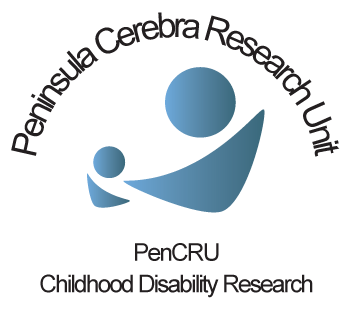
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**Consultation on Research into Dynamic Seating**

**for Children with Cerebral Palsy**

**Notes of meeting at the University of Exeter Medical School on 19/09/2013**

**Attendees**

P1, *Parent*

P2, *Parent*

P3, *Parent*

Meghan McCrory,

*Family Involvement Coordinator, PenCRU, Exeter.*

Chris Morris,

*Senior Research Fellow, PenCRU, Exeter.*

Tim Adlam,

*Head of Mechanical Engineering, Designability (Bath Institute of Medical Engineering), Royal United Hospital, Bath.*

Geraldine Cooney,

*PPI Research Coordinator, Bath Research and Development (BRD), University of Bath.*

**Project aims and objectives**

After introductions, Tim Adlam explained that Designability does a mixture of research, charitable work and making products. He gave a presentation describing this research into dynamic seating for young children with cerebral palsy. He is preparing an application to Sparks charity (application form and protocol was provided for reference).

Tim explained that a pilot study (funded by Action for Medical Research) was completed at the end of 2012. It aimed to design a seat for children that were ‘unseatable’: a seat that was comfortable for children with whole body extensor spasms that would accommodate the spasms and reduce the forces on the child. Designability has produced a seat that allows a lot of movement as well as maintaining posture - nearly all of the seat moves. The pilot study involved one child using the chair for six weeks, although Tim and his team worked with two children to design the seat. The child used it at school and feedback was gathered via sensors on the chair, videos and assessments. One child withdrew near the end of the study so the pilot results were for one child only. The results were positive and indicated that when using the seat, the frequency and strength of spasms was reduced. Other positive outcomes for the child included better social engagement and being able to operate a switch.

Tim explained that the only fixed point on this chair is a bicycle saddle which is the static stable reference point, and supports most of the child’s weight. The child’s upper legs are supported on ‘thigh trays’ and they can move their legs and feet independently. The seat feels stable, you have to apply force to get it to move, but there is enough spring force to get the child sitting up straight again after each spasm. The aim is to have a little movement in the child’s back and most in their legs. The researchers think that this moving seat provides a feeling of core stability, as child’s pelvis is supported consistently, even during a spasm.

However, the pilot study involved only two children (one of whom withdrew because of unrelated medical complications) and it is not known if they are typical – the next step is to involve more children. This new study aims to recruit twelve children aged 2 -5 years (the boy in the pilot study was 8 yrs). Further into the future, Tim would like to investigate appropriate seating for children aged 6 months- 2 years. He thinks if children are able to explore freedom of movement, socialise and vocalise at a young age, their impairment as an adult might be less.

**General Discussion**

* First impressions from parents at the meeting were that this chair would allow children to express themselves and their emotions.
* One parent had been told by professionals that if her child was moving, his vocalising would improve.
* Parents thought it would be important to look at changes over a period of time – they were told this research will be over a three month period.
* Parents agreed that being able to use a switch previously beyond a child’s reach/ability is clearly beneficial and opens up a whole new world eg ability to use a communication aid.
* Parents asked if this type of seat could be used by adults. Tim said a teenager or adult might benefit. Designability has another project looking at a similar foot support for children and adults.
* One participant said that this sort of product and related research should be available / applicable to adults and that innovations should be shared between academics working with children and adults as one could benefit the other.
* Another participant asked if there was any data on whether the seating helped at mealtimes – she wondered if the child is more comfortable when eating that this might ease discomfort after eating (eg wind and gastric reflux). Tim said that they did not gather information on mealtimes in the previous study.
* One parent said that ideally a child should be put into an appropriate moveable seat very young eg at six months – if the child feels safe and contained from a young age it could help their development. Tim said he is hoping to research a younger age group in his next project.
* The parents present all agreed that car seats are an enormous problem– trying to get their child into a car seat is difficult or impossible resulting in upset and traumatic journeys going to groups or appointments, or resulting in parents being unable to go out.
* Another parent said that fatigue is an important issue to measure – would the dynamic chair help with this?

***Action points***

**Consider including eating and fatigue in assessment/outcomes.**

**Specific Feedback**

**The Seat**

*Discussion points*

This group of parents did not react positively to the picture of the prototype chair used in the pilot study. One said when she saw the chair her ‘heart sank’. Other comments were that it looks like a ‘contraption’ ‘special needsy’ and ‘a bit off-putting’. Parents agreed that the diagram that followed the photograph in Tim’s presentation was much better than the photograph of the actual chair itself. They said that the chair should look ‘jolly’ and ‘friendly’ to invite you to put your child into it’. One parent commented that the big red handle doesn’t look very ‘enabling’ or easy to move around. Another parent suggested painting it one single colour might help.

Tim explained that the chair wasn’t manufactured yet and this was a prototype rather than a finished product – and its appearance could be improved. He said that feedback on the appearance of the chair was positive in the pilot, with parents and professionals saying they liked how it looked. He thought that this might be because when the child is in the seat you see the child, not the seat.

Participants asked if the seat can tilt - it can do so but Tim explained that it was not tilted in this study. Parents said that physios often set chairs for younger children on a permanent tilt. This would be possible, as everything on this seat is adjustable. Parents asked where the straps were positioned and whether a tray could be attached – it can be. One parent asked if it could it be used on a power-base. Would it enable/help a child to be able to drive? She said child gets excited and goes round in circles using a joy stick and wondered if this chair would help.

One parent asked why a bicycle seat was used as bike seats are notoriously uncomfortable.

Tim said he chose a bicycle seat as he needed something that would support the child’s weight and not interfere with their leg movement. He bought the biggest, widest, softest bicycle seat he could find (thick gel/ladies saddle). They also checked the children at the beginning of the study for reddening/marking and there were no problems with pressure from weight bearing. He thinks the reason this seat is comfortable is that the forces on the child are reduced and they are sharing the weight with the saddle and the thigh trays – they are supported all along the thigh. On a bike you don’t have the thigh support or the back rest.

***Action points***

* **It was agreed by the participants that for recruitment purposes it might be better to show a picture of a child in the seat, not the seat on its own, then show the diagram which explains the component parts.**
* **Explore possibility of chair as power-base to enable children to drive.**

**Recruitment**

Parents asked if the study would be recruiting locally or nationally. They were told that it will be national. Recruitment has not started yet as the funding has not yet been obtained (application going to Sparks charity).

*Disscussion points*

* Parents present described their informal networks such as opportunity groups and Bobath centres that could help with recruitment – they all attend local groups and know individual families who might be interested. One said that parents love sharing information and she thought the project could be over-run with volunteers.
* It was suggested that national networks could also be used for recruitment eg each local authority has a parent/carer forum that could publicise the research to their membership.
* Another parent highlighted the power of the internet eg mumsnet and YouTube. An online link could make it easy to access details of the study at the click of a mouse. She said that Tim’s TED talk was very powerful and could help with recruitment as he is also the father of a child with CP.
* Another parent said she thought there would be no problem recruiting 12 families. She said she doesn’t know of any parents who are happy with wheelchair seating/provision. Recruiting parents of slightly older children (aged 6-8years olds) might be better as they are in control of emotions, ready to get involved, and start making a difference.
* Participants agreed that recruiting younger children may be more difficult – some of the more severely affected children do not go to groups, and their parents might still be in the grieving stage (some never emerge from the grief stage). It was pointed out that parents are so tired at the beginning, they may not have the energy to get involved.
* Participants said that this project will be recruiting the parent as well as the child – if the parent is grieving or has not come to terms with their child’s condition, they are not going to be right for the study.
* Participants suggested ‘interviewing’ families – they said it is important researchers are clear at the outset what the commitment is in terms of their time and methods of feedback required.
* Participants said it is important to tell families that that the chair will be taken away after three months, although it might later be returned to them or they could buy it (at cost price). [See later discussion page7.]
* One parent said that it is important to make it clear on any recruitment material that this research will not do any harm and that it has ethical approval.
* The consensus was that as the target of twelve children is a relatively small number, recruitment problems were not anticipated.

***Action points***

**Tim asked if he could specify on the funding application that help with recruitment would be provided via parents and their informal networks/contacts. He said expenses would be available for this. One parent said she would be happy to give out information about the study and contact details as well as talk to people she knew who might be interested. However, she said she wouldn’t want another job of ‘recruiter.’ It was agreed that what is possible/appropriate might be different for individuals and that expectations around recruitment need to be clear from the outset. The wider parents’ network could be involved electronically as several parents said they were happy to be contacted via email.**

**Who is included and excluded**

Tim explained that this research intends to recruit young children with Dyskinetic Cerebral Palsy. Participants asked for an explanation of ‘dyskinetic’, and were told that it meant abnormal movements. The pilot study involved children with dystonia - whole body extensor spasms - this new research aims to study a broader range of children. Tim hoped this would make it easier to recruit. None of the parents present had understood ‘dyskinetic’, and it became clear using that term might hinder recruitment. One parent suggested that it might be clearer / simpler to say that the study was seeking to recruit ‘children with CP who extend and have involuntary movements’.

Tim said children with epilepsy would be excluded from the study. There was a discussion about whether those on medication such as Baclofen would also need to be excluded. Parents said that most children would be on this medication. Tim said that if medication is consistent it might be possible to include them, but not if they are stopping or starting the medication

*Discussion points*

* Medical terms used and diagnoses are not always clear cut and can be confusing.
* Professionals may be reluctant to use the term ‘cerebral palsy’ when the child is young. One parent said they call it ‘global developmental delay’ for a very long time. This might affect recruitment of young children.
* Participants discussed the possible implications of using the term cerebral palsy, before parents have had this diagnosis (eg if they come across recruitment information)
* Most parents do want to know, or do know their child has CP, as having the diagnosis can help them access resources. To qualify for this study children will be quite severely affected, and their parents are likely to have come across the term CP.

***Action points***

* **A clear description of CP and the kind of CP required by the study is needed eg stating the specific type of muscle movements of the child.**
* **Designability to consider including children consistently on medication for the course of the study.**

**Evaluation Methods**

Parents asked where the seat would be used and located as children with CP often have different seats at home and school; they would not be able to transport this chair between home and school. Tim said he was considering leaving it up to participants in the study to decide where to use the seat – it could be at pre-school, school or home. In the pilot study it was used at school and the staff videoed the children – this resulted in hours and hours of useful footage. In addition to the video footage there are sensors in the seat that produce a lot of useful data – there is just one on/off button to press, and the sensors have a battery life of one week.

*Questionnaires*

Two questionnaires/tick boxes will be completed at the beginning and end of the study by the research therapist to assess the child’s development and motor skills (CPCHILD and GMFM-66). The research therapist would complete this with the child and parent. The child’s own therapist needs to have given consent and be fully involved and co-operative for the success of this study. Both questionnaires are proxy measures, and Tim said he would like to capture the child’s own view. Parents said this will depend on individual child’s ability, but there are ways of gathering child’s perspective, especially when the school knows the child well.

Parents asked how long the child would have to use the chair before assessment. Would there be a requirement for a certain number of hours per day or could the assessment be carried out after the child had spent a minimum number of hours in total in the chair? Tim said he was considering asking parents to use the chair as much as they are able, rather than requesting a certain number of hours of use.

*Diary*

Tim said he intended to give parents and/or the school a research diary is to capture what would be missed by sensors and forms eg the mood of child, how he/she reacts, anecdotes, thoughts and feelings and reflections. One parent asked if the diary would be structured and include prompts. Tim had thought originally it might be unstructured; that parents would be given a small book without any expectation about what to write or how often. But he agreed that prompts or scales might be useful.

*Discussion points*

* The chair might be used more at school than at home – parents said they would be in the chair for longer at school.
* Several parents felt that using and evaluating the chair would be more difficult at home – the child moves about the house and so using video would be problematic. Siblings also like to get involved.
* Having a video running at home could be intrusive – some families might feel uncomfortable with it.
* Young children don’t stay in one spot or sit in a chair for very long. Parents said their child is not static, they are moving around, especially at home.
* School might be better for this research, especially if there was a good TA (they vary!) who could take it on.
* Concerns were raised about the amount of form filling/record keeping already going on at school and home – would this be duplication?
* Resource implications for already over-stretched schools and TA’s were discussed. Is it expecting too much from the school? But this study is a small number of children.
* Participants said that parents/schools might prefer electronic options to a paper diary - an iPad mini would enable a choice of preferred media and could include photographs, video etc. Other possibilities include a blog, audio diary or email.
* Participants agreed that prompts in the diary would be useful reminders – suggestions included mood, sleep, feeding etc
* Some parents might prefer freestyle writing, emailing or blogging – as long as it was something they could do in their own time when they had a minute available.

***Action points***

* **Tim will consider whether to ask parents to video at home at all, or whether just to video at specific times eg beginning and end of the day.**
* **Consider shifting focus of recruitment onto schools rather than families.**
* **Consider electronic options for diary eg iPad mini –individual preference important - email, video diaries or blogging.**
* **The protocol should commit to gathering view of each individual child. The following wording was suggested; ‘an attempt will be made to gather the child’s view (of the seat) using their familiar communication method’.**

**Parents’ expectations and support issues**

Participants said that support for parents (and/or school staff) should be ongoing during the study – it can be difficult to remember instructions and getting the child into a different chair for the first time can be traumatic. They will need support and training – at the time and afterwards, to ensure they are putting the child into the chair correctly. Tim suggested that the engineer and therapist stay as long as required on delivery day. Families will be given written instructions and Tim’s mobile number. Participants suggested taking photos of the child correctly positioned in the chair would help, or that parents/school could take photos and upload them later to check positioning with the research team.

Participants highlighted the importance of managing parents’ expectations – at the end of the research programme there may be parents whose children who have benefitted and who don’t want to let the chair go. Tim said that in the pilot project each child kept the seat at the end of the project (and Designability committed to maintaining it), but they don’t have resources to build and maintain twelve seats. This project will build 5 seats and use 4 at a time with one spare. Each child will have the chair for 3 months before it moves on to next batch of 4 children. Tim’s current thinking is that the first 5 recruited families could keep the 5 seats, and those who join the study afterwards would be offered the option to purchase a seat made for them at cost price. The participants did not think that this was workable.

*Discussion points*

* Participants were concerned that there will be a gap of six months when each batch of children has the chair taken away. It will be very difficult to give up the chair if the child has benefitted.
* Participants were unsure of the logic of giving a chair to the first 5 participants who may not have benefitted or liked the chair
* There was agreement that a clear and fair system was needed for deciding who keeps the 5 chairs. Rather than giving these ones out free and asking other parents to pay for the cost price of manufacture, it was suggested that the cost of the first 5 chairs could be factored in to bring down the overall cost of making 12 chairs (if they all want a chair). In that way everyone pays something.
* One participant asked what happens when the child has grown out of this dynamic chair, how does one explain that he/she is going back to a rigid/less comfortable seat?
* Could the research team commit to giving support to each family to get funding to help buy/pay for the chair? (eg charities)

***Action points***

* **Build in a further support visit/s shortly after delivery of chair to check positioning (visits at 48 hours and 2 weeks were suggested).**
* **Manage expectations re chair provision at the end of the study for all 12 families in a consistent, transparent and fair way.**
* **Consider supporting families with gaining funding for chair.**

The meeting closed (after a working lunch) and everybody was thanked for their contribution and for taking the time and effort required to attend.

Feedback questionnaires with a freepost envelope were handed out to all participants. Tim said that people could telephone or email him. GC said she would provide notes to be sent out to all interested people who could then comment if they wished via email or questionnaire.