

## Standing frame Focus group schedule

*Note: The focus group schedule is developmental. The questions will need to be tailored to the discussion in the focus group and their level of experience/expertise. The schedule given here is therefore a general topic guide.*

### Plan of interview

1. Introductions and setting the scene.
2. Consent
3. Participants experience of using a standing frame
4. Awareness of research into medical interventions in cerebral palsy
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 with cerebral palsy?
7. Designing a research study into standing frame use in children with cerebral palsy
8. Feedback

### *Setting*

- *Location determined by practicalities of bringing participants together (e.g. hospital, school, meeting room)*

### Introduction

- Thank-you for attending.
- Introductions of everyone involved in group: RA, other research team members and their roles.
- Introductions of participants – acknowledge that some participants may know each other in a personal or professional role. If this is the case – re-inforce confidentiality issues and clarify that they are comfortable with continued participation.
- Explain purpose of project and this focus group:
  - We are looking for feedback from all user of standing frames: professionals, parent carers in focus groups and young people in interviews. We want to know about their experiences of using standing frames, the practicalities – good and bad.
  - No right or wrong answers – not a test of knowledge

- Ground rules of group.
- Consent - written - because we want to be reviewing content and analysing data.
- Explain group discussion recorded both with audio- 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 participants have any questions about care of a relative or client the RA can try to direct the questions to someone who can help, but would it be helpful if we use the focus group to try to find out more about your questions and opinions, so please leave any questions until the end.
- Questions or concerns?

Ask participants to read and sign consent forms.

Participants experience of using a standing frame

- Do you use a standing frame?
  - Where and when - setting of use ? School or home or other
  - How long have you been using frames
  - How many young people have you used frames with?
  - Who prescribes frames
  - What are the good things about using a standing frame - for the children/young people? What do you enjoy ?
  - What are the challenges to use? What do you not like?
- Why do you think children with cerebral palsy use standing frames?
- What other input do young people have with respect to thier 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 audience experience/profession.

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

Brief discussion of survey results – discuss variations in practice:

Age of starting

Duration of standing

Environment used – school, home, both, other

Practical barriers to use of frames

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

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 with cerebral palsy

If you were going to design a research study to investigate standing frames – what would it be about – and what would it be?

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 recruiting?

What would be the barriers to recruitment?

RA will prompt with examples if needed.

RA will present 2 or 3 study design ideas to generate discussion.

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?