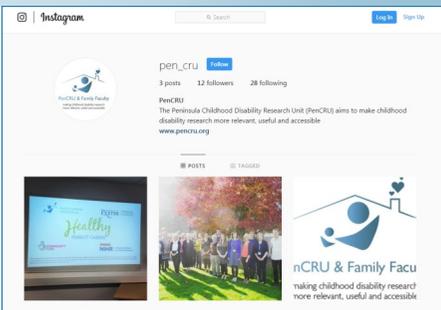


Follow us on Instagram!

Check out our brand new Instagram account!
We will be sharing news, uploading photos of PenCRU team and the Family Faculty engaged in research, images of relevant opportunities to get involved in and more.

https://www.instagram.com/pen_cru/

Follow [pen_cru](https://www.instagram.com/pen_cru/).



Autumn term dates for your diary

Date	Meeting	Who is this for?
Thursday 5th September 10am—2pm, St Luke's campus, Exeter.	PenCRU 10th birthday celebration!	All Family Faculty members welcome.
Saturday 5th October Location to be decided!	PenCRU Family Fun Day	All family Faculty members and their families welcome.
Wednesday 9th October 10am—1pm, St Luke's campus, Exeter.	Healthy Parent Carers working group meeting	Members of the Healthy Parent Carers working group only.

Contact the team

Email: pencru@exeter.ac.uk

Phone: 01392 722968

Website: www.pencru.org

Address: PenCRU, University of Exeter Medical School, South Cloisters, St Luke's Campus, Exeter, EX1 2LU

Find us on Facebook:

www.facebook.com/Pencru



Twitter: www.twitter.com/Pen_CRU



Instagram:

www.instagram.com/pen_cru/



PenCRU & Family Faculty

making childhood disability research more relevant, useful and accessible

PenCRU Newsletter
July 2019, Issue 30

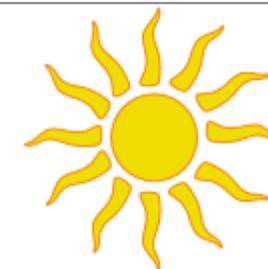


COLLEGE OF MEDICINE AND HEALTH



Inside this issue:

- > ICoN project: register now for the survey!
- > Healthy Parent Carers project update
- > Recent Publications
- > Autumn term dates for your diary



ICoN project

Find out more about the ICoN project inside this issue.

Please do share this ad with your friends and networks and look out for it on our Facebook, Twitter and check out **our new Instagram** account!

Recruiting now!

We are conducting an online survey about toileting with health professionals, parent/carers, young people and education and social care staff.

The NHS wants to improve toileting services for children and young people with special educational needs and disability aged up to 25 years. We need to gather the views and experiences of families, clinicians, and school and social care staff, to establish how toileting is managed currently. The results of the survey will help inform health and care services for children in the future.

For further information and to take part in the survey, visit:

<http://sites.exeter.ac.uk/iconstudy/taking-part/>



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Healthy Parent Carers project update

We have now delivered all the group sessions across the 6 sites for the Healthy Parent Carers project and participants are being asked to fill in the health and wellbeing questionnaire for the 2nd time. The feedback about the programme has been very positive on the whole and we look forward to sharing more details later in the year about delivering the programme when we have collected and analysed more data.



The programme was based on behaviours associated with better health and wellbeing and tailored for parent carers. The behaviours are called CLANGERS: Connect, Learn, be Active, Notice, Give, Eat well, Relax and Sleep. One of the group participants wrote a poem about CLANGERS and her experience of the programme. Thank you Rachel!

Oh Clangers!!

Connecting with myself and others is key,

Learning things to help me through life's journey.

Active routines are now a daily thing,

Noticing what is around me and the joy it can bring.

Giving to myself and being guilt free,

Eating well though is still tricky for me,

Relaxing and taking it one step at a time,

Sleeping well so life doesn't feel like a hilly climb.

Oh Clangers thank you for changing my life,

I'll always remember you through the troubles and strife.

by Rachel, Healthy Parent Carer Participant 2019

For more information about the project please see our website
<http://sites.exeter.ac.uk/healthyparentcarers/>

Improving Continence (ICoN) study



The ICoN study aims to find out how NHS staff assess and treat children with special educational needs and disability to help them become continent. Research to evaluate the ways to improve continence for children with special educational needs and disability

was in the top 10 [research priorities](#) as voted for by families and clinicians. It is really exciting that we have the opportunity to be addressing this often neglected topic in research that is central to the daily lives of children and families.

We want to hear from families, young people, NHS staff, and school and social care staff about their experiences. To take part in the survey go to <http://sites.exeter.ac.uk/iconstudy/taking-part/>



Recent Publications

Two separate academic papers published recently describe research led by colleagues at Sussex Community NHS Foundation Trust on which we have collaborated.

One paper describes research led by Dr Will Farr testing [feasibility of a randomised controlled trial design to evaluate home-based virtual reality therapy for children with cerebral palsy](#). The study suggested a definitive trial is feasible and that therapeutic use of Nintendo Wii Fit in-home was inexpensive and acceptable over periods of around six weeks.

The other paper describes research led by Dr Diane Sellers examining inter-observer [reliability of Eating and Drinking Ability Classification System \(EDACS\) for cerebral palsy](#) when used by speech and language therapists. The research also suggested that EDACS levels mostly stable over time. And that EDACS is best way to describe eating/drinking specifically.

A new scientific paper from our research programme Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy (CASTLE) has been published in the journal *Epilepsia*. The [paper describes development of a core outcome set for childhood epilepsy](#) is free to access.