



Children's oUtcome Measurement Study

The CHUMS project nears completion....

PenCRU enjoyed hosting the co-investigators meeting, which included several parents who are working with us on the project. We met at Reed Hall at the main University of Exeter campus on Wednesday 10th April to consider the emerging results of the CHUMS project. This was an exciting moment when, for the first time, we were to consider the findings emerging from this research.

Summaries of the three work streams: a systematic review, the qualitative study with young people and parents, and the online Delphi survey with health professionals were circulated in advance to all team members. They contained aims, objectives, methods and preliminary insights into the results. The meeting involved verbal presentations of each work stream, and lots of discussions about the findings, and the strengths and limitations of the research.



At the end of April there is a consensus meeting in London with a small number of young people affected by neurodisability, parents and professionals. At this meeting we will reflect further on the results. In particular we will discuss similarities and differences between what health services can do to improve young people's health and how that could be measured using standard patient reported outcome measure questionnaires.

Over the next few weeks we will be heavily focused on writing the final report about the research for the NIHR who funded the research. We will be able to publish more about the findings of this research once the NIHR have approved our report.

A big thank you to those of you who contributed to making the meeting a huge success.

Cerebra visit 2013...



Cerebra
Positively Different

We enjoyed hosting our annual visit from Cerebra on March 7th. Tracey Elliot, head of Research at Cerebra; Liz Fleming, a trustee and Jane Margetson, Lead Research and Education Officer came to listen to presentations from the team about the work we have been doing this year. Many thanks to the parents who came along to be part of the day and the presentations. We are expecting news in the summer of our continued partnership and funding.

Family Fun Day 2013

Date for the diary.....Saturday, 14th September



Yes it is coming to that time of year again; the highlight of our yearthe PenCRU Family Fun Day!

Can we ask you to put your thinking caps on and put forward suggestions for where we might go this year. So far we have had amazing days at Paignton Zoo, World of Country Life and Dartmoor Zoo so where next...?

Once we have put together a list we will send out a 'doodle' vote at the end of April and ask you to select your favorite venue, the one with the most votes will be where we go...provided they can accommodate us. Then we can begin to plan the day and hope for fabulous weather; so far we have been so lucky!

British Academy of Childhood Disability (BACD) regional meeting

We are organising a one day meeting in late September for BACD in the South West in Exeter. Chris is the new regional representative for BACD and we hope to make the programme interesting to both parents and professionals. In order to increase the chances of that, we would like to involve parents to help organise an appropriate format. To learn more about BACD see their website: www.bacdis.org.uk

Please get in touch if you would like to be involved.

Recent publications:

Recent 'What's the Evidence?' reports:

- Massage for Cerebral Palsy
http://www.pencru.org/evidence_what.php?e=8

Coming soon.....

- Emergency medication for status epilepticus
- Updates to our series of reports on complementary therapies for ADHD

Survey now open to find out families, young people & clinicians priorities for childhood disability research!

Childhood Disability Research - A JLA Priority Setting Partnership

The aim of the Childhood Disability Research Priority Setting Partnership is to identify the unanswered questions about the effectiveness of interventions for children and young people affected by neurodisability from both patient and clinical perspectives. It will then prioritise those unanswered questions that young people, parents and clinicians agree are the most important to create a 'top 10' important research topics. To learn more and see the objectives see:

<http://www.lindalliance.org/ChildhoodDisabilityPSP.asp>

To take part in this national survey go to:
www.research.net/s/JLACDRPSP_researchideas

Please feel free to forward the details of this opportunity to participate as widely as possible.

PenCRU evaluation workshop

On March 22nd, we co-hosted an evaluation workshop with our colleagues Andy and Kate from the PenCLAHRC Patient and Public Involvement team. The purpose was for families to evaluate how PenCRU carries out its involvement activities; this will help inform the unit on how we are doing and any areas we can improve in the way we work with families.

Several families attended the workshop and there was lively discussion on their involvement in PenCRU. Andy and Kate are putting together a report and we will let you know when this available on our website.

Thank you to the families who came along and took part and gave honest feedback.



The PenCRU website is being updated.....

The PenCRU website, www.pencru.org, is due a update this month; if you have any suggestions or feedback about the website, areas that we could improve, or new content to include please get in touch. s.e.r.bailey@exeter.ac.uk.

You can find us on Facebook at www.facebook.com/pencru



You can follow us on Twitter https://twitter.com/Pen_CRU



Funding news

Involving young people in research: PenCRU is pleased to have been awarded a small grant from the University of Exeter Catalyst programme for promoting public engagement in research. This grant will help us move forward with a strategy for involving young people in research. www.exeter.ac.uk/research/excellence/catalyst

Hospital communications project: PenCRU's proposal for Phase 3 of this project to develop and pilot a parent delivered training package for ward staff was not selected for the BACD Polani Prize. We are still hopeful of securing funding through an application pending with the RD&E Foundation Trust to support this activity.

Other applications pending decisions include our Healthy Parents project (NIHR Fellowship), and collaborative applications relating to research about Kleine Levin syndrome (NIHR Programme Grant), and peer support for parents of children in NICUs (Wellbeing of Women).

Congratulations..... to Megan MacMillan, PenCLAHRC PhD student who was runner-up for the audience-voted Sir Graham (Bob) Wilkins Postgraduate Research Prize. Earlier this month, PenCLAHRC PhD students and staff joined others from the Plymouth University Peninsula Schools of Medicine and Dentistry, the University of Exeter Medical School and the European Centre for Environment and Human Health to present their research at the Peninsula College of Medicine and Dentistry Graduate School Annual Research Event for 2013.

Megan's presentation, entitled "Understanding Children's Attitudes Towards Disability", discussed a large scale school-based survey on the positive association between the amount of contact children have with disabled people and their attitudes towards disability, and how this association is mediated by increasing empathy and reducing anxiety towards disabled people. For more detail see:

<http://clahrc-peninsula.nihr.ac.uk/promoting-positive-peer-attitudes-towards-childhood-disability.php> or to contact Megan: p3mm0011@exeter.ac.uk



Upcoming PenCRU meetings:

Listed below are the upcoming meetings, see our website for up-to-date information. If you would like to come along then please get in touch.

| Meeting | Date | Time | Location |
|---------------------------------------|---------------------|-----------------------------|----------------------------|
| 'Attitudes to disability' project | Friday, April 26th | 10.00-12.30, includes lunch | Veysey 006 |
| Hospital Communication project | Wednesday, 8th May | 10.30-12.30, includes lunch | St Luke's Campus, room G27 |
| Children and Young People Steer Group | Thursday, May 14th | 10.00-12.30, includes lunch | Veysey 112 |
| Peer Support Project | Tuesday, June 18th | 10-2, includes lunch | Veysey 006 |
| PenCRU Advisory group | Thursday, 27th June | 10.00-12.30, includes lunch | Veysey 006 |

Staff news:

Camilla will be leaving PenCRU at the beginning of June to work on another research project in the Child Health Group. We would like to recognise formally the fabulous contribution that Camilla has made to PenCRU since becoming our first Family Involvement Coordinator. PenCRU was established with the ethos of involving families in all aspects of our research. We quickly recognised that, to achieve this in a meaningful way, required someone to take on the role as a full time job. Camilla has pioneered and developed the role, and her ideas and considerable efforts have enabled a large number of parents and families to become engaged in PenCRU's research. So, a big change is happening at PenCRU as we seek to recruit a new Family Involvement Coordinator. We wish Camilla all the best in her new role.

Contact the team:

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Stuart



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Camilla



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Val



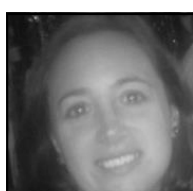
Astrid



Sarah



Megan



Anna



Karen

