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**Notes of PenCRU Advisory Group Meeting**

**Thursday 17 July 2014**

**Present:**

**PenCRU team**

Chris Morris, Katharine Fitzpatrick, Sharon Blake, Astrid Janssens, Anna Stimson

**Family Faculty**

Tricia, Julia, Mary, Jane, Bel, Lynn, Michael, Ian, Mirtha, Catherine

**Apologies:**

**Family Faculty**

Kirstin, Josie, Tracey, Ian

Welcome and introductions

Previous meeting

* There were no actions to follow up from the last meeting in December 2013.
* It was noted that the A4 sized newsletter had been well received and this will be the preferred size to take out with us, while A5 size will be used to send out to minimise postage costs.
* Louise Vennells comments from the last meeting about the power of personal testimonials were reiterated and Chris thanked the parents who have shared their experiences with the media in recent months.

Staff Update

* Val and Meghan have left PenCRU.
* Sharon has joined us as an Associate Research Fellow, and Katharine has replaced Meghan as Family Involvement Coordinator.
* A question was asked if there was an intention to increase staff numbers in the team at present. Chris explained there was no intention to recruit anyone else at present but that this will be something to consider again in the autumn.

Research Projects

* A list of projects and their current status in the research cycle was circulated. (see attached)
* It was noted that SEND and oral health are still ideas we are interested in pursuing, but that they are dependent on collaboration with education and dental academics.
* PenCRU is interested in collaborating on a project for managing sleep problems. 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 wellbeing.
* There is a possibility of collaboration to look at counselling and cognitive behaviour therapy to help children and young people understand their conditions and manage anxiety.

Family Fun Day

* Pennywell Farm is the likely venue. Katharine and two parents will visit to check suitability. It was mentioned that we need to manage parent’s expectations of the facilities, and should note any areas or activities that are not fully accessible on the invitation to attend.
* The date will be 20th September, and Vinny will be attending once again.
* Several parents mentioned they had been to Pennywell and that they thought it was suitable, including for wheelchairs. A reservation parents whether there would be a reserved area for the sole use of our group, and it was agreed that this was a priority.
* **ACTION** – KF will inform Family Faculty once venue is confirmed to allow parents to reserve the date, and invitations will follow later.

Digital strategy

* Sharon made a short presentation about PenCRU’s current social media activity focusing mainly on Twitter and has increased our following to over 200 people.
* It was discussed that our main aims are to drive traffic to our website where all of our output is available in one place (dissemination) but also to use social media to network/build relationships with other disability and PPI organisations.
* A question was asked where PenCRU’s ‘What’s the Evidence’ summaries come on Google searches. It was suggested to find out what actual search terms families typically use.
* Parents agreed that Facebook was something they felt PenCRU should continue to utilise although not all of those present use it themselves. Although PenCRU has a relatively small number of ‘Likes’, when items are shared by the core followers the reach can be substantial.
* Parents said they would like the opportunity to discuss topics online before and/or after meetings either in a dedicated forum or via Facebook if we enabled a messaging facility. Some people expressed concern on opening up a forum and a fear of being targeted by ‘trolls’. Ian suggested the job of approving comments (moderating) could be shared out to interested Family Faculty.
* It was suggested that PenCRU should try to build links with other disability groups on Facebook by sharing and commenting on their Facebook pages similar to re-tweets on Twitter.
* Parents said that they like receiving emails from PenCRU, and noted they know people in the Family Faculty who don’t come to meetings but have said they like our emails. It was suggested we might send out an update email once a month like a mini newsletter with publication and project updates, plus items we have seen from other organisations that may be of interest (perhaps including a ‘Tweet of the week or month’), but to make this visually engaging rather than text based, and if possible have the function to click on items for more detail.
* The idea of parents putting their personal experiences of being involved with the Family Faculty on a blog such as WordPress was discussed.

**ACTION** – SB will investigate options and organise a working group of interested Family Faculty members to move forward. The focus initially will be on investigating ways to facilitate deeper engagement from ‘remote’ members of the Family Faculty.

Building a Partnership feedback

* It was noted that ‘BaP’ is not a widely known term and a new name should be considered.
* Two different priorities were identified - to engage existing members of the Family Faculty in more activities/meetings; to increase membership of the Family Faculty.
* A conflict between welcoming new attendees at meetings and offering ‘catch up details’ and full explanations of terminology etc. against possibly boring long-term members was identified.

Solutions suggested included:

* Inviting new attendees to arrive earlier – have a designated contact to receive them; maybe another Family Faculty member.
* ‘Buddy up’ scheme with other Family Faculty member to make contact before meetings either in person or via email or telephone.

Both these options would give new comers the opportunity to ‘share their story’ and get issues off their chest before rather than during the meeting.

* Provide a glossary/jargon buster
* Make our guidance information accessible to all with additional physical or learning requirements – offer option of audio, large print, easy read etc.
* Ask if we can provide any additional support when inviting people to meetings.

**ACTION** – KF will ask support question for future meetings.

**ACTION** – KF will include these suggestions in considerations for a PenCRU Handbook

Code of Conduct

* It was noted the trial of verbally agreeing this at the start of each meeting had not been successful, mainly because it does not suit the likelihood of late arrivals. It was suggested the code for each meeting could still be agreed at the start of the meeting and then remain written up on display for late comers, with a note they can raise objections/additions if they wish.

Handbook

* It was agreed that PenCRU should have a single document including all our policies and procedures for reference. A copy of PenPIG’s handbook was circulated as an example.
* Consensus was that the handbook should also act as a welcome pack and provide general information about who we are and what we do.

Contents suggested to include:

- Ethos of the unit – involvement from families

* Information on PenCRU’s history

- A glossary/jargon buster

- Who’s who of staff and examples of Family Faculty, including remote members, possibly with photos of themselves and/or children with personal stories of life experience and/or PenCRU experiences.

* Testimonials
* Transport logistics
* Payment policy/expenses and examples of forms we use
* Guidelines for meetings – what is expected of attendees – no research skills
* Clarification on the different levels of involvement open to members
* Code of conduct
* Diary of events
* Privacy/safeguarding policy
* Examples of PenCRU output
* Links to useful resources and support groups
* Include an Easy Read element to each section – like ‘Key Findings’ box on ‘What’s the Evidence?’ reports
* Outline what additional support we can offer for members/attendees with additional needs
* Include photos and graphics to make it more appealing to read.

**ACTION** –KF will investigate options and organise a working group of interested Family Faculty members to move things forward in the new term.

Children and Young People

* This is an area PenCRU is still keen to expand our experience in.
* PenCRU has identified that it does not currently have the resources to create its own Children’s Faculty at present; however, it has successfully engaged with C&YP in school settings.
* We will continue to collect details of special schools and organisations we may be able to work with in the future.
* It was noted that we had not yet been able to interact with C&YP with additional needs in mainstream schools. Attendees suggested contacting groups Young Devon, Moorvision and Young Carers to identify where groups of C&YP with additional needs may be located.

**ACTION** – KF will continue to build relationships with C&YP’s groups.

Conferences

* PenCRU will be co-hosting the British Academy of Childhood Disability south west regional meeting in November. **ACTION** – All: CM asked if any parents would be interested in seeing any particular agenda items added to please let us know.
* Cerebra Annual Conference – Tuesday 7 October 2014, 09.30-16.25, London.
* INVOLVE - 26 and 27 November 2014, NEC Birmingham.

There are limited opportunities for Family Faculty to attend these conferences at PenCRU’s expense.