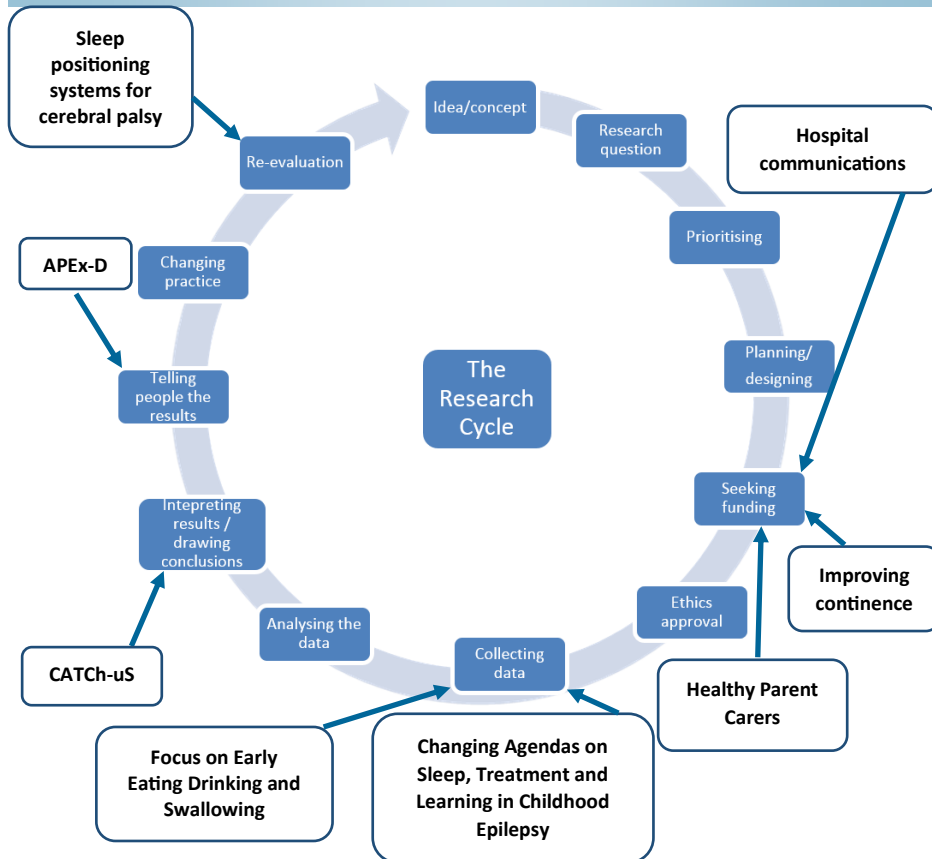


Update on other research project status



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

Contact the team

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PenCRU Newsletter
 March 2018, Issue 27



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Healthy Parent Carers paper published

The academic paper describing the first phase of our health promotion intervention for parents of disabled children - [Healthy Parent Carers](#) - has been published in the journal BMC Public Health. It is published 'Open Access' which means it is [freely available to read](#). There is also a plain language summary that will be added to other [summaries on our website](#). Our Healthy Parent Carers programme aims to improve parent carers' health and wellbeing by encouraging them to take time for themselves and through activities to promote empowerment, confidence, and resilience. The activities are called CLANGERS: Connect, Learn, be Active, Notice, Give, Eat well, Relax and Sleep.

In this paper we describe the development and theory behind the programme, and an initial study to test whether parent carers would participate and whether the programme could be delivered successfully. This enables us to say we have shown the intervention can work 'in principle'. We are proud of our two Family Faculty members who are co-authors. Bel and Mary were heavily involved in designing the programme utilising their years of experience of running peer support groups and training for befrienders. They delivered the sessions in the initial study and helped to refine the programme ready for the next stages. The study has benefitted from contributions from more than 40 members of our Family Faculty over the past 4 years. We are waiting to hear whether the next stage is funded.

CLANGERS



New *What's the Evidence?* summary

We have published a new *What's the Evidence?* summary.

Family Hope Center

This [evidence summary](#) reviews the evidence on whether Family Hope Center programmes help improve speech, movement, or independence in children and young people with neurodisability.

Key findings:

- Family Hope Center is a commercial American company that provides therapy for parents of children and young people with neurodisability.
- The therapy involves a training programme for parents to follow with their children. Typically, this aims to improve speech, movement, and/or learning. Treatment recommended is different for each child.
- We did not find evidence that the Family Hope Center programme is effective for improving speech, movement, or independence in children or young people with neurodisability beyond what could be expected due to development or recovery from brain injury alone, or with standard therapy.



External meetings

Our team has been out and about meeting parent carer groups, special schools and professionals. In January, Silvia and Gretchen attended the Ellen Tinkham School parents evening to talk to parents about the work we do and how to get involved. Chris has been travelling to meet with research teams and healthcare professionals to discuss several ongoing research projects, including the [Hospital Communications project](#) at Bristol Children's Hospital and the [Focus on Early Eating, Drinking and Swallowing \(FEEDS\) project](#) with the team in Newcastle. In March, Silvia attended a Somerset Parent Carers Forum meeting to hear about 'burning issues' concerning Forum members and talk about how they can get involved.

Cerebra visit

In March, Cerebra's Tracy Elliott (Head of Research and Information) and Georgia Mappa (Cerebra Research Officer) visited us at PenCRU. This was a opportunity for us to update Tracy and Georgia on all that we've been up to in the last year that benefits from our funding from Cerebra. We outlined progress with several research projects including Healthy Parent Carers, Hospital Communications and CATCH-uS ADHD Transition studies. Two Family Faculty members shared their experiences of working with PenCRU. Tracy and Georgia shared an update about changes at Cerebra.



Welcome to Tanya Hynd, our new administrator

Tanya Hynd has joined the PenCRU team as our administrator. She has worked in Social Care and Health from the time she got her first job as a care assistant over 20 years ago. Tanya has a BSc Psychology degree and an Advanced Diploma in Integrative Counselling and has been living in Devon since she met her husband in 2006. Tanya has worked as a school counsellor and ran her own private practice until her second son came along in 2012. She then took a career break to focus on her two little boys and start a sewing business which is her own personal therapy.

Tanya has worked with Participation groups in Social Care and Health in many different settings and has been supporting the Patient & Public Involvement (PPI) team at the University of Exeter Medical School since 2016. Tanya is looking forward to supporting both the PenCRU team and the Family Faculty members and although she's met some members through her work with the PPI team, she is looking forward to meeting more!

