

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 1. Introduction

We invite you to take part in this questionnaire as part of the research study: 'Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?'

This study is being done by a research team led by Dr Jill Cadwgan from Newcastle University. You are invited because you are a health professional working with children with cerebral palsy who may use a standing frame.

[You may have already taken part in this study by completing the first questionnaire, or attending a focus group.](#)

*(Please click on the blue writing if you would like to visit our website and review the results summaries so far.)*

We have used information from these earlier stages to think about research ideas. We would now like your opinion on these ideas, by completing a questionnaire.

We want to gain as many people's views as possible. Some questions are very simple. Others may require a little more thought. Apart from confirming your consent, only 4 short questions require an answer, but please fill in as much as you can – your ideas are very important to us.

You may not directly benefit from this research. Your participation will inform future research, and hopefully will improve postural management for children with cerebral palsy. Your answers will be used to produce a report but individual comments will remain anonymous/confidential.

You do not need to give us any contact information. At the end of the questionnaire we will ask if you would like to be contacted regarding further research into standing frames. Any contact information provided will be separated from your responses and kept securely by the research team. It will **ONLY** be used to contact you about further research.

Please **ONLY** input your contact details on the questionnaire if you agree to future contact from the research team and **ONLY** on the page indicated.

Taking part is your choice and you can withdraw at any time.

If you have questions about this project or if you have a research-related problem, you may contact:

**Dr Jill Cadwgan:** [REDACTED]

**Jane Goodwin:** [REDACTED]

**By clicking on “I agree” to the questionnaire on the next page you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.**

Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.



# understanding frames

## Understanding Frames Survey 2: Health professionals

### 2. Consent

\* 1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey.

- I agree to continue and complete the questionnaire
- I do not wish to continue with the questionnaire

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 3. About you

\* 2. My experience of using standing frames for children with cerebral palsy is based on my role as:

- Parent/carer
- Classroom Support/Teacher
- Physiotherapist
- Occupational Therapist
- Therapy Assistant or Technical Instructor
- Paediatrician in Neurodisability
- Paediatric Neurologist
- General Paediatrician
- Orthopaedic Surgeon
- Other (please specify)

*This questionnaire is designed for health professionals who work with children with cerebral palsy who use standing frames.*

There are alternative questionnaires for parents and educational professionals who work with children with cerebral palsy who use standing frames.

*Please click on the links below if you wish to complete any of the other questionnaires.*

[Click here for the link to the questionnaire for parents.](#)

[Click here for the link to the questionnaire for education professionals.](#)

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 4. About you

#### 3. I work with:

- Children (any age from 0 to 18yrs) who use standing frames – but do not prescribe standing frames.
- Children (any age from 0 to 18yrs) and prescribe standing frames.

4. Please tell us the first two letters or numbers at the start of the postcode where you work. If you work across different locations, please use the location of your base employer.

#### 5. Please indicate your current working environments (please tick all that apply)

- In-patient (hospital)
- Outpatients (hospital based clinics)
- Child development or family centre clinic
- Community - home
- Community – **special** education centre (pre-school and/or school)
- Community – **mainstream** education centre (pre-school and/or school)
- Other (please specify)

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 5. Research regarding Standing Frames for children with cerebral palsy.

Standing frames are used for children with cerebral palsy. They may improve how the body grows and develops, what the child can do standing up, and help the child to join in, but there is little evidence that they do. There is also little evidence for whether they cause harm.

The purpose of the "Understanding Frames" project is to think about and design research studies about standing frames for children with cerebral palsy. We believe, as do many professionals, parents and the NHS research organisations, that further research is required to understand the benefits and disadvantages of using standing frames for children with cerebral palsy. However, this does not mean that all children, parents, health and education workers would agree. Therefore, we are asking you the important questions below.

So far we have explored research ideas through focus groups and interviews with people who have experience with standing frames. This has included children who use/d standing frames, parents, educational professionals, physiotherapists, occupational therapists, paediatricians, orthopaedic surgeons, and standing frame engineers.

If a study was to look at how the body grows and develops (body structure), outcomes such as joint range of movement, hip dislocation, preventing need for further surgery, or improvement in bone mineral density would need to be studied over several years and would need a large epidemiological population-based approach. This type of study is unlikely to be feasible or funded.

Therefore, we propose short- to medium-term studies looking at the more immediate benefits that we might see in children with cerebral palsy, such as activity, participation, bowel function, respiratory function, pain, communication, and upper limb function. These studies would need to be in a controlled environment with adequate support to ensure delivery of the intervention. The comparison group would either be involved in a cross-over design or a delayed start design.

Firstly we want to ask you some general questions about research into standing frames; then we will show you a study example and ask you some more specific questions.



# understanding frames

## Understanding Frames Survey 2: Health professionals

### 6. Importance of a research study

6. Do you think standing frames should be used for children with cerebral palsy who are unable to stand independently (GMFCS III-V)?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

7. Do you personally believe that standing frames are clinically effective?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

\* 8. Do you think that further research into the use of standing frames for children with cerebral palsy is necessary?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

If YES or I DON'T KNOW, please proceed to question 10, page 10.  
If NO, please proceed to question 9, page 9.



# understanding frames



## Understanding Frames Survey 2: Health professionals

### 7. General questions regarding research about standing frames.

- \* 9. You have indicated in the question above that you are unsure OR do not believe that there is a need for research about the use of standing frames for children with cerebral palsy.

The remainder of this questionnaire explains more about research, and asks questions about taking part in research. You would be welcome to continue with the questionnaire, and we would value your ideas about research, even if you don't believe in it yourself.

However, if you would rather finish the questionnaire now please indicate below.

- I would like to continue the questionnaire.
- I would like to stop the questionnaire now.

If you would like to continue the questionnaire, please turn to the next page and continue answering.

If you would like to stop the questionnaire, please turn to page 22.

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 8. General questions regarding research about standing frames.

10. Would you agree to take part in a research study which might require you to change your practice during the research?

- Yes
- No
- I don't know

11. If future well designed research provided good quality evidence that standing frames were not beneficial, would you agree for children with cerebral palsy to stop using them?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

12. Which age group of children with cerebral palsy do you think would be most suitable for a standing frames research study?

(Please tick all that apply)

- 0 – 5 years (pre-school and reception class)
- 6 – 10 years (primary school age)
- 11- 15 years (secondary school age)
- 16 – 18 years (sixth form or college students)
- No age groups are suitable for a standing frames research study

Please can you explain why you chose your answer above:

13. Many therapeutic interventions that are used for children with cerebral palsy have little research evidence. Please indicate the extent to which you agree or disagree with the statement below:

	<b>1 (Strongly disagree)</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5 (Strongly agree)</b>
A research study of standing frames could provide valuable information about how to investigate other similar interventions with little evidence.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 9. Research study example

The example provided here is to show how a research study works in general terms. This is not a study that is planned yet, but may help you to consider your answers to questions.

We will be using your answers to the questions below to carefully design research studies; with interested children, parents and experts from across the UK who work with children with cerebral palsy.

#### *Aims and Hypotheses*

##### Aims:

- To determine if standing frames can improve participation in children with cerebral palsy.
- To determine if standing frames can improve aspects of body function in children with cerebral palsy.

##### Hypotheses

- Standing frames can increase participation in children with cerebral palsy. For example:
  - o Joining in with activities in school or home
  - o Developing relationships with other children

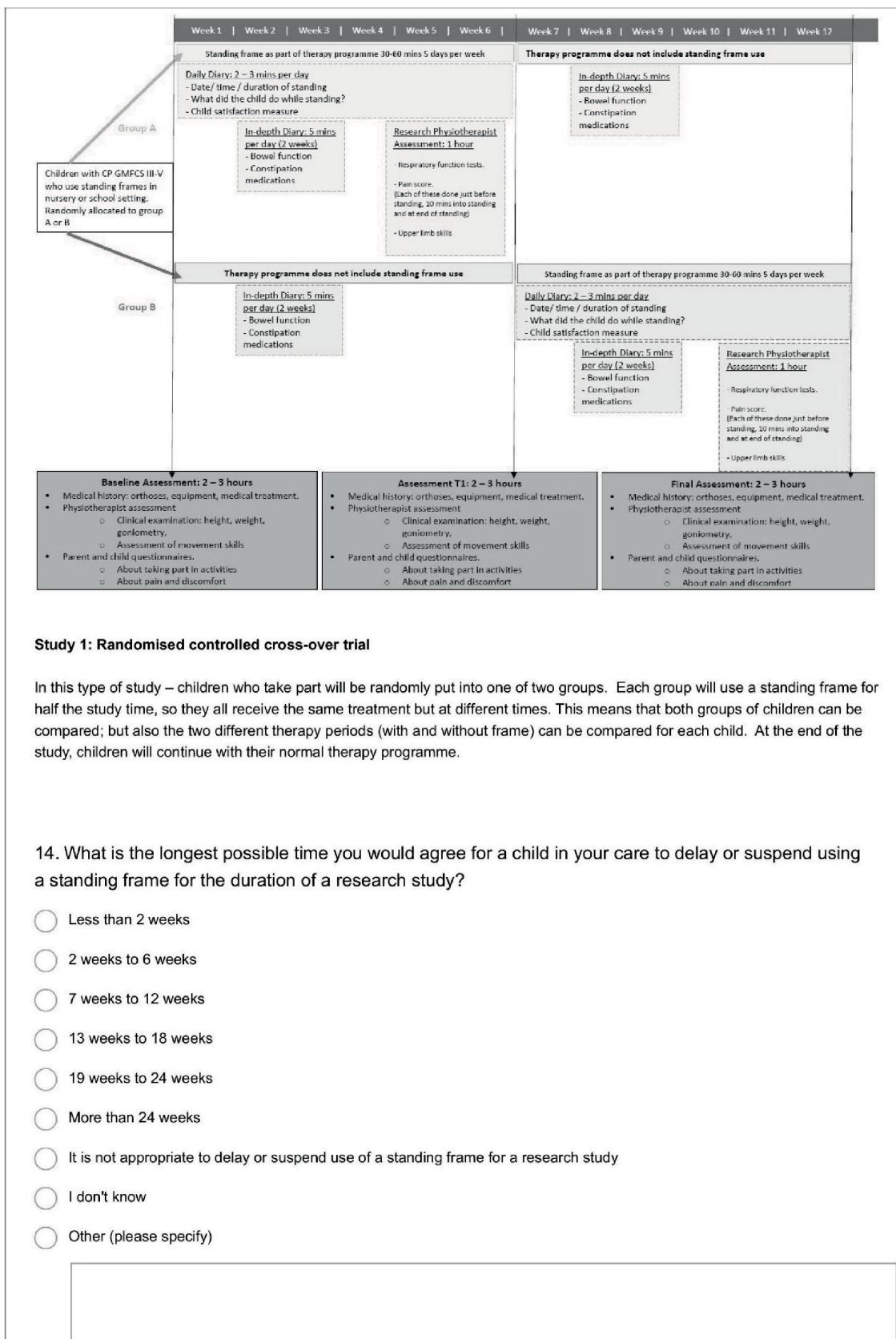
- They may also provide some improvement in body function including:

- o Gross motor function
- o Bowel function
- o Respiratory Function
- o Upper limb function
- o Reduce pain

In this study, the possible benefits or disadvantages of using a standing frame can be seen in a short period of time.

All children would receive their usual treatments but would also have access to a research physiotherapist to support their standing frame use and carry out assessments for the research study. The children may have more detailed assessment by the research physiotherapist than they would normally have in routine care, which will take time, but should be beneficial to their overall care.

The flowchart below explains how a child would be involved in the study. If you are having trouble viewing it, [please click here to view it in PDF form.](#)



**Study 1: Randomised controlled cross-over trial**

In this type of study – children who take part will be randomly put into one of two groups. Each group will use a standing frame for half the study time, so they all receive the same treatment but at different times. This means that both groups of children can be compared; but also the two different therapy periods (with and without frame) can be compared for each child. At the end of the study, children will continue with their normal therapy programme.

14. What is the longest possible time you would agree for a child in your care to delay or suspend using a standing frame for the duration of a research study?

- Less than 2 weeks
- 2 weeks to 6 weeks
- 7 weeks to 12 weeks
- 13 weeks to 18 weeks
- 19 weeks to 24 weeks
- More than 24 weeks
- It is not appropriate to delay or suspend use of a standing frame for a research study
- I don't know
- Other (please specify)

# understanding frames



## Understanding Frames Survey 2: Health professionals

10. Is it possible to do this research?

15. If there was a standing frame research study in your place of work, who would be appropriate to recruit participants? Please select any that apply:

- Physiotherapist
- Occupational Therapist
- Therapy Assistant or Technical Instructor
- Paediatrician
- Orthopaedic Surgeon
- I don't know
- Other (please specify)

16. In principle, would you be willing to recruit participants to this study?

(This would mean identifying children who may be able to take part, discussing the study with them and their parents, and contacting the research team.)

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

17. In reality, could you recruit participants to this study?

(This would mean identifying children who may be able to take part; discussing the study with them and their parents and contacting the research team.)

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

18. Would you have time to recruit participants to a research study in your current role?

- Yes
- No
- I don't know

\* 19. Do you have relevant clinical training which allows you to consent participants to a research study?  
E.g. Good Clinical Practice (GCP) training

- Yes
- No
- I don't know

# understanding frames



## Understanding Frames Survey 2: Health professionals

11. Is it possible to do this research?

20. Would you be prepared to do relevant training e.g. Good Clinical Practice (GCP) training in order to consent children to a standing frame research study?

- Yes
- No
- I don't know

**If YES, please continue to question 21, page 19.  
If NO or I DON'T KNOW, please turn to the next page and  
continue answering from question 20.**





# understanding frames

## Understanding Frames Survey 2: Health professionals

12. Is it possible to do this research?

21. Would you be prepared for a research physiotherapist to be involved in the child's care for the duration of the study? This would mean they are involved in discussion about the child's therapy goals with relation to the use of standing frames, and carrying out assessments for outcome measures.

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 13. Acceptability of research

Before designing this questionnaire, we consulted standing frame users including children who use/d standing frames, parents, educational professionals, physiotherapists, occupational therapists, paediatricians, orthopaedic surgeons, and standing frame engineers.

They came up with a list (below) of reasons that might make a study difficult to do. It may be possible to overcome some of these difficulties, but we need to know which are the most important.

22. From the list of difficulties below, please tick *anythat would stop you recruiting children for a research study about standing frames*:

(please tick all that apply)

#### Practical reasons

- A research study would be too resource intensive to be feasible.
- A research study would be too labour intensive to be feasible.
- Children with CP are individual. It is impossible to research the impact of standing frames.
- Some benefits of standing frames cannot be measured (e.g., "feeling tall")
- It will be too difficult to get children and parents to participate in a research study.
- It will be too difficult to get professionals to participate in a research study.
- I would not have the support in my workplace to take part in a research study.
- Other (please specify)

23. From the list of difficulties below, please tick *anythat would stop you recruiting children for a research study about standing frames*:

(please tick all that apply)

Ethical or personal choice reasons:

- It is not right to withdraw standing frame treatment for a research study.
- I would be worried that stopping standing frame use for a research study would cause harm to children that could not be reversed.
- Participating in a research study about standing frames may affect the child's quality of life negatively.
- The child's choice, rather than a research study should dictate their standing frame use.
- Other (please specify)

24. If a multi-centre research study was to take place, I would want children in my region to have the opportunity to take part in the research:

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

# understanding frames



## Understanding Frames Survey 2: Health professionals

14. Thank you

**Thank you very much for taking the time to complete this questionnaire. Your contribution is highly valued. If you would like more information regarding this research, please contact us:**

**Dr Jill Cadwgan:** [REDACTED]

**Jane Goodwin:** [REDACTED]

**or go to our study webpage/Twitter where we will report on the progress of the study and upload results as they become available.**

**<https://research.ncl.ac.uk/understandingframes/>**  
**[@UnderstandFrame](#)**

**The next stage of the Understanding Frames project is to design robust studies to examine standing frame use in children with cerebral palsy. We would like interested people to join us to make sure we are doing the best job possible.**

25. Please tick any of the below that you may be prepared to do:

- Take part in email discussions regarding research designs
- Attend meetings to design research studies
- Become a participating site in a multi-centre study
- Other (please specify)

26. If you have ticked any of the above or are interested in receiving any further information, please put your contact details below:

<b>Name</b>	<input type="text"/>
<b>Address</b>	<input type="text"/>
<b>Address 2</b>	<input type="text"/>
<b>City/Town</b>	<input type="text"/>
<b>Postal Code</b>	<input type="text"/>
<b>Country</b>	<input type="text"/>
<b>Email Address</b>	<input type="text"/>
<b>Phone Number</b>	<input type="text"/>

27. As you have completed the survey, you are entitled to a £10 gift voucher. Please insert a personal code word below. To claim this voucher, please contact Jane Goodwin: XXXXXXXXXX

*You will need to remember your code word in order to collect the voucher.*

If you have an alternative role working with or caring for children with cerebral palsy who use standing frames, we would be delighted if you completed our other survey/s:

[Click here for the link to the questionnaire for parents.](#)

[Click here for the link to the questionnaire for education professionals.](#)