



Peninsula Cerebra Research Unit

PenCRU Childhood Disability Research

Notes of PenCRU Advisory Group Meeting Thursday 16 July 2015

Present:

PenCRU team

Chris, Kath, Sharon, Ola, Anna

Family Faculty (FF)

Bel, Lyndon, Maria, Maureen, Sian, Ruth

Other

Karin (Scope), Chantelle (Student placement)

Apologies:

PenCRU team

Astrid

Family Faculty

Morwenna, Antonia, Julia, Lisa, Annette, John, Clare, Karen, Sarah, Josie, Penny, Lee, Karen, Gillian

Welcome and introductions

Previous meeting

- There were no individual actions (not covered later in the agenda) to follow up at this point from the last meeting in December 2014.

Engagement with professionals

- All attendees agreed that professionals were an important part of the research partnership, and that their input would be valuable.
- FF members stated that they would not feel restricted in what they would and could say by professionals (even those treating their children) being present at meetings with them.
- It was felt that it was good for professionals to be able to learn from families' experiences and hear the patient perspective on issues.
- A question was asked if educational professionals could be more involved in the light of the switch to EHC plans. It was noted that school SENCOs are included on our professional database and we have links with the SEND research group (Brahm Norwich) to explore ideas on this topic. However PenCRU's remit under the Cerebra funding is specifically to examine health issues.

Family Faculty sign up form

- FF members present felt the current form was easy to understand and not a problem to fill in.
- It was requested the term 'additional needs' was used rather than 'special needs'.
- Parents felt it would be useful to request details of typically developing siblings too.
- It was agreed that it was useful and acceptable to ask if parent carers also had any additional needs.

ACTION – AS will change the form used for future sign ups

Project meetings

- Kath gave a short presentation on what constructive public involvement consisted of, and there was some discussion of how this could be achieved for PenCRU meetings. It was highlighted that there was a difference between the purpose of a 'research meeting' and 'support group' or 'service user consultation', and that although there could be value to parents in obtaining information by attending meetings this is not the purpose of research meetings, it is rather to provide a carer's perspective to inform the research process. In light of this, it was accepted that in some instances meetings would only be relevant for parents of children with specific conditions to attend as experts in that topic. **ACTION** – invitations to meetings will contain information about the parental expertise sought on each occasion.
- It was recognised that some parents may not have any previous experience of research and could benefit from training about public involvement and providing effective input to enable them to participate fully at meetings. **ACTION** – PenCRU will examine levels of interest amongst FF members and possible training opportunities.
- FF members asked if a link to the relevant project page could be included with meeting invitations sent by email, and added to the table of upcoming meetings on the website to allow people to better understand what is likely to be covered in the meetings and allow them to assess their suitability to attend. **ACTION – AS** will add this to the website table.
- Team members asked if FF felt it was made clear enough in meeting invitations the value in informing us if they plan to attend meetings and conversely if they then realise they are no longer able to come along after all. **ACTION** – meeting invitations will include details of the PenCRU mobile number which can be used to contact the team on the day of the meeting and a line explaining that we are funded by the charity Cerebra and that any expenses incurred for lunch, parking permits etc. that are unused take resources from elsewhere.
- There was discussion about St Lukes as a venue for meetings. FF were happy with the ground floor rooms in the Medical School Building being used, but identified that parking could be difficult. It was suggested that given the University-wide sustainable transport policy <http://ow.ly/PPM0l> we should provide details of public transport links to the campus and consider a cap on paying travel expenses for journeys of under 3 miles, (linked again to the charitable funding point above – the cost of claiming for a 3 mile journey is actually £1.35 mileage + £6.00 parking permit and around £6.00 in administrative costs = total of £13.35).
- For attendees traveling a more significant distance it was identified that a list of alternative car parks and park and ride options would be useful.

Family Faculty Handbook

- A significant amount of work by staff and Family Faculty members was put into producing the handbook and we would like to see it fully utilised. However, there is a cost in producing paper copies that needs to be taken into consideration.
- It was identified that several attendees had not seen a copy of the handbook, and it was recognised that sending the online link was not the most engaging way of introducing the document.

ACTION – it was agreed to offer all existing Family Faculty members the option of receiving a paper copy of the handbook, and make this offer available on the website too, but a blanket policy of sending a copy to all FF members was not considered viable.

Code of Conduct for meetings

- FF attendees felt it was not suitable to send the code of conduct for meetings alongside the agenda by email or to ask people to sign to say they accepted the terms.
- After discussion, it was felt appropriate to read through the code at the start of every meeting, and that first time attendees should also be talked through it separately.

Website and social media

- The PenCRU Facebook and Twitter accounts are active and growing.
- The Family Faculty blog has two posts to date, both provided by fathers. We would be keen to have more parents share their experiences of involvement with PenCRU and a little bit of background about their family's story if they felt comfortable doing so. It was acknowledged that some children may not be comfortable being named or pictured in their parent's posts and it was suggested that future posts could be made not using names or personal images if people preferred.

Events

- Attendees felt that the DPCV event went well and we were happy to welcome two new members of the Family Faculty, who signed up at this event, along to this meeting.
- Family Fun Day. It was suggested returning to The World of Countrylife (last visited in 2011) this year as staffing restraints mean we are unable to scope out a new venue this year. One FF member said the venue had been used a lot another local group and so they would rather not go there again, and another FF member suggested there was not enough to do and suggested Crealy or Woodlands instead. However, it was noted these 2 alternative venues would exclude participation in a large number of activities for a significant proportion of children. No consensus was reached.
- The University will be hosting a VIP event to formally celebrate the opening of the new South Cloisters building (where PenCRU is based) in the autumn term and a small number of Family Faculty will be able to attend and share their experiences of involvement with the unit.