

## Upcoming PenCRU meetings:

Listed below are the currently scheduled meetings, please check our website for future dates. If you would like to come along to any of these then please get in touch. If you cannot attend a meeting but would still like to contribute, please do let us know.

Please note we are moving offices in April to St Luke's campus. The meetings below will be held there.



Meeting	Date	Time
Designing a new dynamic specialised seating system	Wednesday 29th April	10.00—12.30, followed by lunch
Catch-Ups (children with ADHD in transition from children's to adult services)	Tuesday 12th May	10.00—12.30, followed by lunch
Healthy Parent Carers	tbc	tbc
Dental Care for Children with ASD	tbc	tbc

## Contact the team

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PenCRU staff and Family Faculty members



PenCRU Newsletter  
April 2015, Issue 18



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## New project: Dental care for children with ASD

PenCRU are excited to be leading the involvement of families in a new project with the Peninsula Dental School (Plymouth University). This project builds on significant interest from families about oral health and dentistry. The project aim is to:

**Identify key strategies to improve access to general dental care for children with autism spectrum disorders in the prevention of dental caries (tooth decay).**

*"I am a Dental Hygienist and a mother of a three year old son with additional needs associated with autism. It isn't until you experience something first hand that you can truly understand the struggles of others; only now being a parent of a child with additional needs can I fully empathise with how oral hygiene is one of the big challenges parents of ASD children have to face with personal care. I personally feel there is a lot that can be improved in general dental services for children with ASD and this will hopefully be a great starting point to making those changes".*

- Nicole Thomas, project lead.

Nicole has secured funding from *Colgate and The Oral & Dental Research Trust*. Later in the year we will be looking for Family Faculty members to be involved as partners to assist with key stages in the project. Do let us know if this is of interest to you! Get in touch: [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

[www.pencru.org](http://www.pencru.org)

Katharine, our Family Involvement Coordinator, will be going on maternity leave in April. Kath Maguire will be taking on some of the role of Family Involvement Coordinator while Katharine is away.

## Staff News



### Meet the new members of the PenCRU team!



Kath is an Associate Research Fellow in public involvement. After 20 years caring for a chronically ill child she completed an Access course and went on to study social and political sciences at university. After volunteering as a lay reviewer she joined the PenCLAHRC public and patient involvement group (PenPIG), similar to our Family Faculty. Since then Kath has completed a PhD study of public and patient involvement in health research and joined the patient and public involvement team staff. Kath is particularly interested in making sure that service users and members of the public are supported to access research evidence, and that research is done to address the questions that matter to them. She lives in Cornwall, working half the week in Exeter and half in Truro. This leaves little time for hobbies – but when work is such fun, who needs a hobby?

### This month we also welcome Aleksander Borek to the PenCRU team



Aleksandra (Ola) has recently joined PenCRU as Associate Research Fellow. Her PhD work in the Psychology Applied to Health (PAH) group here in the Medical School focused on how groups work in health interventions. The main part of her role in PenCRU is to develop a pilot intervention that would offer health and support groups for parent carers (so far called Healthy Parent Carers). If you'd like to get involved with this project please get in touch with Ola on [a.borek@exeter.ac.uk](mailto:a.borek@exeter.ac.uk).

### Recent Publications

We have recently had 5 papers published in academic journals. Plain Language Summaries of these papers are available here: <http://ow.ly/LqBeT>

- ⇒ Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership. The full paper is available here: <http://ow.ly/LqzOo>.
- ⇒ A Systematic Review of Generic Multidimensional Patient-Reported Outcome Measures for Children, Part I: Descriptive Characteristics. The full paper is available here: <http://ow.ly/LqzWo>
- ⇒ A Systematic Review of Generic Multidimensional Patient-Reported Outcome Measures for Children, Part II: Evaluation of Psychometric Performance of English-Language Versions in a General Population. The full paper is available here: <http://ow.ly/LqA2H>
- ⇒ Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study.
- ⇒ Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study.

We have also published the full report from the peer support project.

- ⇒ What are the benefits and costs of providing peer support to parents of disabled children? The report is accessible here: <http://ow.ly/LqB69>

### PenCRU and Family Faculty Handbook

We have a new handbook which has been produced jointly by PenCRU and members of the Family Faculty.

The Handbook is a clear statement about who we are and how PenCRU and the Family Faculty work together. Thank you to all the Family Faculty members who contributed! The handbook can be found here: <http://ow.ly/LqBqP>

