



understanding frames

Survey 1 Standing frames for Prescribers

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 professional who works with children 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. Your role

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)

3. My current role includes:

- Working with children (0–18 years) who use standing frames – but not leading or prescribing or monitoring their use
- Prescribing and monitoring standing frame use for children (0–18 years)

This survey is designed for professionals who lead on prescribing and monitoring the use of standing frames for children with cerebral palsy.

There is an alternative survey for professionals who work with children with cerebral palsy who use standing frames.

3. Experiences of standing frame use

4. For how many years have you prescribed standing frames for children with cerebral palsy?

- Less than 2 years
- 2 – 5 years
- 6 – 10 years
- More than 10 years

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

- In-patient (hospital)
- Out patients (clinics)
- Community - home
- Community – school

Other (please specify)

6. Please indicate below your employment information (please tick all that apply)

- Employed by NHS or I am a clinical academic (university employed – but work in clinical practice)
- Employed via education or social care provider
- Work in private practice only

Other (please specify)

PLEASE NOTE:

IF YOU WORK IN BOTH PRIVATE PRACTICE AND FOR ANOTHER ORGANISATION PLEASE ANSWER THE SURVEY BELOW IN YOUR ROLE AS EMPLOYED BY THE OTHER ORGANISATION.

IF YOU WORK ONLY IN PRIVATE PRACTICE THEN CONTINUE TO ANSWER THE SURVEY IN THIS ROLE.

4. Children using standing frames

7. Which groups of children with cerebral palsy do you prescribe frames? (Please tick all that apply)

- GMFCS I
- GMFCS II
- GMFCS III
- GMFCS IV
- GMFCS V
- I am not familiar with GMFCS (Gross Motor Function Classification Score)

8. How many children with cerebral palsy on your current case load are prescribed standing frames?

- < 10 children
- 11 – 20 children
- 21 – 30 children
- > 30 children

9. How many new prescriptions of standing frames for children with cerebral palsy have you completed in the last 12 months?

- < 10 children
- 11 – 20 children
- 21 – 30 children
- > 30 children

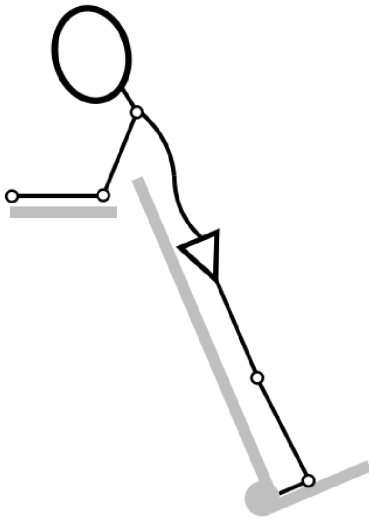
5. Types of standing frames

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

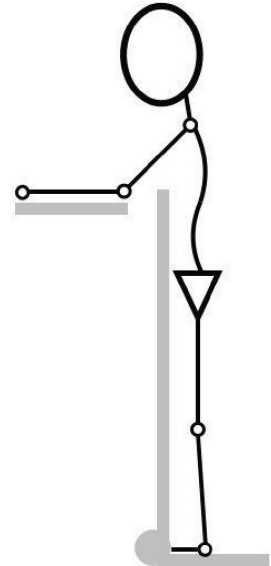
Please refer to the pictures below.

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

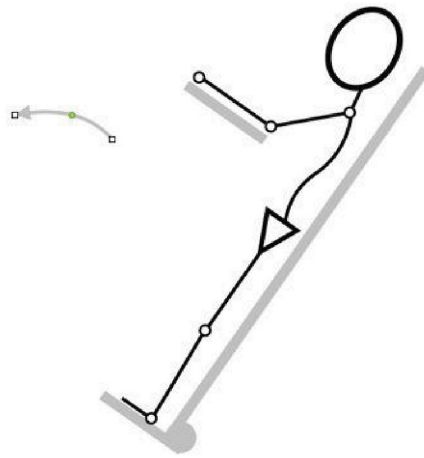
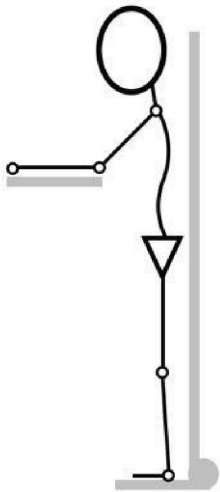
Fixed Prone Standing Frame



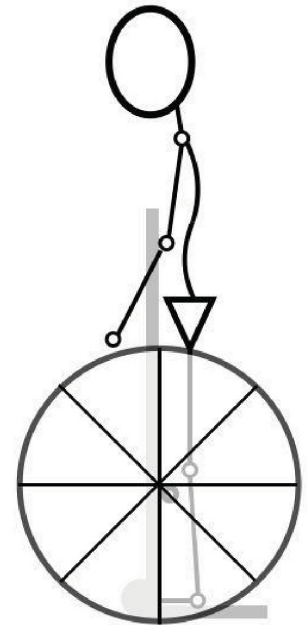
Upright Standing Frame



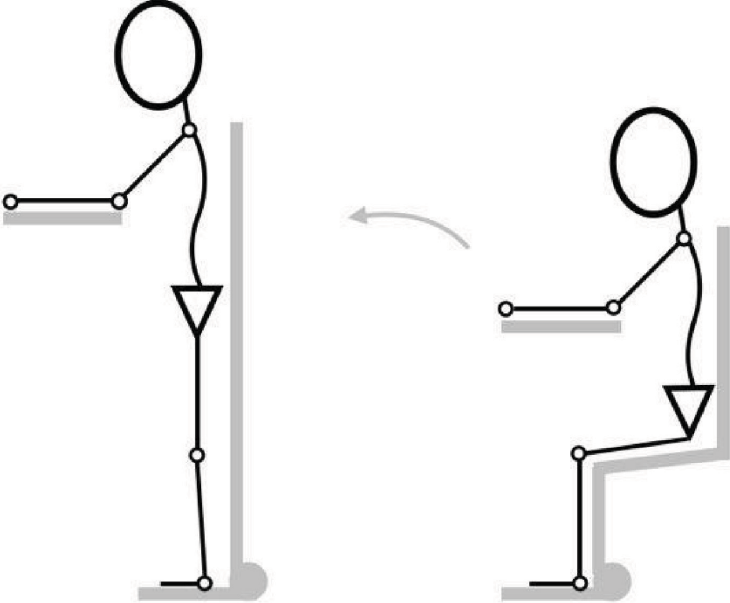
Supine Standing Frame



Dynamic Standing Frame



Sit to Stand Frame



6. Choice of standing frame

11. Have you experienced external factors that have influenced the choice of standing frame for children with cerebral palsy in your practice? (Please tick all that apply)

- Availability of standing frames
- Cost of standing frames or funding pathways
- Physical space
- Parent or young person choice of standing frame

Other (please specify)

7. Challenges to prescribed use of standing frames in children with cerebral palsy

12. There are some recognised challenges to standing frames prescribed use for children with cerebral palsy. Please indicate below any of these that you have experienced in your practice in the last 12 months (Please tick all that apply)

- Allocation of resources or funding for frame
- Allocation of resources for staff to prescribe/monitor use
- Physical space in home
- Availability of parents or carers at home to help position the child in the frame
- Physical space in school
- Availability of staff/carers in school to help position the child in the frame
- Transportation of equipment

Please tell us of any other challenges to standing frame prescribed use in the box below

13. Please indicate below the current waiting times for children with cerebral palsy in your area, from identification of need (prescribers' recommendation) to commencing a programme of standing in a standing frame

The shortest time for standing frame programme in last year:

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

Average waiting time for standing frame programme in last year:

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

Longest waiting time for standing frame programme in last year:

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

8. Prescribing frames for children with cerebral palsy GMFCS IV and V

Please note:

This study is to consider current UK practice and the feasibility of a trial of standing frame use in children with cerebral palsy GMFCS IV and V

Please answer the following questions thinking of these groups only

14. At what age would you first consider starting standing frame use for children with CP GMFCS IV and V?

- Less than 6 months
- 7 – 12 months
- 13 – 18 months
- 19 – 24 months
- 25 – 30 months
- More than 30 months

What factors may influence your decision to delay starting standing frame use in children GMFCS IV or V?

15. Please indicate the frequency that you would IDEALLY recommend that children with cerebral palsy GMFCS IV or V stands in their standing frame?

- Every day
- More than three times each week
- More than once each week
- Once each week
- Less than once each week

Other (please specify)

9. Standing programme for children with cerebral palsy GMFCS IV and V

16. Please indicate the IDEALLY recommended duration of standing, each time a child with cerebral palsy GMFCS IV or V stands in their frame?

- More than 120 minutes (2 hours)
- 91 minutes to 120 minutes (2 hours)
- 61 minutes to 90 minutes
- 31 minutes to 60 minutes (1 hour)
- Less than 30 minutes

17. What influences the standing programme care pathway for children with cerebral palsy GMFCS IV and V in your area? (Please tick all that apply)

- Individual practice of practitioners
- Written local (trust or employer) guidelines
- Written regional guidelines

If you use local or regional guidelines we would value your sharing of these guidelines.
Please provide contact information

10. Monitoring standing frame use in children with GMFCS IV and V

18. For a child with CP GMFCS IV or V in whom you have prescribed a standing frame:

	In an ideal world	In current practice (i.e. what is achievable?)	
How often would you or one of your team routinely monitor the suitability of this equipment for the child?	<input type="checkbox"/> More than once a week <input type="checkbox"/> Weekly <input type="checkbox"/> Fortnightly <input type="checkbox"/> Monthly <input type="checkbox"/> Every 3 months (or termly) <input type="checkbox"/> Less frequently than termly <input type="checkbox"/> When requested	<input type="checkbox"/> More than once a week <input type="checkbox"/> Weekly <input type="checkbox"/> Fortnightly <input type="checkbox"/> Monthly <input type="checkbox"/> Every 3 months (or termly) <input type="checkbox"/> Less frequently than termly <input type="checkbox"/> When requested	

	In an ideal world	In current practice (i.e. what is achievable?)	
How often would you or one of your team review the standing programme for the child?	<input type="checkbox"/> More than once a week <input type="checkbox"/> Weekly <input type="checkbox"/> Fortnightly <input type="checkbox"/> Monthly <input type="checkbox"/> Every 3 months (or termly) <input type="checkbox"/> Less frequently than termly <input type="checkbox"/> When requested	<input type="checkbox"/> More than once a week <input type="checkbox"/> Weekly <input type="checkbox"/> Fortnightly <input type="checkbox"/> Monthly <input type="checkbox"/> Every 3 months (or termly) <input type="checkbox"/> Less frequently than termly <input type="checkbox"/> When requested	

Other (please specify)

19. If it is not always you who reviews the suitability of the standing frame for the child or changes the prescription of the standing programme, please tell us the role/title of the person who would do this

11. Indications for standing frames in children with cerebral palsy GMFCS IV and GMFCS V

There are many different stated indications of standing frame use in children with cerebral palsy GMFCS IV and V at different ages.

20. Please consider below the indications for standing frame use in children with cerebral palsy GMFCS IV and V at different ages; and indicate in which group the indications are relevant at different ages

	Less than 5 years old	5-11 years old	12 years and above
To improve bone density/strength	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure
To reduce risk of fractures	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure
To reduce risk of joint contractures	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure
To reduce risk of hip dislocation or damage	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure	<input type="checkbox"/> GMFCS IV only <input type="checkbox"/> GMFCS V only <input type="checkbox"/> GMFCS IV and V <input type="checkbox"/> Never/not indicated <input type="checkbox"/> I don't know/I am not sure

To participate in activities

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To enjoy activities

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve breathing

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve bladder and bowel functions

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To help the child stand independently in future

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To help them walk in future

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve motor abilities e.g. targeted training or trunk control

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve motor abilities e.g. head control

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve motor abilities e.g. use of upper limbs/hand function

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To give the child an opportunity for a change of position

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve or support communication

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve or support vision

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

To improve or support peer interaction

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

- GMFCS IV only
- GMFCS V only
- GMFCS IV and V
- Never/not indicated
- I don't know/I am not sure

Are there any definite contradictions to standing frame use in children with cerebral palsy GMFCS IV and V? If so please write below.

21. Please add any other comments on standing frame use for children with cerebral palsy in the space below

12. Further research – invitation for prescribers to participate in focus group discussions

As part of this research project we will be arranging some further group discussions for professionals prescribing standing frames for children with cerebral palsy to give us their views about using standing frames and future research into standing frame use.

We will also be completing a further survey in 2017 to consider potential trial designs of standing frames for children with cerebral palsy.

If you would like to hear more about this further research or are interested in taking part – please fill in details on the next pages. 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.

22. Please indicate below if you would like further information regarding participation in focus groups to contribute further in this research

- 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

13. Contact details for participants interested in participating in focus groups – 2016

Thank you for your interest and providing us with your contact details. We will keep you updated with the progress of the study.

Please note that there will be limited numbers of people who can be invited to the focus groups, and we will be inviting people with a variety of experience.

23. 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