

Have you seen our Annual Report?

Every January we publish our annual report. This is mainly a report to Cerebra, the charity that provide our core funding, to show what we have done in the previous year. It is always interesting to reflect on how much we have achieved and how we have evolved over the year. Please follow the link to our website to download and read the report:

www.pencru.org/news.php?id=309

We also have a small number of hard copies, if you would like one please get in touch.

Annual Family Fun day

We have started to think about our annual fun day for this year and we would love to hear your suggestions. For instance do you have an idea for where you would like to go this year?

Previous venues have been Paington Zoo and World of Country Life. Is there a place you have visited recently that you think would be suitable for the PenCRU Family Faculty? Is September still a good time of year? Should we invite Vinny again? Let us know what you think so we can start planning the day.



Staff update:

We are very excited to introduce two new members of staff. Sarah Bailey joined us as an Associate Research Fellow in February and Astrid Janssens joined us as a Research Fellow in March. We very much look forward to working with them and we hope you will too. We will let them tell you more about themselves below.



Hello, I'm Sarah and I started work at PenCRU in February. I completed my Masters in Public Health at Cardiff University in 2010, and prior to that I studied Biomedical Science. Since moving to Devon in January, I've been finding out more about the local area and exploring the beautiful coastline. I will be working on several research studies and I'm looking forward to getting involved with the unit - it's great that families have so much input into the work that we do here. One of the first projects I will be working on is a systematic review of the evidence for complementary and alternative therapies for ADHD, so if you are interesting in finding out more about this project you can email me sarah.bailey@pcmd.ac.uk or call me on 01392 726046.

Hi, I'm Astrid Janssens and will take over the CHUMS project from Becky, who has done a great job to get me off to a good start. Many thanks Becky! I have a Masters in Experimental Psychology and Anthropology, and a PhD in Medical Sciences. For the last 8 years I have been doing research on children and adolescents mental health and the organisation of services taking care of them. I was particularly attracted to working with PenCRU as they aim to make children and their families active partners in their work and do research with children. You will read more about the CHUMS project elsewhere in this newsletter but if you want additional information, do not hesitate to contact me either by email astrid.janssens@pcmd.ac.uk or phone 01392 726002.



Funding news

The way PenCRU works is that we develop ideas for research, and then seek funding for major projects that we cannot carry out with the resources we have. Recently we have been successful in attracting significant funding through the funding streams of the National Institute for Health Research (NIHR).

School-based interventions for Attention-Deficit/Hyperactivity Disorder (ADHD) FUNDED by the NIHR Health Technology Assessment programme

This project will address the question "what non pharmacological interventions for children with or at risk of ADHD have been shown to be effective when delivered in school settings and how do schools best contribute to their effectiveness?" We are part of a team being led by Dr Tamsin Ford at the University of Exeter that will carry out a systematic review to answer the research question. To read more please see link: www.hta.ac.uk/project/2646.asp. One of the parents in the PenCRU Family Faculty was involved in the application for funding and is now an integral member of the research team as a co-investigator. PenCRU's role is to facilitate the involvement of families affected by ADHD to ensure the findings of the research are relevant and useful to families. If you are a parent of a child affected by ADHD and are interested in helping us with the project then we are keen to hear from you, please contact us at pencru@pcmd.ac.uk

Children's Outcome Measurement Study (CHUMS): Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? FUNDED BY NIHR Health Services & Delivery Research Programme

This project was initially developed with a small amount of funding from PenCLAHRC and was subsequently approved for substantive funding from the NIHR Health Services and Delivery Research Programme at the end of last year; see the link for more details: www.netsec.ac.uk/hsdr/news210212.html The CHUMS project is now underway and you can read about our progress in 'project update' section of this newsletter. If you would like further information please contact Astrid at astrid.janssens@pcmd.ac.uk or phone 01392 726002.

Projects awaiting funding decisions

MeASURE: Measurement in autism spectrum disorder.

This project was designed in response to a competitive commissioned call for research by the National Institute for Health Technology Assessment programme. The brief asked for research to address the question "what is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder (ASD); and how well do these reflect and measure issues of importance for patients and carers?" We are part of a team from around the UK, led by colleagues at the University of Newcastle, which has submitted a proposal to carry out a systematic review to answer the research questions. We will hear in the next month or so whether we have been successful, and whether we can begin working on the project.

The next Building a Partnership event will be...

Introduction to research training

We plan to hold another Building a Partnership training event in the early summer. We have had several requests for some introductory training about research. The training would include information about the research process, the different types of research studies, understanding the 'jargon', and what public and patient involvement is and why it is so important. However as this training is for parents, it would be great if one or two parents had a hand in the design of the training.

So... if there is anything you would like to know about research, or if you have some ideas on how you think we should provide this training then please get in contact. Or, if you are at all interested in attending the training, do let us know. We will hold a planning meeting in April so please watch you email and if you have the time to come along and help us design the training and plan the day we would really appreciate your input.

Project update

Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? (The CHUMS project)

Rebecca Taylor began the project in the autumn 2011 and left PenCRU in January this year. Astrid Janssens joined the PenCRU team at the beginning of March to take over the daily management of the project.

Ethics approval - Good news! In December we got the official go ahead from the National Research Ethics Service (NRES); they reviewed all the proposed processes and documents and informed us that the project was approved.

Systematic review - A systematic review aims to provide an exhaustive summary of the literature relevant to the research question. The co-investigators meeting in November proved very helpful in setting out the detailed protocol for the review. We decided to go with a two-stage search. First we will search for patient reported outcome measures (PROMS) used to assess the health of children and young people. In the second stage we will examine how well the candidate PROMs have been used to measure the health of children and young people with neurological conditions.

Qualitative study - this will involve focus groups and interviews with children and parents in collaboration with the Council for Disabled Children. Currently we are working on the topic guide which will be used to structure discussion. In January we had two meetings with parents to consider ways to run the focus groups/interviews to ensure sessions are focused on the topic. We are planning to do a similar session with a group of children/young people to see if the proposed format leads to similar discussion.

Survey of healthcare professionals: We are getting familiar with software called Survey Monkey, which is a way to carry out surveys online. We also are finalising our strategy for recruiting professionals which will begin in April. If you would like to know more about this project, please contact Astrid astrid.janssens@pcmd.ac.uk or phone 01392 726002.

Improving communication with disabled children when they have to spend time in hospital

Systematic Review - Following our work looking at the existing literature in this area, a paper 'The experience of disabled children as inpatients: A structured review and synthesis of qualitative studies reporting children's, parent's and professional views' has been accepted for publication. You can read the summary at the link, or contact us if you would like to read the paper <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2214.2012.01372.x/abstract>

Qualitative study - We have recently completed interviews with nine ward staff about their experiences of caring for children with communication difficulties. The interviews are currently being analysed alongside the interviews that have previously been carried out with parents and other health professionals. Next we want to interview children with communication difficulties who have recently spent time in hospital. We are awaiting ethics approval to change the way in which we recruit children to be interviewed. We are very keen that the views of children and young people are represented in the study. If you would like to know more about this project or be involved, please contact Claire on claire.lloyd@pcmd.ac.uk or phone 01392 722901.

Peer Support Project

The peer support project is looking at the benefits and costs of providing peer support to parents of disabled children and is specifically looking at the service provided by Face2Face in Devon and Cornwall.

Our review paper, bringing together the evidence that is already known about peer support for parents of disabled children, is almost finished. We will be working with our stakeholder group to prepare the final article for submission to an academic journal and to prepare a version for more general distribution.

Since the last newsletter we have also received a positive decision from the medical school ethics committee. This means that we are now able to go ahead with the rest of the study as planned. In April we will begin talking to parents and befrienders who have been involved in the Face2Face programme in Devon in the last year about their experiences of peer support. We will also start the costing study to look at the time and resources needed to provide the service. We will begin the same two pieces of work in Cornwall in September.

If you would like to know more about this project or be involved, please contact Val on val.shilling@pcmd.ac.uk or 01372 726041.

Working group update:

What is a working group?

When an issue or query has been prioritised, the first stage in turning this into a research proposal is to set up a working group. This is a group of people who are particularly interested in the topic and who are willing to feedback and share their ideas, experience or expertise. Working groups often include families, professionals and researchers. The group will meet to develop a research question using the PICO format (patient - intervention - comparison - outcome), and to think about the practicalities of a research project. If a research project is viable we write a protocol for the study and explore potential funding opportunities. Members of working groups continue to support projects as they progress, and are an important part of the research team.

Social inclusion working group

This working group continues to be popular, we held meetings in Exeter on January 19th and in Barnstaple on February 22nd. We always have much discussion at these meetings, to read in more detail the notes of the discussions please see our website www.pencru.org/meeting_notes.php The outcome of these meetings was that the group is keen to support Megan in her PhD, as well as pursuing ideas for measuring inclusion, qualitative research to describe children's and families' experiences, and to evaluate services and interventions which promote inclusion.

Next meetings: Exeter - June 28th, 10-12 noon, Barnstaple - June TBC

Megan has provided an update of her project:

'Promoting positive attitudes towards childhood disability' – Megan MacMillan

For those of you who are not aware I started my PhD project in October 2011 on 'Promoting positive attitudes towards childhood disability'. I am working on a survey which will be administered around Devon mainstream schools measuring children's attitudes towards disability. Currently I am recruiting schools to take part in this survey after the Easter break. There seems to be lots of interest out there which is great, please can I encourage everyone to mention the opportunity to be part of this survey to teachers and head teachers across Devon, Plymouth and Torbay. So far it has been an amazing experience meeting with parents and children, which has really helped with the development of the survey. I had the opportunity to meet with parents at a working groups in Exeter and Barnstaple, these meetings allowed me to hear about different experiences and also to discuss the development of the survey. I have also met with a group of children, aged 8-14, who helped refine the survey further. They read through the questionnaire and we discussed ways to make sure the survey was understandable to all children. They talked through what they already knew about disability and how the instructions and questions should be worded. It was a great way to pilot the survey on those who will actually be completing it! Please get in contact if you would like any further information regarding the survey or my PhD. megan.macmillan@pcmd.ac.uk

Computer Games working group

This group has met twice to develop the idea and we have submitted the research question 'Do active computer games have therapeutic and/or social benefits for children with motor impairments?' to be considered for PenCLAHRC funding.

We hope to hear whether we have been successful in the coming weeks. If we do not receive funding from this source then we will seek alternative forms of funding for this question. Wherever the funding comes from, the next step for this project is likely to involve reviewing the existing literature, and using the findings from the review to narrow down and develop our ideas for a clinical trial alongside interested families. *Next meeting TBC*

Involving children in research

You may remember that we sent an email asking for people who might be interested in being part of a group to explore ideas about how we can involve children and young people in the work we are doing. We have set a date and will meet on April 4th. We would love as many as possible to come along; this includes parents, children with additional health needs, siblings or professionals. If you can make the time that would be brilliant, let Camilla or Claire know so we can make sure there are plenty of sandwiches and cake! *Next meeting: April 4th, 11-2pm*

Travelling working group

North Devon - we hosted our first travelling working group at the Cedars Inn in Barnstaple. We had a great day getting to know each other and there were interesting discussions. To see more details of these please see our website for meeting notes www.pencru.org/meeting_notes.php. We are planning to go back to Barnstaple in June and would also like to hold groups in Torbay and Plymouth, so please watch your emails for details of these events or if you would be interested in helping us hold a working group near you then please contact us.



Do you have a query about a treatment or therapy?

or

Do you want to know what evidence is out there?

or

Do you have a suggestion for research?

Are you aware that PenCRU could help to answer some of these questions for you? We receive queries from people all over the country about a wide variety of treatments and therapies. See our website for our response to some of these queries http://www.pencru.org/research_ques_asked.php.

When a query comes into the unit the first step is to clarify what the question is about, and for this we usually ask that people think about their query using a PICO format (population; intervention; control; outcome). Then we look to see what information or evidence is out there using reliable databases and resources. We write a response to the query which we send to the person who asked the question and also post the summary on our website in our 'What's the Evidence?' series. Often the evidence is not conclusive, or there will be little or no evidence from research. In this instance your query, if you wish it to be, could be thought about as a possible question for research. We hold a prioritisation meeting once a year to decide which questions we can pursue for research, which members of our Family Faculty are invited to attend.

For more information, to submit a question or for a submission form please get in touch.

You may be interested:

- Cerebra are experimenting with different ways of presenting information, one of which is infographics. They have just produced guidance on Disability Living Allowance (DLA). The QR code to the right, when scanned with a smart phone should take you straight to the DLA guide on their website. To give feedback to Cerebra go to info@cerebra.org.uk You can also download the guidance here



www.cerebra.org.uk/ENGLISH/GETINFORMATION/FINANCE/Pages/DisabilityLivingAllowance.aspx

Cerebra's monthly briefing for March is entitled 'Parents' Guide to Education Rights and Entitlements' follow the link to view in more detail: <http://tinyurl.com/boopbqh>

- The Department of Health has established a Children and Young People's Health Outcomes Forum. The forum is gathering views on the health outcomes that matter most for children and young people and how the different parts of the health system will work together to deliver these, see their website for more information: <http://www.dh.gov.uk/health/2012/03/children-views>
- We hosted two seminars recently. The first seminar involved a presentation by Brahm Norwich, who is Professor of Educational Psychology and Special Educational Needs at Exeter. Brahm discussed '**What difference might the Special Educational Needs (SEN) & Disability Green Paper make to SEN and inclusive education policy and practice?**' which generated lots of debate. The second seminar '**Perspectives on integrated services for disabled children**' was a presentation by John Shaw, who is Devon SEND Pathfinder Lead. John described how integrated services are organised and delivered for children with additional health needs in Devon.

Both seminars were well attend by a mixed audience of parents, professionals and researchers, and generated debate. Next we thought it would be very interesting if we could hear families' perspective of what an 'integrated' children's service means to them. Would you or any parent group you know be interested in presenting on this topic? We would be happy to host and support you.

Where we've been

It has been a very busy start to the year with lots going on. We have been out and about and thought we would share what we have been up to!

Plymouth Parent Participation—'your child, your voice'

We went along to meet the families who attend this group and to tell them about PenCRU and the work we do. It was particularly nice to go to Plymouth as this is an area where we don't know many families as yet, but look forward to making more contacts in the area.

Torbay Parent Participation Forum

The Torbay Parent Participation Forum hosted a fantastic day at the Grand Hotel in Torquay on Friday 3rd February. This event was for services and professionals to come and met the parents of Torbay and talk about their services. It was a 'speed dating' format which meant that all the professionals and parents got the opportunity to meet. There were also information stands for parents to find out about other services available to them in the area. PenCRU had our 'new' stand on display and Camilla really enjoyed meeting lots of new faces.

Torbay Disability Council

Camilla and Claire had a lovely evening on January 26th meeting the young people of the Torbay Disability Council. We worked with them about their thoughts on what research is and does; they had so much to say Chris and Camilla went back on February 23rd to talk some more about what they think health research is all about. We hope to continue to work with this group of young people and get them involved in some of our projects.

Aiming High Consultation days

It was fantastic to see so many families out and about at half term at the various 'aiming high' consultation days that Devon County Council put on. Camilla went along to Pennywell Farm, Buckfastleigh and the Milky Way, Bideford. It was great to meet new families and tell them about the work we are doing. Thank you to Devon County Council for inviting us to go along.

Parent Carers Voice information day for parents

We were chuffed to be invited by Parent Carers Voice to present a workshop on accessing information on the internet at this event on Saturday, March 3rd. The day was organised particularly for families with children under the age of eight with additional needs. We gave the workshop three times throughout the day and got some very positive feedback. We would particularly like to thank Tricia, a parent in our Family Faculty, for giving up her time to come along to help us deliver the workshop.

Parent Carers Voice conference

We also went along to the Parent Carers voice annual conference at Buckfast. This was a fantastic day which was really well attended, and the lunch lived up to it's reputation! We delivered the same work shop on accessing information on the internet and it was interesting to deliver it to a mixed audience of parents and professionals. Thank you again to Tricia for coming along.

Upcoming events:

Torbay Disability awareness day

We are really looking forward to having a stall at the Torbay Disability Awareness Day on Saturday April 28th; come along and say hello!

Meetings and events:

PenCRU meetings:

Children's working group

Date: April 4th

Time: 11 –2pm

Location: Veysey Building, Exeter

Social inclusion working group

Date: Thursday June 28th

Time: 10-12 noon followed by lunch

Location: Veysey Building, Exeter

PenCRU Advisory Group

Date: Thursday, June 14th,

Time: 10.00 am – 12 noon followed by lunch

Location: Veysey Building, Exeter

For directions to PCMD, Veysey Building please see our website: http://www.pencru.org/contact_find.php

Reminder:

We are able to reimburse for travel expenses and child care costs and acknowledge you for your time, for more details see our payment policy: http://www.pencru.org/research_payment.php

Events:

PenCRU Building a Partnership training event Introduction to research

Date: May/June

Time: 10-2.30pm

Location: TBC

Recent publications:

Shilling V, Edwards V, Rogers, M, Morris, C. (2012) **The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals.** Published online by Child: Care, Health and Development <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2214.2012.01372.x/abstract>

Contact us if you would like to read the full paper.

We are about to publish a new 'What's the Evidence?' on **Constraint induced movement therapy for children with hemiplegia** you can read this and other summaries of evidence for treatments and therapies here http://www.pencru.org/evidence_main.php

Join our Family Faculty!

We are always keen to hear from parents and carers who would like to be part of our Family Faculty.

Membership of the Family Faculty does

not commit you to anything, but will mean that you are kept informed about the work that we are doing and will be offered the opportunity to get involved at a level that suits you. There are many different ways of getting involved:

- [Join the Family Faculty](#)
- [Take part in the advisory group](#)
- [Suggest topics for research that are important to you](#)
- [Be part of working groups for specific studies](#)
- [Review information leaflets about specific studies](#)
- [Help us in telling people about the results of studies](#)
- [Come with us to conferences](#)
- [Feedback to us on PenCRU publicity materials and the website](#)
- [Tell other families about the work that we do](#)

We are exploring how to involve children in the work of PenCRU. This will help us understand what things they think are important. If you have any ideas about how to involve children we would love to hear from you, we have a meeting on **April 4th**.

Currently, around 200 families are members of the Family Faculty but we would like the group to grow even bigger; the more people that are involved the better!

If you are already involved with us and know of others who may be interested, please tell them about us and the work we do. If you would like to join, please get in touch.

Email: pencru@pcmd.ac.uk

Telephone: 01392 72 2968/2901



Do you have a child with ADHD; would you like to get involved in a new project we are working on?

Systematic review of complimentary therapies for ADHD

There is considerable interest in complementary and alternative therapies to reduce symptoms in children with Attention Deficit Hyperactivity Disorder (ADHD). Complementary and alternative therapies or medicines (CAM) are non-mainstream medical treatments used instead of conventional treatment, or are intended to work alongside conventional medical treatment. Examples include herbal or dietary supplements, or elimination diets such as cutting out artificial colours and sweeteners. The evidence for the effectiveness of these treatments is mixed and there have been concerns about safety and costs. It can be difficult to verify claims of effectiveness, particularly for products sold online.

Last year, Cerebra commissioned the PenCRU team to conduct a scoping review, to ascertain what types of evidence have been published for the efficacy and safety of CAMs for treating ADHD and to guide directions for further research. You may remember that we carried out a 'Complimentary Therapies and ADHD' survey last year, in which we asked members of the Family Faculty to vote on which topic they thought would be worth looking at in more detail. We are hoping to extend the survey this year to gather more opinions.

We are now in the process of writing a protocol for a full systematic review which will be carried out by the team at PenCRU. Systematic reviews bring together the results of all studies addressing a particular research question. We will search a range of academic databases for evidence, and the studies that are found will be appraised and summarised to better inform parents and carers about treatment options.

We would like to recruit a working group of parents of children with ADHD from the Family Faculty who are interested in working with us on this project. If you are interested in being involved please get in touch with Sarah or Camilla

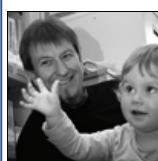
Contact the team:

Email: pencru@pcmd.ac.uk

Phone: 01392 722968/2901

Website: www.pencru.org

Address: Peninsula Cerebra Research Unit, Peninsula Medical School, Veysey Building, Salmon Pool Lane, Exeter, EX2 4SG



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