: are randomised control trials possible? What would be the comparison?
- Are there issues regarding implementing research into routine/everyday practice?
- Are there issues regarding parents/families' willingness to participate in research?

Research priorities (5 mins)

You have already talked about the areas which you believe are key gaps in research evidence. Before we conclude the interview, can I ask you to specify your top research priorities in terms of developing the evidence base on therapy interventions for children with ND (and specifically, non-progressive ND which predominantly impacts on motor function and functional skills)? This might be with respect to:

- the management of a particular functional impairment
 - diagnostic group, or age group
 - the evaluation of a particular intervention.
 - the way therapy is organised and delivered.
- For each research priority identified, ask:
 - What (more) do we need to understand about this topic or issue?
 - *[If not covered above]* What are the key research questions?
 - *[If relevant/appropriate]* Are there any promising approaches in this area?

Anything else? (2 mins)

Is there anything else you would like to add before we close?

CLOSE (2 mins)

- Thank respondent
- Confirm confidentiality
- Explain that once the project has finished (in Spring 2017), we will send all those who participated in the research a summary of the key findings.

Topic guide for individual interviews with practitioners

“What therapy interventions are, could and should be offered to children with neurodisability to help improve participation outcomes?”

Preliminaries

- *Thanks for agreeing to take part & check time available*
- *Brief recap of study*
- *Explain SPRU’s expertise re scoping study (we are not therapists)*
- *Explain confidentiality/ how going to use information*
- *Any questions?*
- *Check OK to record consent & interview? TURN ON RECORDER*
- *Record Consent Form responses*

Introduction

May we start by your telling me what post(s) you hold and your job role(s)?

Could you briefly explain your areas of skills and expertise as a practitioner (*Note: this could be particular approaches, diagnostic groups, types of children, etc*)

Can I just check some details with you:

- How long have you been qualified as a PT?
- Are you a member of any specialist interest groups within [The College of Occupational Therapists / The Chartered Society of Physiotherapy / The Royal College of Speech & Language Therapists]?
- Do you have any voluntary roles within this body?
- Have you had any involvement in research – that may be as an investigator or as a therapist delivering the intervention under investigation?
- *[If appropriate]* Do you have any research qualifications?
- Does your hospital/insitution offer placements to therapy trainees?

[Text for researcher to introduce the scoping study]

Now to remind you about the focus of this scoping study. NIHR have commissioned the study for two reasons. Firstly to find out about current approaches and practice in delivering therapy interventions for children up to school leaving age who have non-progressive neurodisabilities, and secondly to explore perceived research needs from the perspectives of different stakeholder groups. They have asked that the study concentrates particularly on **children with non-progressive neurological conditions that predominantly impact on motor function and motor skills, with varying levels of impairment from mild to severe**. Examples include cerebral palsy, spina bifida, acquired brain injury, developmental coordination disorder, as well as children without a formal diagnosis. The findings will be used by NIHR to inform decisions about research to commission on this topic.

Overview of current practice

[In terms of the children you work with....] What are the key presenting symptoms/areas of need for therapy interventions for this group of children?

- Are any types of need/symptoms prioritised over others? (eg diagnostic group; simple v complex needs)

What factors influence your/a therapist's decisions about what particular therapeutic approach to take with an individual child with a neurodisability presenting with motor impairments?

- Factors about the child /presenting need (eg diagnostic group; simple v complex needs; age)
- 'Menu' of existing approaches:
 - Do core therapy interventions exist (if so, for which areas of need)?
 - Are there distinct approaches/schools of thought? Are any of these approaches overlapping or competing with one another? If so, can you summarise any current debate about this?
 - Have there been any significant shifts in approach over the past ten or so years? If so, what has driven these?
 - Are any therapeutic approaches now discouraged or no longer funded? If so, why?
 - Are there currently any new/emerging approaches in this country or elsewhere?
 - To what extent do standard 'protocols' (or guidance or consensus statements) exist in the delivery of particular therapeutic interventions? If/where these exist, to what extent do therapists adhere to them? Is there any assessment/ designation of competence? Who develops these protocols/guidances?
 - What are the barriers to adhering to such protocols/guidances?
- Research factors [if appropriate] :
 - To what extent would you say current practice is evidence-based / informed by research evidence?
 - What sort of profile do research findings have in your department? In what ways can you/your team be updated on research findings? What are the challenges regarding implementing evidence-based practice?
 - To what extent do you get professional guidance on the latest research/research findings?
 - Do you use your professional body for this?
 - Do you view your professional body as a potential source of support in terms of information, advice and training?
- Any other factors: what other factors influence a therapist's intervention decision? (eg resources)

Can you give me an overview of the different settings in which therapy for children with ND is delivered, and by whom? (*eg therapy assistants, special school TAs, parents*)

- Are there any particular groups of children with ND who would use therapists in private practice? In what ways might this therapy be different?

Therapy Outcomes

In working with a child with ND, what key outcomes would you say you/your staff team are working towards?

- Do you/your staff team prioritise clinical needs/presenting symptoms in any way?
- Are you getting pressure from service management/commissioners about which outcomes your department should prioritise?
- Who would you involve in deciding what should be prioritised – both with respect to an individual child and/or the approach/ethos of a service?
- To what extent are these outcomes made explicit to children and families?

NIHR has identified ‘participation’ as a core outcome for research evaluating therapy interventions. What do you understand by this term?

[Note for researcher: Participation domains include - learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community, social and civic life].

Do you think participation is meaningful/ relevant as a therapy outcome? Why (not)?

Do you think this concept of participation is routinely operationalised by therapists in practice? To what extent is it possible to monitor this sort of outcome?

- Has your staff team been trained in participation outcomes and their measurement?
- How is this training delivered?

The active ingredients of therapy interventions & their measurement

You identified earlier some of the key outcomes which therapists are working towards..., **how** in your view, or by what mechanisms, does a therapy intervention impact on outcomes for a child with ND?

In your view, what is it within a therapy session that is making a difference to the child’s outcomes? (*This might include both ‘technical’ components of the intervention itself (eg massage, working on a particular task with the child, teaching the child a skill) and additional components eg the interaction/quality of the therapist-child relationship*)

- Do you think it’s possible to capture and measure the different components of a therapy intervention? What are the challenges / barriers?

Similarly, in terms of the provision of equipment, is it possible to break this down into different components (the so-called ‘active’ ingredients) which, together, contribute to impact on the child’s outcomes?

- Do you think it’s possible to capture and measure these different components of a therapy intervention? What are the challenges / barriers?

Current state of evidence re intervention effectiveness

Does it surprise you that the effectiveness of therapy interventions for children with ND emerged as the top priority from The James Lind Research Priority-Setting Exercise?

[If appropriate] Views on why this is the state of the evidence: eg imbalance / patchy evidence, why certain groups / types of impairment/ types of intervention approach have received more or less attention.

The challenges to researching and evaluating therapy interventions

The findings from this study will contribute to and inform decision-making by NIHR regarding the commissioning of new research in this area. What messages would you want to convey to them about the likely challenges in researching this topic? *[Note to researcher: we are looking for spontaneous responses but this list may be useful if people are reticent or if you need to give some examples to illustrate the meaning of the question]:*

- Are there issues around research capacity?
- Any issues around therapists accepting the need for research and engaging with it?
- Any inconsistency in interpretation/delivery of any 'standard' interventions?
- Any ethical issues?
- Any research design issues: eg. are randomised control trials possible? What would be the comparison?
- Are there issues regarding parents'/families' willingness to participate in research?

Research priorities

Finally, in terms of having a better evidence base for your own/your service's practices and approach to caring for children with ND (and specifically, non-progressive ND which predominantly impacts on motor function and functional skills), what would be your priorities for future research? *[Note for researcher: if reticent, think back to any research/practice problems raised earlier and refer to these]*

- This might be with respect to the management of a particular functional impairment, or diagnostic group, or age group or be concerned with the evaluation of a particular intervention.
- For each research priority identified, ask:
 - What (more) do we need to understand about this topic or issue?
 - *[If not covered above]* What are the key research questions?
 - *[If relevant]* Are there any promising approaches in this area?

Anything else?

Is there anything else you would like to add?

CLOSE

- Thank respondent
- Confirm confidentiality
- Explain that once the project has finished (in Spring 2017), we will send all those who participated in the research a summary of the key findings.
- For first two interviews only, ask participants how they felt the interview went and whether they would tweak it in any way.