

understanding frames



Understanding Frames Survey 2: Educational 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?' [REDACTED]

This study is being done by a research team led by Dr Jill Cadwgan from Newcastle University. You are invited because you are an education professional who works 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. 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 second questionnaire. *(If you would like to visit the study website and review our findings so far, click on the blue writing above.)*

We want 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 3 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 questionnaire 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 [REDACTED]

Dr Jill Cadwgan: [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.



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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

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3. About you

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

- Classroom Support/Teacher
- Health professional
- Parent
- Other (please specify)

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

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

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

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



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4. About you

3. Please tell us 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.

4. I work with children in the following age groups:

(Please tick all that apply)

Nursery / Preschool

Primary school

Secondary school

Post 16 / College

5. I work in a school/ nursery that is:

Mainstream (state funded)

Special school (state funded)

Mainstream (private)

Special school (private/other e.g. charity funding)

Mainstream school with additional resource for SEND

Other (please specify)

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5. Research about 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 has not been much previous 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, parents and education workers would agree. Therefore, we are asking you the important questions below.

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

If a study was to look at how the body grows and develops (for example: maintaining the range of movement at joints and muscles, preventing hip dislocation, preventing need for surgery, or making bones stronger) then the research would need to take several years and would need many hundreds of young people to take part. This type of study may not be possible; for example, there may be difficulties obtaining funding or recruiting participants.

Shorter term studies looking at the more immediate things that we might see in children with cerebral palsy, such as taking part in activities and how the body works (bowel function, breathing, pain, and using their arms) are more likely to be possible. These studies would need to be carefully organised with support to make sure that all the children and families in the study get the planned treatment.

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.



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6. General questions regarding research about standing frames.

6. Should standing frames be used for children with cerebral palsy who are unable to stand independently?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

* 7. Do you think further research is needed 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 NO or I DON'T KNOW, please proceed to QUESTION 8.

If YES, please proceed to QUESTION 9, SECTION 8.

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7. General questions regarding research about standing frames.

- * 8. 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 keep answering.

If you would like to stop the questionnaire, please turn to SECTION 12.



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8. General questions regarding research about standing frames.

9. Would you be comfortable with changing how a child uses a standing frame for a research study?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

10. 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 comfortable with your students stopping using them?

- 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?

- 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:

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9. 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.

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.

In the example, children would have access to a research physiotherapist to support their therapy programme. The children would have more detailed assessments by the research physiotherapist than they would normally have in routine care, which would take time, but it may help you to understand their abilities more.

What is this study about?

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

How would a child will take part?

With parent consent a child would be allocated by chance to one of two groups:

Group one: Physiotherapy programme for 12 weeks. For the first 6 weeks the child would use a standing frame for five days each week (at school or home), then they would not use standing frame for 6 weeks.

Group two: Physiotherapy programme for 12 weeks. For the first 6 weeks the child would not use a standing frame, then they would use a standing frame for five days each week (at school or home).

What would we have to do?

- 1) Complete a daily diary to record when the child uses their frame at school. This would take 5-10 minutes each day.
- 2) Jointly with parents complete a more detailed diary of a child's bowel habits and medications for 2 weeks whilst the child is using their standing frame and when they are not (if this is relevant during the school day). This would take 5-10 minutes each day.
- 3) When the child is using their standing frame a research physiotherapist will visit them on one occasion, to measure their breathing, reported pain, how they use their arms, and the way they take part in the activities they choose both in their standing frame and in a supported sitting position. This would take approximately one hour, and may occur at school.

What would happen at the end of the study?

At the end of the study the child would return to usual care.

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10. Is it possible to do this research?

12. If children at your school were participating in a study, would you be happy for them to take part regardless of which group they were in?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

13. If more than one child in your classroom was in a study, would it matter if they were in different groups? (i.e. one child using a standing frame and one child not using a standing frame at the same time)

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

14. Would you agree to a research physiotherapist visiting a child at school for an assessment (e.g., to evaluate the child's breathing, to consider their hand function, or to consider if they are in pain) for a maximum of 1 hour during the research study?

- Yes
- No
- I don't know

Please can you explain why you chose your answer above:

15. .

1 (It would be impossible)

2

3

4

5 (It would be easy)

How easy would it be to keep a daily diary of when a child at your school uses their standing frame (5-10 mins per day)?

If a child needed to keep a more detailed diary of their bowel function, medications, and pain could you fill this in for the time they are at school? (5-10 mins per day)

16. How would you prefer to keep a diary for a child at your school's standing frame use?

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

17. Would you agree to work with a research physiotherapist? This would involve having a research physiotherapist come into school to assess and support children participating in the study.

- Yes
- No
- I don't know

Please can you explain why you chose your answer above if possible?

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

Before designing this questionnaire, we consulted standing frame users including young people 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 the biggest ones to consider are.

18. From the list of difficulties below, please tick *anythat would stop you participating 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 children's standing frames 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)

19. From the list of difficulties below, please tick *anythat would stop you participating in a research study:*
(please tick all that apply)

Personal choice reasons

- It is not right to stop 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.
- I would feel guilty if I could not do everything I needed to do for the research study.
- Participating in a research study about standing frames may affect children's quality of life negatively.
- Children's choice should dictate their standing frame use rather than a research study.
- None of these apply
- Other (please specify)

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12. 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.

20. 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)