PenCRU

Childhood Disability Research

University of Exeter Medical School

Annual Report 2020

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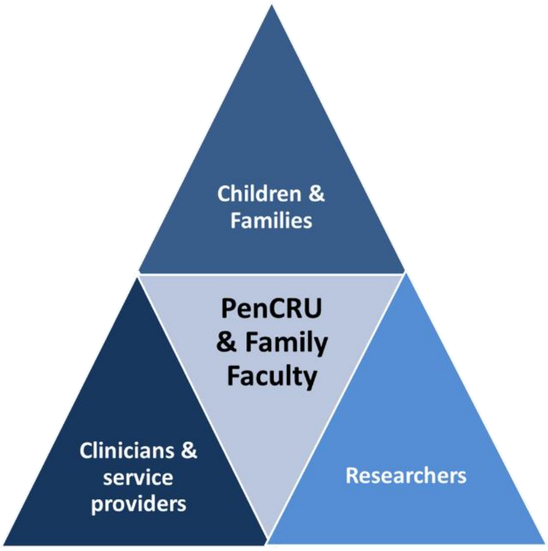
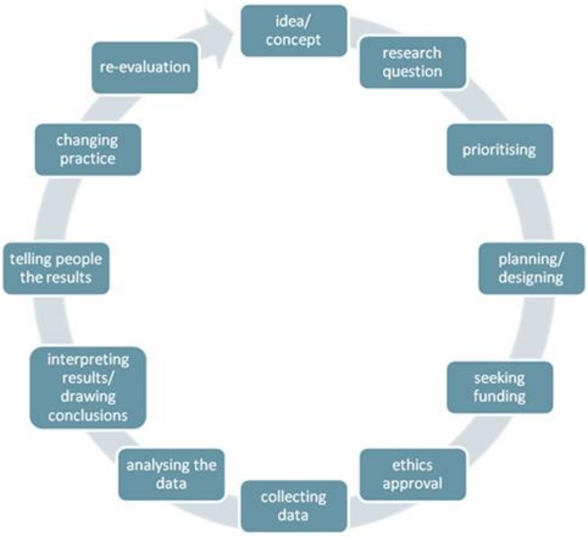




View from the Chairs on 2020

Welcome to the PenCRU Annual Report for 2020.

This has for all of us been a year like no other. PenCRU is all about the families who are the heart of everything we do and for many families this has been more challenging than we could have possibly imagined. I get a sense that many people have felt that children, especially those who have extra difficulties, have been forgotten. Over the years we have heard vivid accounts from members of the Family Faculty of how hard they have to fight to get the help their children need and in many cases how limited the services are. The pandemic has disrupted already stretched services and we all need to recognise just how tough this has been for many families. We all desperately hope to see the virus contained and hope that as we re-group we can ensure that the needs of families are kept properly in view.

I want to say a special thank you to members of the Family Faculty and the PenCRU team who helped to produce a report for the National Institute of Health Research about how young people and families think they should approach research related to people with complex needs. This report has been extremely influential in shaping how the funders will approach work with people from all age groups.

And now, something that has been a welcome positive in these difficult times. This is an opportunity for me to pay tribute to Chris Morris who has been a fantastic colleague and a driving force in research that seeks to make life better for children and families. He has for years been the real leader in PenCRU and I have benefitted hugely from his sharp intellect, warmth and commitment. His promotion to a Personal Chair, becoming Professor of Child Health Research, is richly deserved and gives me enormous pleasure. I look forward to the day when all of us in the PenCRU family can get together and celebrate this great achievement properly with Chris.

Stuart Logan, Professor of Paediatric Epidemiology & Honorary Consultant Paediatrician

Blimey, what a year! However I'll focus first on a personal high point. I was informed of my promotion to a Personal Chair as Professor of Child Health Research at the beginning of the first lockdown in March 2020. This made those first few weeks of adapting to our situation easier, if not less weird, in that I felt quietly quite chuffed, at home, albeit without being able to celebrate wildly other than raising a cup of tea to the goldfinches in the garden and raising a glass with family and friends on Zoom. I celebrated my promotion knowing that it is underpinned by all the support from past and present PenCRU team, our Family Faculty members, and many colleagues who have contributed to our work. Therefore I would like to note my gratitude for support and that of my key career mentors Peter Rosenbaum, Stuart Logan. Jenny Kurinczuk and Ray Fitzpatrick who nurtured my academic aspirations.

The timing of the first lockdown was not as bad for PenCRU as has been for many research studies, groups and researchers. The two main studies we were leading at PenCRU funded by the National Institute for Health Research, had completed data collection and we were able to continue analysing the results and writing the reports during lockdown. You can find out more about our projects and progress later in the report.

We have some exciting opportunities emerging currently that build on work from 2020. We continue to cultivate relationships with key charities in the sector, the Council for Disabled Children and Contact, to implement our Healthy Parent Carers programme. In addition, with support from The Lottery Community Fund, we were able to employ a Family Involvement Coordinator once again which is such a key role for us, and were very pleased to appoint Bel McDonald to this post as an experienced member of our Family Faculty.

There are some changes to the team membership with Helen and Gretchen moving to posts funded by PenARC, Katharine moving to another public involvement post at the University of Exeter; whilst we have been joined this year by Annette, Fleur, Alice and Bel. What's notable is that many colleagues stay involved in our projects when they move, and Ola and Gretchen particularly remain integral to developments with our Healthy Parent Carers research, and Kath continues to work on the Hospital Communications training we developed. We also appreciate our colleagues in Exeter and elsewhere that support our research, and with whom we collaborate as the childhood disability research community.

One positive aspect of the otherwise horrendous circumstances this year is increased connectedness online. I've connected with childhood disability research colleagues worldwide as part of a combined COVID-19 Task Force response to the pandemic on behalf of the International Alliance of Academies of Childhood Disability. I am also pleased to be Co-Chairing the new International Alliance of Academies of Childhood Disability Research Committee with Professor Gulam Khandaker. Just before the first lockdown I attended the British Academy of Childhood Disability meeting in Sheffield, and with Julia and Mary from our Family Faculty we contributed again to the BACD-Castang Fellowship Programme.

It has truly been an unexpected year, and tragic for many families and difficult for us all for a variety of personal reasons. Nevertheless at PenCRU, with the support of our Family Faculty and colleagues locally and elsewhere, we have pushed on and achieved remarkable things in our aim to deliver research that is relevant, useful and accessible.

Chris Morris, Professor of Child Health Research

Mission statement

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

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

PenCRU & Family Faculty
making childhood disability research
more relevant, useful and accessible

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

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

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

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

COMMUNITY
FUND

UK
RI
Economic
and Social
Research Council

FUNDED BY
NIHR | National Institute
for Health Research

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

PenCRU team

Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPCH Professor of Paediatric Epidemiology
Stuart is an Honorary Consultant in Paediatrics in the Royal Devon and Exeter Hospital. His particular interest is the generation of research of direct relevance to policy and practice and useful to practitioners and to families. His major areas of research are the evaluation of complex interventions and the effects of social inequalities on child health.

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

Alice Garrood BA, PG Cert, PG Dip.
Research Fellow in Child Health Research
Alice joined us in February from the Dementia Research team here at the University of Exeter Medical School. She has extensive experience in researching dementia, mental health, ageing and neurology. Alice manages the Healthy Parent Carers project.

Annette Gillett BA, PGCE
Associate Research Fellow in Child Health Research
Annette joined us in January to help with the Healthy Parent Carers project. Annette's background is in learning and development in health and social care, including roles in the local authority, NHS and a health charity. Annette originally trained as a nurse and has a keen interest in programmes and interventions that support health and wellbeing.

Bel McDonald BEd (Hons)
Family Involvement Coordinator
Bel joined the team in November, after over ten years' involvement with PenCRU's Family Faculty. She has a wealth of experience with parent carers and has been instrumental in the development and delivery of the Healthy Parent Carers Programme.

Fleur Boyle MA, MSc
PenCRU Team Administrator
Fleur joined the team in August. She has a background in academic publishing, marketing, community work and childcare.

Team news updates

Gretchen Bjornstad, who so capably managed the Healthy Parent Carers Programme, has moved within the Institute for Health Research to be Programme Manager for the PenARC Child Health and Maternity national priority programme. Gretchen continues as a co-investigator with us on Healthy Parent Carers research.

Katharine Fitzpatrick was our Family Involvement Coordinator for 5 years and this year after returning from maternity leave has taken another public involvement role in the university.

Reluctantly we said goodbye to **Tanya Hynd** who has been our administrator for 5 years. She continues in the medical school working with colleagues in the Patient and Public Engagement team.

Helen Eke, efficiently managed the Improving CoNtinence (ICoN) Study, and in May had her first baby. Helen will return having moved within the Institute for Health Research to be Programme Manager for the PenARC Child Health and Maternity national priority programme.

Helen and baby Pippa on a winter walk.

Kath Wilkinson worked on our Hospital Communications Project before leaving to have baby Ella. Kath is now working for PenARC with her research focused on supporting vulnerable individuals including children and families and the elderly.

Family Faculty and community involvement

The ethos of the unit is to involve families in all aspects of our research and related activities. We achieve this through our Family Faculty, which is made up of families of disabled children who are interested in contributing to our work. Our Family Faculty members are mainly parent carers living in Devon or elsewhere in the South West, with a few from further afield. There are currently over 170 non-professional members and over 90 professional members. If you would like to join the Family Faculty, do get in touch; we are always keen to welcome new members.

Due to funding limitations we started 2020 without a Family Involvement Coordinator after Katharine went on maternity leave. It served to remind us how crucial this pivotal role is for the team, to ensure we are truly family centred in all we do. Nevertheless we continued to involve families in the completion of our Healthy Parent Carers feasibility trial and Improving Continence study, aided by some advice and support from colleagues in our PenARC Public Involvement team.

Liabo *et al. Research Involvement and Engagement* (2020) 6:11
https://doi.org/10.1186/s40900-020-0183-x

Research Involvement
and Engagement

METHODOLOGY Open Access

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

Kristin Liabo[1*], Kate Boddy[1], Silvia Bortoli[2,3], Jenny Irvine[4], Heather Boult[5], Mary Fredlund[6], Neil Joseph[7], Gretchen Bjornstad[3] and Christopher Morris[3]

People who wish to emulate our model often ask us how to go about involving families in research. So we were pleased to see published our paper with colleagues in the PenARC and North West ARC public involvement teams. This open (free) access paper describes a review of standards for public involvement and we reflect jointly with members of our involvement groups on what enables our collaborative work, and what the challenges are for everyone involved.

We were pleased to welcome Bente van Oort as a visiting student from the Netherlands. Bente produced a report describing Involvement of young experts by experience in research. With Bente and Linda Nguyen at CanChild and colleagues in the Netherlands, Canada and UK, we continue to collaborate on involving disabled young people in research.

L to R: Bel, Alice, Chris, Annette and Fleur

We were excited to receive short term funding from The National Lottery Community Fund Coronavirus Support scheme to fund our Family Involvement Coordinator role in the autumn, and following a recruitment process appointed Bel McDonald to join the team, Bel introduces herself below…

“I have been a member of the Family Faculty for about 10 years and have been involved in several research projects in that time. I have witnessed firsthand the difference it makes to parent carers’ feelings of self worth as the research team really appreciates and values the input that they make.

I am particularly proud of the work we did in developing The Healthy Parent Carers Programme. I am a co-author and a co-investigator in the project and I delivered the first training to the trial group with another member of the Family Faculty. The project has already made a huge difference to the health and wellbeing of the parents who have taken part in the training and I am so excited to see how this project could develop.

I am delighted to take on the role of the Family Involvement Coordinator and am looking forward to consulting with members of the Family Faculty about how we can modify the training for online delivery due to the social restrictions that Covid-19 have imposed on us all. Life as a parent carer can be isolating in normal circumstances but the enforced isolation that Covid-19 has caused has been really hard for many of our members. Some of us have been shielding our children and in sometimes very difficult circumstances as their lives were put on hold completely between March and September, without access to any of the usual support services. Just as we were starting to return to something nearing normal, due to the second lockdown, many of us are in that situation again as our children and young people are considered to be Clinically Extremely Vulnerable.

Looking after our own health and wellbeing has never been more important than it is now and I really believe that the Healthy Parent Carers programme could make a real difference to our community. Being involved with helping shape the future of the project will really benefit our members by giving them something positive to focus on and to help them regain the sense of community that being part of the Family Faculty can bring. The role of the Family Involvement Coordinator is so vital to enable this work to happen."

Bel McDonald, Family Faculty member & Family Involvement Coordinator

Family Faculty Christmas Party on Zoom

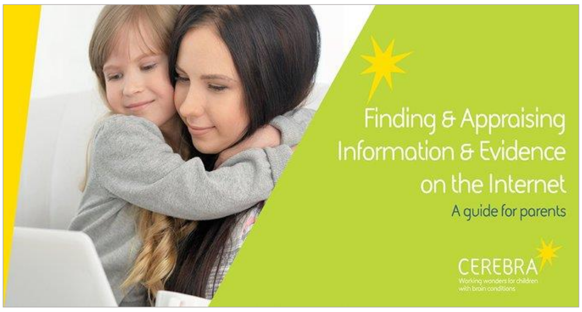
Once we got ourselves reorganised following the first lockdown, our Family Faculty began again and continues online using Zoom and Teams. Through this we learned new ways to engage and found that people who lived further away who were unable to travel to Exeter were able to join in. We revised our ground rules to take account of the circumstances of meeting online. For instance, whereas in a room there is a certain level of privacy, online one cannot be sure who may overhear what is said, so headphones may be advisable.

Members of the Family Faculty are helping support several on-going and planned studies as well as Healthy Parent Carers and Improving Continence studies. For example there is a small working group that advises on the Parrot trial run from Liverpool that will evaluate prophylactic antibiotics to reduce respiratory admissions to hospital. We also share opportunities to advise or participate in research through emails to the Family Faculty and/or sharing on social media.

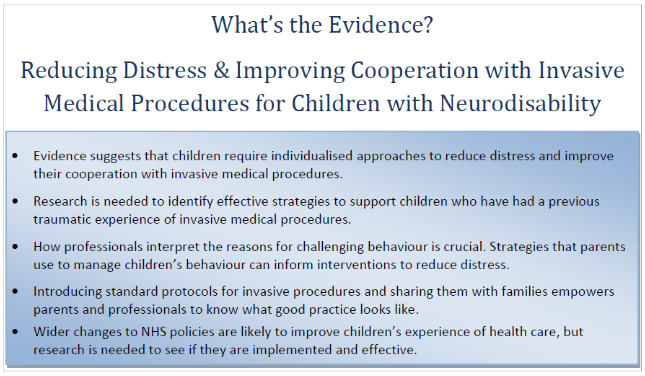
Family Fun Day

Unfortunately we couldn’t hold our annual Family Fun Day this year, so here are some photos to remind us of the fun we have had in previous years. We did have our Family Faculty Zoom Christmas get together and Bel has started some regular drop-in Family Faculty online meetings.

Accessible dissemination of research



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



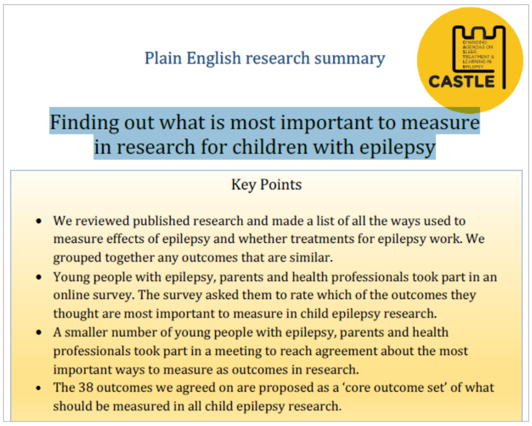
What’s the Evidence?

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

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

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

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



Plain English research summary

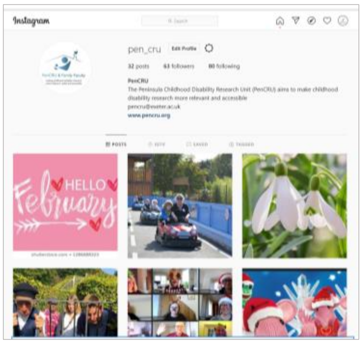
Finding out what is most important to measure in research for children with epilepsy

Key Points

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

Keep up with all our acivities and updates via social media and our website.

- Follow us on Twitter @Pen_CRU
- Find us on Facebook @PenCRU
- We're also now on Instagram! @pen_cru

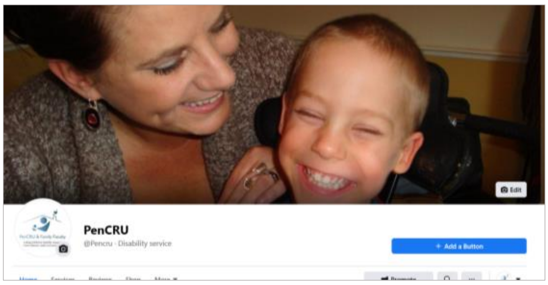


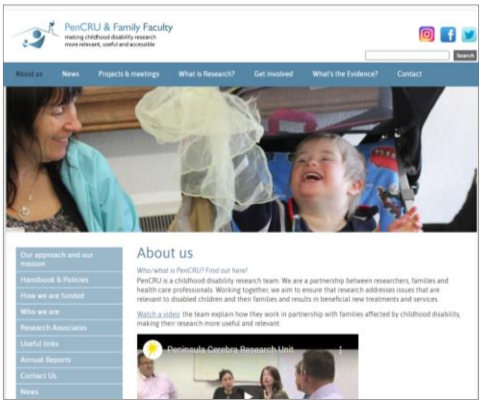
PenCRU

The Peninsula Childhood Disability Research Unit (PenCRU) aims to make childhood disability research more relevant and accessible

pencru@exeter.ac.uk

www.pencru.org



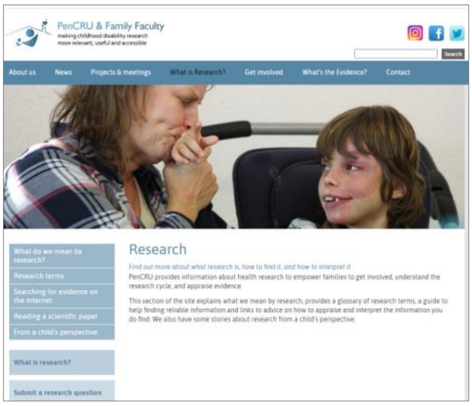


About us

Who/what is PenCRU? Find out here!

PenCRU is a childhood disability research team. We are a partnership between researchers, families and health care professionals. Working together, we aim to ensure that research addresses issues that are relevant to disabled children and their families and results in beneficial new treatments and services.

Watch a video: the team explain how they work in partnership with families affected by childhood disability, making their research more useful and relevant.



Research

Find out more about what research is, how to find it, and how to interpret it

PenCRU provides information about health research to empower families to get involved, understand the research cycle, and appraise evidence.

This section of the site explains what we mean by research, provides a glossary of research terms, a guide to help finding reliable information and links to advice on how to appraise and interpret the information you do find. We also have some stories about research from a child's perspective.

Programme of research

The following pages describe our programme of research, and progress made in 2020.

Healthy Parent Carers programme

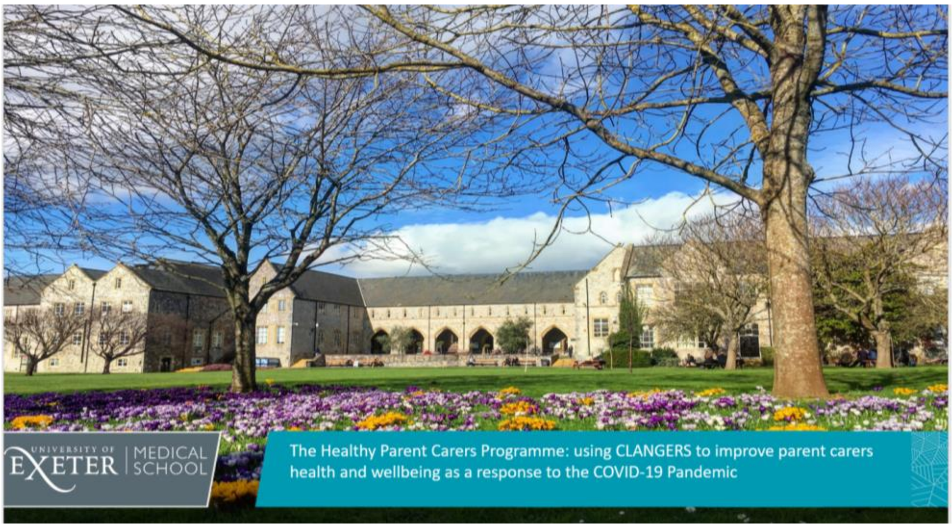
C. Morris, G. Bjornstad, A. Borek, A. Garrood, M. Fredlund, A. McDonald, S. Brand, V. Berry, M. Tarrant, A. Hawton, J. Lloyd, O. Ukoumunne, K. Wilkinson, B. Cuffe-Fuller, A. Gillett, S. Logan.

Our novel peer-led Healthy Parent Carers (HPC) programme offers transformative ways of encouraging parents to prioritise their own health and resilience, which is crucial when caring and benefits the wider family.

In 2020 we completed the feasibility trial that demonstrated the programme could be delivered in community settings by facilitators who we trained. There was considerable interest with 90 individuals participating and nearly 200 parent carers expressing interest in taking part.

Also in 2020, supported by an Economic and Social Research Council Impact Accelerator Award, we began piloting implementation with two leading charities in the sector, the Council for Disabled Children and Contact. The pandemic and requirements for social distancing mean we have had to develop ways to deliver the programme online. We have benefited from The National Lottery Community Fund Coronavirus Support Grant to help this work. Ultimately it may actually improve the accessibility of the programme for those parent carers unable to attend a programme in person.

We produced several videos to share reflections of people who have taken part in our study: hear from parent carers https://vimeo.com/376771910 and facilitators https://vimeo.com/432838782



The Healthy Parent Carers Programme: using CLANGERS to improve parent carers health and wellbeing as a response to the COVID-19 Pandemic

ICoN
improving continence
for children and young
people with neurodisability

Improving continence for children and young people with neurodisability (ICON Study)

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

Learning to go to the toilet is an important skill. Becoming continent involves knowing when you need to go, holding on until you find the right place, going to the toilet, cleaning and getting dressed again. Many children and young people with special educational needs or disability can learn to become clean and dry, sometimes with help or equipment.

This research aimed to find out how families and professionals measure and improve continence, and if there was evidence about which treatments are useful. We brought together results of studies that have tested ways to assess and improve toilet training for children and young people with special educational needs or disability. We carried out four online surveys with health professionals, education and care staff, parent carers, and disabled young people. We brought together and explained the findings from the surveys and the studies with help from parent carers and professionals.

The survey and systematic review were completed in 2020 and we submitted the Final Report to NIHR. The report, findings and recommendation will be published in the NIHR Library in 2021.

The research was funded by the NIHR Health Technology Assessment programme

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

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

CASTLE
Changing Agendas on Sleep,
Treatment and Learning in Epilepsy

This programme of research focuses on children with the most common type of epilepsy and is led by colleagues at King's College London. Inter-related studies address uncertainties about drug treatment, reducing sleep disturbance, and knock on effects on learning.

PenCRU led the first work package called Core Health Outcomes In Child Epilepsy (CHOICE) which is now completed. With children, parents and clinicians we identified the best ways to measure health and quality of life for children with epilepsy. There are three papers published form the study. The marvellous Holly Crudgington who did much of the work for the CHOICE study was selected deservedly to take up a PhD studentship at Kings College London in 2020.

The trial had problems recruiting related to treatment preferences over and above the pandemic and is consequently being redesigned to focus on evaluating the behavioural sleep intervention.

The research is funded by a NIHR Programme Grant

Focus on Early Eating Drinking & Swallowing (FEEDS)

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

This study identified which treatments are regularly recommended in the NHS, which types of improvement in eating and drinking are considered most important by parents and professionals, and how best to measure a child's progress. Colleagues at the University of Newcastle led the research.

We reviewed published research to see what is known about the effectiveness of treatments to improve eating, drinking and swallowing and gathered information using focus groups and surveys with families and clinicians. The final report will be published by the NIHR Library in 2021.

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

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

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

This research tested 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 led the study. We published a review of potential health related quality of life questionnaire measures for children who have survived brain tumours or other acquired brain injury.

This research was funded by The Brain Tumour Charity

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

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

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

The work to produce a core outcome set for research evaluating ways to help children with cerebral vision impairment was completed in 2020.

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

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

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

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

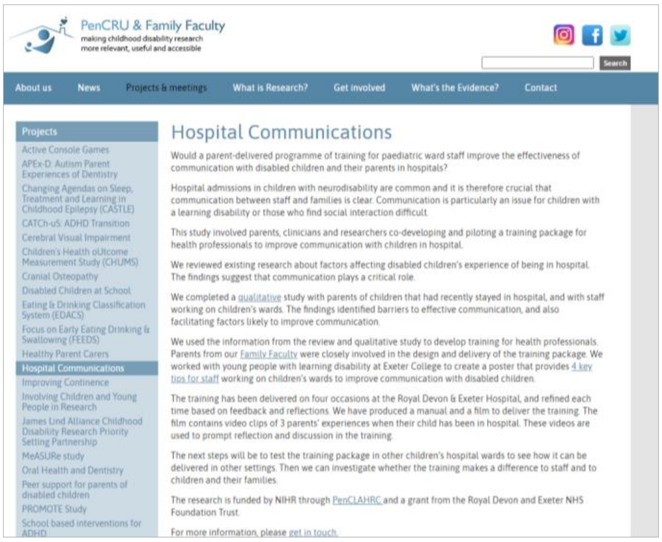
The trial has started in Australia but has been held up in part by the pandemic and required some redesigning to be able to begin. The trial will begin in England when NHS and NIHR Clinical Research Network teams are once again able to support clinical non-COVID-19 studies.

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

Hospital Communications

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

Improving children's experience of health care is a priority for the NHS. Disabled children are admitted to hospital more often than other children. This study involved parent carers, clinicians and researchers collaborating to develop and test a training package for health professionals to improve their communication with disabled children when they are inpatients. We evaluated the training being delivered in several hospitals around England by local teams using our manual and videos. The feedback continues to be positive. There remains scope for further evaluation and implementation.



Hospital Communications

Would a parent-delivered programme of training for paediatric ward staff improve the effectiveness of communication with disabled children and their parents in hospitals?

Hospital admissions in children with neurodisability are common and it is therefore crucial that communication between staff and families is clear. Communication is particularly an issue for children with a learning disability or those who find social interaction difficult.

This study involved parents, clinicians and researchers co-developing and piloting a training package for health professionals to improve communication with children in hospital.

We reviewed existing research about factors affecting disabled children's experience of being in hospital. The findings suggest that communication plays a critical role.

We completed a qualitative study with parents of children that had recently stayed in hospital, and with staff working on children's wards. The findings identified barriers to effective communication, and also facilitating factors likely to improve communication.

We used the information from the review and qualitative study to develop training for health professionals. Parents from our Family Faculty were closely involved in the design and delivery of the training package. We worked with young people with learning disability at Exeter College to create a poster that provides 4 key tips for staff working on children's wards to improve communication with disabled children.

The training has been delivered on four occasions at the Royal Devon & Exeter Hospital, and refined each time based on feedback and reflections. We have produced a manual and a film to deliver the training. The film contains video clips of 3 parents' experiences when their child has been in hospital. These videos are used to prompt reflection and discussion in the training.

The next steps will be to test the training package in other children's hospital wards to see how it can be delivered in other settings. Then we can investigate whether the training makes a difference to staff and to children and their families.

The research is funded by NIHR through PenCLAHRC and a grant from the Royal Devon and Exeter NHS Foundation Trust.

For more information, please get in touch.

The research was supported by **NIHR PenARC**

Research capacity building - PhD students

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

We are excited to support new pre-doctoral awardees:

- Rachel Knight Lozano, NIHR / HEE Pre-Doctoral Clinical Academic Fellow, University of Plymouth & Children's Physiotherapist, Children and Family Health Devon.
  Community-based interventions to improve respiratory fitness and function in children with complex neurodisability.
- Xanthe Hodgson, NIHR / HEE Pre-Doctoral Clinical Academic Fellow, University College London & Physiotherapist, Great Ormond Street Hospital For Children NHS Foundation Trust
  Holistic health-affirming Physiotherapy interventions to facilitate disabled children and young people (CYP) to live well and participate fully.
- Eileen Morrow, NIHR / HEE Pre-Doctoral Clinical Academic Fellow, University of Oxford & Orthotist, University of Oxford University Hospitals NHS Foundation Trust
  Development of a Core Outcome Set for Elective Paediatric Lower Limb Orthopaedic Surgery

We continue to support doctoral awardees:

- Lesley Katchburian NIHR / HEE Clinical Doctoral Research Fellow, University College London & Clinical Specialist Physiotherapist in Neurodisability, Great Ormond Street Hospital
  Use of Botulinum Toxin A in Ambulant Children with Cerebral Palsy
- Rachel Rapson NIHR / HEE Clinical Doctoral Research Fellow, Plymouth University & Clinical Manager Children and Learning Disability Physiotherapy Teams, Torbay
  A novel interactive training device to improve walking Ability and quality of life for Children with CErebral Palsy Trial (ACCEPT study): A multi-centred feasibility RCT with an embedded qualitative study
- Marilyn Poole, NIHR / HEE Clinical Doctoral Research Fellow, University of Birmingham Senior Community Paediatric Physiotherapist, Birmingham

DO MORE

Does a child or young person in your family use a wheelchair? ✓

Could they benefit from being more active? ✓

Would you like to be involved in research? ✓

Want to help other wheelchair users to improve their lifestyle too? ✓

SCAN TO ACCESS WEBSITE:

HANNAH DINES

Hannah Dines is supporting the #DoMore study. She is a cyclist with the GB cycling team and a race runner at World level. Hannah has cerebral palsy. She represented Great Britain at the Paralympics in Rio.

GET INVOLVED!

Join the #DoMore study via our online workshops or a virtual focus group. Help researchers to design software that tracks wheelchair users' body movements and supports them to move more.

VISIT do-more.org.uk, **EMAIL** domore.study@nhs.net or **CALL** 07701371838

IRAS ID: 271259
v0.3 03/10/2019

Developing interventions to reduce sedentary behaviour in non-ambulant children with long term disabilities

- Phillip Harniess, NIHR / HEE Clinical Doctoral Research Fellow, University College London & Senior Research Physiotherapist, Great Ormond Street Hospital. Optimising Parent Engagement with Early Intervention Physical Therapy for Their Infants with Emerging Cerebral Palsy

Chris Morris is co-supervisor to PhD students:

- Javiera Salazar Rivera, Paediatric Occupational Therapist, Chile, Graduate School of Education, College of Social Sciences and International Studies, University of Exeter
  School-based occupational therapy interventions for children with special educational need or disability
- Fatema Shamsaddin, Paediatric Physiotherapist, Saudi Arabia, Sport and Health Sciences, College of Life and Environmental Sciences, University of Exeter
  Neuromuscular Functions and Adaptations Following Training in Children with Cerebral palsy

Javiera Salazar Rivera

- Pegah Firouzeh, Department of Rehabilitation Medicine, University of Alberta
  Evaluation of the Immediate Effects of Ankle Foot Orthoses on Function, Activity, and Participation of Young Children with Cerebral Palsy: A Mixed-Methods Study

Academic publications in 2020

Heys M, Lakhanpaul M, Allaham S, Manikam L, Owugha J, Oulton K, Morris C, Martin KR, Tann C, Martin J, et al (2020). Community-based family and carer-support programmes for children with disabilities. Paediatrics and Child Health (United Kingdom), 30(5), 180-185. https://doi.org/10.1016/j.paed.2020.02.004

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Crudgington, H, Rogers, M, Morris, H, Gringras, P, Pal, DK, Morris, C. Epilepsy-specific patient-reported outcome measures of children's health-related quality of life: A systematic review of measurement properties. Epilepsia. 2020; 00: 1-19 https://doi.org/10.1111/epi.16430

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