



**Cerebra Research Unit Advisory Group Meeting
Minutes of Meeting: Tuesday 30th June 2009**

Present: Stuart Logan, Katrina Wyatt, Becky Hart, Sallie Parker, Kate Bratt-Farrar, Claire Lloyd, Camilla McHugh, Andy Gibson.

Apologies: Richard Tomlinson, Tamsin Ford, Sarah Dean, Ginny Humphries

1. Introduction and Welcome to Sallie and Becky

Becky and Sallie introduced themselves. Becky has one daughter with Cerebral Palsy and one daughter with a congenital heart defect, and Sallie has a son with Cerebral Palsy.

Stuart introduced the CRU, giving some background information. He explained that the CRU would focus on research into what works for children with complex needs. There is a gap in the research in this area – 40% of NHS expenditure for children is spent on children with disabilities, but there is very little research being carried out. As well as research into interventions, the CRU will look at the effect of these interventions on people's lives, and will aim to translate research from data into information that makes sense and is useful to parents, carers and children. We also welcomed Andy Gibson (PPI lead for PenCLARHC) to the meeting.

2. Feedback from CRU event in Exeter

Claire fed back on the CRU launch event in Exeter. The event was attended by 20 parents and carers, and everybody who attended seemed really interested and enthusiastic about the unit. Wendy (Folk.us) gave some great training, which Becky, who attended the event, said she had found useful. Lots of ideas for potential research were suggested, many of which were things that we never would have known were relevant and important to parents and carers.

A summary of the Exeter event and the Plymouth event on Wednesday 1st July will be posted on the website and the forum so that people can see the ideas that were generated and contribute to ongoing discussions.

Action CL/CM to post summary on CRU website

3. Update on potential research ideas

Claire highlighted that everyone present had been given a table of previously discussed research ideas, and this table will be kept up to date as further ideas are suggested and discussed. The ideas generated from the launch events will be posted on the website and forum for further discussion and this may also apply to other research ideas that are being discussed in the future.

Kate suggested a hyperlink with Cerebra website and their forum which is soon to be launched, as this will make the ideas available to a wider group of people. Kate also suggested that an article in the Cerebra bulletin might be useful, and this is coming up soon. The idea of 5/10 minute podcasts of conferences/events etc was also raised as a potential idea for the Cerebra and CRU website.

Action CL/CM – article for Cerebra bulletin

4. Methods for prioritizing research ideas

Discussions on how we prioritise the ideas that are generated.

Claire talked through a flow chart (see below) of how an idea might go from being suggested to becoming a research trial. This flow chart was seen to be an acceptable method of working by all present; however we still need to think about the method by which the Advisory Group might prioritise ideas. One idea is to have a voting system on the website, and to see what discussions are generated on the forum once ideas are posted. At the moment this process has not been formalised. The plan is to use a couple of ideas, one which has come from a junior doctor about children with disabilities being admitted to hospital and whether their needs are met, and put them through the system to get a feel for what is possible

Any ideas that are not able to be taken forward by the CRU will always be publicised and we need to ensure that people know there are other organisations that would be interested. Examples of these are the HTA, who have a process for questions about interventions, and the James Lind Library charity which documents unanswered questions.

Katrina suggested that junior doctors may be keen to take on projects so this may be another avenue for ideas. There have been discussions with Alice Martin, Junior Doctor, about whether the needs of children with disabilities, particularly communication disorders, are being met when they are admitted to hospital. Claire is due to meet with Alice and Emily Chesshyre about this research. Stuart suggested we look at the response we get on the forum/email everyone on the CRU database. Becky and Sallie both felt that this was an important issue, and Becky was able to give an example of communication problems when her daughter had been admitted to hospital – this will be posted on the forum and will hopefully generate discussion.

In the future it was agreed that there needed to be timescales for a decision to be made about whether to take an idea forward.

Action CL – hospital admissions idea on forum and email to all on database

5. Additional advisory group members

The CRU will start to build up a bank of people who are interested in getting involved in Steering Groups for specific trials, and in joining the Advisory Group for the CRU.

6. Website and forum update

Claire reported that people are not yet using the forum on the website. Becky felt that there was a potential problem in that parents are probably using forums specific to their child's condition so we need to think about how to draw them across. Claire/Camilla could join these forums and let people know about the CRU.

Camilla has been looking at forums for different conditions and plans to keep an eye on these for potential research ideas. It was decided that when people give their details for the database we should ask them which forums they tend to use.

Action CM – to amend the contact details form to ask about other possible websites/forums

7. Update on current research

Claire reported on the two pieces of research that are currently ongoing. Firstly, the systematic review of sleep positioning for children with cerebral palsy. Sallie has been involved in this. The review is registered with Cochrane and is moving forwards. Secondly Katrina, Claire and Camilla are analysing the transcripts about the diagnosis of CP from the OCP trial interviews.

The main paper for the OCP trial is being written at the moment and will be submitted to the BMJ.

8. Ongoing publicity

Sallie and Becky suggested that school newsletters were a good source of information for parents, both Ellen Tinkham (Exeter) and Pathfields School (Barnstaple) send out a weekly newsletter.

SENCO's in mainstream schools are also a good contact.

Action CM – is there a lead SENCO for Devon?

9. Training

Opportunity for Becky and Sallie to go on any training courses that they feel would be beneficial – no specific training needs identified at the moment.

Folk.us run a series of training events for both parents and service providers, Katrina can provide the programme for this training.

Kate reported that Cerebra have an e-learning programme that will be available in the autumn, and this is free to parents. To access this programme parents need to become a member of Cerebra, there is no charge for this.

10. AOB

New Staff

Sarah Dean has recently started in post and will be involved in the CRU. She is a physiotherapist/health psychologist, and is particularly interested in what influences people's treatment choices.

Chris Morris will be starting as a Senior Research Fellow in September. His background is orthotics.

Dissertation

Stuart Read (SR) is a third year psychology student who is keen to do his dissertation on something to do with CP, Tamsin Ford is supervising. He has hemiplegia himself and would like to base his research on depression in children with CP. Claire suggested that SR might think about drawing his sample from the children who took part in the OCP trial, whose parents have agreed that we can keep in touch with them about future research. Claire asked Becky and Sallie if they felt this was appropriate and they didn't think it would be a problem because the parents were not under any obligation to take part. It was agreed that SR would post something on the forum about his research and see what the response was. He might also be able to consult with parents to think about the best way of carrying out the research.

Action CL to discuss with Tamsin Ford

BIBIC

Kate queried whether we had got any further with an idea about evaluating BIBIC. Cerebra have looked into it – at present there is no external evaluation of the therapy, but BIBIC say that they have commissioned something. Kate will send the paper that Cerebra produced as a result of their evaluation.

Action KBF to send paper to CL

Stuart requested that Claire send the table of potential research questions to Kate Boddy/Ken Stein for Pen CLARHC

Action CL

Katrina re-iterated that it was important for people not to feel 'burdened' by the level or nature of their involvement and asked that people tell us when we are doing either!

The next meeting is 10th December 2009 from 10 – 12 noon in the WK Norman