



PenCRU

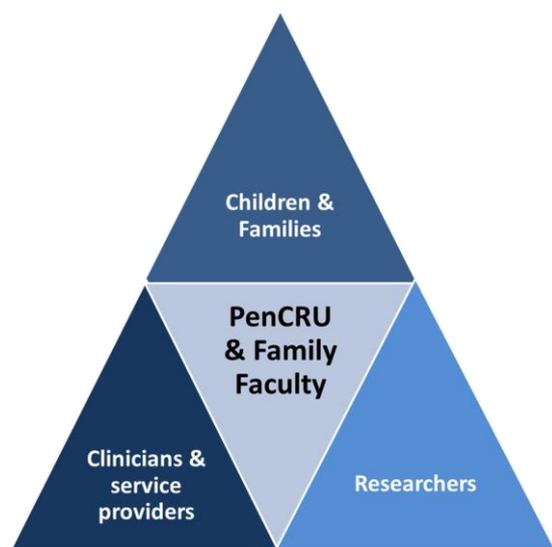
Childhood Disability Research



University of Exeter Medical School
Annual Report 2019

Contents

View from the Chair on 2019	2
Mission statement	3
How we are funded.....	3
PenCRU team	4
Team news updates	5
Family Faculty and community involvement	6
Accessible dissemination of research	8
Programme of research	9
Research capacity building - PhD students.....	12
Academic publications in 2019	13
Research Associates.....	14



View from the Chair on 2019



Welcome to the PenCRU Annual Report for 2019.

This year we celebrated 10 years of PenCRU's activities in childhood disability research at the University of Exeter. It is amazing to see how it has developed over the decade, benefitting from the input of so many people into a world-renown childhood disability research unit.

First, as always, I want to highlight our ongoing partnership with our Family Faculty. It is PenCRU's innovative approach and our model of family engagement in research that has attracted much international attention.

Partnerships with families and clinicians are central to the unit's approach to closing the gap between evidence, policy and practice.

We had a small but nonetheless super celebration for PenCRU's 10th birthday #PenCRUat10 with colleagues, particularly members of the PenARC Public Involvement Team and our pioneering first Family Involvement Coordinator, Camilla. We reflected on the journey and our shared desire to see things continue and flourish. Thanks to everyone who has contributed over the years.

Another personal triumph is Mary from our Family Faculty. We are simply so lucky to have Mary to work with us. She has transformed many of our bids before, and most notably in applying for re-funding on the Applied Research Collaboration where, at the interview, she blew the NIHR Panel away. Mary now has her own PhD project supervised by our Evidence Synthesis Team. Her thesis aims to develop new methods to ensure that evidence influences decision-making for one of the most pressing challenges resulting from an ageing population.

My favourite project, which makes it worth getting out of bed in the morning, is our Healthy Parent Carers programme. This research topic has developed with parents from inception to intervention development to evaluation, and hopefully, in the near future implementation. For me, this project exemplifies what PenCRU and health research is about and makes research feel worth doing. I literally welled up and cried at the launch event for the video of participants' reflections on what they got out of participating in the Healthy Parent Carers programme.

Must mention the 'poo study'. We had a meeting of the whole team recently and it felt wonderful to be in a room full of people who are so passionate about continence in kids with disabilities. I really feel that this research, driven by families and funded by the National Institute for Health Research, can help make a difference to one of the most basic elements of human function and dignity.

This year, having stepped down from 17 years in a senior management role in our medical school in September, I found time to engage in Twitter. I enjoy seeing and sharing the tweets of PenCRU and other work going on in Exeter and PenARC. One of the things we are proud of is our evidence summaries #WhatsTheEvidence. Although we are unable to produce new ones at the moment, the legacy of the summaries that are on our website are still useful. For instance, our evidence summary on effective ways to reduce distress and improve cooperation with invasive medical procedures for children with neurodisability addresses a hugely important and timeless issue in looking after children.

Professor Stuart Logan

Professor of Paediatric Epidemiology; Director, NIHR PenARC; Honorary Consultant Paediatrician, Royal Devon and Exeter Foundation NHS Trust

@ProfStuartL

Mission statement

PenCRU carries out a broad programme of applied health research that aims to improve the health and wellbeing of disabled children and their families.

The meaningful involvement of families affected by childhood disability in all aspects of our research and related activities is fundamental to the way the unit functions, and is central to our ethos. We encourage family involvement through our 'Family Faculty' and parents play a part in setting our research agenda and deciding how to carry out specific research projects. There are many examples of how families are involved in our work in this report.

In addition, we work in partnership with clinicians and agencies providing health, social and education services for children in Devon, Plymouth and Torbay. We also pursue research with colleagues engaged in childhood disability research across the UK and worldwide. We believe that the partnership between families, service providers and researchers is vital to improving the lives of people affected by disability.



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

How we are funded

From 2009 until autumn 2018 PenCRU benefited from funding from the charity Cerebra. The charity faced extreme income challenges and, with regret, we accepted the decision of Cerebra to terminate our research funding contract early. In the short term the University of Exeter Medical School has supported the unit whilst we seek alternative sources of funding to secure the future of the unit.

For major research projects we require substantive additional funding for which we apply to programmes operated by the NIHR, Medical Research Council and charities that fund research.

PenCRU has been successful in securing funding from National Institute for Health Research to support several major projects as chief or co-investigators. PenCRU also benefits from being integral to the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula (known as PenARC). We were also pleased to be funded by the Lottery Community Fund for the delivery of the Healthy Parent Carers programme.



FUNDED BY

NIHR | National Institute
for Health Research

PenCRU is an independent academic research unit at the University of Exeter Medical School. The views and opinions expressed by PenCRU in this report are those of the PenCRU team and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

PenCRU team



**Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPCH
Professor of Paediatric Epidemiology**

Stuart is an Honorary Consultant in Paediatrics in the Royal Devon and Exeter Hospital. His particular interest is the generation of research of direct relevance to policy and practice and useful to practitioners and to families. His major areas of research are the evaluation of complex interventions and the effects of social inequalities on child health.



**Chris Morris MSc DPhil
Associate Professor in Child Health Research**

Chris has previous clinical experience as an orthotist and expertise in health research methods and childhood disability research. Chris has provided academic leadership for PenCRU since 2009. His interests include appraisal of outcome measures and involving families in research.



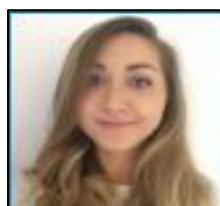
**Gretchen Bjornstad MSc, DPhil
Postdoctoral Research Associate in Child Health**

Gretchen's research background is in the evaluation of interventions for improving the health and well-being of children and families. She has also worked with children in residential treatment settings and as a family counsellor. Gretchen manages the Healthy Parent Carers project.



**Helen Eke MA, PhD
Postdoctoral Research Fellow in Child Health**

Helen previously worked as an Associate Research Fellow and PhD student on the CATchUS Study (Children and Adolescents with ADHD in Transition between Children's and Adult Services) and on the Healthy Lifestyles Programme (HeLP) and the Helping Children Achieve (HCA) study. Helen manages the Improving CoNtinence (ICoN) Study.



**Beth Cuffe-Fuller BSc (Hons)
Research Assistant**

Beth joined PenCRU in 2018 and is primarily working on the Healthy Parent Carers project. Prior to this, Beth was working as a frontline practitioner with children and families experiencing domestic abuse, as a training coordinator for a suicide prevention charity, and worked on a number of social research projects.



**Katharine Fitzpatrick BSc (Hons) PhD
Family Involvement Coordinator**

Katharine's academic background is in Physical Geography and she also has experience as a learning advisor for young people with learning disabilities and additional needs in a Further Education College. Her work focuses on widening participation of Family Faculty members.



**Tanya Hynd
PenCRU Team Administrator**

Tanya has a background in Service User Participation and is also trained as an Integrative Mental Health Counsellor. Tanya has been administrator to the PenCLAHRC Patient and Public Involvement Team and joined PenCRU in 2017. Tanya supports the smooth running of the team in multiple ways.

Team news updates



Our Family Involvement Coordinator Katharine Fitzpatrick has had another little boy called Conall, her third child. Her oldest son is featured on the front cover at our 2019 Family Fun Day.



Reluctantly we waved goodbye to Beth Cuffe-Fuller our Research Assistant who did so much to help with the setting up and running the Healthy Parent Carers project. Beth has decided to train as a Child Wellbeing Practitioner that works alongside or as part of NHS Children and Adult Mental Health Services (CAMHS). Although we miss her we suspect she will be very good at this role.



Annette Gillett joins us in January 2020 as a Research Assistant in Child Health to help with the Healthy Parent Carers project. Annette previously worked as an Academic Mentor at the Business School and prior to that her work focused on learning and development in health and social care, including roles in the local authority, NHS and a health charity. Annette originally trained as a nurse and has keen interest in programmes and interventions that support health and wellbeing. Annette is working on the Healthy Parent Carers project.



In December, we were very pleased to celebrate the achievement of Dr Helen Eke on the award of her PhD! Helen is currently working on our ICoN study that will describe NHS practice and summarise research evidence in relation to interventions aiming to improve continence for children and young people with neurodisability.

Family Faculty and community involvement

The ethos of the unit is to involve families in all aspects of our research and related activities. We achieve this through our Family Faculty which is made up of families of disabled children who are interested in our work. Our members are mainly parent carers living in Devon, or elsewhere in the South West, with a few from further afield.

Family Fun Day 2019

We had another great day, this year at Crealy Adventure Park. It is always lovely for us to meet the children of the families and say thank you to the members who have been involved in our work. It is also an opportunity for families to connect with each other. Vinnie entertained us all again with his amazing plate spinning skills!



Family Faculty and community involvement in the ICoN study



Our ICoN study Family Faculty working group has met regularly throughout the project. Members have contributed significantly to the content of the online surveys for parent carers and young people, and also helped shape the systematic review. Together with parents in the group and voiced by one of the members we produced a video about the ICoN project <https://vimeo.com/359251511>.

We also liaised with two young adults, a female with cerebral palsy who is profoundly deaf, and a male with cerebral palsy, who we consulted on different aspects of the study, such as the website content and the participant information sheets for the survey. Both of these members also piloted the young person's survey and offered feedback on the design and the questions asked.

The 'Pelican Project' is a local community group for young adults with disabilities that aims to assist them make a contribution to the community. A group of four young adults from the group met with us in the early stages of the ICoN study, assisted by their carers. The group were asked how we could access young people and encourage them to participate in the survey, and were also consulted about the information sheets for young people and the relevant study webpages for the survey.



We also convened a group of young people at a local special school with the help of an advocate. They were asked for their comments and feedback regarding the questions in the survey for young people, the language used, and how they might feel about answering personal questions on their toileting ability.



We were able to collaborate with the existing group of Professional Advisory Committee for ERIC, the children's bowel and bladder charity, who have diverse representation across key clinical specialties and education. The members doubled up as the Professional Advisory Group for the ICoN study, and provided extensive experience and knowledge informing the design and interpretation of the survey and systematic review.

Family Faculty and community involvement in Healthy Parent Carer Project

In November, we held an event for our Healthy Parent Carer Family Faculty working group and Stakeholders for the Healthy Parent Carers project. We celebrated completing delivery of the programme in six sites across the South West. It was a lovely event and it was brilliant to hear reflections from two of our Healthy Parent Carers facilitators. We also screened our new film, showing reflections from parent carers who took part <https://vimeo.com/376771910>. The event ended with a fantastic discussion about where to take the research next – and lunch.



Accessible dissemination of research

As well as doing research that is relevant and useful PenCRU aims to provide accessible information from research to help families and professionals. We try to help families seek out the best current evidence to help them in making decisions. The guide we produced for Cerebra on Finding and Appraising Information and Evidence on the Internet is still available online <https://cerebra.org.uk/download/finding-and-appraising-information-and-evidence-on-the-internet/>



What's the Evidence?

Reducing Distress & Improving Cooperation with Invasive Medical Procedures for Children with Neurodisability

- Evidence suggests that children require individualised approaches to reduce distress and improve their cooperation with invasive medical procedures.
- Research is needed to identify effective strategies to support children who have had a previous traumatic experience of invasive medical procedures.
- How professionals interpret the reasons for challenging behaviour is crucial. Strategies that parents use to manage children's behaviour can inform interventions to reduce distress.
- Introducing standard protocols for invasive procedures and sharing them with families empowers parents and professionals to know what good practice looks like.
- Wider changes to NHS policies are likely to improve children's experience of health care, but research is needed to see if they are implemented and effective.

Our hugely popular 'What's the Evidence?' summaries are designed to summarise existing research about specific questions raised by families. Unfortunately we are unable to produce new evidence summaries at the moment until we can secure further funding for this activity. There are over 40 summaries available on our website, which you can explore either by condition, through the A to Z list of therapies, or by searching using the search box <http://www.pencru.org/evidence/>

PenCRU produce plain language summaries of some of our academic publications. These are written first by researchers, and then edited with feedback from several families. An example this year was one from our epilepsy project about what is most important to measure in research for children with epilepsy. Look out for a new one coming soon on - which questionnaires are best to assess the health-related quality of life in children with epilepsy?

Plain English research summary



Finding out what is most important to measure in research for children with epilepsy

Key Points

- We reviewed published research and made a list of all the ways used to measure effects of epilepsy and whether treatments for epilepsy work. We grouped together any outcomes that are similar.
- Young people with epilepsy, parents and health professionals took part in an online survey. The survey asked them to rate which of the outcomes they thought are most important to measure in child epilepsy research.
- A smaller number of young people with epilepsy, parents and health professionals took part in a meeting to reach agreement about the most important ways to measure as outcomes in research.
- The 38 outcomes we agreed on are proposed as a 'core outcome set' of what should be measured in all child epilepsy research.



Keep up with all our activities and updates via social media:

Follow us on Twitter @Pen_CRU



Find us on Facebook @Pencru



Programme of research

The following pages describe our programme of research, and progress made in 2019.



[Healthy Parent Carers programme](#)

C. Morris, G. Bjornstad, A. Borek, M. Fredlund, A. McDonald, V. Berry, M. Tarrant, A. Hawton, J. Lloyd, O. Ukoumunne, K. Wilkinson, B. Cuffe-Fuller, A. Gillett, S. Logan.

This project is investigating a programme that aims to improve the health and wellbeing of parent carers. We are currently running a trial to see if the programme can be delivered in community settings and to prepare for a larger study to test whether it is effective for improving health and wellbeing.

The protocol for this study has been published in the journal *Pilot and Feasibility Studies*. It is available open access which means everyone can read the full text. A research protocol is a full description of the methods to be followed, and is used to monitor progress and evaluate outcomes. Publishing protocols enhances transparency and raises awareness of studies in progress. You can access the [published protocol here](#).



We have also produced a video to share some reflections of parent carers who have taken part in our study. You can see the video here: <https://vimeo.com/376771910>



[Improving continence for children and young people with neurodisability \(ICoN Study\)](#)

C. Morris, H. Eke, H. Hunt, J. Thompson Coon, R. Anderson, A. Wright, E. Hutton, J. Melluish, A. Allinson, J. Rogers, C. Lindsay, D. Richardson, N. Madden, S. Logan.

Research to evaluate ways to promote continence for children with neurodisability was ranked number 7 in a top 10 of research topics prioritised by young people with neurodisability, parent carers, charity representatives and clinicians. Subsequently NIHR commissioned a survey of practice and a systematic review of interventions to improve continence for children with neurodisability. The survey and systematic review have now been completed, we are integrating the findings of both studies and consulting stakeholders about the findings. Results of the study will be written in a report and available from summer 2020.



The research is funded by the [NIHR Health Technology Assessment programme](#)

[Changing Agendas on Sleep, Treatment and Learning in Epilepsy - A Long Term Condition of Children \(CASTLE\)](#)

D. Pal, P. Gringras, C. Morris, C. Dunkley, B. Carter, L. Bray, D. Hughes, L. Wiggs, J. Currier, D. Roberts, C. Tudor-Smith, H. Hickey, F. Gibbon, L. Smith, H. Hiscock, H. Gillard.

CASTLE

Changing Agendas on Sleep,
Treatment and Learning in Epilepsy

This programme of research is focusing on children with the most common type of epilepsy. Professors Deb Pal and Paul Gringras at King's College London lead the work. Inter-related studies will address uncertainties about drug treatment, reducing sleep disturbance, and knock on effects on learning, and promoting evidence-based practice using the findings.

PenCRU is leading the Core Health Outcomes In Child Epilepsy (CHOICE) Study with children, parents, doctors and nurses to identify the best ways to measure health and quality of life for children with rolandic epilepsy.

The research is funded by a [NIHR Programme Grant](#)

[Focus on Early Eating Drinking & Swallowing \(FEEDS\)](#)

J. Parr, L. Pennington, C. Morris, D. Sellers, J. Cadwgan, J. Kisler, D. Craig, C. Buswell, J. Thomas, C. Gibb, S. Lee, N. Mather, H. McConachie, A. Colver.



Focus on Early Eating, Drinking & Swallowing

This study identified which treatments are regularly recommended in the NHS, which types of improvement in eating and drinking are considered most important by parents and professionals, and how best to measure a child's progress. The research gathered information using focus groups and surveys with families and clinicians. We will also examine the published research to see what is known about the effectiveness of treatments to improve eating, drinking and swallowing. The aim is to make recommendations about how future studies should be designed and conducted. The final report was submitted to NIHR in 2019.

The research is being funded by the [NIHR Health Technology Assessment programme](#).

[The PROMOTE Study: Patient Reported Outcome Measures Online to Enhance Communication and Quality of Life after childhood brain tumour](#)

C. Kennedy, K. Bull, M. Grootenhuis, C. Morris D. Hargrave, D. Walker, C. Lioffi, A.S. Darlington.

This research is tested feasibility of using patient reported outcome measure questionnaires in outpatient clinics with children who have survived brain tumours as a way of shifting the focus of consultations towards families' priorities for quality of life. Professor Colin Kennedy at the University of Southampton leads the study.

This research is funded by [The Brain Tumour Charity](#)

[CATCH-uS - transition of young people with ADHD to adult services](#)

T. Ford, A. Janssens, A. Price, H. Eke, S. Logan and collaborators around the UK.



This project was the first national study examining the level of need, as well as practice and processes, around the transition of young people with ADHD into adult services. The study was led by Astrid Janssens, Tamsin Ford and Stuart Logan. Parent carers from our Family Faculty have helped to shape the design of this project and are meeting throughout the project to discuss and influence the processes. The

surveillance study, qualitative interviews, and the first round of the mapping study were completed in 2017. The project is completed and the final report will be published in 2020.

This project is funded by the NIHR [Health Services and Delivery Research programme](#)

[Cerebral visual impairment in primary school age children: prevalence, impact and effectiveness of support](#)

C. Williams, A. Pease, R. Watanabe, T. Goodenough, R. Clark, K. Fitzpatrick, C. Morris.



PenCRU is part of the team led by Dr Cathy Williams at Bristol University evaluating ways to help children with cerebral vision impairment. PenCRU advises on aspects of research methods and helps to involve families from our Family Faculty as partners in the research

The [CVI project](#) is funded by the NIHR through a Senior Research Fellowship held by Cathy Williams.

Prophylactic antibiotics to prevent recurrent lower respiratory tract infections (PARROT)

P. McNamara, H. Smallman, R. Lingam, M. Peak, J. Parr, L. Turner, J. Grigg, P. Williamson, D. Everett, C. Morris, D. Hughes, H. Hickey, A. Jones, D. Reddihough, K. Williams, M. Semple, P. Gringras, M. Wan, A. Chang.



This international multicentre randomised controlled trial will evaluate whether prophylactic antibiotics reduce hospital admissions for children with neurological impairments. The trial is led by colleagues at the University of Liverpool; PenCRU provides expertise on outcome measures and public involvement in the research with members of our Family.

The research is funded by the [NIHR Health Technology Assessment programme](#).

[Hospital Communications](#)

E. Thomas, R. Gumm, S. Blake, R. Tomlinson, C. Morris, S. Logan.

Improving children's experience of health care is a priority for the NHS. Disabled children are admitted to hospital more often than other children. This study involved parent carers, clinicians and researchers collaborating to develop and test a training package for health professionals to improve their communication with disabled children when they are inpatients. We tested the training in several hospitals around England. There remains scope for further evaluation and implementation.

The research was supported by [NIHR PenCLAHRC](#).

Research capacity building - PhD students

We are pleased to be supporting a growing number of allied health professionals who have approached PenCRU for advice or academic supervision when preparing their applications for NIHR / HEE Clinical Doctoral Research Fellowships with the NIHR Academy.

Completed in 2019 – Well done Jen, Helen and Harriet!

- Dr Jen McAnuff, NIHR / HEE Clinical Doctoral Research Fellow, University of Newcastle. Supporting participation in leisure in children aged 8-12 years with communication and mobility difficulties.
- Dr Helen Eke and Dr Harriet Hunt were awarded PhD at graduation in Exeter in December. Helen and Harriet are currently working on our ICoN study.

Ongoing

- Lesley Katchburian NIHR / HEE Clinical Doctoral Research Fellow, University College London & Clinical Specialist Physiotherapist in Neurodisability, Great Ormond Street Hospital
Use of Botulinum Toxin A in Ambulant Children with Cerebral Palsy
- Rachel Rapson NIHR / HEE Clinical Doctoral Research Fellow, Plymouth University & Clinical Manager Children and Learning Disability Physiotherapy Teams, Torbay
A novel interactive training device to improve walking Ability and quality of life for Children with CErebral Palsy Trial (ACCEPT study): A multi-centred feasibility RCT with an embedded qualitative study
- Marilyn Poole, NIHR / HEE Clinical Doctoral Research Fellow, University of Birmingham Senior Community Paediatric Physiotherapist, Birmingham
Developing interventions to reduce sedentary behaviour in non-ambulant children with long term disabilities
- Phillip Harniess, NIHR / HEE Clinical Doctoral Research Fellow, University College London & Senior Research Physiotherapist, Great Ormond Street Hospital
Optimising Parent Engagement with Early Intervention Physical Therapy for Their Infants with Emerging Cerebral Palsy

Chris Morris is a co-supervisor to two PhD students in other colleges at University of Exeter who started in 2019, both are allied health professionals and one in Canada:

- Javiera Salazar Rivera, Paediatric Occupational Therapist, Chile, Graduate School of Education, College of Social Sciences and International Studies
School-based occupational therapy interventions for children with special educational need or disability
- Fatema Shamsaddin, Paediatric Physiotherapist, Saudi Arabia, Sport and Health Sciences, College of Life and Environmental Sciences
Neuromuscular Functions and Adaptations Following Training in Children with Cerebral palsy
- Pegah Firouzeh, Department of Rehabilitation Medicine, University of Alberta
Evaluation of the Immediate Effects of Ankle Foot Orthoses on Function, Activity, and Participation of Young Children with Cerebral Palsy: A Mixed-Methods Study

Academic publications in 2019

- Eke H, Janssens A, Downs J, *et al.* (2019) How to measure the need for transition to adult services among young people with Attention Deficit Hyperactivity Disorder (ADHD): a comparison of surveillance versus case note review methods. *BMC Med Res Methodol* **19**, 179 [doi:10.1186/s12874-019-0820-y](https://doi.org/10.1186/s12874-019-0820-y)
- Bjornstad GJ, Sonthalia S, Rouse B, Timmons L, Whybra L, Axford N (2020). PROTOCOL: a comparison of the effectiveness of cognitive behavioural interventions based on delivery features for elevated symptoms of depression in adolescents. *Campbell Systematic Reviews*, **16**(1).
- Systematic review: measurement properties of patient-reported outcome measures evaluated with childhood brain tumor survivors or other acquired brain injury Kim Bull & Co (PROMOTE Study) *Neuro-Oncology Practice* <https://doi.org/10.1093/nop/npz064>
- Crudgington, H, Rogers, M, Morris, H, Gringras, P, Pal, DK, Morris, C. (2020) Epilepsy-specific patient-reported outcome measures of children's health-related quality of life: A systematic review of measurement properties. *Epilepsia*. 2020; 00: 1– 19. <https://doi.org/10.1111/epi.16430>
- Bjornstad G, Wilkinson K, Cuffe-Fuller B, Fitzpatrick K, Borek A, Ukoumunne OC, Hawton A, Tarrant M, Berry V, Lloyd J, McDonald A, Fredlund M, Rhodes S, Logan S & Christopher Morris (2019). Healthy Parent Carers peer-led group-based health promotion intervention for parent carers of disabled children: protocol for a feasibility study using a parallel group randomised controlled trial design. *Pilot and Feasibility Studies*, **5**(1). <https://doi.org/10.1186/s40814-019-0517-3>
- Crudgington H, Rogers M, Bray L, Carter B, Currier J, Dunkley C, Gibbon FM, Hughes D, Lyle S, Roberts D, et al (2019). Core Health Outcomes in Childhood Epilepsy (CHOICE): Development of a core outcome set using systematic review methods and a Delphi survey consensus. *Epilepsia*, **60**(5), 857-871. <https://doi.org/10.1111/epi.14735>
- Eke H, Ford T, Newlove-Delgado T, Price A, Young S, Ani C, Sayal K, Lynn RM, Paul M, Janssens A, et al (2019). Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. *Br J Psychiatry*, **1-7**. <https://doi.org/10.1192/bjp.2019.131>
- Farr WJ, Green D, Bremner S, Male I, Gage H, Bailey S, Speller S, Colville V, Jackson M, Memon A, et al (2019). Feasibility of a randomised controlled trial to evaluate home-based virtual reality therapy in children with cerebral palsy. *Disabil Rehabil*, **1-13**. <https://doi.org/10.1080/09638288.2019.1618400>
- Clarkson S, Charles JM, Saville CWN, Bjornstad GJ, Hutchings J (2019). Introducing KiVa school-based antibullying programme to the UK: a preliminary examination of effectiveness and programme cost. *School Psychology International* <https://doi.org/10.1177/0143034319841099>
- Humphreys G, King T, Jex J, Rogers M, Blake S, Thompson-Coon J, Morris C (2019). Sleep positioning systems for children and adults with a neurodisability: a systematic review. *British Journal of Occupational Therapy*, **82**(1), 5-14. <https://doi.org/10.1177/0308022618778254>
- Sellers D, Bryant E, Hunter A, Campbell V, Morris C (2019). The eating and drinking ability classification system for cerebral palsy: a study of reliability and stability over time. *J Pediatr Rehabil Med* <https://doi.org/10.3233/PRM-180581>
- Hunt H, Abbott R, Boddy K, Whear R, Wakely L, Bethel A, Morris C, Prosser S, Collinson A, Kurinczuk J, et al (2019). They've walked the walk": a systematic review of quantitative and qualitative evidence for parent-to-parent support for parents of babies in neonatal care. *Journal of Neonatal Nursing* <https://doi.org/10.1016/j.jnn.2019.03.011>
- Kandiyali R, Hawton A, Cabral C, Mytton J, Shilling V, Morris C, Ingram J (2019). Working with Patients and Members of the Public: Informing Health Economics in Child Health Research. *Pharmacoecoon Open*, **3**(2), 133-141. <https://doi.org/10.1007/s41669-018-0099-7>

Research Associates

PenCRU benefits from close collaboration with many colleagues in Exeter, UK and worldwide. The following are researchers and health professionals not from University of Exeter with whom we have collaborated substantively in 2019, or who lead projects on which we are coinvestigators:

- **Deb Pal PhD MRCP**

Professor of Paediatric Epilepsy, King's College London

- **Paul Gringras MBChB, MRCP**

Professor of Children's Sleep Medicine and Neurodisability

- **Bernie Carter SRN RSCN PGCE BSc (Hons) PhD**

Professor of Children's Nursing, Edge Hill University

- **Lucy Bray RN BA (Hons) MSc PhD**

Professor in Child Health Literacy, Edge Hill University

- **Colin Kennedy BA, MBBS, MD**

Professor in Neurology and Paediatrics, University of Southampton

- **Paul McNamara MBBS MRCPCH PhD**

Professor in Child Health, Honorary Consultant in Paediatric Respiratory Medicine

- **Jeremy Parr MB ChB MD**

Professor of Paediatric Neurodisability, University of Newcastle

- **Lindsay Pennington BSc MSc PhD**

Reader in Communication Disorders, University of Newcastle

- **Anne Wright MBBCh, MRCPCH, MSc**

Consultant Paediatrician, Children's Bladder Clinic, Evelina Children's Hospital

- **Cathy Williams BSc MBBS PhD FRCOphth.**

Reader in Paediatric Ophthalmology & NIHR Senior Research Fellow, University of Bristol

- **Aleksandra Borek BA (Hons) MA**

Qualitative Researcher in Behavioural Science, University of Oxford

- **Diane Sellers BA MA PhD MRCSLT**

Research Fellow & Speech and Language Therapist, Chailey Heritage Clinical Services

- **Dr Rebecca Gumm MB BS MRCPCH**

Paediatric Clinical Trials Research Fellow, Royal Devon & Exeter NHS Foundation Trust

PenCRU

University of Exeter Medical School

St Luke's Campus

Heavitree Road

Exeter, EX1 2LU

Email: pencru@exeter.ac.uk

Tel: +44 (0)1392 722968/6046

Website: www.pencru.org



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

