



**Cerebra Research Unit Steering Group Meeting  
Minutes of Meeting: Tuesday 5<sup>th</sup> May**

**Present: Stuart Logan, Richard Tomlinson, Tamsin Ford, Camilla McHugh, Claire Lloyd**

**Apologies: Katrina Wyatt**

**1. Steering Group**

Stuart suggested that the Steering Group was referred to as an Advisory Group and this was agreed.

It was decided that the Advisory Group would meet every 6 months

Claire advised that one parent had expressed an interest in joining the Advisory Group and would attend all future meetings. The hope is that at least one other parent will be interested in joining the Group.

The need for external clinicians to be members of the Advisory Group was discussed. It was agreed that Ginny Humphreys, Head of Therapy at Vranck House, would be approached and Tamsin suggested that Tom Allport, paediatrician in Bristol, might also be interested.

**Action CL to contact Ginny Humphreys;**

**Action SL to contact Tom Allport**

**2. CRU Events**

Claire explained that events were being organised to 'launch' the Cerebra Research Unit (CRU) to parents. It was agreed that these events were a good idea, however Stuart felt that the events were too long (originally suggested to be 10am-3pm) and that shorter events might be more appropriate. It was agreed that the events will now be held over either a morning or an afternoon.

The dates for these events are 23<sup>rd</sup> June in Exeter at the Innovation Centre, Exeter University, and 1<sup>st</sup> July in Plymouth at the Rolle Building, Plymouth University. The programme will include an 'Introduction to Research' training session, provided by Wendy Rickard from Folk.us, Stuart giving a brief introduction to the CRU and a chance for discussion about issues important to parents over lunch.

It was suggested that the events would be interesting to clinicians as well as parents/carers, but this may depend on whether Wendy is happy to offer training to parents/carers and clinicians at the same time.

**Action CL to discuss with Wendy**

### **3. Publicity**

#### ***CRU Events***

The CRU events will be advertised with posters in CDC's (Child Development Centres - e.g. Vranth House and Honeylands in Exeter and equivalent in Plymouth/Torbay).

Schools in these areas will be contacted to ask whether we can send flyers home in children's school bags as this proved very effective with the OCP trial.

Claire has arranged for an article to appear in the DISCplus newsletter which will be distributed in early June.

Tamsin suggested that the Dartington Research Group may be able to help publicise the events.

#### **Action CL/ CM to contact Dartington Research Group**

Richard suggested that Lynette Chapman, Research and Evaluation Manger at DCC, might also be able to help publicise the events.

#### **Action CL/ CM to contact Lynette Chapman**

It was agreed that an article in local newspapers about the Unit and the launch events would also be a good way to publicise the events.

#### **Action CL to contact Andrew Gould**

#### ***Ongoing Publicity***

The CRU will be publicised through regular leaflets in school bags, articles in school newsletters and the DISCplus newsletter, and posters in outpatient's departments/CDCs.

### **4. Update on website**

Claire updated the group on the progress of the CRU website. Hannah Parsons has installed a Google Analytics package which enables us to see how many people are looking at the website and what they are looking at. Claire reported that the CRU site is not having many visitors at the moment and nobody has signed up to the forum yet. This was not seen as a concern and the group felt that the site would be accessed more frequently when more people knew about the CRU and there were specific projects underway.

Claire advised that a sound facility on the children's pages of the website was being developed. This will mean that all of the pages in the children's section of the site will be able to be listened to.

## **5. Engaging Children**

Claire discussed the possibility of using games to engage children in research. Claire has a list of suggested games that might be appropriate, and could be played in schools or after school/holiday clubs. The group agreed that games would be a good way to involve children in research but decided that the best use of this method would be when we had a specific project or question that we wanted to talk to children about.

## **6. Update on current research**

### ***Systematic Review of Sleep Positioning for Children with Cerebral Palsy***

Claire reported that the title for the systematic review has been registered with the Cochrane Collaboration in the Movement Disorders Group. Ginny Humphreys is involved in the systematic review and has identified a couple of parents who are also working with us.

The next step is to write the protocol for the review. Richard suggested that we could discuss this at one of the regular Friday afternoon meetings that are attended by local paediatricians. These happen every Friday from 1-2pm and are organised by Karen Street ([karen.street@rdefnhs.uk](mailto:karen.street@rdefnhs.uk)).

### **Action CL to arrange with Karen Street**

### ***Thematic Analysis of the OCP trial interviews***

The interviews carried out with the control parents as part of the Osteopathy trial are being analysed by Katrina, Camilla and Claire

## **7. Research Suggestions**

Claire gave out a table (attached) detailing all of the suggestions for research that have been put forward, some of which have previously been discussed. It was agreed that for now all research ideas that are put forward would be documented in this table.

Other research ideas were discussed:

Richard is involved in a couple of audits at the moment looking at 50 sets of notes to see whether admission needs meet the identified needs of the child. Alice Martin, SHO, is working with Richard on this. Richard will put the relevant people in touch with Claire as there is very little parent/carer involvement in this audit at the moment.

Tamsin discussed the possibility of a study following excluded children to see how they progress. Children are often excluded because of a failure to detect mental health issues or child abuse. A possible trail could look at assessing excluded children and tracking whether they return to school sooner than those who aren't assessed.

Stuart suggested that this could go through PenClahrc. Tamsin suggested that Miles Hapgood (Director of Children and Families at Exeter PCT) might be interested, and Richard suggested John Shaw (Strategic Commissioner for Children with Additional Needs)

**Action TF to contact Miles Hapgood; Action RT to contact John Shaw**

Stuart raised the idea of a school based intervention for ADHD, i.e. large effect size found from providing teachers with information about ADHD, even when they had not read the information (Tymms, 2006). Looking at teacher outcomes might be interesting.

Richard talked about starting a sleep service in Devon. At present there is no formal service, but evidence from the melatonin study suggests that sleep management advice is very effective. Stuart queried whether there was a systematic review looking at sleep training for children with disabilities.

**Action CL to look for systematic review**

#### **8. Cerebra Training – Participatory Research with Children and Young People**

Kate Bratt-Farrar from Cerebra is organising some training for her researchers, entitled 'Sustaining Participation and Reaching Beyond Consultation'. She has offered this to the CRU staff as well. Claire reported that she would be happy to attend but that some of the training content has already been covered in previous training events that she has attended.

**Action SL to contact Kate**

#### **9. Any other business**

It was agreed that although the full Advisory Group would aim to meet every six months, we should meet internally every 2/3 months.

**Action CM to arrange meetings for next 12 months**