



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

PenCRU Newsletter
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COLLEGE OF MEDICINE AND HEALTH



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Project Updates

Core Health Outcomes In Childhood Epilepsy (CHOICE) Study

Our CHOICE research on core outcomes for children with epilepsy has reached a conclusion. There have been three main outputs related to recommending the ways to evaluate treatments for children with epilepsy. The [latest paper](#) describes how we explored potential for measuring core outcomes for children with epilepsy using existing condition-specific health-related quality of life questionnaires. If researchers all measure the same most important outcomes in the same way, then we can bring findings together and use the research more efficiently. The other outputs and plain language summaries are on the [project page](#) on the website.

Improving Continence (ICoN) Study

We completed the analysis of the findings from the [surveys with families and professionals and the systematic review](#) earlier this year. We interpreted the findings with some of our Family Faculty and with our professional advisors from the charity ERIC. During lockdown the team met online a couple of times and completed writing and editing the final report (360 pages!) for the National Institute for Health Research. Chris has recorded a presentation about the study and key findings for the [ERIC conference](#).



Healthy Parent Carers programme

We completed the feasibility trial shortly before lockdown and were able to demonstrate that it was feasible to recruit and train facilitators and deliver the programme in the community. There was lots of interest and participants seemed to find the trial design acceptable. There are various barriers to accessing the programme that we still need to improve upon. There are some great videos describing the programme and participant's experiences on the website. <https://healthyparentcarers.org/news>

Over the summer we started the next phase with the charities *Contact* and *Council for Disabled Children* to pilot them delivering the programme. In the circumstances we are having to consider alternative ways to deliver the programme using Zoom, or a blended model incorporating a range of methods. Thank you to those of you who volunteered to be part of the trialling of the online programme. We have also secured Coronavirus Community Support Funding from The National Lottery Community Fund which will enable modification of the Healthy Parent Carers programme in consultation with our Family Faculty.

Share your ideas for research

Super opportunity to influence childhood disability research - the Childhood Neurological Conditions Research Priority Setting Partnership

This is your chance to shape the future of research into childhood neurological conditions. The British Paediatric Neurology Association and the James Lind Alliance are working together in a Priority Setting Partnership and need your help.

https://www.surveymonkey.co.uk/r/BPNA_JLA_RESEARCH_PSP

The aim is to shape future research by bringing together ideas from children and young people, their families, friends and professionals.

They are asking you to suggest your questions about treatments, therapies or procedures aimed at improving the health and wellbeing of children and young adults (aged 0-25 years) with neurological conditions.

Their childhood disability priority setting partnership, over 5 years ago, on behalf of British Academy of Childhood Disability ([BACD](#)) was hugely influential for focusing efforts on [priorities rated as of most importance to families](#) and professionals.



Latest publications from PenCRU

Check out the latest research from the team:

Mapping epilepsy-specific patient-reported outcome measures for children to a proposed core outcome set for childhood epilepsy.

<https://doi.org/10.1016/j.yebeh.2020.107372>

Public involvement in health research: what does 'good' look like in practice?

<https://doi.org/10.1186/s40900-020-0183-x>

Resources for parents raising a disabled child in the UK.

<http://doi.org/10.1016/j.paed.2016.04.019>

Community-based family and carer-support programmes for children with disabilities. <https://doi.org/10.1016/j.paed.2020.02.004>

If you have any difficulty accessing our scientific papers we can send you a copy, just email us: pencru@exeter.ac.uk

Payment Policy

Updated payment policy

In collaboration with our colleagues in the [PenARC Patient and Public Involvement in Research](#) team we've updated our 'acknowledgement' payment policy rates and taken account that these will be online at present.

- Casual meeting (no preparation required): **£15**
- Formal Meeting up to half day (requires some preparation work): **£30**
- Formal Meeting up to whole day (requiring some preparation work): **£60**
- Online Meetings (additional to above to cover data usage): **£5**

Family Fun Day



Ever feel like you're spinning plates? Unfortunately we weren't able to celebrate our annual Family Fun Day as we usually do at this time of year.

However we are cheered up by a photo of the wonderful Vinny enabling young people in our Family Faculty to achieve remarkable skills.

This newsletter should also have been emailed to you so you can view the links. If you didn't receive it, please let us know and we'll re-send.

Staff updates

All change

All change in the core PenCRU team once again. Gretchen is moving to a fabulous opportunity with the new NIHR ARC South West Peninsula (PenARC) [Children's health and maternity team](#) which also comes with a deserved promotion. We're pleased that Gretchen will still contribute her considerable experience and expertise to Healthy Parent Carers work. In her stead we've been joined in the summer by Alice Garrood who has moved internally within the medical school to project manage the next stage of the Healthy Parent Carers research programme.

Tanya Hynd has been our expert PenCRU administrator for several years is stepping down whilst continuing her role as administrator for our colleagues in the PenARC Patient and Public Involvement in Research team. We are pleased to welcome Fleur Boyle as our administrator who has joined us and experienced a slightly surreal induction without meeting us in person yet!

Katharine Fitzpatrick our fabulous Family Involvement Coordinator will return from maternity leave in the autumn but has let us know she will not be coming back to PenCRU. Katharine has joined the Global Challenges Research Fund, and will re-engage with former colleagues in geography, which was her PhD subject. We are delighted that we have just received funding from the Lottery Community Fund to support the role of Family Involvement Coordinator. More news on this in our next edition...



Alice



Fleur

Let's stay in touch

Our research wouldn't happen without you, our Family Faculty members. We love to hear from you, so do stay in touch via social media or email.

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