



JLA priority setting partnership workshop participants

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CHILDHOOD DISABILITY RESEARCH PRIORITIES - Top 10 published

PenCRU are part of the JLA Childhood Disability Research Priority Setting Partnership. The aim of the partnership was to bring patients, parent-carers and clinicians together to identify and prioritise unanswered research questions about the effectiveness of interventions aiming to improve the health of children and young people with neurodisability.

Through an online survey with families and clinicians, 700 topics were suggested for consideration. The suggested topics were sorted and grouped and then checked against existing research evidence to make sure the research questions suggested had not been answered before. Participants at a one-day workshop then agreed a top 10!

Workshop participants included three young people with neurodisability, seven parent carers, eight health professionals, three representatives from child disability charities and a disability advisor in education.

The Top 10 'shared priorities' for research, and other topics identified, are a resource to inform government and charitable agencies that commission and fund research.

Please use your networks to tell as many people as possible about the topics prioritised!

A summary of the research priorities

The top three shared research priorities related to :

- (i) establishing the optimal frequency and intensity (dose) for mainstream therapies,
- (ii) means for selecting and encouraging use of communication strategies, and
- (iii) ways to improve children's attitudes towards disability.

The top 10 included evaluating interventions to promote mobility, self-efficacy, mental health, continence, physical fitness, educational inclusion, and reduce the impacts of sleep disturbance.

You can read full details about the list of topics selected here:

<http://ow.ly/B4tAM>

"The final prioritisation genuinely reflected what families wanted and would make a difference to our children's lives." - Mary, National Network of Parent Carer Forums



We're on Film!

Cerebra, the charity that fund the core work of the Unit, have worked with us to produce a short video about what we do.

Thanks so much to the Family Faculty members who took part!

To see the video please go to the link below.
<https://www.youtube.com/watch?>

"The more people that there are involved, the better and more in-depth the research will be"

- Family Faculty member

PenCRU is 5 years old!

PenCRU was founded as the 'Cerebra Research Unit' in 2009, with launch events in Exeter and Plymouth. That means we're now 5 years old, and growing up (in some ways). PenCRU has been defined by and become a success because of, the involvement of families, so a BIG "Thank You" to everyone.

How would you like PenCRU to develop further? What would you like PenCRU to be aged 10 years? Do get involved where you can and be part of the 'us' – researchers, families and professionals working together to make research more relevant and useful to families' lives.

Recent Summaries of Evidence

A new 'What's the Evidence?' has been produced since the last newsletter:

Is therapy with horses effective to reduce symptoms and improve functioning for children with disabilities, particularly children with ADHD? <http://ow.ly/zUOpJ>



We also recently answered questions about the evidence for:

- Probiotics for children with Autistic Spectrum Disorder (ASD) <http://ow.ly/zUOFH>
- Cocoa for children with Tourette Syndrome <http://ow.ly/zUONw>
- Augmentative & Alternative Communication Systems, such as Makaton <http://ow.ly/zUOVE>

Do you have a question about a treatment or therapy that you would like us to answer? Get in touch pencru@exeter.ac.uk

You can see some examples of questions we have been asked and the outcomes of these questions on our website, alongside all our previous 'What's the Evidence?' reports at www.pencru.org/evidence/

Recent Publications

Morris C, Janssens A, Allard A, Thompson Coon J, Shilling V, Tomlinson R, Williams J, Fellowes A, Rogers M, Fellowes A, et al (2014). **Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting.** *Health Serv Deliv Res*, 15(2).

Janssens A, Williams J, Tomlinson R, Logan S, Morris C. (2014) **Health outcomes for children with neurodisability: what do professionals regard as primary targets?** *Arch Dis Child*. 2014 May 22. pii: archdischild-2013-305803. doi: 10.1136/archdischild-2013-305803. [Epub ahead of print]

Sharkey S, Lloyd C, Tomlinson R, Thomas E, Martin A, Logan S, Morris C. **Communicating with disabled children when inpatients: Barriers and facilitators identified by parents and professionals in a qualitative study.** *Health expectations* (Accepted, In Press).

PenCRU on Social Media

An important part of the research cycle is telling people about the results. In academic life, this is traditionally done by attending conferences but following a review of our online communications, we have started to engage more through Twitter and Facebook to raise awareness of PenCRU.



We have grown our followers on Twitter to 250 and other disability & research organisations are now re-tweeting some of our tweets to their followers. In July, this meant we had a potential audience of over 75,000 twitter users! We also have 85 likes on Facebook. Do you use Facebook or Twitter? Do check out our posts and let us know what you think.



Find us on Facebook
Facebook.com/



Join us on Twitter
pencru @pen_cru

Plain Language Summaries

Our Plain Language Summaries have been featured as an example of good practice by the National Institute for Health Research (NIHR) in their 'make it clear' campaign <http://ow.ly/zUSg6>.

These summaries are produced together with members of our Family Faculty to provide a shorter summary of the main points from our academic papers. Many thanks and congratulations to all those who have contributed to this success!

PenCRU Handbook

We are producing a PenCRU 'handbook' which will contain information about PenCRU and the Family Faculty. After reflecting on experience and discussions between parents and researchers in the last Building a Partnership and Advisory Group meetings, and now that we're more established and our ways of working have developed, we want the PenCRU and Family Faculty Handbook to be co-produced with families, setting out what PenCRU is and how we work together. The handbook will be a useful resource for both existing and new members.

If you are interested in joining a working group to discuss and develop ideas for the handbook

Engaging remote members

We know it's difficult for many members of the Family Faculty to attend meetings because of time, distance or work commitments and we are always pleased to hear ideas by email/ phone etc. However we'd like to do more. PenCRU is exploring ways to engage with our 'remote' members so everyone has the chance to contribute to our activities. Some of the options we will explore include a Facebook Forum, a YouTube Channel and Interactive email.

If you would like to be involved in helping us engage remote members, or have any other ideas of methods we could employ let us know.

Involving Children and Young People

An ongoing aim is to involve children and young people in the activities of PenCRU. We are currently building relations with local schools and groups and ran some sessions in schools last term.

We have a meeting scheduled in September with Young Devon and look forward to our potential future collaboration with them and others. Do you know of any group that might be interested in working with us? Would you be interested in designing the content for these meetings?

Staff News

New Family Involvement Coordinator!



Hi I'm Katharine and I joined PenCRU in June. Please feel free to get in contact k.fitzpatrick@exeter.ac.uk if you have any questions about how you can get involved.

Farewell Val and Meghan

Meghan left us in May to pursue a career in child psychology and we said cheerio to Val in June who has taken a research position at Sussex University in Brighton. We were very sorry to see them go and wish them both well for the future!



Upcoming PenCRU meetings:

Listed below are the upcoming meetings, please see our website for up-to-date information. If you would like to come along to any of these then please get in touch. We also welcome attendance via Skype or FaceTime and will be trialling other methods for engaging.

Meeting	Date	Time	Location
PenCRU and Family Faculty Handbook	Tuesday 14th October	10.00—12.30, followed by lunch	Veysey
Sleep Positioning Systems	tbc		Veysey
Computer Games	tbc		Veysey
Hospital Communications	tbc		Veysey
Healthy Parents	tbc		Veysey
PenCRU Advisory Group	Tuesday 2nd December	10.00—12.30, followed by	Veysey

Contact the team

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PenCRU staff and Family Faculty members after advisory group meeting