



## Standing frame young person's interview schedule

*Note: The interview schedule is developmental. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.*

### Plan of interview

1. Introduction
2. Consent
3. The young person – their use of a standing frame
4. Awareness of research into medical interventions (in cerebral palsy) be aware – check if child knows diagnosis/ understands CP
5. What we have found out about standing frame use in the for other young people with cerebral palsy from the survey
6. What questions do you have about using standing frames and how they help young people?
7. Designing a research study into standing frame use in children?
8. Feedback

### *Setting*

- *Location of interviewee's choice – home/school/ usual clinical environment*
- *Carer/ communication support worker as chosen by young person.*
- *Lone working policy to be followed by RA*

### Introduction

- Introductions of everyone involved in interview: RA, young person, communication support and parent/carer if present.
- Explain purpose of project and this interview:
  - Won't affect care – separate from medical care
  - We're looking for feedback from young people about their experiences of using standing frames
  - No right or wrong answers – not a test of your knowledge

- Consent – written, because this is extra to standard care.
  - Explain interview recorded both with audio and video – to make sure that it is recorded accurately but details will be confidential
  - The RA is not a clinician, but the wider research team includes doctors and therapists who do look after patients with cerebral palsy. If have any questions about your condition they will try to answer them at a later date or point you in the direction of someone who can help. It would be helpful if we use the interview to try to find out more about your questions, rather than spend time answering them – could we leave those questions until the end.
  - Questions or concerns?
- 2) Consent and assent form signed and checked.

The young person – their diagnosis of cerebral palsy and use of a standing frame

- Tell us your story
- When people ask you about cerebral palsy (\* check child knows/ understands with parent/carers before), how do you explain how this/your condition affects you? Do you use a standing frame?
  - When and where do you use the frame? School or home or both
  - When did you first start using a standing frame?
  - What activities do you use it for? Who decides when it is used and what you do when you are using it?
  - Whose idea was it? Yours? Your parents? A doctor? A physio or other therapist?
  - What are the good things about using a standing frame? What do you enjoy?
  - What are the bad things? What do you not like?
  - what makes it easier or harder to use a standing frame – either external things (e.g. uneven surfaces) or internal things (e.g. they feel it is a lot of hassle)
- why do you think using a standing frame is good for you or just why they think they are using a standing frame? Do you it's helping and if so, in what way? What don't you like about using one
- What other input do you have with respect to your movement and position at home, school – daytime and night time?
  - Equipment e.g. special chairs, sleep system,
  - People e.g. physio, OT, teachers parents
  - Activities – therapy, sport, leisure

### Awareness of research into interventions in cerebral palsy

RA to explain concepts of treatments and how research is designed to develop evidence

Reasons why evidence is limited

Pictures can help with explanations

General aspects of how we go about research – at a level according to the young person's developmental/ cognitive level.

### What we have found out about standing frame use in the for other young people from the survey

Brief discussion of survey results – discuss variations in practice:

Age of starting

Duration of standing

Environment used – school, home, both, other

### What questions do you have about using standing frames and how they help young people?

Are you surprised by any of the information above from the survey?

If so – what is surprising?

### Designing a research study into standing frame use in children?

If you were going to check how well standing frame's work, what would be most important for you to know?

If there was a research trial in which you were allocated by chance to a different standing frame of treatment programme – would you be interested in participating?

RA will prompt with examples

### Feedback

- Thank you
- Are we asking the right questions?
- Do these questions relate to your own experience?
- Do these questions allow you to talk about what is important for you?
- Is there anything else you think it would be useful for us to know?