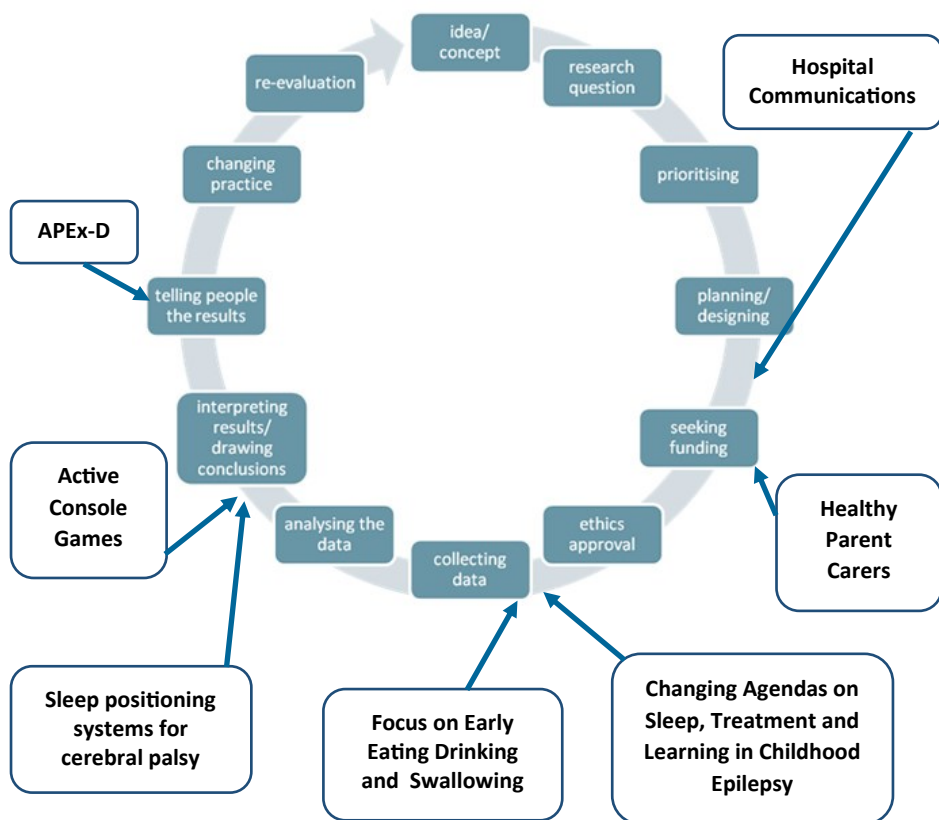


## Update on other research project status



Find out more about the above research projects on our [website](#).

### Contact the team

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PenCRU Newsletter  
July 2017, Issue 25



### Inside this issue:

- > New and continuing projects
- > New What's the Evidence?
- > EACD 2017 conference
- > Family Fun Day

### New working group: Improving Continence

The National Institute for Health Research (NIHR) is commissioning research to look at the evidence for interventions to improve continence in children with neurodisability. We are putting together an Expression of Interest application to carry out the study with several clinical specialists in the topic. We have created a Family Faculty working group and their first meeting was held in June. This was very helpful for planning how we will approach the research if we are funded. We will find out in the autumn whether the NIHR invite us to submit a full application.

### Healthy Parent Carers project update

We're continuing with our [Healthy Parent Carers project](#). You may recall we've run the programme as a 6 week course once. Now we want to see if it can be replicated more widely. An application to fund the next stage is about to be submitted. Gretchen has done a fabulous job bringing this together! In June we held a meeting with parent carer forums, public health specialists, school and charity representatives to collaborate with us on this project. In July the Family Faculty project working group met to discuss the application. You can read the meeting notes [here](#).

### Family Fun Day 2017 in September

The annual Family Fun Day is our way of saying thank you to members of the Family Faculty. At the end of September we're going to be heading to [Wildwood Escot](#) for this year's event! More details will follow.

## New What's the Evidence? summaries

- ⇒ One What's the Evidence? looked at [Functional Electrical Stimulation](#) to improve gait for children with cerebral palsy.
- ⇒ Another recent summary reviewed the evidence for interventions for [improving social skills of young adults with autism](#).

## Cerebra Head Awareness Week

3-8th July saw the return of Head Awareness Week! The PenCRU team, Family Faculty members and colleagues wore silly headwear to raise awareness of Cerebra. Together we raised £112.75!



## CATCh-uS project update

The [CATCh-uS Project](#) looking at transition for young people with ADHD is now around the mid-way point. The first round of the surveillance study, where clinicians informed us of patient numbers, ended in November 2016. We have conducted 130 interviews with young people, their parents and clinicians; and the online survey, identifying adult ADHD services nationally, was open from June to December 2016.

We are incredibly grateful to the interviewees for giving up their valuable time to talk frankly with Anna and Helen; and their personal impressions of how services, and transition between them, works in practice has been invaluable to us.

We received just under 1,500 responses to the mapping survey and we will be producing resources to let people know what is available nationally. The survey will also run again at the beginning of 2018 to see how, if at all, the provision has changed.

A group of parents of young people with ADHD have supported the project so far and **we would like to extend the invitation to join the working group to any other young people, or parents of 16-25 year olds, with a confirmed diagnosis of ADHD.** The group will be looking predominantly at ways we can use to share the information we have to make it useful and accessible to young people and families, as well as influence future service provision. If you think this opportunity might interest you please contact [catchadmin@exeter.ac.uk](mailto:catchadmin@exeter.ac.uk) Look out for updates via Twitter #catchusADHD as well as our [website](#); and please re-tweet and share!

## European Academy of Childhood Disability conference



In May, Chris, Stuart and four Family Faculty members travelled to Amsterdam to present at the [European Academy of Childhood Disability \(EACD\)](#) conference. Chris was invited to give a keynote speech on involving families in childhood disability research and prioritising research questions. He used videos of Family Faculty members to help describe their involvement and experiences of

being involved. You can watch the lecture online <http://edu.eacd.org/node/296>

Family Faculty members also participated in two symposiums to present about their experiences of being involved in research and how to enhance cooperation between parent carers, professionals and researchers.

We also presented a poster about the development of our Healthy Parent Carers programme. This was nominated for the Best Poster Prize (but unfortunately didn't win against stiff competition...) You can read the Family Faculty's accounts of their experiences of participating at the conference in their [blogs on our website](#).



## Hospital Communications project update

The [Hospital Communications](#) study is ongoing. This project is testing training we developed for hospital ward staff. The aim is to improve communication with disabled children in hospital. We delivered the training at the Royal Devon and Exeter Hospital. Next we want to deliver and evaluate the training in several other hospitals. Helen has put together an application for funding the next stage of the research. Helen has also been out liaising and visiting hospitals keen to try out the training. If your organisation would like to be involved please [contact us](#).