

understanding frames



Survey 1 Standing frames for parents and carers

1. Introduction and Consent

We would like to invite you to participate in this national 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 carried out by a research team from Newcastle University and is funded by The National Institute for Health Research Health Technology Assessment (NIHR HTA) Programme.

You are invited to participate in this study because you are a parent or carer of a child with cerebral palsy who may use a standing frame.

The purpose of this research study is to understand the current use of standing frames in children with cerebral palsy in the UK. If you agree to take part in this study, you will be asked to complete the survey on the next page. This survey will ask about your experience of standing frame use, and current postural management using standing frames for children with cerebral palsy. It will take you approximately 15 minutes to complete.

You may not directly benefit from this research; however, we hope that your participation in the study may improve understanding of current practice in standing frame use in the UK, to inform future research into standing frames as part of postural management for children with cerebral palsy. Your answers in this study will remain anonymous.

You do not need to give us any contact information; however at the end of the survey we will ask if you would like to be contacted regarding further research into standing frames; if you do provide us with your contact information at this stage; this information will be separated from your survey responses and kept securely by the research team. It will not be used for any other purpose than contacting you about further research. We will not give these details to any other parties. Your participation in this study is completely voluntary 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 the researcher(s).

By clicking on “I agree” to the survey/questionnaire below 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. Please print a copy of this page for your records. Please ONLY input your contact details on the survey/questionnaire if you agree to future contact from the research team and ONLY on the page indicated.

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 survey.
- I do not wish to continue with the survey.

2. About you

Many parents and carers may also have a professional role working with children with cerebral palsy who use standing frames.

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

(please tick all that apply)

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

If you do have an alternative professional role working with children with cerebral palsy who use standing frames:

Please complete this survey as a parent/carer.

However, we would be delighted if you also access the website link at the end of the survey to complete our survey for professionals who work with children with cerebral palsy.

3. Details of your child

3. Please tell us the age of your child

4. 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 they have another named diagnosis

5. Their cerebral palsy affects

- One side of their body only
- Both sides of their body but mainly legs rather than arms
- Their whole body

6. My child's level of mobility (please tick all the answers that apply to your child)

- My child can walk independently without a walking aid
- My child can walk with a walking aid (frame or stick)
- My child uses a walking aid (frame or sticks) indoors only
- My child uses a walking aid (frame or sticks) both in and outdoors
- My child uses a walking aid (frame or sticks) in therapy sessions only
- My child can sit independently
- My child can weight bear to transfer independently
- My child can weight bear to transfer with carer support
- My child needs lifting or hoisting for transfer
- My child can maintain head position in supportive seating independently
- My child is unable to maintain head position without support

4. Your child's standing frame use

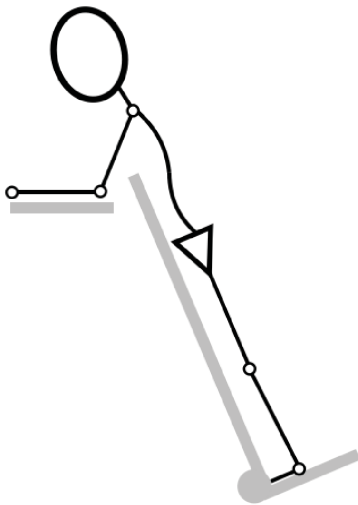
7. Which type(s) of standing frame(s) do you and your child have experience of using? (Please tick all that apply)

Please refer to the pictures below.

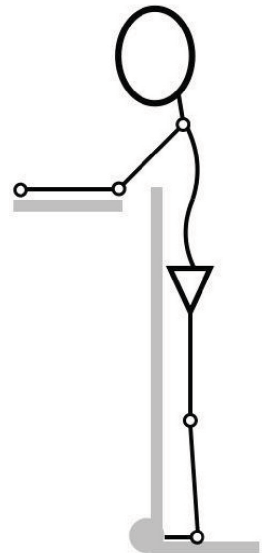
- Fixed prone standing frame
- Upright standing frame
- Supine standing frame
- Dynamic frame
- Sit to stand frame

If you are not sure about the type(s) of standing frame(s) you have used, you can enter a description of the frame(s) or name(s) below.

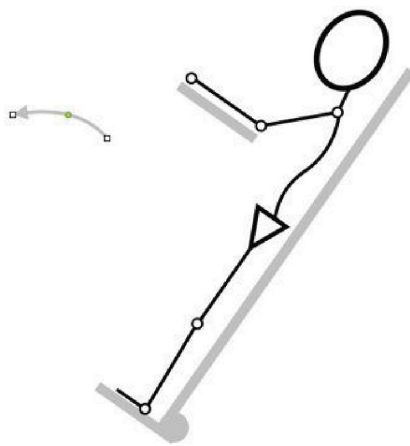
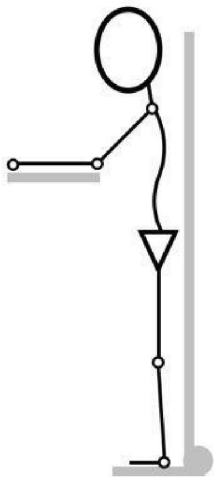
Fixed Prone Standing Frame



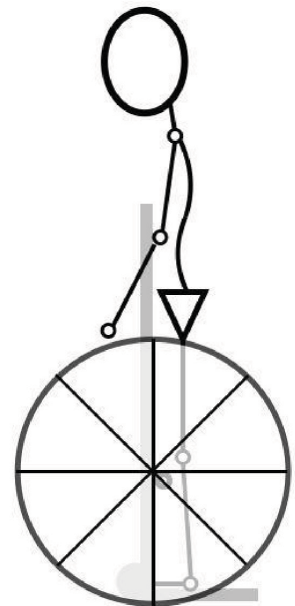
Upright Standing Frame



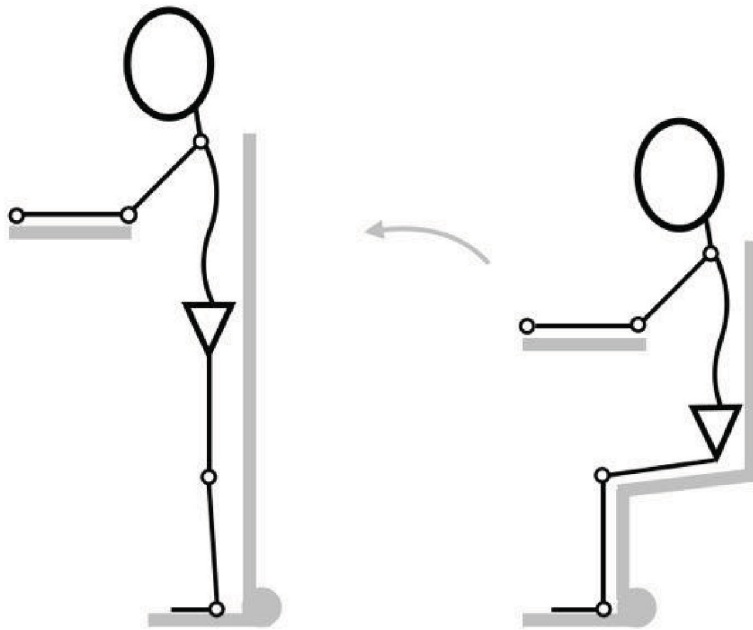
Supine Standing Frame



Dynamic Standing Frame



Sit to Stand Frame



5. Your child's standing frame

8a. How have your child's standing frame(s) been funded? (Please tick all that apply)

- Statutory services (health, social care or education)
- Charity funding
- Private or self funding
- I don't know

If you have sought charity funding or privately funded a standing frame for your child, please state why in the box below.

8b. Please tell us the type of school your child attends. If your child has split placement, please tick all that apply:

Mainstream school

- Local Authority (maintained) (including voluntary aided faith schools)
- Academy
- Independent or voluntary sector
- Local Authority school with additionally resourced provision (ARP) or centre (ARC)

Special school

- Local Authority school or 6th form college
- Academy
- Independent or voluntary sector

Post 16 placement

Mainstream 6th Form

- Local Authority school or 6th form college
- Academy
- Independent or voluntary sector school or 6th form college

Special School

- Local Authority school
- Independent or voluntary sector school or 6th form college

College of Further Education

- Mainstream course of study
- Specialist curriculum (Learning Difficulties and/or Physical Disabilities)

Specialist College (independent or voluntary sector)

- Day pupil
- Residential placement

If other (e.g. EOTAS [education other than at school], PRU [pupil referral unit] etc) please specify in the box below.

6. Assessment and monitoring of your child and their standing frame use

9. Who assessed and fitted your child's current or most recent standing frame? (Please tick all that apply)

- Physiotherapist
- Occupational Therapist
- Paediatrician
- Orthopaedic Surgeon
- Frame Manufacturer/Representative
- Therapy Assistant
- I don't know

Other (please specify)

10. Who has monitored your child's current or most recent standing frame? (Please tick all that apply)

- Physiotherapist
- Occupational Therapist
- Paediatrician
- Orthopaedic Surgeon
- Frame Manufacturer/Representative
- Therapy Assistant
- I don't know

Other (please specify)

7. The current recommendation for your child regarding using a standing frame

Not all children with cerebral palsy are prescribed a standing frame at all ages.

11. At what age did your child first use a standing frame?

12. The current recommendation for using a standing frame for your child

- A standing frame has previously been recommended and used by my child; but is not recommended at the current time
- A standing frame is currently recommended for my child

If a standing frame has previously been recommended and used by your child; but is not recommended at the current time, please go to QUESTION 13, SECTION 8.

If a standing frame is currently recommended for your child, please go to QUESTION 15, SECTION 9.

8. Your child's experience of previously using a standing frame

13. Please tell us the age your child stopped using a standing frame

We are an experienced team of clinicians and researchers and have developed this survey with parents and young people who have used standing frames.

We recognise that there are lots of practical reasons why using standing frames can be difficult. Please help us to understand more about your experience of using standing frames in the following questions.

14. Have you or your child experienced any of these recognised difficulties of using a standing frame?

- There was sometimes not enough time for my child to use a standing frame at home
- We have had difficulties with other equipment (e.g. a hoist) to use to position our child into the standing frame
- My child sometimes wanted a rest from using a standing frame
- There were sometimes moving and handling difficulties at home for my child (e.g. safety concerns)
- There was limited space to use or store the standing from
- There were not always enough people (parents or carers) to position my child in the standing frame
- My child disliked standing in their standing frame
- My child experienced pain when standing in their standing frame

Other (please specify)

Please go to **QUESTION 24, SECTION 14**

9. Using standing frames at home

We are an experienced team of clinicians and researchers and have developed this survey with parents and young people who have used standing frames.

We recognise that there are lots of practical reasons why using standing frames at home can be difficult. Please help us to understand more about your experience of using standing frames at home in the following questions.

15. Does your child use a standing frame at home?

- Yes – and they continue to use a standing frame at home
- No – a frame is available for use at home but it is not currently being used
- No – they do not have a standing frame at home at present but they have used a standing frame at home previously
- No – they have never used a standing frame at home

If a standing frame is used at home, please go to QUESTION 13, SECTION 8.

If a standing frame is not used at home, please go to QUESTION 20, SECTION 12.

10. Using standing frames

16. Does your child use a standing frame during the school/nursery holidays?

- Yes
- No
- I don't know

If Yes, where do they use a standing frame?

17. Please tell us the reason(s) why your child does not use a standing frame at home currently (please tick all that apply)

- Using a standing frame at home has not been recommended for my child
- There is not enough time for my child to use a standing frame at home
- We do not have a standing frame at home
- We do not have access to equipment (e.g. a hoist) to use to position our child into the standing frame
- My child wants a rest from therapy at home or in school holidays
- There are moving and handling difficulties at home for my child (e.g. safety concerns)
- There is not enough space at home to use or store the standing frame
- There are not enough people (parents or carers) at home to position my child in the standing frame
- My child dislikes standing in a standing frame
- My child experiences pain when standing in a standing frame

Other reasons (please specify)

11. Your child's current standing programme

We know that not all children are able to stand in their frames as much as it is recommended – please try to answer the following questions as honestly as possible – we need to understand how easy or difficult it is for families to use standing frames.

18. Firstly we'd like to know how often your child stands in their frame

	At school	At short break care or other location
How often is it recommended that your child stands in their standing frame currently?	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure

	At school	At short break care or other location
How often does your child manage to stand in their standing frame currently?	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it, please can you tell us the reasons why?

19. Secondly, we'd like to know how long your child stands in their frame – each time they stand

At school

How long is it recommended that your child stands in their standing frame currently?

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At short break care or other location

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- My child does not attend short break care or stay at another location
- I am not sure

At school

How long does your child manage to stand in their standing frame currently?

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At short break care or other location

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- My child does not attend short break care or stay at another location
- I am not sure

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it, please can you tell us the reasons why?

Please go to QUESTION 24, SECTION 14.

12. Using standing frames at home

20. When does your child use their standing frame at home (please tick all that apply)

- On weekdays outside school/nursery hours
- At weekends
- During school holidays

21. Have you or your child experienced any of these recognised difficulties with using standing frames at home in the last 6 months? (please tick all that apply)

- There is sometimes not enough time for my child to use a standing frame at home
- We have had difficulties with other equipment (e.g. a hoist) to use to position our child into the standing frame
- My child sometimes wants a rest from therapy at home
- There are sometimes moving and handling difficulties at home for my child (e.g. safety concerns)
- There is limited space at home to use or store the standing frame
- There are not always enough people (parents or carers) at home to position my child in the standing frame
- My child dislikes standing in their standing frames
- My child experiences pain when standing in their standing frame

Other reasons (please specify)

13. Your child's current standing programme

We know that not all children are able to stand in their frames as much as it is recommended – please try to answer the following questions as honestly as possible – we need to understand how easy or difficult it is for families to use standing frames.

22. Firstly we'd like to know how often your child stands in their frame

	At home	At school	At short break or other location
How often is it recommended that your child stands in their standing frame currently?	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure

	At home	At school	At short break or other location
How often does your child manage to stand in their standing frame currently?	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure	<input type="checkbox"/> Every day <input type="checkbox"/> More than 3 times each week <input type="checkbox"/> More than once each week <input type="checkbox"/> Once each week <input type="checkbox"/> Less than once each week <input type="checkbox"/> Not recommended in this location <input type="checkbox"/> I am not sure

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it - please can you tell us the reasons why?

23. Secondly, we'd like to know how long your child stands in their frame – each time they stand

How often is it recommended that your child stands in their standing frame currently?

At home

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At school

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At short break or other location

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- My child does not attend short break care or stay at another location
- I am not sure

How often does your child manage to stand in their standing frame currently?

At home

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At school

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- I am not sure

At short break or other location

- More than 2 hours
- 1 to 2 hours
- 30 minutes to 1 hour
- Less than 30 minutes
- Not recommended in this location
- My child does not attend short break care or stay at another location
- I am not sure

Is there a difference between the time it is recommended that your child stands in their frame and how long they manage to stand – please can you tell us the reason why there is a difference?

14. Benefits for children with cerebral palsy using standing frames

There are many reported benefits of using standing frames for children with cerebral palsy. Below some of them are listed. You will see the list twice.

In the first question, we would be grateful if you could tick all the benefits that you may have seen. In the second question, please only tick 3 benefits that you feel have been most important to your child.

24. How do you think your child benefits or has benefited from using a standing frame? (please tick all that apply)

- To participate in activities
- To enjoy activities
- To help my child communicate
- To be at the same level as his/her peers and to interact/play with them
- To give my child an opportunity for a change of position
- To help my child use their vision
- To improve breathing
- To improve bladder and bowel functions
- To help my child stand independently in future
- To help my child walk in future
- To improve my child's motor abilities e.g. trunk control
- To improve my child's motor abilities e.g. head control
- To improve my child's motor abilities e.g. using their hands
- To reduce risk of joint contractions (keep their legs straight as they grow)
- To reduce risk of hip dislocation or damage
- To improve my child's bone strength
- To reduce risk of fractures

Other reasons (please specify)

25. Please indicate from the repeated list below the 3 most important benefits to your child

- To participate in activities
- To enjoy activities
- To help my child communicate
- To be at the same level as his/her peers and to interact/play with them
- To give my child an opportunity for a change of position
- To help my child use their vision
- To improve breathing
- To improve bladder and bowel functions
- To help my child stand independently in future
- To help my child walk in future
- To improve my child's motor abilities e.g. trunk control
- To improve my child's motor abilities e.g. head control
- To improve my child's motor abilities e.g. using their hands
- To reduce risk of joint contractions (keep their legs straight as they grow)
- To reduce risk of hip dislocation or damage
- To improve my child's bone strength
- To reduce risk of fractures

Other reasons (please specify)

26. In our experience there are often delays in starting a standing programme, or replacing equipment for children who use standing frames. Please indicate the waiting times your child has experienced below

The shortest time that my child has waited for standing frame after it has been recommended:

- Less than 4 weeks
- 4 – 8 weeks
- 9 – 13 weeks
- 14 – 20 weeks
- 21 – 25 weeks
- More than 26 weeks
- I don't remember

The longest time that my child has waited for standing frame after it has been recommended:

- Less than 4 weeks
- 4 – 8 weeks
- 9 – 13 weeks
- 14 – 20 weeks
- 21 – 25 weeks
- More than 26 weeks
- I don't remember

27. Please add any other comments regarding you and your child's experience of using standing frames that you have not included in the questions above

15. Further research – invitation for parents and carers to participate in focus group discussions

As part of this research project we will be arranging some further group discussions for parents and individual interviews for young people with cerebral palsy to give us their views about using standing frames.

If you would like to hear more about this further research or you and/or your child are interested in taking part – please fill in details below. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.

28. Please indicate below if you are a parent who would like further information to participate further in this research

- I am a parent/carer and I would be interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects
- I am not interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects

16. Contact details for parents and carers interested in participating in focus groups

Thank you very much for your input with the survey so far and your interest in participating further in the study.

We have invited a large number of parents and carers to complete the survey; and will only be inviting 15-20 parents to focus groups. Please don't be too disappointed if you're not invited.

Please note that by providing your contact details you are not committed to attending the focus group, we will contact you with more information and you can choose not to participate at any time, without needing to give us a reason.

We will, of course, keep you updated with the progress of this research and results of the survey.

29. Please leave your contact details below for us to contact you regarding further information on the research and participation in focus groups

Name

Address

Address 2

City/Town

Postcode

Country

Email address

Phone number

17. Further research – invitation for young people to attend an interview about using standing frames

As part of this research project we will be arranging some individual interviews for young people age 8-18 years with cerebral palsy to give us their views about using standing frames.

If you would like to hear more about this further research or you and/or your child are interested in taking part – please fill in details below. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.

30. Please indicate below if you would be interested in further research and participation of your child in individual interviews to give us their views about standing frames

- My child is 8-18 years and I am happy to provide my child's information and to be contacted with more information about interviews
- I do not wish to provide my child's information or be contacted about my child participating in interviews

16. Contact details for information regarding your child's participation in an interview

Thank you very much for your input with the survey so far and your interest in participating further in the study.

We have invited a large number of parents and carers to complete the survey; and will only be inviting 15-20 parents to focus groups. Please don't be too disappointed if you're not invited. Please note that by providing your contact details you are not committed to attending the focus group, we will contact you with more information and you can choose not to participate at any time, without needing to give us a reason.

We will, of course, keep you updated with the progress of this research and results of the survey.

31. Please leave your contact details below for us to contact you regarding further information on the research and participation of your child in interviews or focus groups

Name

Address

Address 2

City/Town

Postcode

Country

Email address

Phone number

32. What is your child's name?

33. What is your child's date of birth?