



understanding frames

Understanding Frames Survey 2: Parents and carers

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 [REDACTED] from Newcastle University. You are invited because you are a parent/carer of a child 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. Your child may have participated in an interview.](#)

(Please click on the blue writing above if you would like to visit the study website and see summaries of the results 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 this second 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. Taking part will help us plan 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.

At the end of the questionnaire we will ask if you would like to be contacted regarding further research into standing frames. You do not need to give us any contact information if you do not wish to. 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:

[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.

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2. Consent

*** 1. I am over 18 years of age and have read and understood the introduction page and I agree to completing this questionnaire.**

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

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3. About you

2. You have been invited to do this questionnaire as you are a parent/carer of a child with cerebral palsy who may use or have used a standing frame.

Some parents and carers also work with children who have cerebral palsy and use standing frames. Please tick below to indicate which role this is:

(Please tick all that apply)

- Classroom Support/Teacher
- Physiotherapist
- Occupational Therapist
- Therapy assistant or technical instructor
- Paediatrician in Neurodisability
- Paediatric Neurologist
- General Paediatrician
- Orthopaedic Surgeon
- None of the above
- Other (please specify)

If you do have a professional role working with children with cerebral palsy who use standing frames, ***please continue to complete this survey from the point of view of a parent/carer.***

However, you would be welcome to click the website link below to complete our survey for professionals who work with children with cerebral palsy also.

[Click here for the link to the questionnaire for education or school workers.](#)

[Click here for the link to the questionnaire for health-care workers.](#)

3. Please tell us the first two letters or numbers at the start of your postcode.

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4. About your child

4. Please tell us the age (in years) of your child(ren) who uses (or has previously used) a standing frame.

If you have more than one child who uses a standing frame, please put the ages of all your children.

Child 1	<input type="text"/>
Child 2	<input type="text"/>
Child 3	<input type="text"/>
Child 4	<input type="text"/>

If you have more than one child who uses a standing frame, please answer this questionnaire for *the eldest child*. If you would like you can repeat the questionnaire, answering for your other child(ren) afterwards.

5. My child has cerebral palsy

- Yes
- No
- I don't know

If no or I don't know, please write in the box below if your child has another named diagnosis.

6. My child attends a school/ nursery that is:

- Mainstream (state funded)
- Special school (state funded)
- Mainstream (private)
- Special school (private/other e.g. charity funding)
- Mixed mainstream and special school environment
- Other (please specify)

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5. Research about standing frame use 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 has not been much research to prove that they do.

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 and parents would agree. Therefore, we are asking you the important questions below.

So far we have talked to many people who use standing frames: including young people who use/d standing frames, parents, educational and health professionals. From these discussions we have thought about possible research studies.

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

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6. General questions regarding research about standing frames.

7. Should standing frames be used for children with cerebral palsy?

- Yes
- No
- I don't know

Why?

* 8. Do you think we should do further research about standing frames for children with cerebral palsy?

- 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 11.
If NO, please proceed to question 9, page 10.

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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 24.

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8. General questions regarding research about standing frames.

10. Would you allow your child to take part in a research study about standing frames if you and your child were given the right support?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

11. Which age group of children with cerebral palsy 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 or comment if you have other ideas.

*** 12. Does your child currently use a standing frame?**

- Yes
- No, they have never used a standing frame
- No, but they previously used a standing frame

If YES, please continue to question 13,
page 13.
If NO, please continue to question 16,
page 14.

9. For parents whose children currently use a standing frame

13. Would you be prepared to change how your child uses their standing frame for the purpose of a research study?

- Yes
- No
- I don't know

14. What is the longest possible time you would allow your child to have a break in using their standing frame for a research study?

- Less than 2 weeks
- 2 weeks – 6 weeks
- 7 weeks - 12 weeks
- 13 weeks - 18 weeks
- 19 weeks - 24 weeks
- More than 24 weeks
- I would not let them stop using their standing frame
- I don't know

15. If future research showed that standing frames were not useful (e.g., don't prevent contractures, don't increase enjoyment of participation in group activities with peers, etc.), would you be prepared for your child to stop using their standing frame?

- Yes
- No
- I don't know

After answering this question, please turn to page 16.

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10. For parents whose children do not currently use a standing frame

16. You have indicated in the question above that your child does not currently use a standing frame, but has used one previously, OR has never used a standing frame.

The remainder of this questionnaire asks questions about standing frames research, which may require you think back to when your child was using a standing frame and/or imagine that your child uses a standing frame. You would be welcome to continue with the questionnaire, and we would value your ideas.

Please indicate below how you would like to proceed.

- I would like to finish the questionnaire
- I would like to stop the questionnaire now

If you would like to finish the questionnaire, please turn the page and continue answering from question 17.
If you would like to stop the questionnaire, please turn to page 24.

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11. For parents whose children do not currently use a standing frame

17. If a standing frame was recommended for your child, how long would you be prepared to delay using it for a research study?

- Less than 2 weeks
- 2 weeks – 6 weeks
- 7 weeks - 12 weeks
- 13 weeks - 18 weeks
- 19 weeks - 24 weeks
- More than 24 weeks
- I wouldn't delay standing frame use
- I don't know

12. Research study example: Do standing frames help children with cerebral palsy?

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.* In the example, children would have access to a research physiotherapist to support their therapy programme.

We will be using your answers to the questions below to carefully design research studies.

What is this study about?

This study would see how children with cerebral palsy who use a standing frame benefit from using it compared to children with cerebral palsy who do not use a standing frame.

How would my child take part?

If you decided to take part then your child would be allocated by chance to one of two groups:

Group one: Physiotherapy programme for 12 weeks. For the first 6 weeks they would use standing frame for five days each week, then they would not use a standing frame for 6 weeks.

Group two: Physiotherapy programme for 12 weeks. For the first 6 weeks they would not use a standing frame, then for 6 weeks they would use a standing frame for five days each week.

What would we have to do?

- 1) Attend 3 assessments with a research physiotherapist. These may take 2-3 hours in total to complete, but your child will have time to rest.
- 2) Complete a diary of when your child uses their frame. (We will ask school staff to do this if your child stands in their frame in the classroom). This would take 5-10 minutes each day.
- 3) Complete another diary of your child's bowel habits and medications for 2 weeks whilst your child is using their standing frame and 2 weeks when they are not. This would take 5-10 minutes each day.
- 4) Agree for the research physiotherapist to visit your child, when they are using their frame, to measure their breathing, reported pain (or lack of), how they use their arms, and how they take part in the activities, in their standing frame and in supported sitting. This would take approximately one hour.

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13. Is it possible to do this research?

18. If a standing frames research study was taking place, would you be comfortable with a health-worker asking you if you and your child would like to take part?

The health worker would explain the research study and what would be involved for you and your child. It would not mean that you and your child would have to take part. Taking part would be entirely your choice and if you decided not to take part your child's care would be exactly the same as they would normally be offered.

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

19. Would you be happy for your child to take part regardless of which group they were in?

- Group one: For the first 6 weeks they would use standing frame for five days each week, then they would not use a standing frame for 6 weeks.

- Group two: For the first 6 weeks they would not use a standing frame, then for 6 weeks they would use a standing frame for five days each week.

- Yes
- No
- I don't know

Please give a reason for your answer:

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14. Study assessments: Diary

20. How easy would it be:

1 (It would be impossible)

2

3

4

5 (It would be easy)

to keep note of when your child uses their standing frame at home every day during the study (approx. 5-10 mins per day)?

to keep a detailed diary of your child's bowel function, medications and pain daily for 2 weeks during the study (approx. 5-10 mins per day)?

21. How would you prefer to keep a diary of your child's standing frame use?

- Electronic (e.g., iPad, phone, computer)
- Hard copy (e.g., a book)
- Either electronic or hard copy
- I would not keep a diary
- Other (please specify)

22. Please indicate if you would be prepared for you and your child to do any of these: (tick all that apply)

- Provide medical information for the purpose of research (it would remain anonymous)
- Complete questionnaires with your child about their participation and activities
- Allow your child to have detailed assessment by the research physiotherapist (measuring height, weight, and joints and movement skills)
- I would not agree to any of these.

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15. Study assessments

23. In considering how we may design research studies, we need to consider the best location for assessments.

Please indicate below where you would agree for the assessments to take place at: (please tick all that apply)

- School
- Home
- A clinic or centre where my child receives care usually
- A different clinic or hospital to where my child usually visits.

Please can you explain why you chose your answer above:

24. During the research study example above, you and your child would need to attend up to 3 detailed assessments across the 12 weeks. The assessments could take up to 3 hours but we would ensure that your child would be given rest breaks and could stop at any time if they were tired. Travel expenses would be provided if needed.

How many of this type of assessment would you and your child would be able to do for a research study?

- More than 3 assessments
- 3 assessments
- 2 assessments
- 1 assessment
- No assessments

Please can you explain why you chose your answer above:

25. Would you agree to a research physiotherapist visiting your child for a shorter (maximum 1 hour) assessment (e.g., breathing, looking at the way they use their hands and asking them about pain) both in and out of their standing frame during the research study? You would be welcome to be there at the same time.

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

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16. Reasons why people may not want to take part in research

In our discussions with people who use standing frames, they came up with a list of reasons (below) that might make a study difficult to do.

It may be possible to overcome some of these difficulties, but we need to know if any of them would stop you and your child taking part in this research.

26. From the list of difficulties below, please tick any *that would stop you allowing your child to participate in a research study*:

(Please tick all that apply)

Practical reasons

- Children and young people with cerebral palsy are individual. This makes it impossible to research what standing frames do.
- Some benefits of standing frames cannot be measured (e.g., "feeling tall")
- There would not be enough space for the standing frame at home.
- There would not be enough space for the standing frame at school.
- None of these apply
- Other (please specify. E.g., I would not have time to take part, the school could not fit it into the daily routine, there are not enough school staff, there are not enough adults at home to help)

27. From the list of difficulties below, please tick any *that would stop you allowing your child to participate in a research study*:

(Please tick all that apply)

Family or personal choice

- It is not right to stop standing frame treatment even for a short time for a research study.
- Standing frames are often recommended near to the time a child is diagnosed with cerebral palsy. It would be too much to ask parents to take part in research so soon after the diagnosis.
- I would be worried that stopping standing frame use for a research study would cause harm to my child that could not be reversed.
- I would feel guilty if I could not do everything I needed to do for the research study.
- It is an emotionally significant moment to see my child stand, it is more important to me than a research study.
- Taking part in a research study about standing frames may affect my child's quality of life negatively.
- My child's choice whether to use a standing frame is more important than a research study.
- None of these apply
- Other

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17. Thank you

Thank you very much for taking the time to complete this questionnaire. Your ideas are very important to us. If you would like more information about this research, please contact us:



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](#)

After this survey, we will be using your feedback to carefully design research studies.

The research study examples in this questionnaire are not final. We would like interested people to join us to make sure we are doing the best job possible.

28. 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
- Other (please specify)