Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research

University of Exeter Medical School

Annual Report 2016

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View from the Cerebra Chair on 2016

The theme of this introduction to our seventh Annual Report is our desire to celebrate the involvement of families in PenCRU. We are so grateful and feel privileged that families continue to want to work with us given their busy and often complex lives.

Having families work with us completely changes the feel of doing research. This year I have had the pleasure of being with parents in research meetings, in interviews for new staff, and of course meeting their families at our Family Fun Day at Paignton Zoo. A highlight for me was the visit we hosted of some of the Cerebra staff and trustees. Several parents from the Family Faculty took part, talking to our visitors about research they have been involved in, what they got out of it, and how they enjoyed working with us.

It has also been gratifying to see the impact of some of our projects. Notably, the priority setting for childhood neurodisability research, which we carried out in collaboration with the James Lind Alliance and British Academy of Childhood Disability, appears to have had a major impact on research funded by the National Institute for Health Research. Commissioned and researcher-led projects, funded by the Health Technology Assessment and the Health Services and Delivery Research programmes, directly linked to topics that we prioritised with families and clinicians are now underway.

Our series of *What's the Evidence?* summaries, focusing on treatments and therapies that families and clinicians asked us about, continues to receive a lot of attention on our website. We assume that if one family asks about something then other families are probably also considering the same issue. It is also apparent that clinicians (like me) find these summaries useful too, as a way to discuss therapies with families in clinic. One such summary that stood out for me this year focused on ways to reduce distress and encourage cooperation when children have to undergo invasive medical procedures. Lots of practical tips gleaned from published research on this topic!

The PenCRU programme of research includes a diverse portfolio of studies, but all are addressing topics that attract families to want to be involved. Of particular interest to me is a programme focusing on improving parent carer health and wellbeing. This work has been driven by a number of members of the Family Faculty, working with PenCRU staff. Thus far we have completed a study to test the feasibility and acceptability of a new parent-led group intervention and are looking to take this work further this next year. Another highlight has been research work we are supporting, led by Nicole Thomas, mother of a child with autism and a dental hygienist, investigating experiences of families of children with autism using high street dentists, perhaps emblematic of the PenCRU ethos of family-focused research.

We are pleased to have succeeded in securing funding for new projects starting in 2017. These include research studies focusing on children with epilepsy, brain tumour survivors, and feeding issues for children with neurodisability. All of these are collaborative projects with research colleagues in universities across the UK, and are testament to the reputation of PenCRU expertise, particularly involving families as meaningful partners in research.

I hope you enjoy reading this year's report to find out more about our work.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

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 a key factor in 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.

How we are funded

Cerebra is a UK charity that aims to improve the lives of children and young people with brain-related and other neurological conditions. PenCRU is one of several academic centres to receive funding from the Cerebra charity. Professor Stuart Logan is the Cerebra Chair in Paediatric Epidemiology.

The charitable funding from Cerebra supports the core activities of the research unit, principally building partnerships with local families and service providers, identifying issues and research questions and reviewing the evidence, and then designing research studies to address these questions. PenCRU also receives support from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for the South West (PenCLAHRC). 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 NIHR to support various studies.

PenCRU is an independent academic research unit at the University of Exeter Medical School. The views and opinions expressed by PenCRU do not necessarily represent the views of the National Institute for Health Research or the Cerebra charity.

PenCRU team

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

Stuart is the Director of the Institute of Health Research at the University of Exeter Medical School and 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 on the effects of social inequalities on child health.

Chris Morris MSc DPhil
Senior Research Fellow in Child Health

Chris had 20 years clinical experience as an orthotist and now 18 years in childhood disability research. He was awarded Masters and Doctoral degrees by the University of Oxford for research about children with cerebral palsy. His main research interests include strategies to involve families in research, epidemiology, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

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 and strategies to involve children and young people.

Sharon Blake LLB (Hons) MA
Associate Research Fellow in Child Health

Sharon trained as a social worker and has worked with children and families across social care, fostering, youth offending, early years and youth action work with young people with disabilities. Her degrees are in Law and Social Studies and her research interests include listening to children, children's rights and integrated services.

Aleksandra Borek BA (Hons) MA
Associate Research Fellow in Child Health

Aleksandra (Ola) joined PenCRU in 2015 as an Associate Research Fellow to develop a group-based intervention for parent carers to improve health and wellbeing. Her PhD and postdoctoral work is in the Psychology Applied to Health (PAtH) group within the Medical School focuses on how groups work in health interventions.

Hannah Morris BMedSci, MSc
Associate Research Fellow in Child Health

Hannah's background is in public health, previously working on alcohol harm reduction and self-management for long term conditions. Hannah joined PenCRU in 2016 and focused on updating and reorganising our *What's the Evidence?* summaries.

Astrid Janssens BSc (Hons) MSc PhD
Senior Research Fellow in Child Health
Astrid has a Master's degree in Experimental Psychology and Anthropology, and a Doctorate in Medical Sciences. Her research background is in child and adolescent mental health and the organisation of services taking care of them. Astrid leads the CATCh-uS study evaluating transition to adult services for young people with ADHD.

Anna Stimson BA (Hons)
Research Administrator
Anna provides part-time administrative support to the unit. As a mother to three children (one with ASD), and a secondary school governor, she has an active interest in our work.

Nicole Thomas
Research Associate
Nicole is a Dental Hygienist and a mother of a son with additional needs associated with autism. Nicole is being supported by PenCRU to complete the APEx-D Autism Dentistry project.

Team news updates

Sharon Blake left PenCRU in September to pursue a postgraduate research degree with the Law Department of the university. However, Sharon continues to be a research associate with the unit and is supporting Nicole with her work on our APEx-D Autism Dentistry project. We are very grateful for all her contributions to the unit over the past couple of years.

Hannah joined this year and then began her maternity leave at the end of November and we wish her well of course as we await her news!

We interviewed for new researchers at the beginning of December and look forward to Dr Gretchen Bjornstad and Dr Helen Hambly joining us as Postdoctoral Research Associates in February 2017.

Family 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 parents living in Devon, or elsewhere in the south west, with a few from further afield.

Family Involvement in PenCRU activities

We held several project working group meetings in 2016 where we invited Family Faculty members to participate. These included meetings for the following research projects:

- CATCh-uS: ADHD Transition
- Cerebral Visual Impairment
- Healthy Parent Carers
- Mac Keith Press Handbook
- Oral Health and Dentistry
- Specialist Seating Systems

We also held a meeting specifically for our more experienced members to work with us on creating resources for the PenCRU website, to reflect on our engagement with the Family Faculty and to plan for upcoming conferences and meetings. Currently we have a core group of 12-15 Family Faculty members that attend project meetings regularly and other members that dip in and out when they can, in line with our code of flexible involvement to accommodate busy family lives.

We also have members who are unable to attend project meetings due to work commitments, distance to travel or various other reasons. However they contribute remotely to our work, for example by reviewing and commenting on plain language summaries and evidence summaries. We would like to thank everyone that has been involved in our research activities this year!

We have recently been piloting a new way of seeking feedback on our '*What's The Evidence?*' summaries. Members of our Family Faculty who express an interest in reviewing an evidence summary are now asked to complete a feedback form and are reimbursed £10 for their time. We prioritise Family Faculty reviewers who have direct experience of the summary subject and who are unable to attend project meetings to give them an opportunity to be involved in PenCRU research activities.

While our Family Involvement Coordinator, Katharine, was on maternity leave, one of our Family Faculty members, Jane Ring, worked with Dr Kath Maguire, a PenCLAHRC researcher, to consult Family Faculty members to explore how to improve the partnership. Jane also undertook a City and Guilds Award in Education and Training at Exeter College, supported by PenCLAHRC, to help develop her knowledge of inclusive learning. Using the information, Jane and Kath then developed and delivered 2 training workshops for PenCRU staff and the Family Faculty so they could work together more effectively.

> *"Being part of the Family Faculty has given me a different focus and a place where I am more that 'just a parent'. The philosophy of the team is that we are the experts and our voice, our experiences, can be used to influence the lives of disabled children and young people in the future through research". – Jane Ring, Family Faculty member.*

Katharine returned to work after maternity leave in July 2016 and was invited to attend several events in the community which helps us to understand issues that families are faced with in their day to day lives, and also gives us the opportunity to tell them about PenCRU and what we do. Many attendees were interested in PenCRU and Katharine was able to help encourage and support families to come and get involved in research. During Katharine's leave, Chris Morris and Hannah Morris attended events run by Devon Parent Carer Voice, to allow PenCRU to still be represented. In 2016 we welcomed 28 new members to the Family Faculty and we look forward to continuing and widening our involvement in 2017.

Staff recognition in public engagement

We were proud to see Sharon Blake awarded a University of Exeter Postgraduate and Early Career Engagement Award. These awards recognise and celebrate high quality public engagement undertaken by Postgraduate and Early Career Researchers.

Family Fun Day 2016

We had a brilliant day out in September at Paignton Zoo for our Annual Family Fun Day. The purpose of the day is to say thank you to members of the Family Faculty who have been involved in our work and to keep in touch with some members who we haven't seen for a while. 20 families joined us for the day and as usual the amazing Vinny was there to entertain us and get us juggling and spinning plates, much to everyone's delight, and a great day was had by all.

JOKER

Communicating about research

PenCRU aims to provide accessible information for professionals, families and people with brain injury and neurological disorders. We try to help families obtain the best current evidence to help them in making decisions. We want to involve families in setting the research agenda and enable active engagement of parents and young people in all aspects of the research process. We want to inform clinicians and commissioners about research findings to enable them to make their decisions based on evidence as well as their experience and family preferences.

What's the Evidence?

PenCRU responds to questions received directly from families and professionals about the effectiveness of treatments and therapies. To ensure that research evidence is available to families and practitioners in a form that is comprehensible and accessible we appraise and summarise the research available on a chosen topic in our '*What's the Evidence?*' summaries. We produce reports about both NHS and alternative therapies. The summaries are published electronically on our website and are widely accessed. They aim to help families make informed decisions about care for their child. We hear that some clinicians find them useful for directing parents to the evidence.

In 2016 we produced four new *What's The Evidence?* summaries. These summaries were all reviewed by both experts in the field and members of our Family Faculty. Our summaries are all published on our website and publicised through our Facebook and Twitter accounts.
You can read our new evidence summaries by clicking on the links below:

- Reducing distress and improving cooperation with invasive medical procedures for children with neurodisability
- Brain Surgery to Reduce Seizures in Children with Sturge-Weber Syndrome
- Psychotherapy and the Frankish model for children and young people with learning disabilities
- Speech and Language Therapy & Occupational Therapy for children and young people with autism and/or learning disabilities

We have also updated these summaries:

- Selective Dorsal Rhizotomy for children with cerebral palsy
- Probiotics for children with Autistic Spectrum Disorder
- Siblings of children with a disability

Following feedback from our Family Faculty, we have redesigned the *What's the Evidence?* pages on our website to improve navigation. We have categorised our summaries by both condition and in an A-Z format for therapies so that they can be browsed more easily. We have also revised the presentations of all our evidence summaries with the webpage for each topic providing a short bullet point overview of what we were asked and the key findings. For those that want to find out more details, a link is provided to a downloadable PDF document that provides the full report.

Social media

Over the past year we have continued to developing our online social networking to raise awareness of our work, build relationships with related individuals and organisations, and share ideas with others in the childhood disability research community. We have both a Twitter account and a Facebook page to communicate our news and link with others.

Twitter @Pen_CRU

This year we were pleased to exceed 1000 followers of our Twitter feed. A big Thank You to all our followers and those who engage with us to help to get our messages out and share information.

Our most popular tweets in 2016 ranged from amusing photos of the PenCRU team and other colleagues from the Exeter University Medical School participating in the Cerebra Head Awareness campaign, to information about the invasive medical procedures summary and resources for parents of disabled children publication.

Facebook

During 2016, we have also grown our Facebook audience from 143 ‘likes’ in January to 177 in December. Our Facebook page has continued to be used primarily to communicate directly with families, but we have also made efforts to network with other organisations through this channel. As well as posting our news, we post information we think will be helpful from other organisations such as Cerebra. This year we have focused on communicating directly with other organisations and replying to comments made on posts. Posts that were popular with people commenting and sharing include posts about resources, (such as CanChild ASD communication tool and resources for healthy parent carers), our ‘*What’s the Evidence*?’ summaries (the Sturge-Weber summary in particular), and posts about free local events. The Cerebra Head Awareness campaign photos also attracted a lot of views!

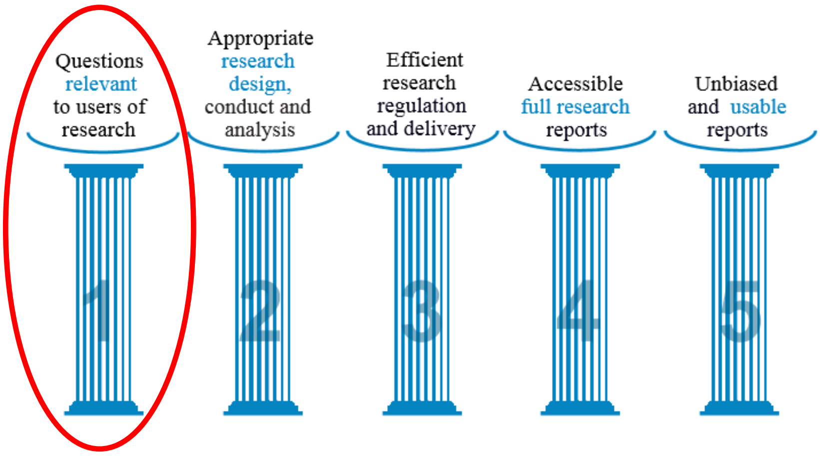
Featured

The new Healthcare Play Specialist Education Trust (HPSET) website have suggested a link to our ‘Reducing Distress & Improving Cooperation with Invasive Medical Procedures for Children with Neurodisability’ *What’s The Evidence?* summary: http://hpset.org.uk/publications/

Our Cochrane review of sleep positioning systems for children with Cerebral Palsy has been included as a reference on the main Cerebral Palsy Wikipedia page – in the assistive technology section: https://en.wikipedia.org/wiki/Cerebral_palsy

Chris Morris was invited by Cochrane UK to write a blog for their award-winning Evidently Cochrane series. The piece is titled Evidence for Everyday Orthotists. Chris reflects on his 20 years working as an orthotist and his experience in research. The blog is featured in their campaign Evidence for Everyday Allied Health (#EEAHP).

The JLA Childhood Disability Research Priority Setting Partnership project has been featured as an example of how the National Institute for Health Research is Adding Value In Research as a case study to illustrate that questions should be relevant for users of research.



Collaboration with Cerebra

PenCRU continued to enjoy working supportively with the team at Cerebra throughout the year.

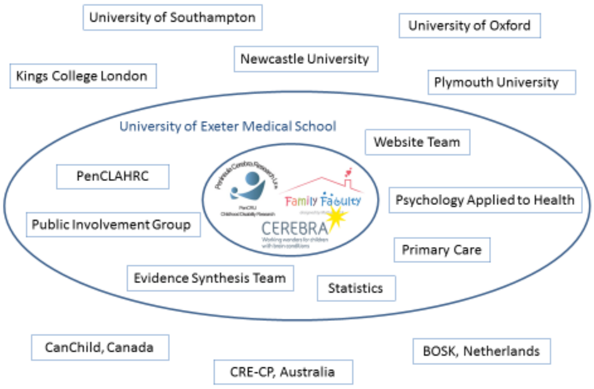
PenCRU was very pleased to be able to once again support a group of Family Faculty members to attend Cerebra's Annual Conference at the Royal Society of Medicine in London on 'Improving Mental Health and Well-being for Young People with Autism, ADHD and Learning Disabilities'. The conference was Chaired by Stuart Logan, and Tamsin Ford and Astrid Janssens presented details of the CATCh-uS project focusing on what happens to young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services.

In mid-June PenCRU welcomed Luke Clements, the Cerebra Professor of Law at Leeds University, alongside Beverley Hitchcock and Lisa Reakes from Cerebra, to run a session with members of the Family Faculty to demonstrate and gain feedback on their Problem-Solving Toolkit. 15 parent carers, and representatives of the local Scope and Contact a Family groups, came to learn more about the resource to support disabled people and carers who are encountering difficulties with the statutory agencies in relation to the provision of health, social care and education support services. We received very positive feedback from the parents who attended, with one informing us that she had subsequently used the Toolkit's documents to get additional support for her son to arrange an apprenticeship, that she had previously been told was impossible.

We had a lot of fun joining in with Cerebra's Head Awareness fundraising week in October, both wearing silly headwear ourselves and encouraging others to do likewise, while collecting donations. The photos (see above) that we shared via social media were very popular with our followers!

Katharine also attended a Cerebra sleep event in Exeter where she was able to see some of Cerebra's outreach work in action, and introduce PenCRU to more parent carers.

In December we hosted Cerebra's Head of Research & Education Tracy Elliot; Sleep Practitioner Sarah Coldrey; Legal Entitlements Development Officer Derek Tilley; Corporate Fundraiser Garth Owen and Chair of Trustees David Rose in Exeter to meet with members of the Family Faculty and the team. The parents who attended shared their experiences of working with PenCRU, and wowed everyone with their dedication and enthusiasm. We explained how the core funding from Cerebra for PenCRU enabled collaborative research across UK and worldwide.



Cerebra Chair, Professor Stuart Logan selected activities in 2016

- Appointed as NIHR Senior Investigator.
- Member of the Data Monitoring (and Ethics) Committee (DM(E)C) HTA Project: 13/88/11 - Efficacy, safety and impact on antimicrobial resistance of duration and dose of antibiotic treatment for children with Community-Acquired Pneumonia (CAP): a randomIsed controlled Trial - CAP-IT.
- Chair of the Trial Steering Committee and Data Monitoring (and Ethics) Committee NIHR funded MAGENTA study: The feasibility and acceptability of conducting a trial investigating the effectiveness and cost effectiveness of graded exercise therapy compared to activity management for paediatric CFS/ME: A feasibility randomised controlled trial
- Chair of the Trial Steering Committee NIHR EME - 13/119/18 - Preschool Autism Communication Trial - Generalised (PACT-G).
- Panel Member on our Policy Research Unit Commissioning Panel, Department of Health (DH) Policy Research Programme (PRP).
- Making Sense of Evidence lecture series for medical students Year 1 lecture: Becoming a good doctor: How to avoid harming your patients. Year 2 lecture: Knowing when and when not to order another diagnostic test.
- Convener and Chair NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Child Health research meeting.
- Keynote lecturer IVth Turkish National Congress of Social Pediatrics.
- Keynote lecturer NIHR Research Design Service National Grant Writing Retreat: The requirements of NIHR funding programmes.
- Keynote lecturer: Exeter Policing, Evidence and Research Translation Project Making Sense of Evidence and research workshop - Why evidence and research matter.
- Keynote lecturer: #CountMeIn! Conference 2016.
- Invited expert: Astellas Innovation Debate 2016: Situation Critical: Making Healthcare Fit for the Future
- Expert Advisor: Outcome Measures for Acute General Paediatric Services project, Royal College of Paediatrics and Child Health.
- Expert Advisor: Evaluation of strategies for supporting innovation in the NHS to improve quality and efficiency – DH Policy Research Programme.
- Expert Advisor: NIHR Themed Review on Pre-Hospital Emergency Care.
- Expert Advisor: NIHR research on improving the health of those receiving salary support from NIHR.
- Advisory Board of the Children’s Policy Research Unit, UCL Institute of Child Health.

Chris Morris selected activities in 2016

- British Academy of Childhood Disability, Executive Committee and South West Regional Representative.
- Steering Group member for James Lind Alliance Scoliosis Research Priority Setting Partnership.
- International Collaborator, CanChild Centre for Childhood Disability Research, McMaster University, Canada
- Advisor for Autistica/James Lind Alliance Autism: Top Ten Research Priorities project
- Trustee/Director for Mac Keith Press, publishers of leading childhood disability journal Developmental Medicine and Child Neurology and book series.
- Peer reviewer for NIHR Public Health Research panel, several journals
- Invited contributor, HealthWatch for Science and Integrity in Medicine, newsletter
- Invited speaker Centre for Child and Adolescent Health, School for Social and Community Medicine, University of Bristol: A workshop on developing PROMs for children.

Developing capacity in childhood disability research

PenCRU has been pleased to support several childhood disability researchers in the UK during 2016.

Lesley Katchburian is a NIHR Clinical Doctoral Research Fellow and Lead Clinical Specialist Physiotherapist (Neurodisability) at Great Ormond Street Hospital. Lesley's PhD research is titled: Understanding clinical and patient reported response of children and young people with Cerebral Palsy to Botulinum Toxin A: a longitudinal observational study.

Jennifer McAnuff is a NIHR Clinical Doctoral Research Fellow at the University of Newcastle and Clinical Lead Occupational Therapist, Leeds Community Healthcare NHS Trust. Jen's PhD research is titled: Supporting participation in leisure in children aged 8-12 years with communication and mobility limitations: **a**n intervention-development study.

We also supported two other applications for personal NIHR fellowship awards but unfortunately these were not successful in 2016.

Programme of research

The following pages describe our programme of research, and the progress we made in 2016.

Autism: Parent EXperiences of Dentistry (APEX-D)

N. Thomas, S. Blake, D. Moles, C. Morris

PenCRU and Professor David Moles at the Peninsula Dental School are supporting Nicole Thomas, a parent of a child with autism and a dental hygienist, to undertake her first qualitative research project. The project aims to identify key strategies to improve access to general dental care for children with autism spectrum disorders in the prevention of dental caries (tooth decay). This research has involved interviewing parents of primary school aged children with autism about their experiences of taking their child with autism for a dental examination. In 2016 the interviews and analyses were completed and the findings are being written up.

This project is funded by a Dental Care Professional Award from the Oral & Dental Research Trust.

Healthy Parent Carers programme

A. Borek, C. Morris, B. McDonald, M. Fredlund, S. Logan

Parent carers have increased risks of poorer mental and physical health. They prioritise the health and wellbeing of their children and their caregiving responsibilities, sometimes to the neglect of their own needs. Many parent carers don't feel empowered to look after their own health. Working closely with parent carers in our Family Faculty we developed a peer-led group-based intervention called the Healthy Parent Carers programme. The aim of the programme is to improve parent carers' health and wellbeing by promoting empowerment, confidence, and resilience. In 2016 we evaluated the feasibility and acceptability of the programme.

The work is supported by PenCLAHRC and the charity, Cerebra.

Hospital Communications

E. Thomas, R. Gumm, S. Blake, R. Tomlinson, S. Sharkey, 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 involves parents, 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 used information from our systematic review and qualitative study to develop a training package for health professionals. Parents from our Family Faculty were involved in designing and delivering the intervention. The training was delivered on five occasions in 2015, and refined each time based on feedback and reflections. In 2016 the procedures have been documented in a manual to enable the training to be replicated by others and a paper has been drafted describing the development and preliminary evaluation of the intervention.

The research was funded by NIHR PenCLAHRC and a 'small grant' from the Royal Devon and Exeter NHS Foundation Trust held by paediatricians Dr Eleanor Thomas and Dr Rebecca Gumm.

Sleep positioning systems for children with cerebral palsy

G. Humphreys, T. King, J. Jex, S. Blake, M. Rogers, J. Thompson Coon, C. Morris

This research sought to find out if using a sleep positioning system helps children with cerebral palsy to be more comfortable in bed, reduces pain, improves sleep, prevents deformity, and avoids the need for surgery. Previously, we conducted two studies (i) we reviewed the available evidence from randomized controlled trials in a Cochrane Review, and (ii) we collaborated with colleagues in Sussex to conduct a randomised controlled trial to identify whether clinicians and families will participate in a trial. Both of these studies are now completed. In 2016 Ginny Humphreys led a wider-ranging systematic review that sought evidence across other neurodisability conditions in children and adults and included studies that were not eligible for inclusion in the Cochrane Review.

PenCLAHRC and Cerebra supported the systematic reviews, the randomised controlled trial was funded by the NIHR Research for Patient Benefit (RfPB) programme.

Specialist seating for children with whole body dystonia

T. Adlam, N. McQuaid, K, Martin, C. Morris, A. Richardson

Some children with cerebral palsy and other conditions experience whole body spasms and find their posture and movement difficult to control. Currently, children with these difficulties are typically strapped into seating systems which limit their freedom of body movements. A team at Bath Institute of Medical Engineering, led by Dr Tim Adlam, is designing a new type of seat that moves with the child rather than restraining them. PenCRU convened two meetings in 2016 to enable Tim and the team consult with families about the design of the equipment.

The study is funded by the charity Sparks.

Supporting Teachers And childRen in Schools (STARS): a cluster randomised controlled trial

T. Ford, V. Edwards, C. Shotton, B. Norwich, S. Logan, O. Okoumunne, S. Byford, W. Pritchard, P. Jones

The STARS study is led by Professor Tamsin Ford in the Child Mental Health Research Group. STARS examines whether the Incredible Years Teacher Classroom Management course enhances teachers' skills in promoting socio-emotional well-being among their pupils and improves children's academic attainment and enjoyment of school. Cerebra Chair Stuart Logan and a parent from the PenCRU Family Faculty are involved. STARS is entering its final data collection for its last cohort – we will be spending the Spring term collecting data from 35 schools and are looking forward to analysing all our data and having our results in 2017.

The study is funded by the NIHR Public Health Research programme.

CATCh-uS - transition of young people with ADHD to adult services

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

This project is 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 is led by Astrid Janssens and Tamsin Ford, in the Child Mental Health Research Group, and Cerebra Chair 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 first round of the qualitative interviews, surveillance and mapping studies have been completed in 2016.

This project is funded by the NIHR Health Services and Delivery Research programme

Active Console Games

W. Farr, I. Male, S. Bailey, D. Green, C. Morris

This research theme is evaluating using active console games as therapy for children and young people with motor impairments. With clinical and research colleagues in Sussex and Oxford, we designed a study to test a method for evaluating a commercially available console game (Wii-Fit) with children with cerebral palsy. This research is a feasibility study to test whether the randomised controlled trial we designed is successful in terms of recruitment and processes, and whether the outcome measures work as expected. In 2016 recruitment was completed successfully and the participants were followed up. The analyses were completed and the report is being drafted.

The study is funded by the NIHR Research for Patient Benefit (RfPB) programme.

James Lind Alliance (JLA) Childhood Neurodisability Research Priority Setting Partnership

C. Morris, K. Cowan, M. Busk, A. Walker, A. Allard, M. Fenton, K. Robison, D. Simkiss

The JLA Childhood Disability Research Priority Setting Partnership successfully prioritised topics suggested by families and clinicians using the methods advocated by the James Lind Alliance. The work was completed in collaboration with the National Network of Parent Carer Forums, Council for Disabled Children and the British Academy of Childhood Disability. The project was completed in 2015, however further work on dissemination has led to a number of studies being funded by the NIHR Health Technology Assessment and the Health Services & Delivery Research programmes. The project is also featured as an example of how the National Institute for Health Research is Adding Value In Research. The first pillar of Adding Value In Research is ensuring that the questions being researched are those most important to patients, carers, the public and clinicians.

The project was supported by a grant from the Paul Polani Fund administered by the Royal College of Paediatrics and Child Health.

Cerebral visual impairment in primary school age children: prevalence, impact and effectiveness of support

C. Williams, A. Pease, S. Blake, K. Fitzpatrick, C. Morris

Children with brain-related (cerebral) visual impairment have difficulty seeing the world around them. The visual impairment underlying these problems can be hidden, as the child may appear to have good eyesight. It is not known how many children are affected by cerebral visual impairment (CVI). While it is recognised that some children are at increased risk of having CVI, especially children with cerebral palsy, there is not yet a good way to decide who needs to be assessed for CVI. This research is led by Dr Cathy Williams at Bristol University; PenCRU is part of the team with the specific role to involve families from our Family Faculty as partners in the research.

The study is funded by the NIHR through a Senior Research Fellowship held by Cathy Williams.

Promoting children's positive attitudes towards disability

M. Armstrong, M. Tarrant, O. Okoumunne, C. Abraham, C. Morris

This study sought to identify modifiable factors that affect children's attitudes towards disability. In this study we conducted a survey with over 1800 children across 20 mainstream schools in Devon. The analyses examined factors associated with children's attitudes to disability and the robustness of a commonly used questionnaire that measures children's attitudes towards disability. In 2016 Megan has led two publications from her thesis. One paper evaluated a commonly recommended questionnaire designed to measure children's attitudes towards disability; the other paper was a systematic review of the effectiveness of school-based interventions for improving children's attitudes towards disability through contact with people with disabilities.

This research was funded by NIHR PenCLAHRC through a PhD studentship held by Megan Armstrong (formerly MacMillan).

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. Liossi, A.S. Darlington

This research will test the 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. The study was approved for funding in 2016 and we have begun work on the systematic review to identify suitable patient reported outcome measures.

This research is funded by The Brain Tumour Charity

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

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

This programme of research is focusing on children with the most common types of epilepsy. Professor Deb Pal at King's College London leads the work, for which we secured funding in 2016 to begin next year. 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 a study with children, parents, doctors and nurses to choose the best ways to measure health and quality of life for children with epilepsy.

The research is being funded by a NIHR Programme Grant

What interventions, which could be delivered at home by parents, are available to improve eating in young children with neurodisability and are suitable for investigation in pragmatic trials?

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

This study was prompted by a commissioned call from the NIHR for research focusing on feeding interventions aiming to improve eating and drinking in young children with neurodisability. The research will involve qualitative research and surveys. It will begin in 2017.

The research is being funded by the NIHR Health Technology Assessment programme.

Academic publications

- Farr W, Green D, Male I, Morris C, Bailey S, Gage H, Speller S, Colville V, Jackson M, Bremner S, Memon A. Therapeutic potential and ownership of commercially available consoles in children with cerebral palsy. British Journal of Occupational Therapy (In press)

- Morris C, Blake S, Stimson A, Borek A, Maguire K (2016). Resources for parents raising a disabled child in the UK. Paediatrics and Child Health 26(9):406–408.

- Armstrong M, Morris C, Abraham C, Ukoumunne OC, Tarrant M (2016). Children's contact with people with disabilities and their attitudes towards disability: a cross-sectional study. Disability and Rehabilitation 38(9):879-888.

- Coon JT, Gwernan-Jones R, Moore D, Richardson M, Shotton C, Pritchard W, Morris C, Stein K, Ford T (2016). End-user involvement in a systematic review of quantitative and qualitative research of non-pharmacological interventions for attention deficit hyperactivity disorder delivered in school settings: reflections on the impacts and challenges. Health Expectations 19(5): 1084-1097.

- Armstrong M, Morris C, Abraham C, Tarrant M (2016). Interventions utilising contact with people with disabilities to improve children's attitudes towards disability: a systematic review and meta-analysis. Disability and Health Journal. doi.org/10.1016/j.dhjo.2016.10.003.

- Armstrong M, Morris C, Tarrant M, Abraham, Horton M (2016). Rasch analysis of the Chedoke–McMaster Attitudes towards Children with Handicaps scale. Disability and Rehabilitation doi.org/10.3109/09638288.2016.1140833.

- Janssens, A, Rogers, M, Gumm, R, Jenkinson, C, Tennant, A, Logan, S, Morris, C (2016). Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies. Dev Med Child Neurol, 58: 437–451.

Some key people we work with

We collaborate with a large number of colleagues at the University of Exeter Medical School and the University of Exeter, and also with NHS clinicians and people in other universities and organisations. The list below recognises some of the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2016.

Tamsin Ford MRCPsych PhD
Professor of Child and Adolescent Psychiatry
Tamsin is a child psychiatrist and collaborates closely with the unit on studies relating to child mental health and ADHD. Tamsin leads the STARS and Catch-uS projects.

Katrina Wyatt BSc (Hons) PhD
Professor of Health Services Research
Katrina advises the unit on methods for involving children, families and members of the public in research; and also research methods for promoting health.

Sarah Bailey BSc (Hons) MPH PhD
Research Fellow in Primary Care
Sarah is a former member of the PenCRU team and is still involved in our trial evaluating the Wii Fit as a therapeutic intervention. Sarah has also been exploring the potential of using the Clinical Practice Research Database as a means to evaluate the health of parent carers.

Mark Tarrant BA (Hons) PhD
Senior Lecturer in Human Sciences
Mark is a social psychologist and works with us on the programme of work about social inclusion, specifically promoting positive attitudes towards childhood disability.

Kristin Liabo MSc PhD
PenCLAHRC Senior Research Fellow for Patient and Public Involvement
Kristin is a member of the PenCLAHRC Patient and Public Involvement Team, and has a background in childhood studies and systematic reviewing.

Kate Boddy BA MA MSc
PenCLAHRC Research Fellow for Patient and Public Involvement
Kate has expertise in systematic reviews and involving patients and members of the public in research.

Jo Thompson Coon BSc PhD
PenCLAHRC Senior Research Fellow in Evidence Synthesis
Jo has considerable expertise in evidence synthesis and has been working with us on several systematic reviews.

Morwenna Rogers MSc BSc
PenCLAHRC Information Specialist
Morwenna has been involved in several systematic reviews by helping us design and manage comprehensive searches of academic databases.

Annie Hawton BSc MSc
Research Fellow in Health Economics
Annie's interests span both psychology and health economics approaches. Annie has worked with PenCRU on the costing component of the peer support evaluation study.

Charles Abraham BA DPhil
Professor of Psychology Applied to Health
Charles is a behavioural scientist and practising health psychologist. He co-supervised Megan's PhD studies and advises on our Healthy Parent Carer programme.

Brahm Norwich MA MSc PhD
Professor of Educational Psychology and Special Educational Needs
Professor Norwich's broad area of interest is special needs and inclusive education. He is part of the team for the systematic review of school-based interventions for ADHD.

Local NHS staff, other universities and organisations

Eleanor Thomas BSc (Hons) MRCPCH
Consultant Paediatrician
Ellie specialises in community child health and has been particularly involved in the 'Communication in Hospital' study.

Rebecca Gumm BMBS MRCPCH
Paediatric Neurodisability Trainee
Rebecca has been leading the training for hospital staff, designed with parents' input, to improve communication with disabled children when they have to spend time on the ward.

Bel McDonald BEd (Hons)
Face2Face coordinator, Exeter, Mid and East Devon
Bel has considerable expertise in providing peer support and training and mentoring befrienders for the Face2Face service. Bel was involved in our peer support study, and is integral to developing and testing the feasibility of our Healthy Parent Carer programme.

Valerie Shilling BA (Hons) PhD CPsychol
Research Fellow, Sussex Health Outcomes, Research & Education in Cancer (SHORE-C)
Val is a former member of the PenCRU team and led out evaluation of peer support for parent carers of disabled children. Val initiated and now consults on our Healthy Parent Carer programme.

Diane Sellers BA MA PhD MRCSLT
Research Fellow & Speech and Language Therapist, Chailey Heritage Clinical Services
Diane is a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex. Diane led the development of the eating and drinking classification system for children with cerebral palsy.

Tim Adlam BEng (Hons) MSc PhD CEng MIMechE CSci MIPEM
Head of Mechanical Engineering, Designability & Visiting Research Fellow, University of Bath
Tim approached us to help with his research to develop appropriate seating systems for children with whole body extensor spasticity, particularly because of our ability to engage families.

William Farr PGCE MA NPQH PhD
Senior Research Fellow in Neurodisability/Psychology, Sussex Community NHS Trust
Will has a keen interest in technology application in health care, and leads the NIHR funded trial evaluating the Wii Fit as a therapeutic intervention for children with cerebral palsy.

Dido Green MSc PhD
Reader in Rehabilitation, Oxford Brookes University
Dido is an occupational therapist and experienced researcher in occupational therapy. Dido is a key collaborator on the trial evaluating the Wii Fit as a therapeutic intervention.

David Moles PhD BDS MSc MSc(Hons) DDPHRCS(Eng) MIHPE FHEA FFGDP(UK)
Professor of Oral Health Services Research, Peninsula Dental School, Plymouth University
David's experience and expertise is valuable in our collaborative research on oral health and dentistry for disabled children, and our APEX-D project on dentistry for children with autism.

Deb Pal PhD MRCP
Professor of Paediatric Epilepsy, King's College London
Deb leads a developing a programme of research to improve holistic care of children with the most common type of epilepsy.

Paul Gringras MBChB, MRCP
Professor of Children's Sleep Medicine and Neurodisability
Paul co-leads the developing research programme on epilepsy with Deb. Paul's focus is on improving sleep using behavioural interventions, and the effects on learning due to sleep disruption.

Paul McNamara MBBS MRCPCH PhD
Professor in Child Health, Honorary Consultant in Paediatric Respiratory Medicine
Paul has engaged PenCRU in the development of a proposal for a randomised controlled trial to evaluate the use of prophylactic antibiotics to prevent recurrent respiratory infections.

Colin Kennedy BA, MBBS, MD
Professor in Neurology and Paediatrics, University of Southampton
Colin leads the development of research on the individualised clinical use of patient reported outcome questionnaires with paediatric oncology survivors.

Jeremy Parr MB ChB MD
Senior Lecturer in Paediatric Neurodisability, University of Newcastle upon Tyne
Jeremy leads the new research programme evaluating interventions to improve eating and drinking for children with neurodisability.

Lindsay Pennington BSc MSc PhD
Senior Lecturer & Speech and Language Therapist
We collaborated with Lindsay to develop the Eating & Drinking Classification System (EDACS) and will work together on interventions to improve eating and drinking for children with neurodisability.

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

Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

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Family Faculty
designed by Matt aged 14