# penCRU-flat-sm.png

**Notes of PenCRU Advisory Group Meeting**

**Tuesday 2 December 2014**

**Present:**

**PenCRU team**

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

**Family Faculty**

Lucy, Kirstin, Tricia, Bel, Ellen, Lara, Annette, John, Emma-Jane

**Apologies:**

**Family Faculty**

Julia, Mary, Jane, Lynn, Mirtha, Ruth

Welcome and introductions

Previous meeting

* There were no individual actions to follow up at this point from the last meeting in July 2014.

Website and Social Media

* Sharon presented a short analysis of current traffic to our website; and Twitter and Facebook activity – see separate document.
* The PenCRU website has around 540 unique visitors (IP addresses) each month, split about 50/50 between new and returning individuals.
* Attendees were asked what search terms they use when looking for information online. It was agreed that people tend to be more specific than ‘childhood disability’, and look for specific diagnosis, conditions and interventions. It was noted that often those most desperate for information are those without a diagnosis, so we should also focus on symptoms and behaviours.
* Astrid suggested re-writing the home page to include examples of specific conditions, etc. so these will be picked up by search engines. **ACTION** – SB to consider during 2015.
* Sharon explained an idea to link with more active parent forums on Facebook and only use our own for project specific conversations at present. Attendees suggested the following sites: Mumsnet, Ouch (BBC), Special Needs Jungle and Challenging Behaviour Foundation. **ACTION** – ALL to forward any other suggestions to Sharon.
* Tricia suggested leaving comments on popular sites to get our profile known.
* Astrid suggested monitoring what topics people engage with most in forums to assess levels of interest in particular subjects.
* Emma-Jane suggested trying to get a link to PenCRU on every local authority’s local offer information.
* Sharon reported that the You Tube video trial had not been very successful in encouraging two-way engagement, and that people seemed to prefer the option of passively watching rather than commenting as well. Tricia pointed out that to leave comments on You Tube you need to have registered a Google Account, which some people may not want to do. Therefore, in future videos should be posted alongside a weblink to another place to comment either on our website, Facebook page or similar.

Remote working group

* Sharon reported back on findings of this project. Please see separate sheet for more details.

Communications

* Attendees were shown the updated version of the PenCRU leaflets. They were well received and after a couple of very small grammatical changes, will be used going forward.
* Annette suggested sending leaflets out to GP surgeries to display. However, it was noted that some surgeries are better than others at actually putting leaflets out.
* Katharine will prepare a short newsletter before Christmas. Attendees agreed that they definitely still want to receive a paper copy even if the electronic version is made more interactive. Given the time constraints, the next issue will be sent out both in paper form and electronically. A more interactive version will be prepared for the next issue. There was some discussion about opting in or out of electronic and paper mailings, but it was noted that this would be very difficult to administer using our current database set up so will be left for the time being.
* Attendees agreed that the best way to publicise PenCRU was in person. The new Family Faculty members at the meeting all said that meeting Katharine person had been a major reason in deciding to come along themselves today.
* It was noted that we sometimes have made the assumption that people already have a level of understanding about a topic or the purpose of a meeting when sending out invitations to attend. In future we will try to be clearer about exactly what will be happening, and what will be expected of attendees when sending out email invites – perhaps including sample questions to consider in advance etc. We will also comment where the project is at (start, mid-way, concluding).
* The idea of FF members taking it in turns to write a blog was raised. Those present thought this was quite a daunting suggestion to agree to when they already have a lot of demands on their time. Parents agreed to the alternative suggestion of being interviewed either in person or by phone by Katharine, who would then write up the interview for them. **ACTION** – in the New Year KF will send out a request for those willing to either write their own blog, or be interviewed, to register their interest and will then allocate one person per month.

‘Code of conduct’ for meetings.

* 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

* Katharine presented the work she had done on the Handbook to date. Those who had seen the previous version agreed this copy was much more engaging.
* General comment was that the Family Faculty was not mentioned until a few pages in, but it was noted that the order of contents was as had been agreed by FF at the Handbook working group meeting.
* It was suggested we try to be clearer about who can join the FF – not just parents of <25 year old children.
* ‘Terms of Reference’ was thought to be very formal and ‘Agreement’ was preferred as a title. It was also suggested using less points and amalgamating some into a single bullet point. Tone was felt to be ‘ordering’ and it was agreed to use ‘we’ at the start of each point.
* It was suggested that text heavy pages switch to two column side by side rather than span the entire length of the page.
* Add a jargon buster at the back.

Staff

* Katharine will be taking maternity leave in 2015.
* Chris will be looking to appoint a junior researcher for a one year contract in 2015 – possibly to work on Healthy Parents, but this is still to be decided.

Conferences

* PenCRU will be co-hosting the British Academy of Childhood Disability south west regional meeting in January. **ACTION** – KF to send agenda out to FF, but need to register to attend with Stella Imong NOT PenCRU.

AOB

* The idea of hosting a PenCRU Open Day in mid-2015 was tentatively raised. Ellen suggested a music based activity, Chris was keen to keep it research focussed rather than another ‘Fun Day’.
* It was suggested PenCRU try to secure a slot presenting or running a workshop at DPCV Annual event either instead of or as well as hosting our own Open Day, but it was noted time was running out to arrange this. **ACTION** - KF to find out in early Jan 2015 if there is a slot available at a DPCV event between Feb-Apr to plan a workshop in with FF.