

**Notes of PenCRU Advisory Group Meeting**

**Thursday 5 December 2013**

**Present:** Pat Teague,Tricia Stone, Julia Melluish, Mary Fredlund, Bel McDonald, Deborah Fox, Kate Tapp, Jenni Smith, Kelly Adlard, Helen Featherstone, Chris Morris, Meghan McCrory, Val Shilling, Astrid Janssens, Sarah Bailey, Megan MacMillan, Anna Stimson. Louise Vennells (joined midway).

**Apologies:** Allen Lewis, Josie Roberts, Heather Davison, Stephen Bell

Welcome and introductions

Funding

* Cerebra will continue to fund PenCRU’s core activities through to 2019.
* A proposal has been submitted to the NIHR on active computer games as rehabilitation for children with movement issues and a decision is pending.
* An application will be submitted in the New Year for a systematic review on peer support in neonatal intensive care units.

Conferences

* Most of the PenCRU team, and Bel and Julia from the Family Faculty, attended the European Academy of Childhood Disability conference in Newcastle and presented a wide range of our research to attendees.
* PenCRU co-hosted the British Academy of Childhood Disability south west regional meeting at the Veysey Building which a number of Family Faculty attended. There were several presentations from PenCRU, including a novel and engaging ‘play’ from Mary, Bel and Val about PPI.
* Our colleagues in PenCHLARC ran a PPI conference in Exeter which was again attended by staff and Family Faculty where Mary, Bel and Val made the same presentation to a wider audience.
* It was noted that parents appreciate the opportunity to attend conferences to both expand their knowledge of research at other institutions and to share their views with professionals. It was agreed that it was important these kind of events were not just there for academics. Julia mentioned it was interesting to learn that a lot of medical practitioners are actively involved in research as well as day to day treatment of patients too.

Research Projects

* A list of current projects was circulated.
* Deborah mentioned an interest in the genetics of autism and although Chris responded this was not an area of specialism for PenCRU, he suggested Newcastle University may be an interesting contact. Kelly also suggested contacting Babylab.
* Chris updated the group on the JLA childhood disability research priority setting project. The questionnaires have now been collated and there will be upcoming opportunities for parents to get involved in later stages if they are interested. There will be a meeting of the steering group in London in January and then the prioritising will begin.

Newsletter and Annual Report

* Parents agreed an annual report was of interest to them and helped to illustrate the full body of activity the unit undertakes.
* The newsletters are still valued in paper copy and the larger A4 version was well received. It was agreed that when there is a larger amount of information to include it was better to increase from A5 to A4 rather than add additional pages in A5 size.
* Tricia suggested sending copies of the newsletter to doctors’ surgeries to publicise to new parents.
* Kelly suggested asking DiscPlus to feature more items from the newsletter. However, it was noted this was not so effective at reaching parents who have yet to secure a diagnosis.

Collaborations

* SEN issues are still recognised as very important to Family Faculty parents. Chris and Meghan have met with Brahm Norwich at UoE Faculty of Education who is keen to get involved in public engagement, and collaboration looks possible. A pre-meeting will be organised in January to set boundaries for what kind of issues this collaboration could consider and to manage expectations of what can be achieved before a more detailed working group is set up. Anyone who would like to be involved should contact Meghan to express their interest.
* Dental care for children with additional needs was raised as an issue by a parent via our website. After contacting the Family Faculty we discovered this was relevant to a number of parents and attendees at this meeting colluded. Chris has met with dentists at Plymouth medical school who are interested in possibly collaborating on a project in this area. Julia asked if special care dentists in practice would also be invited to be involved and it was suggested that the invitation should go out to all dentists in practice regardless of specialism.
* An NIHR funding call has gone out for managing sleep problems in children with non-respiratory conditions. There is interest in looking at the subject from the view point of parental outcomes, and examining the effect of how children’s disturbed sleeping impacts on parents sleep and resulting well being. The project would not be led by PenCRU. There will possibly be a meeting to examine this further in January. Meghan will circulate the link to the NIHR website detailing what they are looking for and Bryony Beresford’s report on the subject. Helen mentioned an App that can link the amount of sleep taken to general felling of well being during the day which may be useful. Julia suggested this could be used to provide ‘evidence’ of the need for respite care!
* Chris’ fellowship application, on the topic of parental wellbeing was unfortunately unsuccessful. However, the peer reviewers all agreed that the topic was an important one for the NHS to look at which is heartening for future propositions. It is expected Val will run a pre-meeting in the new year to consider where to take this idea next.
* There is a possibility of a collaboration with Tamsin Ford’s team also based within the Child Health group here at UEMS to look at counselling and cognitive behaviour therapy to help children and young people understand their conditions and manage anxiety. Dame Sally Davis, the Chief Medical Officer’s, report suggested there is likely to be a call for applications launched in February.

How to convey what we do to the media

* Louise showed recent examples of press coverage PenCRU has received featuring Julia and her sons, which everyone agreed was very professionally presented and was good for informing local families about PenCRU.
* Louise suggested that the most effective way of publicising the unit was through personal testimonials and asked if any other parents were willing to be featured in the press to please pass on their details. It is OK to set boundaries of what you are and are not willing to do and discuss (newspapers/radio/ TV – yourself/your child/wider family/etc.). If you are willing to be contacted when opportunities arise – with no obligation to be involved on any specific occasion - please let Meghan have your details.
* It was discussed how important a professional and up to date website was in both informing parents but also in attracting collaborative partners from other organisations.
* Meghan suggested visual representations were often very useful to quickly and clearly illustrate what PenCRU does. There was some discussion around the quality of recordings that could be produced. Meghan suggested basic self-filmed ‘shorts’ of meetings would still be beneficial. Anna mentioned initial links have been made with Exeter College’s media production course leader and there is a possible opportunity to have students produce and edit short films on our behalf as part of their coursework. Louise reiterated that testimonials and personal accounts of their experiences were most effective.
* It was suggested that the first film could be of Val, Bel and Mary’s presentation. Mary did not wish to appear herself and Meghan will look at the possibility of either using pictures/animation with a voice over or a stand-in ‘actor’ to film the item.
* Louise raised the idea of hiring a professional photographer for events such as the family fun day to ensure top quality images that could be used for publicity purposes.
* Louise suggested using ‘speech bubbles’ on the website with comments from Family Faculty members about their experience of working with PenCRU.
* It was noted that no media clips should be put directly on the PenCRU website as they would breach BBC copyright.

Building a Partnership

* Chris reiterated the shared learning ethos of BaP events, and noted that PenCRU staff hope to learn from parents’ experience at these events too.
* The media, and particularly social media, was suggested as a possible topic for a future BaP event.
* Mary put forward the idea of examining the concept of ‘4 reasons for PPI’ that came out of the PPI event in Exeter. In particular it was suggested that this could be a good way of trying to encourage more of the Family Faculty members to get involved with projects on a wider level and attend meetings, etc.
* If anyone has any other ideas please send them to Meghan.

Family Faculty and Children and Young People

* Meghan circulated copies of the current Family Faculty leaflets and asked for people’s opinions on them and suggestions for improvements. Meghan will collate responses and report back in the new year.
* Meghan noted that some parents have expressed an interest in getting involved in projects on a deeper level, and we are trying to find ways to facilitate this.
* We have received requests to hold meetings during holiday times ,and to ensure we meet the needs of as many people as possible Meghan will soon be circulating a doodle poll to ask Family Faculty members’ preferences for meeting times and dates. Please do take the time to return this if you possibly can so we take your preferences into account when planning the next set of meetings.
* Meghan will be holding a meeting for the Children and Young People’s project on 21 January. Invitations to follow soon.

Family Fun Day

* Parents noted that they had enjoyed the event at Bicton park.
* It was agreed that it was difficult to find venues that catered to everyone’s preferences, when all the Family Faculty members had a disparate range of needs, and attendees accepted that on some occasions not everyone would find every event suitable for them.
* Julia noted that she appreciated her concerns regarding Living Coasts had been acted upon.

Staff Update

* Both Claire and Sarah will be moving on from PenCRU at the end of this term. Chris thanked them for their hard work and commitment to PenCRU, which was echoed by all present.
* A new Associate Research Fellow, Sharon, will join the team in January. She will be working 3.5 days a week.

Links and additional supporting information

* NIHR call for research on non-respiratory sleep disorders [Access commissioning brief (pdf, 132.37 KB)](http://www.nets.nihr.ac.uk/funding/eme-commissioned/briefs/sleep-comms-brief.pdf)
* Previous research on Managing Behaviour and Sleep Problems in Disabled Children: An investigation into the effectiveness and costs of parent-training interventions  <http://php.york.ac.uk/inst/spru/pubs/2192/>
* NIHR Themed Call for research on Long-term conditions in children and young people <http://www.nets.nihr.ac.uk/news/all/2013/nihr-themed-call-for-research-on-long-term-conditions-in-children-and-young-people>
* Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>
* Dates of already scheduled meetings next term with:

SEND group <http://socialsciences.exeter.ac.uk/education/research/centres/specialeducationalneeds/>

 Dentists

<http://www.plymouth.ac.uk/researchcover/rcp.asp?page=426&pagetype=G>