

Congratulations Megan!

We are very pleased to be able to share the news that Megan Armstrong (née MacMillan) has defended her PhD thesis successfully in examination in July 2015. Her research focused on furthering our understanding of children's attitudes towards disability: a topic that was prioritised by members of the PenCRU Family Faculty. Megan's PhD studies were funded by [NIHR through PenCLAHRC](#).



On the same day as Megan's viva voce examination, we received news that the main analysis from her thesis was accepted for publication in a peer reviewed journal. We will report further findings as and when they are published.

Autumn term meetings

Once the school holidays are over we will be holding parent meetings for our Wii-fit for children with Cerebral Palsy, Dentistry for children with autism and Healthy Parent Carers projects. Dates will be announced on our website next term:

<http://ow.ly/PAnHq>

Please [contact us](#) if you would like to know more.

Social Media



Did you know we have a [Twitter](#) and [Facebook](#) page?

We use both to send out news of our research as well as other disability news. We'd love to get to 1,000 followers on Twitter. So if, you haven't yet, do follow us or recommend our account to the tweeters you know! If you prefer Facebook, it's a great way to comment on what we are doing and share information you think would be useful for other families. We look forward to seeing your tweets or posts!

Contact the team

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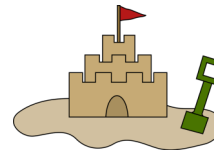
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PenCRU Newsletter July 2015, Issue 19



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Healthy Parent Carers project progressing

The idea for the Healthy Parent Carers programme came from discussions with the Family Faculty. It is recognised that parent carers have increased health risks and challenges to their wellbeing related to their caregiving role. Ola is leading the research, which aims to empower parent carers to take care of their own health and wellbeing. An intervention is being developed to provide parent carers with knowledge, skills and practical strategies they can adopt, and by encouraging health-promoting behaviours. The work is structured around the idea of 'CLANGERS' introduced in the book *'Staying Alive: How to get the best from the NHS'* by Dr Phil Hammond who regularly appears on TV and radio (<http://drphilhammond.com>). CLANGERS are a set of actions we can all take to promote our health and wellbeing. The actions are supported by evidence from research. **Connect** (with people around you), **Learn** (about new things and interests), be **Active**, **Notice** (the world around you), **Give** (to others and yourself), **Eat well**, **Rest** and **Sleep**. There are specific challenges for parent carers to adopt these strategies. Our Family Faculty have participated in several meetings to design the intervention and 'Healthy Parent Carers' resource. You can read more about this project at <http://ow.ly/QgJol>



What's the Evidence?

One of the things we do here at PenCRU is to answer parents' and professionals' questions about the evidence for treatments or therapies for disabled children. You can find the summaries we produce on our website: www.pencru.org/evidence/

We have recently updated our summary of the evidence for *Applied Behaviour Analysis* for children with autism. We are currently reviewing the evidence in response to a parent's question: *What interventions improve co-operation and reduce distress for disabled children having invasive medical procedures in hospital?*

If you would like to know more or have your own question about the evidence for a treatment or therapy, let us know: pencru@exeter.ac.uk

Advisory Group

A group of Family Faculty and staff met in mid-July to share ideas and discuss general operational issues. There was a special guest appearance from Katharine, our family involvement coordinator currently on maternity leave, and her lovely new son James! You can read the notes from this and any of our other meetings on our website: <http://ow.ly/PATex>

Nuffield Student Placement



PenCRU is very pleased to be able to participate in the Nuffield Research Placement scheme this year. The scheme matches students in the first year of a post-16 science, technology, engineering and maths (STEM) course with relevant research opportunities.

We are welcoming Chantelle O'Brien to the team. Chantelle is an A level student from Plymouth who is hoping to become a paediatrician in the future. She is with us for 4 weeks to learn more about child health research, and is working with Sharon to prepare a new 'What's the Evidence?' summary.

You can find out more about the Nuffield Foundation and the Research Placement Scheme on their website: www.nuffieldfoundation.org



Recent Publications



Evaluating evidence for strategies to reduce the impact of ADHD in the classroom

Children with ADHD are typically restless and often struggle to concentrate in classrooms. A report, evaluating the evidence for strategies to reduce the impact of ADHD in the classroom, has been published in the [NIHR Library](#) and is free to access. A parent from the [PenCRU Family Faculty](#) was involved initially as a co-applicant when we applied for funding, and then throughout as a member of the research team interpreting the findings. The project found that children with ADHD may well be successfully supported in classrooms through strategies that do not involve drugs. However, so many different types of strategies have been evaluated, combined in different ways, and different outcomes measured, that it is not currently possible to identify which strategies work best. The review also examined research about attitudes and experiences of children, teachers, parents and others using ADHD interventions in school settings. This part of the review highlighted how differences in beliefs can create tensions in relationships between teachers, pupils and parents.

Meaningful health outcomes for paediatric neurodisability: Stakeholder prioritisation and appropriateness of patient reported outcome measures.

In order to judge if particular treatments and interventions are effective, we need suitable ways to measure whether outcomes for disabled children are improving. One way to do this is to use patient questionnaires to assess key aspects of health. However, to be meaningful, the outcomes measured need to be things patients and clinicians consider important. The aim of our CHUMs project was to prioritise a list of key aspects of health, and identify existing patient-reported outcome measures (PROMs) that measure these outcomes. An academic paper describing the last stage of the research has just been [published in Health and Quality of Life Outcomes](#) and is free to access, there is also a [plain language summary](#) available on our website. The aspects of health agreed to be most important were: communication, emotional wellbeing, pain, sleep, mobility, self-care, independence, mental health, community and social life, behavior, toileting and safety.