Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research

University of Exeter Medical School

Annual Report 2017

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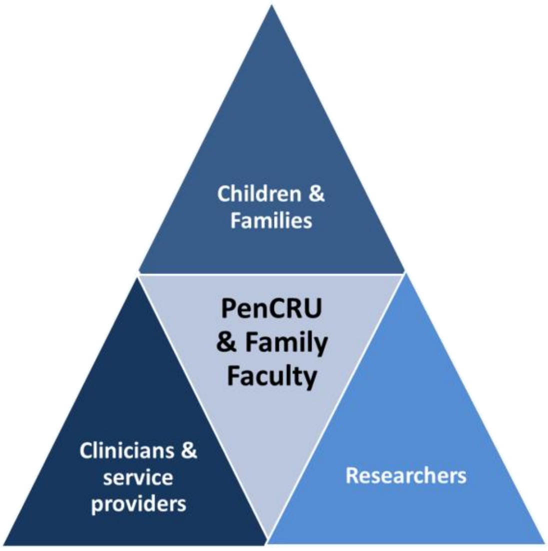
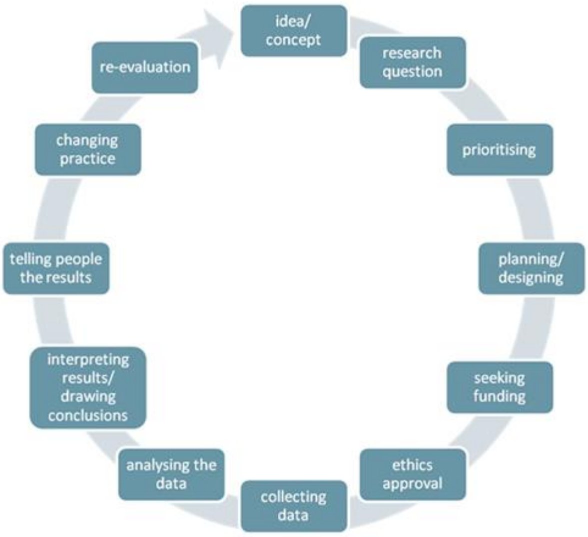




View from the Cerebra Chair on 2017

Welcome to our Annual Report for 2017. It has been another outstanding year for PenCRU and we are pleased to reflect on what we have accomplished and share what we have achieved. As ever, the thing I am most proud of is the way the families with disabled children who work with us in PenCRU are such fabulous partners in the research we carry out. The Family Faculty are the centre of all that we do at PenCRU and drive our success.

A massive highlight for me this year was participating with four members of our Family Faculty at the international conference European Academy of Childhood Disability. Chris Morris was invited to open the conference with a keynote presentation about involving families in research and prioritising research questions. Chris had prepared the presentation with members of the Family Faculty and incorporated video clips of them talking about examples of how they have been involved and their experiences of working with us. It blew many in the audience away as Chris described our approach to involving families in research. I may even have shed a tear! Parent carers from our Family Faculty each presented in person as part of two conference workshops and were great ambassadors for the unit. They were very much the stars of the conference. Our national and international reputation was also marked by colleagues from around the UK and Australia and Ireland asking to visit us to find out more about how we involve families. Next year we look forward to hosting visitors from the Netherlands who are keen to understand how to establish and maintain family involvement in childhood disability research.

The programme of research that the unit carries out continues to grow. One project close to the hearts of many in our Family Faculty is the Healthy Parent Carers programme. This is a peer-led, group-based intervention for parent carers that aims to improve their health and wellbeing by promoting empowerment, confidence, and resilience. We have co-developed the intervention over the past four years with parent carers in our Family Faculty and completed an initial study to test the principle. Our application for funding for a study to see whether the programme can be delivered in the community and whether it's feasible to evaluate the intervention in a randomised controlled trial was submitted this year and has been shortlisted, so we remain hopeful.

We remain proud of the James Lind Alliance research priority setting partnership that PenCRU staff led on behalf of the British Academy of Childhood Disability. At least two commissioned calls for research by the National Institute for Health Research were inspired by the research priorities we identified; these were powered mobility for very young children which ranked number 4, and improving continence for children and young people with neurodisability which was number 7 in the Top 10.

The PenCRU team is very proud to have supported Nicole Thomas, a parent of a child with autism and a dental hygienist, to complete her research examining the experience of parents taking children with autism for dental check-ups. The work has been published in the International Journal of Paediatric Dentistry and the video explaining the study and interpreting the findings in plain language is outstanding. Nicole has now taken up a PhD studentship at Peninsula Dental School.

PenCRU would not exist if it wasn't for the core funding we receive from the charity Cerebra. On behalf of the PenCRU team I want to say thank you to the Trustees and staff at Cerebra and all those who work hard to raise funding for Cerebra and thereby support childhood disability research.

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 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 research interests include strategies to involve families in research, epidemiology, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

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.

Helen Hambly BSc (Hons), MSc, PhD
Postdoctoral Research Associate in Child Health
Helen's research interests include communication in healthcare settings, listening to children's perspectives and support for children with speech, language and communication needs.

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.

Silvia Bortoli BA (Hons)
Family Involvement Coordinator – Maternity Cover
Silvia has previously worked for several policy institutes and think tanks. Her last role was on a project involving patients in health service improvement. Her work at PenCRU focuses on widening participation of Family Faculty members.

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 a research study about experiences of children with autism using high street dentists.

Katharine Fitzpatrick BSc (Hons) PhD
Family Involvement Coordinator – Maternity Leave
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.

Hannah Morris BMedSci, MSc
Associate Research Fellow in Child Health – Maternity Leave
Hannah's background is in public health, previously working on alcohol harm reduction and self-management for long term conditions. At PenCRU Hannah has worked on several of our *What's the Evidence?* summaries.

Team news updates

In February this year, we were pleased to recruit Dr Gretchen Bjornstad and Dr Helen Hambly as Postdoctoral Research Associate researchers. At the time Helen was moving to Cornwall and worked much of the time from the University of Exeter office in Truro. However, Helen has since found employment locally and left PenCRU in October 2017. We remain hugely grateful for Helen's contributions on our Communication in Hospital project and to our *What's the Evidence?* series.

Our Family Involvement Coordinator Katharine Fitzpatrick went on maternity leave in March. Her second child Naomi was born a few weeks later. Hannah, who went on maternity leave last year had her son Rupert earlier this year.

Silvia Bortoli joined us as maternity cover for the Family Involvement Coordinator role and continues to perform admirably in the interim.

In December, our lovely and super-organised administrator Anna Stimson left PenCRU to take on a new role as a Probation Service Officer and will be greatly missed. We are fortunate to have Tanya Hynd as our new administrator; Tanya also supports the PenCLAHRC Public Involvement Team.

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-specific working group meetings in 2017 where we invited Family Faculty members to participate. These included meetings for the following research projects:

- Autism: Parent EXperiences of Dentistry
- Cerebral Visual Impairment
- Healthy Parent Carers
- Hospital Communications
- CATCh-uS ADHD Transition
- Prophylactic antibiotics to prevent respiratory infections
- Improving Continence
- ‘What’s the Evidence?’ prioritisation

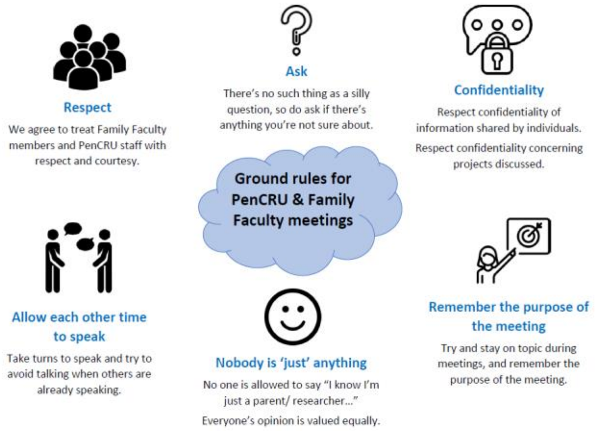
We established a new working group for a project looking at evidence for interventions to improve continence in children with neurodisability. The NIHR is commissioning this research, and in the autumn we submitted a full application to carry out the study with several clinical specialists in the topic. The Family Faculty working group meetings in June and October were very helpful for planning how we will approach the research if we are funded.

Some members 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. And also by sharing our information through social media (you know who you are). We would like to thank everyone that has been involved in all our research activities in various ways this year!

Katharine and Silvia attended several community events this year, including Devon Parent Carers Voice networking events, and North Devon Forum for Autism information day for families and professionals meet and greet event. In October, Silvia went along to the North Devon Forum for Autism coffee morning to present on PenCRU and how families can get involved.

At the end of 2017, we have 432 members of the Family Faculty and we look forward to continuing and widening our involvement in 2018.

We interviewed two Family Faculty members, asking them why they are involved in the PenCRU Family Faculty, and to give examples of how they have worked with us. These interviews were filmed and have been published on our website as ‘Parent voices videos’. These videos were promoted via Twitter and Facebook, and we plan to use these videos in conferences and community events.



Ground rules for PenCRU & Family Faculty meetings

Respect
We agree to treat Family Faculty members and PenCRU staff with respect and courtesy.

Ask
There's no such thing as a silly question, so do ask if there's anything you're not sure about.

Confidentiality
Respect confidentiality of information shared by individuals.
Respect confidentiality concerning projects discussed.

Allow each other time to speak
Take turns to speak and try to avoid talking when others are already speaking.

Nobody is 'just' anything
No one is allowed to say "I know I'm just a parent/ researcher..."
Everyone's opinion is valued equally.

Remember the purpose of the meeting
Try and stay on topic during meetings, and remember the purpose of the meeting.

Silvia created a 'Ground Rules for PenCRU and Family Faculty meetings' poster, which depicts the meeting ground rules contained in our Handbook in a creative and accessible way. These are now used at all PenCRU and Family Faculty meetings.

Conferences

In May, Chris, Stuart and four Family Faculty members travelled to Amsterdam to present at the European Academy of Childhood Disability (EACD) conference. Chris was invited to give a keynote speech on involving families in childhood disability research and prioritising research questions. He used videos of Family Faculty members to help describe their involvement and experiences of being involved. Family Faculty members also participated in two seminars to present about their experiences of being involved in research and how to enhance cooperation between parent carers, professionals and researchers. We also presented a poster about the development of our Healthy Parent Carers programme. This was nominated for the Best Poster Prize (but unfortunately didn't win against stiff competition...). You can read the Family Faculty's accounts of their experiences of participating at the conference in their blogs on our website.

In March, we were very pleased to be able to invite two members of the Family Faculty to meet with Zoe Gray, the Director of INVOLVE, on her recent visit to the University of Exeter Medical School. INVOLVE supports active public involvement in NHS, public health and social care research. Zoe was very interested to hear Jane and Karen share their stories of how they have added value to PenCRU research, and what they have gained personally through their participation.

Collaboration with the PenCLAHRC Patient and Public Involvement (PPI) team

We are currently working with Kristin Liabo, Kate Boddy and Heather Boult (PenCLAHRC Public Involvement Group PenPIG member) from PenCLAHRC PPI team, and Jenny Irvine and Neil Joseph (Public Reference Panel member) from North West Coast CLAHRC, to write a paper on what public involvement looks like in practice using our units as case studies. Our contribution is being led by one of our Family Faculty members. In June, we held a meeting with Family Faculty members to help inform our contribution, specifically discussing how the PenCRU Family Faculty is best described, what makes it work and what challenges we face.

PenCRU contributed to a joint response to the NIHR National Standards for Public Involvement in Research consultation, together with the PenCLAHRC PPI team and the European Centre for Environment & Human Health Public Engagement team. Four Family Faculty members attended a meeting during the summer, led by Kate Boddy, and provided feedback on the draft standards which informed our consultation response. Members of the Family Faculty were also encouraged to submit an individual response to the consultation.

Family Faculty development and trajectories

Two Family Faculty members co-produced and hosted a "Working Together" training workshop, alongside Emma Cockcroft from PenCLAHRC PPI team and a member of PenPIG. This workshop was intended to bring 'involvees' and researchers together to gain a better understanding of each other and the roles involved, and contained several exercises designed to identify and address potential barriers to involvement from both sides.

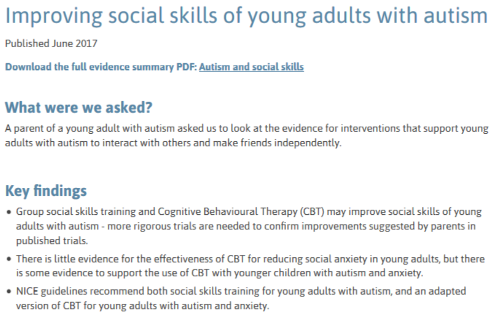
Another Family Faculty member has been successful in her application to become a Public Member for the NIHR Health Technology Assessment Programme Advisory Panels.

Family Fun Day 2017

We had a brilliant day out for our Annual Family Fun Day in September. This year we visited Wildwood Escot. 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 of the members who we haven't seen in a while. As usual the amazing Vinny was there to entertain us (supported at times by his young apprentice) and he got us juggling and spinning plates, in addition to talks about wolves (not as scary as might sound) and otters (very cute), and a great day was had by all. We did find ourselves lost in the maze for a slightly unsettlingly prolonged period at one point though!

Accessible dissemination of 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 have heard from our Family Faculty members that academic papers can be difficult to obtain information from, as they are often lengthy and time consuming to digest. Therefore, we produce both plain language summaries of our full academic papers, and standalone '*What's the Evidence?*' reports appraising and summarising the research available on a chosen topic, in response to questions received from families and clinicians. We produce reports about both NHS and alternative therapies. The summaries are published electronically on our website and are widely accessed.



Improving social skills of young adults with autism

Published June 2017

Download the full evidence summary PDF: Autism and social skills

What were we asked?

A parent of a young adult with autism asked us to look at the evidence for interventions that support young adults with autism to interact with others and make friends independently.

Key findings

- Group social skills training and Cognitive Behavioural Therapy (CBT) may improve social skills of young adults with autism - more rigorous trials are needed to confirm improvements suggested by parents in published trials.
- There is little evidence for the effectiveness of CBT for reducing social anxiety in young adults, but there is some evidence to support the use of CBT with younger children with autism and anxiety.
- NICE guidelines recommend both social skills training for young adults with autism, and an adapted version of CBT for young adults with autism and anxiety.

In 2017 we produced three new '*What's The Evidence?'* summaries. These summaries were all reviewed by both experts in the field and members of our Family Faculty.

You can read our new evidence summaries by clicking on the links below:

- Snowdrop for brain injured children
- FES to improve gait in children with cerebral palsy
- Improving social skills of young adults with autism

We have also produced two plain language summaries:

- Autism: Parent Experiences of Dentistry (APEx-D): Parent experiences of taking a child with autism for a dental check up
- Hospital Communications: Improving disabled children's experiences in hospital

Results from the Autism Experiences of Dentistry project were published in November. Full results were published in a paper in the International Journal of Paediatric Dentistry. To further disseminate the research findings, Nicole produced a creative and engaging video, which was promoted via social media. The video was also used as an example in the PenCLAHRC Creative Communications seminar series. The project was featured in several media channels such as Medical Press, and Nicole was also interviewed by Radio Plymouth about her work.

Alongside the PenCLAHRC PPI team, we co-produced and delivered a seminar on 'Public Involvement and Creative Communications', where we discussed how public involvement can help make research communications more creative. We presented our approach to producing our plain language summaries and *What's the Evidence*? summaries with our Family Faculty as a case study.

In 2017, PenCRU and our research activities have featured in Primary Times, a family magazine distributed through primary schools, and in the DiscPLUS newsletter.

Twitter @Pen_CRU

PenCRU has continued to share details of our own research projects and publications on Twitter, as well as retweet posts we think our followers will find interesting and relevant. At the end of December 2016 we had 1086 Twitter followers, and this has increased to over 1300 by the end of 2017. We discovered that using images on tweets increases their popularity and pictures of the PenCRU team and our colleagues participating in the Cerebra Head Awareness campaign have been our most popular tweets!

Facebook

During 2017, we have also grown our Facebook audience from 177 'likes' in January to 212 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. Posts that were popular with people commenting and sharing include posts about results on our Autism Parent Experiences of Dentistry (APEx-D) project being available, Disabled Children's Partnership survey to gather the views of disabled children and young people, photos from our Family Fun Day, and our '*What's the Evidence*?' summaries (the summary on improving social skills of young adults with autism in particular).

Our Cerebra Head Awareness campaign photos also attracted a lot of views!

External visitors

PenCRU has gained an international reputation as an exemplar for public involvement in research. This year we were visited by several researchers who wanted to learn more about how we work in partnership with parent carers and meet with our Family Faculty.

In May, we were visited by Margaret Wallen from the Australian Catholic University, Karen McConnell from Queen's University Belfast and Sheila McNeill from Leckey, who wanted to learn more about PenCRU and how we work with families. After the meeting, Margaret shared a thank you letter with the Family Faculty:

> *"It was such a pleasure and a privilege to learn from you and I felt so kindly and warmly welcomed. I found your experiences, wisdom, commitment and passion to family partnership in the research of PenCRU inspiring as well as practically incredibly helpful" – Margaret Wallen*

Jennifer McAnuff, an occupational therapist and PhD researcher based in Leeds Community NHS Trust and Newcastle University, is working on a project aiming to develop intervention strategies for supporting participation in leisure in children with communication and mobility difficulties. In September, Jennifer met with our Family Faculty to discuss her project and gather feedback.

The Eden Project is currently piloting a project called *'It's Great Outdoors'* investigating ways to support parents with young children to spend more time playing outside. They have developed a model that uses a variety of outdoors play activities that are organised by small family groups on a regular basis. In December, representatives from the Eden Project came to meet with members of the Family Faculty, and Katrina Wyatt and Jenny Lloyd from the Medical School Child Health team to share their approach and the activities, and to gather thoughts on how to make sure the activities are as inclusive as possible. In particular, Family Faculty members gave feedback on how to make the activities accessible and fun for children with neurodisability and their families.

Four Family Faculty members represented PenCRU at a meeting with the PenCLAHRC PPI team and public advisors and researchers from North Thames CLAHRC. The aim of this visit was for the groups to meet, learn from each other and to have preliminary discussions about potential joint work.

Cerebra Chair, Professor Stuart Logan selected activities in 2017

Conferences and Meetings

- Chaired session at the Children's Policy Research Unit conference: *Drawing on data to transform lives: improving services for vulnerable adolescents*
- 29th European Academy of Childhood Disability Conference 2017: Steps into the future
- University of Exeter Global Vision 2050 Workshops
- PenCLAHRC Making Sense of Health Research Plenary: Why do we need evidence based practice?
- Newcastle University: Neurodevelopment and Disability Research Day
- NIHR Workshop: Developing and Delivering NIHR Electronic Studies
- Co-hosted visit by Tim Gardam, Chief Executive, Nuffield Foundation, to University of Exeter
- Academy Health Annual Research meeting in New Orleans

Consultations

- NIHR Interview to inform the development of an NIHR wide communications strategy
- NIHR 'Health Futures' 20 year forward view
- NHS Improvement *Patient safety review and response: April to September 2016*
- External Advisor in the University of Birmingham's Vice-Chancellor's Integrated Review of the Institute of Applied Health Research

Education

- PhD external examiner: *The impact of suboptimal asthma control and adherence to medication on health-related outcomes for children with asthma*
- Chaired PhD Upgrade presentation: *Autism diagnosis as social process: an exploration of clinicians' diagnostic decision-making*
- Chaired PhD Upgrade presentation: *Health Service Transitions for Young People with Attention Deficit Hyperactivity Disorder: The Role of 'Information' and 'Service Availability' in the Transition Process*
- UEMS Graduate School Annual Research Event 2017
- UEMS Post-Graduate Researchers' induction
- Tutor for Making Sense of Evidence components of the BMBS undergraduate medical programme; Year 1: Making Sense of Evidence session for Qualitative Research. Year 3: Making Sense of Evidence: How to do a critical appraisal summary whilst on placement.

Memberships

- Research & Implementation Advisory Group of the National Group for Sustainable Development in Health & Care.
- University of Exeter Autism and Neurodiversity Group
- CLAHRC West External Advisory Group

PenCRU Academic Lead, Chris Morris selected activities in 2017

Conferences and Meetings

- Invited Keynote: Involving families in research & prioritising research questions 29th European Academy of Childhood Disability Conference 2017, Amsterdam, Netherlands http://edu.eacd.org/node/296
- British Academy of Childhood Disability Annual Scientific Meeting
- Steering Group member for James Lind Alliance Scoliosis Research Priority Setting Partnership.
- Newcastle University: Neurodevelopment and Disability Research Day

Consultations

- National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Chronic Neurodisability Study Advisory Group

Education

- Taught two modules on the British Academy of Childhood Disability Castang Foundation Neurodisability Research Fellowship workshops
- Independent Internal Examiner MSc Applied Health Services Research, University of Exeter

Memberships

- 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.
- British Academy of Childhood Disability, completed his term on the Executive Committee and South West Regional Representative.

Stuart, Chris and Family Faculty members at
European Academy of Childhood Disability 2017 conference

Programme of research

The following pages describe our programme of research, and progress made in 2017.

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 supported Nicole Thomas, a parent of a child with autism and a dental hygienist, to undertake her first qualitative research project. The project aimed 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).

The results of this research have been published in the International Journal of Paediatric Dentistry. We have also produced a plain language summary, and Nicole produced a creative and engaging video which summarises the research project.

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

Healthy Parent Carers programme

C. Morris, G. Bjornstad, A. Borek, M. Fredlund, A. McDonald, V. Berry, M. Tarrant, A. Hawton, J. Lloyd, O. Ukoumunne, 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 2017 we co-designed a feasibility study of this programme with our Family Faculty working group and a Professional Advisory Group. In this study, we want to see whether the programme can be delivered in the community through organisations that have links with parent carers. We also want to find out whether we can test the group-based programme to see whether it improves health and wellbeing, compared to providing the programme materials on the internet, and whether it is good value for money. We have applied for NIHR funding for this proposed research and the application has been shortlisted. The final funding decision will be made in March 2018.

This research has been supported by PenCLAHRC and the charity, Cerebra.

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 involves 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.

The training was delivered on five occasions in Exeter, and refined each time based on feedback and reflections. The procedures have been documented in a manual with professional videos to enable the training to be replicated by others. In 2017 an academic paper was published in BMJ Paediatrics Open describing the development and preliminary evaluation of the intervention. In addition we have secured ethics and NHS approvals to test the training in several other hospitals.

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.

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. After five years of data collection, all of the data are now in. The team are busy analysing the data and then will begin writing papers on our findings. We cannot tell you the results yet, but we hope to do so soon.

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, A. Price, H. Eke, 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 surveillance study, qualitative interviews, and the first round of the mapping study were completed in 2017. The second round of the mapping study will be launched in early 2018.

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, S. Blake, K. Fitzpatrick, C. Morris

Children with cerebral vision 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 vision 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. PenCRU is part of the team led by Dr Cathy Williams at Bristol University with a specific role to involve families from our Family Faculty as partners in the research. In 2017 we convened Family Faculty meetings to discuss the findings from the first stage and to plan subsequent phases of the work. We are also collaborating on devising a core outcome set for evaluative research in cerebral vision impairment

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

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. In 2017 we continued to work on the systematic review to identify suitable patient reported outcome measures, interviewed families about their views on emerging candidate questionnaires, and met to plan the subsequent phases.

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

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 a study with children, parents, doctors and nurses to choose a core outcome set and 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, J. C. Morris, D. Sellers, Cadwgan, J. Kisler, D. Craig, C. Buswell, J. Thomas, C. Gibb, S. Lee, N. Mather, H. McConachie, A. Colver.

This study will identify 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 will gather 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 study began in 2017 and work on the systematic review is in progress and we prepared for the qualitative research and surveys and submitted an application for ethics and other approvals to proceed.

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

Parent-to-parent support interventions for parents of babies cared for in a neonatal unit

R. Whear, R. Abbott, C. Morris, A. Bethel, K. Boddy, A. Collinson, S. Prosser, L. Wakely, J. Kurinczuk, J. Thompson-Coon.

This study starting in 2018 is a systematic review of qualitative and quantitative evidence on the effectiveness of peer support interventions for parents of babies cared for in a neonatal units. It is led by a colleagues in PenCLAHRC Evidence Synthesis Team, clinicians with experience of neonatal care, and the parent mentoring and befriending service at the neonatal unit in Devon.

The research is being funded by the NIHR Research for Patient Benefit programme

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 starting in 2018, funded by NIHR and the Australian Medical Research Council and led by colleagues at the University of Liverpool will evaluate whether prophylactic antibiotics reduce hospital admissions for children with neurological impairments. PenCRU provides expertise on outcome measures and public involvement in the research; members of our Family Faculty are advising on aspects of the research design to ensure the methods are likely to be acceptable for participating families.

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

Improving continence for children and young people with neurodisability

C. Morris, 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 in our James Lind Alliance Research Priority Setting Partnership. Subsequently NIHR commissioned a survey of practice and a systematic review of interventions to improve continence for children with neurodisability. PenCRU led a formal Expression of Interest with colleagues with expertise in the management continence issues in children, and were invited to submit a full application. Members of our Family Faculty participated in a project-specific working group to help prepare the application and plan the research. The decision is pending and we will hear further in 2018.

Academic publications in 2017

Morris C, Dunkley C, Gibbon FM, Currie J, Roberts D, Rogers M, Crudgington H, Bray L, Carter B, Hughes D, Tudur Smith C, Williamson PR, Gringras P and Pal DK (2017) Core Health Outcomes In Childhood Epilepsy (CHOICE): protocol for the selection of a core outcome set. Trials 18:572 doi.10.1186/s13063-017-2323-7

Thomas N, Blake S, Morris C, Moles DR. (2017) Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. *International Journal of Paediatric Dentistry* doi.10.1111/ipd.12345

Gumm R, Thomas E, Lloyd C, Hambly H, Tomlinson R, Logan S. and Morris C (2017) Improving communication between staff and disabled children in hospital wards: testing the feasibility of a training intervention developed through intervention mapping. *BMJ Paediatrics Open* 1:e000103 doi.10.1136/bmjpo-2017-000103

Farr W, Green D, Male I, Morris C, Bailey S, Gage H, Speller S, Colville V, Jackson M, Bremner S, et al (2017). Therapeutic potential and ownership of commercially available consoles in children with cerebral palsy. British Journal of Occupational Therapy, 80(2), 108-116 doi.10.1177/0308022616678635

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C. (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 2017*;* 358 doi.10.1136/bmj.j3453

Brett J, Staniszewska S, Simera I, Seers K, Mockford C, Goodlad S, Altman D, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C. (2017). Reaching consensus on reporting patient and public involvement (PPI) in research: methods and lessons learned from the development of reporting guidelines. BMJ Open, 7 doi.10.1136/bmjopen-2017-016948

McConachie H, Livingstone N, Morris C, Beresford B, Le Couteur A, Gringras P, Garland D, Jones G, Macdonald G, Williams K, Parr JR (2017). Parents Suggest Which Indicators of Progress and Outcomes Should be Measured in Young Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* doi.10.1007/s10803-017-3282-2

Ford T, Parker C, Salim J, Goodman R, Logan S, Henley W. (2017). The relationship between exclusion from school and mental health: A secondary analysis of the British Child and Adolescent Mental Health Surveys 2004 and 2007. *Psychological Medicine,* 1-13 doi.10.1017/S003329171700215X

Ford TJ, Paget A, Parker C, Heron J, Logan S, Henley W, Emond A (2017). Which children and young people are excluded from school? Findings from a large British birth cohort study, the Avon Longitudinal Study of Parents and Children (ALSPAC). Child: Care, Health and Development 25:1-13. doi.10.1017/S003329171700215X

Paget A, Parker C, Heron J, Logan S, Henley W, Emond A, Ford T. Which children and young people are excluded from school? Findings from a large British birth cohort study, the Avon Longitudinal Study of Parents and Children (ALSPAC). Child Care Health Dev. 1–12. doi.org/10.1111/cch.12525

Some key people we worked with in 2017

We collaborate with a large number of colleagues at the University of Exeter and with NHS clinicians and people in other universities and organisations. The list below recognises some of the key people we were fortunate to have worked with this year.

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

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.

Obi Ukoumunne BSc, MSc, PhD
Associate Professor in Medical Statistics
Obi is an accomplished research statistician and a key member of the team advising on design and analysis for the randomised controlled trial of our Healthy Parent Carers programme.

Jo Thompson Coon BSc PhD
PenCLAHRC Associate Professor 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.

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.

Vashti Berry BSc, MSc, PhD
PenCLAHRC Senior Research Fellow in Health Services Research
Vashti's research focuses on how parents and families can be supported to promote children's mental health and development and is part of our Healthy Parent Carers programme team.

Jenny Lloyd BA (Ed) Hons, MSc, PhD
Senior Research Fellow in Child Health
Jenny's expertise is developing and evaluating complex interventions aiming to promote healthy lifestyles, wellbeing and resilience, and is part of our Healthy Parent Carers programme team.

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 members of the public in research.

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.

Sharon Blake LLB (Hons) MA
Associate Research Fellow
Sharon worked previously at PenCRU, and is now working on a collaborative project between Law School and the Medical School. She has continued to support Nicole on the APEx-D project.

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.

Pam Baxter
Senior Research Governance Officer
Pam joined the University of Exeter Research Ethics and Governance Office in 2017 and supported the work of PenCRU in her role a Sponsor for several of our research studies.

Local NHS staff, other universities and organisations

Aleksandra Borek BA (Hons) MA PhD
Qualitative Researcher in Behavioural Science, University of Oxford
Aleksandra (Ola) joined PenCRU in 2015 on a short term project as an Associate Research Fellow to develop a group-based intervention for parent carers to improve health and wellbeing. Since leaving PenCRU, she has continued to support the Healthy Parent Carers project.

Eleanor Thomas BSc (Hons) MRCPCH
Consultant Paediatrician, Royal Devon & Exeter NHS Foundation Trust
Ellie specialises in community child health and has been involved in our study to improve communication with disabled children when they have to spend time on the ward.

Rebecca Gumm BMBS MRCPCH
Paediatric Neurodisability Trainee, Sheffield Children's Hospital
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)
A Brighter Tomorrow peer support coordinator for Exeter, Mid and East Devon
Bel has considerable expertise in providing peer support and training and mentoring befrienders. Bel is integral to developing and testing the feasibility of our Healthy Parent Carer programme.

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 the Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy (CASTLE) 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, King's College London
Paul co-leads the CASTLE programme of research. 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, University of Liverpool, Hon Consultant in Paediatric Respiratory Medicine
Paul 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 to be funded by NIHR.

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

Cathy Williams BSc, MBBS, PhD, FRCOphth
Reader in Paediatric Opthalmology, University of Bristol
We are collaborating with Cathy on her NIHR Senior Research Fellowship projects focusing on children with cerebral vision impairments.

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

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.

Lindsay Pennington BSc MSc PhD
Senior Lecturer & Speech and Language Therapist, University of Newcastle
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.

Jennifer McAnuff BSc (Hons), MSc
Occupational Therapist & NIHR/HEE Clinical Doctoral Research Fellow University of Newcastle
We have supported Jen's doctoral research focusing on participation in recreation and leisure for children with neurodisability and training workshop for the British Academy of Childhood Disability.

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.

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