



**Cerebra Research Unit Advisory Group Meeting  
Minutes of Meeting: Thursday 3<sup>rd</sup> February 2011**

**Present: Chris Morris (Chair), Kim Antonio, Amy Francis, Becky Hart, Claire Lloyd, Camilla McHugh, Val Shilling, Ellen Williams**

- 1. Introductions and Apologies from: Ginny Humphries, Margaret Ladbury, Sallie Parker, Richard Tomlinson**
- 2. Matters arising not on agenda and actions from last meeting**
  - The NHS Outcome Framework (outcomes from disabled children) project has been submitted to the Health Services Research Programme as an outline application. We will hear in the next few weeks whether the project has made it through the first round and can be submitted as a full application.
  - At the September meeting we discussed a possible slot on the BBC's Inside Out programme, with a focus on public attitudes and social inclusion. The group felt that this matter should be revisited but that it was important to know more about what the BBC expected and wanted from the piece.  
**Action: CM to restart conversation with Greg at BBC, perhaps with a view to a videoconference to discuss what both groups would want from the piece.**
- 3. Update on CRU staff**
  - Claire will return to work part time in March. We hope that Val will be staying with the group to work on a specific research project after Claire's return.
  - Camilla has moved into a new role as Family Involvement Coordinator and is now working 4 days a week.
  -
- 4. Building a Partnership**
  - At the Building a Partnership event in October we discussed shared learning events. Two topics have been suggested 'developing a research question' which could be delivered by Andy Gibson who is the Public and Patient Involvement lead for PenCLAHRC and 'searching for information and evidence' which could be delivered with the help of the information specialists at Exeter University.
  - The group agreed that both were a good idea, as was anything that can help parents to learn about how the research process works.

- It was decided to hold both events on the same day so that parents could decide whether to come to one or both sessions.
- A 'jargon buster' used by Andy with the PenCLAHRC group has been sent to all families by email. The responses so far by email have been positive and constructive. The group thought this was a good idea to give to new families and to have at meetings.

**Action: CMC to investigate a date and venue to hold the learning event. Anyone who would like to be involved in the planning of the event should contact Camilla.**

**CRU to produce a flow chart of the research process for the website and for new families/professionals**

**CRU to review the jargon buster in light of parents' email responses**

## 5. Question Prioritisation

- Since the last meeting Val and Camilla have been working to clear the backlog of suggestions/queries by making contact with the parents who suggested them.
- They have also developed standard procedures to ensure that when new queries come in they are dealt with quickly.
- We do still have a backlog of topics that could be What's the Evidence summaries. We would like families to help us prioritise these and future queries and suggestions.
- It was felt that it wouldn't be appropriate for the advisory group to also take on question prioritisation – AF suggested rather than forming another group, parents attending other meetings could be asked to 'tick' their top three suggestions.
- 

**Action: CRU to look into feasibility of asking parents to rate research suggestions when attending other meetings and also other ways of opening the process up to families that can't attend meetings – such as using doodle.**

## 6. Continence Services

- The group agreed that the work to date on the continence services topic has been important but that it is not a topic for research.
- The emphasis needs to be on complaints/campaigns which is not our remit. Every Disabled Child Matters can raise the profile if parents contact them to flag the issue as an ongoing problem
- 

**Action: CRU will not pursue this as a research topic but will pass the information we have gathered so far to Every Disabled Child Matters and facilitate contact with EDCM for our families.**

## 7. Website and marketing

- We viewed some mock-ups of web pages from Hannah. The group felt that the landing page should include a universal statement to be fully inclusive and that the text should have a positive spin to counter the often negative tone of information websites. Text needs careful consideration for example listing examples of specific

conditions could be off-putting to other families who may not feel we are appropriate for them.

- Although we discussed the use of language for the website (disabled or impaired) it is important that the language we use aligns with the Department of Health and other official bodies so we will continue to use 'disabled children'.
- The group thought that there should be many more pictures of young people and that they should not be in a photo frame and did not like the large titles 'so what's it all about?' and 'then what happens?'
- The group agreed that the proposed new structure of the website was clearer and that we should go ahead with this.
- At the same time as launching the website we suggested renaming the Unit as we are often confused with Cerebra the charity. The group were happy to have a new name that says more about what the Unit actually does and suggested a competition to come up with the new name.

**Actions: CRU team to meet with Hannah and feedback**

**Launch competition in the newsletter for the best new name for the Unit and also ask Ambassadors Club for suggestions**

**CRU team to check with Cerebra about renaming the unit and any requirements they may have**

**8. Involving children and young people**

We have previously discussed working with Dame Hannah's speech and language team to facilitate our work with young people with communication difficulties. It is important to involve young people of all ages and abilities and we discussed whether we needed a strategic approach, to ensure we consider carefully how we want to involve them, what we want them to do and the possibility of different groups of children doing different some different projects and working together on others. Chris has recently met with the Council for Disabled Children and the Children's Society who have done lots of work with young people; how best to involve young people in research could be a piece of methodology research in itself.

However, there is a group of young people at Dame Hannah's who are keen to be involved in our work immediately and Kim suggested that perhaps a less structured approach would be better in this instance and that we should seize the moment, giving them the opportunity to be involved in prioritising research topics. Claire is keen to develop this further on her return to work.

Action: CL/CMc to coordinate work with young people at Dame Hannah's  
CRU meeting with Whizz-kidz Ambassadors Club at the end of February

**9. Annual event**

The zoo was very popular with families in 2010 but it may not be entirely inclusive for all families. We discussed a number of alternative venues including the Calvert Trust, Haldon Forest, Pennywell, Country Life, the Donkey Sanctuary and the Miniature Pony Centre.

**Action: CRU team to make contact with Calvert Trust to see if they do day visits and investigate other suggested venues**

**10. AOB**

There was no other business

The next advisory group meeting will be on the 30<sup>th</sup> June