Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research

University of Exeter Medical School

Annual Report 2015

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View from the Cerebra Chair on 2015

Welcome to our 2015 Annual Report as we celebrate what has been another successful year for the unit. We have had a hugely productive year in terms of unit publications from various projects, and have been very pleased to receive positive feedback from colleagues at Cerebra and researchers in the UK and worldwide about how we involve families in our research.

However, what pleases us most is the positive feedback we hear from the families who are working with us, and how much they tell us they enjoy being involved. We are enormously grateful for their hard work which continues to influence all that we do. We are always looking for ways to deepen the involvement of families in research in line with their interests and the time they have available. We recognise just how full families' lives are, and continue to be amazed by the commitment they make to developing evidence that will be useful for others in their position. We are very keen to try to provide trajectories of opportunity for those people who want to get more involved in research, while recognizing the need for people to vary their commitment over time.

I would like to highlight a couple of projects where families have really driven the work from the beginning. A number of families who have children with disabilities have talked about the difficulties that can be encountered in getting suitable dental care for their children. The view that oral health and dentistry is a major, and potentially neglected issue, for many families with disabled children was reinforced by the overwhelming response we received to our '*What's the Evidence'* summary on the topic. We have worked with our colleagues and neighbours at the Plymouth University Peninsula School of Dentistry and held a meeting with members of our Family Faculty and local dentists. Subsequently, Nicole Thomas, a parent of a young child with autism who is also a dental hygienist got in contact, keen to pursue research related to autism and dentistry. Nicole secured funding from the Oral & Dental Research Trust to enable her to conduct qualitative research using interviews to explore the experiences of parents of children with autism using high-street dentists. Following further meetings with the Family Faculty to design the study, she will start recruiting this December using a novel video featuring Nicole (as suggested by the Family Faculty working group), and we look forward to following progress in 2016.

Another project heavily influenced by our Family Faculty from the start is the Healthy Parent Carers study. Many parents talk about how difficult it can be for them to stay healthy with all the stresses in their lives and the simple lack of time. In close collaboration with members of the Family Faculty we developed a peer-led and group-based intervention called the Healthy Parent Carers programme. The programme aims to encourage and enable parent carers to focus on taking time for themselves to improve their health and wellbeing. This has proved a popular working group for the Family Faculty and many of the parents who have been involved in the work tell us they feel they have benefited from thinking about the issues. The next step for this study is to test how feasible it is to deliver the programme over several weeks with parents who have not been involved in the development work, and to see whether the participants perceive the programme to be acceptable and useful.

None of our work would be possible without the commitment of the members of the Family Faculty or without the fantastic, dedicated PenCRU team and the hard work they do. I owe them all a huge debt of gratitude.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

Mission statement

PenCRU carries out a broad programme of applied 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. A new award was granted for the period 2014-2019. Cerebra also maintain their own in-house research staff and provide direct grants and advice to parents, carers and professionals.

The charitable funding from Cerebra supports the core activities of the research unit, principally building partnerships with local families and service providers, identifying issues and research questions and reviewing the evidence, and then designing research studies to address these questions. PenCRU also receives support from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for the South West (PenCLAHRC). For major research projects we require substantive additional funding for which we apply to programmes operated by the NIHR, Medical Research Council and charities that fund research. PenCRU has been successful in securing funding from NIHR to support various studies.

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

PenCRU team

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

Chris Morris MSc DPhil
Senior Research Fellow in Child Health
Chris had 20 years clinical experience as an orthotist and now 15 years in childhood disability research. He was awarded Masters and Doctoral degrees by the University of Oxford for research about children with cerebral palsy. His main research interests include strategies to involve families in research, epidemiology, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

Katharine Fitzpatrick BSc (Hons) PhD
Family Involvement Coordinator
Katharine's academic background is in Physical Geography and she also has experience as a learning advisor for young people with learning disabilities and additional needs in a Further Education College. Her work is widening participation of Family Faculty members and strategies to involve children and young people.

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

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

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. Astrid's research background is in child and adolescent mental health and the organisation of services taking care of them. Astrid leads the CATCh-uS study evaluating transition to adult services for young people with ADHD.

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

Megan MacMillan BSc (Hons) MSc PhD

Megan completed her PhD, supervised by Mark Tarrant, Chris Morris and Professor Charles Abraham during 2015. The PhD is titled ‘Understanding children’s attitudes towards disability and promoting positive attitudes’.

Kath Maguire MA PhD

Kath is a Research Fellow with the PenCLAHRC public and patient involvement group. Kath studied social and political sciences and has gone on to complete a PhD study of public and patient involvement in health research. Kath is particularly interested in making sure that service users and members of the public are supported to access research evidence, and that research is done to address the questions that matter to them.

Team news update

During 2015 Katharine Fitzpatrick took maternity leave, and we congratulate her and husband Steve on their beautiful son James. In Katharine’s absence the continuing involvement of families has been facilitated by Kath Maguire.

Family and Community Involvement

The ethos of the unit is to involve families in all aspects of our research and related activities. There are lots of parent carers in the Family Faculty who have worked with us over several years, and we have also been pleased to welcome new members of the Family Faculty who joined us in 2015.

The Family Involvement Coordinator is a key role for PenCRU to facilitate the involvement of families. With Katharine being on maternity leave from June 2015, we sought closer working ties with our colleagues in the PenCLAHRC Involvement Team. The PenCLAHRC team facilitate public involvement in a wide range of health research projects across various conditions and age-groups. Hence this was an opportunity for us to consider new ways of involving families in our work.

Family Faculty Handbook

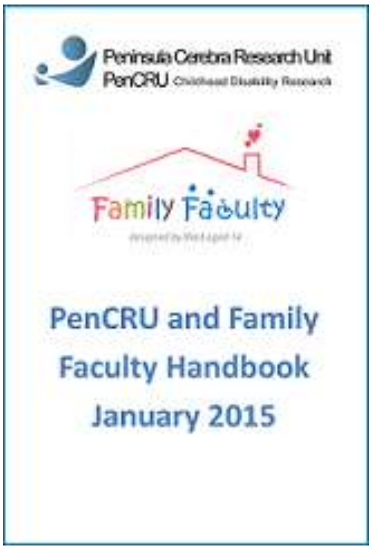
This year we published our PenCRU Family Faculty Handbook.

The handbook was co-created with members of the Family Faculty to explain who PenCRU and the Family Faculty are, what we do, and to provide clear statements about how we work together.

Parents who worked with us to design the handbook were keen that it be visually appealing with pictures, illustrations, examples and quotes from members of the Family Faculty.

The handbook was circulated electronically to all members of the Family Faculty and a link is provided to new members in their welcome email.

We're really proud of the handbook, and we were flattered to be contacted by a research group in Australia who wanted to produce something similar and asked permission to copy some parts.



Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

Family Faculty

PenCRU and Family
Faculty Handbook
January 2015

Young people's involvement

We continue to seek ways to involve young people with neurodisability in PenCRU's activities. We have some good links with local schools and colleges and are always keen to collaborate with more.

Earlier in 2015 our Family Involvement Coordinator Katharine spent a couple of days working with students with learning disabilities at Exeter College.

Together the students created a poster describing 4 top tips to improve communicating with disabled children. The poster is a really useful component in our training package for hospital staff working on children's wards to improve communication with disabled children when they are inpatients.

Following piloting of the training at the Royal Devon & Exeter Hospital, several copies of the poster are being displayed on the children's ward as a reminder.

Training

In previous years, we have addressed training for members of the Family Faculty and PenCRU staff in a collaborative way as part of our Building a Partnership programme.

With new members joining, we are conscious that the levels of knowledge about involvement in research varies in our working groups. Following discussion about this issue at our summer Advisory Group we sought to identify parent and staff perceptions of their training needs.

We are really grateful to Jane Ring, who is a parent carer and experienced member of the Family Faculty, for carrying out a consultation exercise with a small number of newer and more experienced members of the Family Faculty and members of the PenCRU team. Jane's findings and reflections will help us to build our strategy for training events in 2016. We will also ways to support the 'trajectories' for more experienced members of the Family Faculty who want to expand their opportunities to be involved in research or use the generic and transferable skills in other areas.

With our now closer ties to the PenCLAHRC Involvement Team we are developing a joint strategy that can be used across the PenCLAHRC and the Exeter Institute for Health Research.

Nuffield Student Placement

This summer PenCRU was pleased to host a Nuffield Research Placement for a talented and enthusiastic A-Level Student, Chantelle O'Brien. The scheme matches students in the first year of a post-16 science, technology, engineering and maths (STEM) course with relevant research opportunities. Chantelle is hoping to go on to study medicine at university, with a view to one day becoming a paediatrician.

Chantelle spent 4 weeks, being mentored by our Associate Research Fellow Sharon, to learn about evidence based medicine. After receiving some training, Chantelle prepared a new 'What's the Evidence?' summary. Sharon also arranged for Chantelle to meet several other researchers within Child Health and attended a Family Faculty meeting to give her a taste of research here at PenCRU.

"I've met some very inspirational, intellectual people who I have learned a lot from, not only about research but also about the importance of the applications of research and the importance of the people it will be effecting being involved in the research process … This has been a fantastic experience that I have thoroughly enjoyed and will be referring back to for the rest of my life!"

Chantelle O'Brien

Devon Parent Carer Voice Conference

PenCRU was offered a presentation slot at the annual Devon Parent Carer Voice Conference. This was a great opportunity for us to meet parent carers locally and share information about our work and how the involvement of families is crucial to the research that we do.

We held a planning meeting with several members of the Family Faculty to prepare our presentation. This was vital and ensured our messages were communicated clearly and effectively to the audience. For example, one suggestion was that we produce a 'wordcloud tree' to show that we were inclusive in our approach to the conditions of children that are the focus of PenCRU's research.

The presentation was well received and we are especially grateful to Bel McDonald for stepping up to present her experience as a parent carer member of the Family Faculty.

We also took along our exhibition stand, leaflets and examples of the research we produce in terms of our *What's the Evidence?* and study-specific plain language summaries. We were pleased that this led to several more parent carers joining the Family Faculty.

PenCRU appreciates our remote members!

Devon and the South West is a large geographical area, and a some members of our Family Faculty live even further away. So we understand that not everyone is able to travel to participate in PenCRU meetings. That doesn't prevent our remote members from getting involved though.

For example, we advertise the opportunity to comment on our *What's the Evidence?* and plain language summaries before they are published on the website. This work done outside of meetings is valuable to ensure that the materials we produce are accessible and understandable to families. Remote members also contribute via email and phone and receive the notes of meetings.

Another example is that NIHR asked twice this year whether a member of our Family Faculty could review commissioned research briefs to ensure their relevance to families. We were able to facilitate connections and enabled parents to contribute to NIHR remotely by email, which they tell us they enjoyed because their opinions were sought and respected, and acknowledged finacially.

Relocation

PenCRU moved to a new base in the South Cloisters building on the University's St Luke's campus in April this year, which means we are now based on the same site as the most of the University of Exeter Medical School. This has opened up several new opportunities to engage more with other departments and students. Our Associate Research Fellow, Sharon is now acting as an academic tutor to medical students and helping to develop the next generation of doctors!

Acting local, thinking global

Most of our research is carried out with families in Devon and the Southwest, although some of our studies do recruit across England or the UK. However PenCRU is also part of a global childhood disability research network as an international collaborator with the *CanChild* team. This network spans countries across the world and facilitates connections, sharing of ideas and collaboration. In 2015 PenCRU was asked by colleagues in Canada to support a bid for funding for Patient-Oriented Research because of our reputation involving families in childhood disability research.

Communicating about research

PenCRU aims to provide accessible information to all families and people with brain injury and neurological disorders. We try to help families obtain the best current evidence to help them in making decisions. We want to involve families in setting the research agenda and enable active engagement of parents and young people in all aspects of the research process.

We also want to inform clinicians and commissioners about research findings to enable them to make their decisions based on evidence as well as their experience and family preferences.

What's the Evidence?

PenCRU responds to questions received directly from families and professionals about interventions and health services. To ensure that research evidence is available to families and practitioners in a form that is comprehensible and accessible, and any implications for policy and practice are highlighted, we have developed a system of appraising and summarising the current research available on a chosen topic in our '*What's the Evidence?*' summaries. We produce reports about both NHS and alternative therapies. The summaries are published electronically on our website and are widely accessed. They aim to help families make informed decisions about care for their child. We hear that some clinicians find them useful for directing parents to the evidence.

During 2015 we produced or updated five *What's the Evidence?* summaries:

- Advanced Biomechanical Rehabilitation for children with cerebral palsy and/or learning disability
- Maternal thyroid issues and ADHD/ASD
- Epilepsy and ASD
- Early Intensive Behavioural Intervention/Applied Behaviour Analysis
- Feldenkrais and Anat Banal

Plain language summaries of research papers

During 2015 five new summaries of research findings published in academic papers were co-produced with parent carers from our Family Faculty:

- Which questionnaire is best for assessing health and quality of life o children with neurodisability?
- Questionnaires assessing children's health and quality of life: which one to use?
- Prioritising health outcomes for children and young people with neurodisability.
- Sleep Positioning Systems for Children with Cerebral Palsy: what evidence is there that they are they effective?
- Top 10 research topics on interventions for children and young people with neurodisability.
- Children's contact with disabled people linked with having more positive attitudes about disability.

Newsletter

PenCRU produces a termly newsletter which is e-mailed to all of the families and professionals who have asked to join our database. This allows us to keep them up to date with information about our programme of work, activities, upcoming meetings, recent publications and other items of interest. Past issues are also available on the PenCRU website. A paper copy of the newsletter is also sent by post to all families who have registered an address with the Family Faculty, as parents have told us they still want to receive a hard copy. We take copies of the newsletters to events, and have provided them on request for other organisations to circulate to their members at relevant times.

Social media

We have both a Twitter account and a Facebook page to communicate our news and raise awareness of our work.

Twitter @Pen_CRU

We use Twitter to disseminate our research findings and to network within our field, e.g. by sharing information provided by others, following conferences & tweet-chats. During 2015, we almost doubled the number of followers on Twitter from 363 (December 2014) to 710 (December 2015). On average our messages have been re-tweeted 45 times each month by other organisations and interested individuals, giving us an audience of around 17,000 users. We have found that Twitter is a really powerful tool to refer people to our website, with up to 14% of the traffic to our website coming from links sent out via this platform (Source: twitter and google analytics).

Earlier this year, the PenCRU team took part in a social media campaign #WhyWeDoResearch whywedoresearch.weebly.com/background.html to help challenge the stereotype that all researchers wear white coats and work in labs, and show the real people behind research. Members of our Family Faculty and PenCRU staff posed for pictures with their answer to the question. Initially, the campaign aimed to draw attention to opportunities to take part in clinical research. However, we found it was also a great way to highlight the shared motivation and the empowerment that comes from involving the public in research. The research nurse who initially started the campaign tweeted us to say the blog was 'fabulous'!

Facebook

Our audience on Facebook is currently more individual families, so we use a more personal style of communicating. As well as posting our news, we post information we think will be helpful from other organisations such as Cerebra. We hope that over time our Facebook page will become more interactive and an additional way to communicate with Family Faculty members. We are starting to head in that direction as Family Faculty members have posted messages directly to the page and are sharing the advert for participants to our dentistry study with other families and organisations on Facebook. We currently have 143 'likes' (December 2015).

Website

The PenCRU website is often families and professionals' first point of contact with the unit. It provides information about research and our programme of work at the unit. There are sections giving information on how families can get involved and the evidence summaries we produce. On average we have had 600 individual users of the website each month (not including PenCRU staff who visit it more than once a day!), with half being from within the UK and half international users.

With the success of the digital communication strategy introduced last year and growing awareness of PenCRU, we are now receiving on average 1 new evidence summary question and 1 new member of the Family Faculty via the website each month.

We have this year redesigned the project pages of the website, to enable more information about the studies to be displayed without become too dense to read. We are also for the first time using the website to recruit participants for the dentistry project by embedding a video of the researcher describing the study and using an electronic form to collect interested people's contact details. We are excited to see if this recruitment method works!

Also this year we consulted members of our Family Faculty about how we could better present our *What's the Evidence?* summaries as there are now quite a lot of summaries to navigate! We are working with the University of Exeter Medical Team web team to finish these changes but hope to re-launch the evidence summaries pages in 2016.

Impact of Communication

The effort we put in to build relationships and communicate via different methods results in our work being shared more widely. Here are a few highlights of how our information has been shared or used in 2015:

- This year our guide to searching for reliable evidence on the internet has proven to be popular. SENDirect (an online directory of services) have featured it on their website (launched in January 2015) www.sendirect.org.uk/information/i-need-information-on/my-childs-needs/a-guide-to-searching-for-evidence-on-the-internet/
- Our systematic review on involving disabled children and young people in research has been added to INVOLVE's evidence library www.invo.org.uk/find-out-more/involving-children-and-young-people/references-on-involving-children-and-young-people-in-research/
- Our website information on 'what do we mean by research?' and the research cycle diagram are featured (recycled) on the Canadian research group *Canchild's* website and is creating additional referrals to our own website. www.canchild.ca/en/research-in-practice/knowledge-translation-exchange

- Our *What's the Evidence?* summary on constraint therapy is referenced in Hemihelp Spring 2015 magazine (Issue 92) www.hemihelp.org.uk/about_us/what_we_do/newsletter
- We are listed as a source of Evidence Summaries and Critically Appraised Topics (CATS) on the Child Development & Rehabilitation international site www.childdevelopment.ca/best.aspx
- A tweet from RD&E Hospital dieticians complemented us on our communications training: *"Local research helping local AHPs improve care - our paediatric dietitians found the training v.helpful "*
- The COMET Initiative approached us to feature our CHUMS research paper on meaningful outcomes for children with neurodisability and the plain language summary in their newsletter.
- NIHR PenCLAHRC featured findings from PenCRU's research aiming to improve communication with disabled children when they have to stay in hospital in a new CLAHRC BITE (Brokering Innovation Through Evidence). These are short summaries that aim to break down research into accessible bite-sized pieces.

NIHR CLAHRC South West Peninsula

CLAHRC BITE

National Institute for Health Research

Brokering Innovation Through Evidence – a BITE-sized summary of NIHR PenCLAHRC research

October 2015

Communicating with disabled children and their families in hospital

Julia Melluish, a parent involved in the project:
"For me this was a perfect example of how a piece of research then leads to a change in practice with a positive outcome for disabled children and their families. I have really enjoyed helping to shape and design the training."

Children with neurological conditions tend to be admitted to hospital more frequently than other children. Many of these children will have difficulties with communication. The aim of the project was to work in partnership with families to improve how staff communicate with disabled children when they are in hospital, so that the experience is less stressful for children and families. Improving communication would also enable staff to better manage the treatment children receive.

A training package for hospital staff was developed by clinicians, researchers and parents of disabled children. The training was trialled and developed with staff from the paediatric ward at the Royal Devon and Exeter Hospital. This training involved encouraging empathy through understanding the child's perspective, alongside key practical tips, with the benefit that better communication might actually save time. Students at a local community college designed a poster to put up in the ward to remind staff of key tips for communication.

Selected conferences & presentations

South-West childhood disability seminar

PenCRU hosted the South-West BACD/BACCH childhood disability seminar in January 2015. In total there were 59 participants, of which 24 were paediatricians, 16 were allied health professionals, 8 were parent carers, 5 were academic researchers and 6 were presenters.

Feedback was very positive; the top rated speakers were Tim Adlam (seating for children with dystonia) and Corinne Rees (attachment and disability).

South-West Neurodisability Network Day

Chris Morris presented at the South-West Spasticity Network Day. He appraised, and promoted discussion, about a controversial paper published in Developmental Medicine & Child Neurology, the leading childhood disability research journal. The paper titled: A systematic review of interventions for children with cerebral palsy: state of the evidence by Iona Novak and colleagues provoked widespread debate and correspondence in the journal due to their use of a ‘traffic light system’ to suggest some common therapies should cease to be provided.

PenCRU goes Dutch

Astrid Janssens was a guest speaker at a conference organised by Johanna Kinderfinds to mark their 115th anniversary. Johanna Kinderfinds is a Dutch charity that supports projects and research aimed at improving the wellbeing and development of children and young people with a physical disability.

Astrid’s presentation focused on how PenCRU involves parents in all aspects of the research cycle. She illustrated each step in the research cycle with an example of a project conducted by PenCRU and showed what we had learned from doing so. The presentation was well received and we are looking forward to working further with our Dutch colleagues.

The Cerebra Chair, Professor Logan’s, selected additional activities

- Stuart travelled to Ankara in Turkey to teach on an Evidence Based Well Child Care course organised by the International Society of Social Pediatrics and Child Health (ISSOP).
- Stuart has continued to undertake undergraduate teaching opportunities in years 1 and 2.
- Stuart presented the Paediatric Acute Care project at the South West Maternity and Children’s Strategic Clinical Network Annual Event.
- Stuart presented to the Cornwall Health & Wellbeing Board.

International Complex Interventions Conference

Stuart Logan gave the opening address at the ‘Researching complex interventions in health: the state of the art’ conference in Exeter. Ola presented a poster about the Healthy Parent Carers programme entitled 'Healthy Parent Carers: developing an intervention to improve the health and wellbeing of parents of disabled children'.

HEALTHY PARENT CARERS

Collaboration with Cerebra

We continue to liaise closely with the team at Cerebra to provide useful information for families. This is achieved by sharing our evidence summaries and other resources, and by collaborating on the dissemination of materials and information through social networking sites, Twitter and Facebook.

In March this year we were pleased to host with members of our Family Faculty the annual visit to Exeter for Cerebra's Head of Research & Education Tracy Elliot, Team Leader Beverley Hitchcock, and Trustee Lillemor Jernqvist.

In November Cerebra Professor Stuart Logan participated in the prestigious fundraising reception at 10 Downing Street hosted by Samantha Cameron to celebrate the charity's work.

Cerebra has collaborated on a number of projects and grant applications related to ADHD including the new CATCh-uS study relating to transition from children's to adult health services.

The Cerebra charity also funds several other Academic Chairs and we are always keen to make links. This year Professor Stuart Logan met with Cerebra Professors Chris Oliver and Richard Hastings to discuss potential shared areas of work. We continue to be impressed and share the ethos of the work done by the Cardiff University-Cerebra Legal Rights Entitlement Research Project.

Cerebra
Positively Different

Programme of research

The following pages describe our programme of research, and the progress we made in 2015.

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

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

The aim of the JLA Childhood Neurodisability Research Priority Setting Partnership was to identify and rank unanswered questions about the effectiveness of interventions for children and young people with neurodisability from both families and clinical perspectives. This project was managed by PenCRU on behalf of the British Academy of Childhood Disability, and completed this year.

The work involved a national survey, bringing together similar topics, framing representative research questions, checking if the questions and uncertainties were not already answered by research, and prioritising them with young people, parent carers, charity representatives and clinicians from different professions. A Top 10 ‘shared priority’ topics were selected by participants at a one-day face-to-face workshop.

All the priorities were published on the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). Press releases were circulated to publicise the Top 10 priority topics and the full list of unanswered questions identified. A paper in BMJ Open was published along with a plain language summary. An article providing an update on the considerable impact of the work in 2015, particularly through collaboration with NIHR, was published by the JLA.

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

The Children’s Health oUtcome Measurement Study (CHUMS)

C. Morris , A. Janssens, A. Allard, J. Thompson Coon, V. Shilling, R. Tomlinson, J. Williams, A. Fellowes, M. Rogers, K. Allen, B. Beresford, C. Green, C. Jenkinson, A. Tennant, S. Logan.

This study examined what outcomes of NHS care should be measured for children with neurodisability using questionnaires completed by children and/or parents. The research work was completed in 2013 and the report published in the NIHR Library in 2014.

Two further papers from the study were published in 2015 and another paper was accepted for publication, bringing the total academic output for this study up to seven papers.

This project was funded by the National Institute for Health Research Health Services and Delivery Research (NIHR HS&DR) programme (project number 10/2002/16).

Hospital Communications

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

Improving children's experience of health care is a priority for the NHS. Disabled children are admitted to hospital more often than other children. This study involves parents, clinicians and researchers collaborating to develop and test a training package for health professionals to improve their communication with disabled children when they are inpatients.

We used information from our previous systematic review and qualitative study to develop the training package for health professionals. Parents from our Family Faculty were involved in designing and delivering the training package. The training was delivered on five occasions, and refined each time based on feedback and reflections. Early feedback was encouraging and indicated a staff commitment to behaviour change. Currently the procedures are being documented in a manual to enable the training to be replicated by others. Further testing is required to establish the transferability of the intervention to other hospitals, followed by consideration of ways to evaluate the effects on children's inpatient experience. An academic article is being written.

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

Benefits and costs of peer support for parents of disabled children

V. Shilling, C. Morris, A. Hawton, J. Thompson-Coon, M. Rogers, O. Ukoumunne, S. Logan.

This study evaluated the benefits and costs of providing one-to-one peer support to parents of children with disabilities by Face2Face in Devon and Cornwall. Face2Face is a national network which offers peer support to parents of disabled children from trained befrienders. In this study we conducted interviews with parents who had given or received support through Face2Face and a group of relevant health and social care professions who might refer to the service. The work was completed in 2014.

Two papers describing the qualitative research have been were published in 2015 in the journal Child: Care, Health and Development. The first paper describes perceived outcomes of a one-to-one service, and the second paper describes how key organisational and process factors of the Face2Face service cultivate the sense of 'shared experience' between parents that is central to effective peer support.

This research was funded by NIHR through PenCLAHRC.

Promoting children's positive attitudes towards disability

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

This study sought to identify modifiable factors that affect children's attitudes towards disability. In this study we conducted a survey with over 1800 children across 20 mainstream schools in Devon. The analyses examined factors associated with children's attitudes to disability and the robustness of a commonly used questionnaire that measures children's attitudes towards disability.

A paper describing the main analysis was published this year in Disability and Rehabilitation.

This research was funded by NIHR PenCLAHRC through a PhD studentship held by Megan Armstrong (formerly MacMillan). Megan (Dr Armstrong) successfully defended her PhD in summer 2015.

Sleep positioning in cerebral palsy: a Cochrane review

S. Blake, S. Logan, G. Humphreys, J. Matthews, M. Rogers, J. Thompson-Coon, K. Wyatt, C. Morris.

This systematic review appraised evidence of whether commercially available night-time postural management systems reduce hip deformity in children with cerebral palsy. The focus of the review was whether sleep positioning systems help to prevent or reduce hip migration. We also looked for evidence for the impact sleep positioning systems have on physical functioning, pain, quality of sleep and quality of life for the family and child using the equipment. This review was conducted for The Cochrane Library, one of the best sources of high level evidence available. Cochrane reviews of the effectiveness of interventions tend to include only evidence from randomised controlled trials as the most robust evidence for treatments.

The review found that there is very little high-quality evidence of the impact of sleep positioning systems and no high-quality evidence that using them reduces or prevents hip migration for children with cerebral palsy. The report of the Cochrane review is freely available, and parents from our Family Faculty helped to write a plain language summary. We have shared the review widely and received a positive response from physiotherapists in the UK, Australia and the US.

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

Sleep systems for children with cerebral palsy: a pilot randomised controlled trial

D. Cowan, T. Pountney, D. Porter, J. Underhill, G. Humphreys, C. Morris.

The aim of this research was to find out if using a sleep positioning system to control posture helps children with cerebral palsy to be more comfortable in bed, reduces pain, improves sleep, prevents deformity, and avoids the need for surgery. This was a pilot clinical trial led by Dr Donna Cowan at Chailey Heritage Clinical Services (Sussex Community NHS Trust) to identify whether clinicians and families will participate in a trial, whether families find such systems acceptable, and whether they will be able to use them as prescribed. The findings were presented at the 2015 Annual Meeting of the European Academy of Childhood Disability.

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

The MeASURe study

H. McConachie, A. Le Couteur, J. Parr J, E. McColl, J. Law, J. Rodgers, G. Jones, P. Gringras, T. Charman, E. Simonoff, J. Green, D. Garland, C. Morris, G. Macdonald, N. Livingstone, B. Beresford, A. Pickles, G. Baird, C. Terwee.

PenCRU were part of a large team of researchers around the UK led by Professor Helen McConachie at the University of Newcastle who carried out a systematic review appraising the validity of tools and outcome measures used for young children with autism. We also examined how well the types of outcomes measured reflect issues of importance for people with autism and parent carers. Parents of children with autism from our Family Faculty met on several occasions throughout the study to influence the review and consider the findings. The final report of the study was published in the NIHR Library in 2015. A paper describing how parents input provided valuable insights into appropriate indicators of progress for young children with autism has been submitted to a journal.

This research was commissioned by the NIHR Health Technology Assessment (HTA) programme.

Involving disabled children and young people as partners in research

K. Fitzpatrick, M. McCrory, S. Bailey, K. Boddy, S. Briscoe, S. Blake, V. Shilling, S. Logan, C. Morris.

This methodological research is evaluating ways to involve disabled children and young people as partners in PenCRU research and activities. Contacts have been made with several local schools. We have also liaised with local and national organisations to build our networks. We are currently writing a paper on this work and some of the issues it raised.

This work is supported by the Exeter Catalyst public engagement scheme, PenCLAHRC and Cerebra.

Specialist seating for children with whole body dystonia

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

Some children with cerebral palsy and other conditions experience whole body spasms and find their posture and movement difficult to control. Currently, children with these difficulties are typically strapped into seating systems which limit their freedom of body movements. A team at Bath Institute of Medical Engineering, led by Dr Tim Adlam, is designing a new type of seat that moves with the child rather than restraining them. PenCRU is part of the team with a specific role to involve families as partners in the research through our Family Faculty.

The study is funded by the charity Sparks.

School based interventions for ADHD

D. Moore, J. Thompson Coon, B. Norwich, E. Taylor, C. Shotton, C. Morris, W. Pritchard, R. Garside, S. Logan, K. Stein, T. Ford.

This systematic review examined non-drug interventions for children with ADHD delivered in schools. The review was completed in 2014. A parent from our Family Faculty was involved in this research from the application for funding through to the production of the report. The full report was published in the NIHR Library in 2015. A paper has been published describing how intended 'end-users' were involved during the project in order to make the findings more useful and relevant in practice. Potential end-users were families of children with ADHD, education, health and social care professionals, and third sector charities.

This research was commissioned by the NIHR Health Technology Assessment (HTA) programme.

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. The STARS team and PenCLAHRC have a new website to tell people about the study penclahrc.exposure.co/transforming-teaching. The research is expanding to test the feasibility of training Teaching Assistants & Learning Support Assistants and special schools.

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

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

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

This recently funded research project will be the first national study examining the level of need, as well as practice and process, 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 will be meeting again throughout the project to discuss and influence the process

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

Active Console Games

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

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

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

Healthy Parent Carers programme

A. Borek, S. Logan, C. Morris

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 have 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. Early in 2016 we will evaluate the feasibility of delivering the programme and whether participants feel the intervention is acceptable, perceived to be helpful, and could be improved in any way.

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

Clinical Effectiveness of Increased Standing Time in Non-ambulant Children with Cerebral Palsy: a Pilot Study

R. Rapson, J. Marsden, R. Jeffrey, T. Gibson, C. Stephens, J. Melluish, C. Morris

PenCRU is part of a team led by physiotherapist Rachel Rapson and Professor Jon Marsden at Plymouth University. The study is testing the feasibility of conducting a randomised controlled trial to compare different dosages of time children with cerebral palsy spend using standing frames.

The study is funded by the Chartered Society of Physiotherapy and Plymouth University

Autism: Parent EXperiences of Dentistry (APEX-D)

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

PenCRU and Professor David Moles at the Peninsula Dental School are supporting Nicole Thomas, a parent of a child with autism and a dental hygienist, to undertake her first qualitative research project. The project aims to identify key strategies to improve access to general dental care for children with autism spectrum disorders in the prevention of dental caries (tooth decay). This research will involve interviewing parents of primary school aged children with autism about their experiences of taking their child with autism for a dental examination. Members of our Family Faculty have helped design this research which has now received ethics approval and recruitment began in December 2015.

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

Projects in development

PenCRU's growing reputation in topic areas such as outcomes and outcome measures and our methods to facilitate families in research means that we are often approached by other researchers and group to collaborate on developing projects as applications for funding.

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

Miss Cathy Williams is a Consultant Paediatric Ophthalmologist and Senior Lecturer in Bristol. After working with Sharon on an Evidence Summary, Cathy approached PenCRU for assistance in involving families in her research about children with cerebral visual impairment. We emailed our Family Faculty and the topic was a popular one for many parents. We organised a meeting that was well attended, and Cathy received considerable feedback on her proposed ideas. The feedback was incorporated into her final submission and we were pleased to hear Cathy was successful in being awarded a Senior Research Fellowship. Cathy said: "at the interview - the quality and impact of their [FF] views were commented on and I think really clinched the deal"

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

Colin Kennedy is Professor of Paediatric Neurology at the University of Southampton with particular expertise in children's neuro-oncology. Colin approached PenCRU after reviewing our research on patient reported outcome measures for children with neurodisability. We are collaborating with Colin and his team to develop research to test the feasibility of using patient reported outcome measure questionnaires in out-patient clinics as a way of giving individualised feedback and shifting the focus of consultations towards families' priorities for quality of life.

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

Deb Pal is Professor of Paediatric Epilepsy at King's College London. Deb approached us because of our reputation in both involving families in research, outcomes and health services research. Deb is developing a programme of research related to children with rolandic epilepsy, which is one of the most common types of epilepsy. The studies under development would address uncertainties about drug treatments for children, reducing sleep disturbance in children with nocturnal seizures and knock on effects on learning, and promoting evidence-based practice using the findings.

Academic publications in 2015

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- Janssens, A., Thompson-Coon, J., Rogers, M., Allen, K., Green, C., Jenkinson, C., Tennant, A., Logan, S., Morris, C. (2015). A Systematic Review of Generic Multidimensional Patient-Reported Outcome Measures for Children, Part I: Descriptive Characteristics. *Value in Health, 18(2)*, 315-333.

- Janssens, A., Rogers, M., Thompson Coon, J., Allen, K., Green, C., Jenkinson, C., Tennant, A., Logan, S., Morris, C. (2015). A Systematic Review of Generic Multidimensional Patient-Reported Outcome Measures for Children, Part II: Evaluation of Psychometric Performance of English-Language Versions in a General Population. *Value in Health, 18(2)*, 334-345.

- Janssens, A., Rogers, M., Gumm, R., Jenkinson, C., Tennant, A., Logan, S. and Morris, C. (2015), Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies. Developmental Medicine & Child Neurology. doi: 10.1111/dmcn.12982

- Moore DA, Richardson M, Gwernan-Jones R, Thompson-Coon J, Stein, K., Rogers M, Garside R, Logan S, Ford TJ. (2015). Non-pharmacological interventions for ADHD in school settings: an overarching synthesis of systematic reviews. *Journal of Attention Disorders*, 1-14.

- Hansford L, Sharkey S, Edwards V, Ukoumunne O, Byford S, Norwich B, Logan S, Ford T (2015). Understanding influences on teachers' uptake and use of behaviour management strategies within the STARS trial: process evaluation protocol for a randomised controlled trial. *Bmc Public Health, 15.*

- Borek A, Abraham C, Smith JR, Greaves CJ, Tarrant M. (2015) A checklist to improve reporting of group-based behaviour-change interventions. BMC Public Health 2015, 15:963

- Armstrong M, Morris C, Abraham C, Ukoumunne OC, Tarrant M. (2015) Children’s contact with people with disabilities and their attitudes towards disability: a cross-sectional study. Disability and Rehabilitation. doi:10.3109/09638288.2015.1074727

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- Morris, C., Janssens, A., Shilling, V., Allard, A., Fellows, A., Tomlinson, R., William, J., Thompson Coon, J., Rogers, M., Beresford, B., Green, C., Jenkinson, C., Tennant, A., Logan, S. (2015). Meaningful health outcomes for paediatric neurodisability: Stakeholder prioritisation and appropriateness of patient reported outcome measures. Health and Quality of Life Outcomes 2015; 13:87 doi:10.1186/s12955-015-0284-7

- Richardson M, Moore DA, Gwernan-Jones R, Thompson-Coon J, Ukoumunne O, Rogers M, Whear R, Newlove-Delgado TV, Logan S, Morris C, Taylor E, Cooper P, Stein K, Garside R, Ford TJ. (2015) Non-pharmacological interventions for attention-deficit/hyperactivity disorder (ADHD) delivered in school settings: systematic reviews of quantitative and qualitative research. Health Technol Assess:19(45)

- McConachie H, Parr JR, Glod M, Hanratty J, Livingstone N, Oono IP, Robalino S, Baird G, Beresford B, Charman T, Garland D, Green J, Gringras P, Jones G, Law J, Le Couteur AS, Macdonald G, McColl EM, Morris C, Rodgers J, Simonoff E, Terwee CB, Williams K. Systematic review of tools to measure outcomes for young children with autism spectrum disorder. Health Technol Assess 2015;19(41)

- Morris, C., Simkiss, D., Busk, M., Morris, M., Allard, A., Denness, J., Janssens, A., Stimson, A., Coghill, J., Robinson, K., et al (2015). Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership. Bmj Open, 1(5):e006233. doi: 10.1136/bmjopen-2014-006233.

- Shilling, V., Morris, C., Hawton, A., Bailey, S., Logan, S. (2015). What are the benefits and costs of providing peer support to parents of disabled children? Final Report: PenCLAHRC, University of Exeter Medical School.

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Some key people we work with

We collaborate with a large number of colleagues at the University of Exeter Medical School and the University of Exeter; also NHS clinicians and people in other universities and organisations. The list below recognises some of the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2015.

Tamsin Ford MRCPsych PhD
Professor of Child and Adolescent Psychiatry
Tamsin is a child psychiatrist and collaborates closely with the unit for studies relating to child mental health topics, specifically Autistic Spectrum Disorders and ADHD.

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

Sarah Bailey BSc (Hons) MPH
Associate Research Fellow with Diagnosis of Symptomatic Cancer Optimally (DISCO) group
Sarah is a former member of the PenCRU team and is still involved in our trial evaluating the Wii Fit as a therapeutic intervention. Sarah is studying for a PhD related to optimal diagnosis for cancer.

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.

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

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

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

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

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

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

Local NHS staff, other universities and organisations

Richard Tomlinson B Med Sci MB BS MSc MRCPCH
Consultant Paediatrician
Richard was a founding member of our advisory group and has been involved in several previous and current projects including the CHUMS project.

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

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

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

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

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

Amanda Allard BA BSc MSc
Assistant Director, Council for Disabled Children
Amanda is Assistant Director, National Children's Bureau and Council for Disabled Children and was a key collaborator in the CHUMS project appraising NHS outcomes for disabled children.

Bryony Beresford BSc (Hons) PhD
Director, Children and Families Team, Social Policy Research Unit, University of York
Bryony has a strong track record in applied childhood disability research and qualitative research and developing methods/supporting the inclusion of disabled children in research.

Helen McConachie MA MPhil PhD

Professor of Child Clinical Psychology, University of Newcastle

Professor McConachie’s research focuses broadly on the health and wellbeing of disabled children. Helen led the MeASURe research on appropriate outcomes for young children affected by autism.

Crispin Jenkinson BA MSc DPhil

Professor of Health Service Research, University of Oxford

Professor Jenkinson’s interests include quality of life and health status measurement. He has collaborated with PenCRU on the CHUMS project.

Tim Adlam BEng (Hons) MSc PhD CEng MIMechE CSci MIPEM

Head of Mechanical Engineering, Designability & Visiting Research Fellow, University of Bath

Tim approached us to help with his research to develop appropriate seating systems for children with whole body extensor spasticity, particularly because of our ability to engage families.

William Farr PGCE MA NPQH PhD

Senior Research Fellow in Neurodisability/Psychology, Sussex Community NHS Trust

Will has a keen interest in technology application in health care, and leads the NIHR funded trial evaluating the Wii Fit as a therapeutic intervention for children with cerebral palsy.

Dido Green MSc PhD

Reader in Rehabilitation, Oxford Brookes University

Dido is an occupational therapist and experienced researcher in occupational therapy. Dido is a key collaborator on the trial evaluating the Wii Fit as a therapeutic intervention.

David Moles PhD BDS MSc MSc(Hons) DDPHRCS(Eng) MIHPE FHEA FFGDP(UK)

Professor of Oral Health Services Research, Peninsula Dental School, Plymouth University

David’s experience and expertise is valuable in our collaborative research on oral health and dentistry for disabled children, and our APEX-D project on dentistry for children with autism.

Deb Pal PhD MRCP

Professor of Paediatric Epilepsy, King’s College London

Deb leads a developing a programme of research to improve holistic care of children with the most common type of epilepsy.

Paul Gringras MBChB, MRCP

Professor of Children's Sleep Medicine and Neurodisability

Paul co-leads the developing research programme on epilepsy with Deb. Paul’s focus is on improving sleep using behavioural interventions, and the effects on learning due to sleep disruption.

Colin Kennedy BA, MBBS, MD

Professor in Neurology and Paediatrics, University of Southampton

Colin leads the development of research on the individualised clinical use of patient reported outcome questionnaires with paediatric oncology survivors

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