



# Peninsula Cerebra Research Unit

## PenCRU Childhood Disability Research

### Notes of PenCRU Advisory Group Meeting Monday 30 November 2015

#### **Present:**

##### **PenCRU team**

Chris, Kath, Sharon, Ola, Anna, Astrid

##### **Family Faculty (FF)**

Ursula, Jen, Jane, Liz, John, Annette

#### **Apologies:**

##### **Family Faculty**

Julia, Mary, Karen, Lisa, Josie, Lynn, Mirtha, Sharon, Karen, Bel, Lyndon, Ruth

#### Welcome and introductions

#### Previous meeting

- There were no items or actions not covered later in the agenda.

#### Training

- Jane presented recommendations from her consultation with a small sample of Family Faculty members and PenCRU staff about training needs and ways to provide training opportunities for both new and experienced Family Faculty members and PenCRU staff.
- The need to devise training that was useful and relevant for both those newer to PenCRU and those who have had a longer relationship with the unit was recognised.
- It was discussed that parents want to be involved in effective participation and not to be included in research in a tokenistic manner, and that to be able to do this they need to be given more knowledge of the research process and the tools to enable them to do this.
- Using the 'research cycle' diagram at the beginning of project meetings would quickly orientate Family Faculty participants as to the stage of the project.
- **ACTION** – Chris, Kath and Jane will meet in January to discuss this further, and work towards a training workshop to be run in early Spring. Any other Family Faculty members who wish to comment on ideas for suitable training are also encouraged to contact PenCRU.
- **ACTION** – PenCRU will work collaboratively with Kath and the wider PenCLAHRC Patient and Public Involvement Group (PenPIG) to develop a strategy for effective involvement with service users and their families.

## Meetings

- Family Faculty highlighted the difficulties in scheduling meetings into their other commitments when meetings for the same project are arranged on different days, and often only a week or two in advance. **ACTION** – PenCRU will endeavour to schedule all meetings for individual projects on the same day of the week insofar it's possible, and will publicise dates of meetings sooner well as issuing reminders nearer the actual meetings dates.
- New members attending meetings for the first time would benefit from the ability to access additional guidance and support. It was agreed that it would be advantageous for them to either be telephoned in advance, or asked to arrive early, for a brief discussion on what to expect at the meeting and be given the opportunity to ask and questions. The possibility of an existing Family Faculty member who is also attending the meeting offering to arrive half an hour early and meet the new member was also suggested, and this is already offered as an option as the 'Buddy' scheme explained in the Handbook
- It was suggested that a short single sheet 'main points' guide be created from information in the Family Faculty handbook as a quick guide on public involvement in research and how Family Faculty members can best make effective contributions.

## Involvement outside of meetings

- There was discussion on alternative methods of engaging with the unit's activities without attending meetings. Several ideas have been trialled (online forums, Skype and Facetime, telephone conferencing, individual consultation), but there has been a low level of take up from Family Faculty to date. However, these options remain available and open.
- The 'What's the Evidence?' (WtE) and plain language summaries (PLS) produced by the unit benefit from Family Faculty input, but on some occasions it has been difficult to harness parental input into the latter. Family Faculty members said this could be because it is sometimes unclear exactly what is required of them. **ACTION** - The opportunity to comment on PLS would now follow the process the WtE summaries take i.e. sent by email either to the full Family Faculty database or project-working group as appropriate. Invitation will include details of the topic, what questions we want answered, an idea of how long we would expect it to take, a deadline date, and the level of acknowledgement payment on offer (with reference to PenCLAHRC policy which is being drafted). Those interested would be asked to reply saying whether they would like to be sent an electronic or paper copy to comment on. If a large volume of responses was received not everyone would be consulted on every occasion.

## Project Updates

- The Healthy Parents project has received approval from the university Ethics Committee to progress on to the next stage, recruitment will begin imminently for sessions in January.
- APEX – Autism Dentistry project has also received ethics approval and recruitment to participate in interviews with parents of children with autism will start in December.
- Full details of all current projects are available on the [PenCRU website](#).

## Future of the Advisory Group

- Chris introduced a proposal (see appendix) to reform the Advisory Group, to allow it to better perform the function of a strategic advisor to the unit. The proposal is to create a small standing group of Family Faculty members rather than our dip in/out approach used in other meetings.
- Membership would be for a fixed term to provide stability and allow other Family Faculty members to become involved in future. There was discussion about a suitable term of office. One or two years were suggested but some felt this was not a long enough period of time.
- Frequency of Advisory Group meetings was discussed. Our current two meetings per year was felt a low number and could be more effective if 3 or 4 times/year.
- It was recognised Advisory Group meetings should have a different emphasis to project meetings, and that certain qualities would be required from members of the group, and that training may be required.
- We discussed how Family Faculty members would be selected. A formal selection and recruitment process would be ideal, though resource intensive and time-consuming.
- A list of desirable attributes for members was suggested:
  - Approachability
  - Impartiality
  - Able to attend face-to-face meetings or experienced in using video/teleconferencing
  - Experienced in participating and presenting in boardroom style meetings
  - Networked with other parent carer groups
  - A mix of parental experiences/children's conditions and ages
- The Advisory Group would ideally include professional members too (as we did previously) and ways of facilitating this were considered:
  - Make meetings shorter – more documents circulated in advance
  - Lunchtime meetings
  - Meetings at RD&E
- Involving young people would be fabulous, but school and university terms may be barrier.
- Family Faculty members at the meeting supported the idea of reform of the Advisory Group.
- It was noted that forming select groups in organisations could be divisive if processes and perceptions are not handled sensitively.
- PenCRU is open to hearing views from Family Faculty members unable to attend this meeting.

**ACTION** – Chris will consider the implications and the practical considerations to take in to account to implement the change with the anticipation of relaunching the Advisory Group in the Spring term.

Meeting closed and was followed by lunch and mince pies.

## **APPENDIX: PenCRU Advisory Group Proposal**

### **Purpose of the Advisory Group**

The purpose of the PenCRU Advisory Group is to inform and advise on the overall strategy and governance of PenCRU, the Family Faculty and the research we undertake.

### **Background**

Until today, attendance at the Advisory Group meetings has been open to all Family Faculty members consistent with our dip in/out policy. Meetings have been organised with an invitation for anyone from the Family Faculty who is available at that time to attend on the date set. At first, meetings included both parent/carers and health care professionals. This helped to ensure PenCRU's research was focused on what is needed and what is achievable. For various reasons, over time, health professionals have become less involved in the Advisory Group, changing the balance of the meetings and leading to a gap in the information and advice available to us.

At the same time the Family Faculty network has grown. As we welcome involvement in different ways and recognise the time pressures on families, some parent/carers have been very active in PenCRU, others contribute by email/phone, or maintain their interest through our newsletters and reports. Some have become very knowledgeable about research; others have got involved more recently.

There are challenges for PenCRU with the Advisory Group being a transient group and/or an undefined number of people for continuity of decision-making. We are also keen to avoid newer Family Faculty members feeling overwhelmed and excluded or put off from attending project meetings where they could have more influence when supported appropriately.

### **Proposal**

Our proposal is to set up a standing group to perform this Advisory Group function. This would be made up of X? members of the Family Faculty and potentially be composed of representative parent carers, young person/people with neurodisability, siblings and health professionals. Members would make a longer-term commitment to being on the Advisory Group and unsalaried people would be remunerated with the usual acknowledgement.

The Advisory Group would help to make shared decisions about how PenCRU and the Family Faculty operate. For example, prioritising which questions to answer for WtE summaries, helping to organise the Family Fun Day, presenting about PenCRU and Family Faculty to interested audiences and media, consulting with other members of the Family Faculty to represent wider views, and advise on how to communicate with our Family Faculty members and what to include in the annual report.

We would have to decide how Family Faculty members would be recruited and appointed, and how long they would serve on the Advisory Group? Would members will be appointed for a set period with the option of serving another term by mutual agreement?

Meetings will be X? frequency and the dates will be agreed by the group at least six months in advance. This will help ensure better involvement of healthcare professionals.

Opportunities will continue as present for all Family Faculty members to get involved in individual research projects, commenting on plain language summaries, evidence summaries etc. All members of the Family Faculty will be made aware of opportunities for learning exchanges and training with PenCLAHRC.