

**Cerebra Research Unit Advisory Group Meeting
Minutes of Meeting: Thursday 30th June 2011**

Present: Chris Morris (Chair), Amy Francis, Ginny Humphreys, Julia Hunt, Claire Lloyd, Camilla McHugh, Karen Rees, Val Shilling,

1. Introductions and Apologies from: Kim Antonio, Becky Hart, Richard Tomlinson

2. Matters arising not on agenda and actions from last meeting

- DEMOS. Cerebra asked whether we would be willing to circulate document regarding consultation about 'assisted dying' to children involved in PenCRU.
- Agreed that we were not comfortable giving this to children so it was not appropriate for the Family Faculty.
- JH suggested Torbay Disability Council (run by Children's Society) might be appropriate to ask – group of young people who take part in consultations.

**Action: JH will email the contact details of this group: participation coordinator is Rebekah Redshaw, email: rebekah.redshaw@childrensociety.org.uk
CL/CMc to contact Rebekah to possibly arrange visit to group**

3. Staff update

- Claire has returned from Maternity leave
- Val is now working on the Peer Support project
- Becky has been appointed to work on the PROMS study. She will work for 6 days over the summer and then 4 days a week from Sept.

4. Project update

- Circulated summary of projects in advance, any questions?
- AF expressed an interest in the Hospital Communication project, would be keen to get involved in this.
**Action: CM to talk to Siobhan about where AF could get involved
CL to keep AF up to date**
- Chris explained other projects that had not been circulated prior to the meeting.

- ADHD and complementary therapies – a scoping review has led to discussion about which complementary therapies to target for a systematic review. It was advised that Liz Bell might be interested in this.
- Virtual Technology project – Claire explained that there didn't seem to be much interest in setting up a working group for this project. The group discussed this and decided that there were definitely parents who would be interested in this project but probably didn't have the time to come to meetings. Look into video/teleconferencing and see what the response is.
- GH advised that there were a group of physios who would be interested, lots about this in the physio press at the moment. Also knows of families who are using Wii etc and may be happy to share experiences.
- St Luke's college use the Wii, and AF informed that Millwater school are looking for funding to get one.

Action: CL to ask the Family Faculty to vote on which complementary therapy to target for ADHD review, hope to focus on therapies where there is a potential risk of harm

CL to recontact Family Faculty about this project with teleconferencing options

CL to contact GH for info about potentially interested families and physios

5. BaP

- Event in May (morning 'developing a research question'; afternoon 'searching for information and evidence') was a success and there have been several requests for us to repeat this event, particularly the afternoon session.
- The group agreed that it should be offered again, possibly as a half day session focusing more on searching for information and evidence. Needs to be within school hours. Could consider offering the training remotely (i.e. can log in and do it from home) so that parents who were unable to travel could take part.
- There were no other suggestions for future training sessions.

Action: CMc to look into the possibility of offering the training remotely and arrange repeat of the training day

6. Question Prioritisation

- Circulated the flow chart detailing the process for prioritising research suggestions. The group was happy with the process, all agreed that it needed testing. Claire explained that PenCRU would only go through the process when there were a few questions to decide between and when the team had the capacity to take begin another project.
- The group advised that when PenCRU send emails out about projects or suggestions we need to be careful about using normal language and titles that make sense.

7. Website and marketing

- The group advised that we should have an article in each newsletter to explain the link with Cerebra, i.e. that we are funded by them.
- Suggestion that we mailshot/piece in Newsbeat all the Cerebra members in the south west to explain the differences between the charity and PenCRU and offer the

opportunity to become part of the Family Faculty if they want to receive information about us. JH felt that most parents think they will automatically get info from PenCRU if they are on Cerebra mailing list. Could offer entry into a prize draw if register by a certain date?

- Discussed simplifying the Family faculty questionnaire and asking for info in email
- Discussed strategy for involving more families of children in mainstream schools.
- Group advised that SENCOs were the best link. We could potentially go to a training session and talk to them all. Teenagers would appreciate having a voice.
- JH advised that Dorothy Hadley had just been appointed SEN Manager for Torbay. She has previously been involved in CDC/CaF/Aiming High so may be a good contact.
- PenCRU need to re-do posters for paediatric outpatients and CDCs
- Torbay centre for disability has an area for leaflets
- Exeter mobility centre might be able to display leaflets
- AF told the group about King George IV playing fields – inclusive play area in Exeter.

Action: CMc to simplify Family faculty questionnaire

CMc/CL to mailshot southwest Cerebra members, put article in Newsbeat and send posters to CDCs and Paediatric outpatients;

JH to forward details of Torbay centre for disability: Torbay Disability Information Service, Torbay Care Trust, Chadwell Annexe, Torquay Road, Preston, Paignton, TQ3 2DW. Email: dis.torbay@nhs.net

CMc/CL to contact re-do posters and contact Torbay centre for disability and Exeter mobility centre re possibility of displaying leaflets.

8. Involving children and young people

- CMc and CL have attended student council meetings at Dame Hannah Rogers.
- The group felt that student councils were a good opportunity to get children involved, majority of school councils would be pleased to be approached. We could offer a certificate for taking part, this would be well received.
- Torbay disability council are a group of young disabled people who take part in consultations, might be worth approaching them.
- To target children in mainstream schools PenCRU could approach clinical groups, e.g. physio for physically disabled children, SaLT for children with communication difficulties. Also social groups eg. Sports clubs – DISCplus would be able to provide information about these groups.
- There was a suggestion that we could hold 'Research Days' for children who have just finished their GCSEs. They have a long gap now until September and their parents would be keen for them to be doing something
- Website for young people in Torbay – Mybay. Might be worth contacting them?

9. Annual event

- Camilla and Julia visited Seale Hayne to plan the annual event. It is still very much under development and there were several potential problems, including the possibility that there would be no disabled toilet in the room we are thinking of using.

- The group decided to put out a new vote, asking the Family faculty to choose between the next 3 on the previous Doodle vote.

Action: CMC to check availability at other venues before putting out new Doodle vote with sentence about each venue.

10. AOB

- PenCRU have the option of a slot on BBC Radio Devon on Tues 12th July to talk about what we do. Would like to have parents talking about experiences of working with us. Let JH know if we can't get anyone else.

A couple of issues were raised during the meeting.

- A potential research question was discussed. There are issues around medication – different families receive medication in different forms depending on who is prescribing. Seem to depend on contracts that your surgery holds. We are aware that the information about navigating through the system is in the community, how can it be shared?
- There are 3 potential research questions here 1)How do clinicians decide what to provide; 2) Issues around information giving to patients surrounding medication; 3) why are decisions made without consulting parents. i.e. about changing contracts. These questions will be logged with PenCRU. When we are in a position to begin a new research project they will go through the question prioritisation process.
- PenCRU need to be careful about what we call meetings etc as sometimes the names we use can be off-putting. We should consult parents about what to call things, and make sure that we use normal language. We should state clearly that there is no commitment, and put an 'outcome' in the email so that parents know what they are working towards, i.e. 'by the end of the meeting we hope to have achieved...'

The next meeting will be Thursday 1st December, 10.00 am – 12 noon