PenCRU
Childhood Disability Research

University of Exeter Medical School
Annual Report 2018

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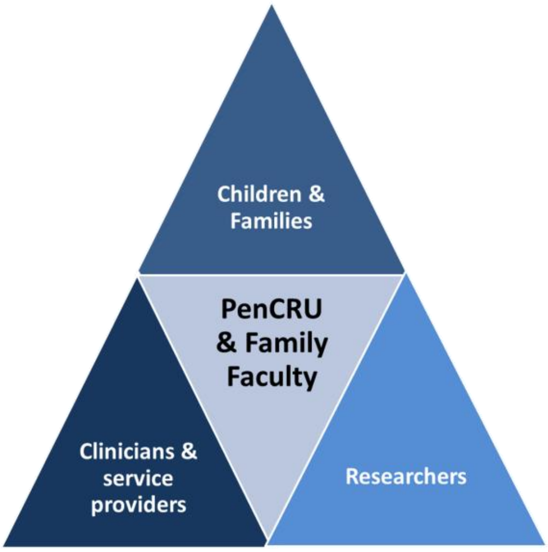

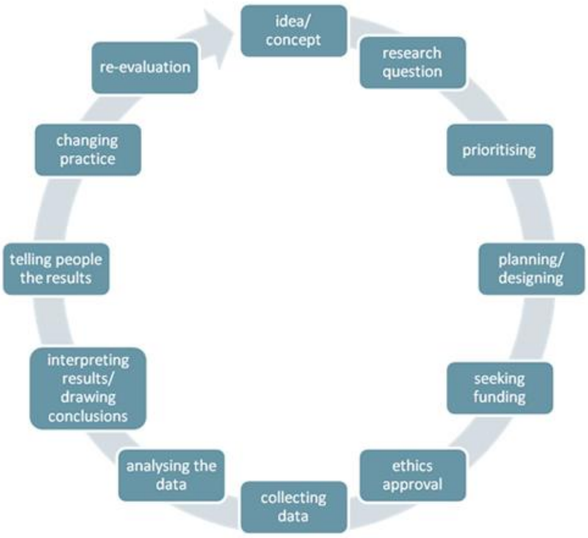

View from the Chair on 2018

Welcome to the PenCRU Annual Report for 2018. It has been another year of solid achievement for the unit and we are pleased to reflect on what we accomplished. As ever, first and foremost, I want to celebrate our ongoing partnership with our Family Faculty. The Family Faculty are families with disabled children who are at the centre of all that we do at PenCRU, influencing what research we do and how we do it. They continue to be the primary driver of the Unit's success.

I also want to take this opportunity to celebrate Chris Morris' promotion to Associate Professor in Child Health Research. Chris has an international reputation for the quality of his research and for the contribution he has made to improving the lives of children with disabilities and the lives of their families. As well as being a stellar researcher, he is known for championing the involvement of families and children in research. His drive and vision which have been central to everything the Unit has achieved.

Major effort this year has focused on the next stage of the Healthy Parent Carers programme. This peer-led, group-based intervention for parent carers aims to improve their health and wellbeing by promoting empowerment, confidence, and resilience. We co-developed programme in close collaboration with members of our Family Faculty, and particularly with two parent carers with experience in training befrienders to provide peer support. Our study to test whether it is feasible to set up and deliver the programme in the community and evaluate the intervention in a randomised controlled trial was funded by the National Institute for Health Research, the research part of the NHS. In December we were excited to hear that delivery of the Healthy Parent Carers programme will be supported by the National Lottery through the Big Lottery Fund.

We successfully led a team to take on a commissioned call for research by the National Institute for Health Research focusing on improving continence for children and young people with neurodisability. This topic ranked number 7 in the Top 10 priorities from the James Lind Alliance research priority setting partnership that PenCRU led on behalf of the British Academy of Childhood Disability. The study includes surveys with health, education and social care professionals, and also with families about their experiences, and systematic review bringing together all the evidence.

PenCRU continues to collaborate on research studies with colleagues around the UK and worldwide. We are coinvestigators on research focusing on difficulties with eating, drinking and swallowing for children and young people with neurodisability, and another focusing on the most common type of childhood epilepsy that led to the development of a new core outcome set. With colleagues locally we completed systematic reviews examining evidence for parent-to-parent support in neonatal units and sleep positioning systems for children and adults with a neurodisability

On a somewhat sadder note this year, with regret, we accepted the decision of Cerebra to terminate our research funding contract early as the charity had faced extreme income challenges in the last year. We have had a productive relationship with Cerebra since PenCRU was established in 2009. The funding from Cerebra enabled us to achieve an international reputation for childhood disability research and for our innovative approach to public engagement through our Family Faculty. We would like to put on record our appreciation to Cerebra that the funding they provided helped make this success possible. In the short term the University of Exeter Medical School is supporting the unit whilst we seek alternative partnerships and other sources of funding to secure the future of the unit.

Professor Stuart Logan

Mission statement

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

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

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

How we are funded

From 2009 until autumn 2018 PenCRU benefited from funding from the charity Cerebra. The charity has faced extreme income challenges in the last year 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 is supporting the unit whilst we seek alternative partnerships and other sources of funding to secure the future of the unit.

PenCRU has been successful in securing funding from National Institute for Health Research to support several individual studies as chief or co-investigators. PenCRU also benefits from being integral to the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for the South West (known as 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 is an independent academic research unit at the University of Exeter Medical School. The views and opinions expressed by PenCRU in this report are those of the PenCRU team and not necessarily those of the NHS, the NIHR, 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 the Director of the Institute of Health Research at the University of Exeter Medical School and Honorary Consultant in Paediatrics in the Royal Devon and Exeter Hospital. His particular interest is the generation of research of direct relevance to policy and practice and useful to practitioners and to families. His major areas of research are the evaluation of complex interventions and the effects of social inequalities on child health.

Chris Morris MSc DPhil
Associate Professor in Child Health Research
Chris has clinical experience as an orthotist and in health research methods and childhood disability research. He was awarded Masters and Doctoral degrees by the University of Oxford for research about children with cerebral palsy. Chris has provided academic leadership for PenCRU since joining the University of Exeter in 2009.

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

Gretchen Bjornstad MSc, DPhil
Postdoctoral Research Associate in Child Health
Gretchen's research background is in the evaluation of interventions for improving the health and well-being of children and families. She has also worked with children in residential treatment settings and as a family counsellor.

Kath Wilkinson BSc (Hons), PGCert, MSc
Associate Research Fellow
Kath joined PenCLAHRC in September 2016 to work across Child Health projects. Kath has a background in Psychology and experience of managing and delivering research and evaluation projects across the education, health and social care sectors.

Beth Cuffe-Fuller BA (Hons), MRes
Graduate Research Assistant
Beth joined PenCRU in 2018 and is primarily working on the Healthy Parent Carers project. Prior to this, Beth was working as a frontline practitioner with children and families experiencing domestic abuse, as a training coordinator for a suicide prevention charity, and worked on a number of social research projects.

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

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

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

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

Team news updates

Our Family Involvement Coordinator Katharine Fitzpatrick returned from maternity leave in March.

Silvia Bortoli who had been covering the Family Involvement Coordinator role initially stayed on with PenCRU until the summer when she moved to take up a new post in the University of Exeter Living Systems Institute as Communities Engagement Manager.

Hannah Morris returned from maternity leave in March this year and left PenCRU in October to look after her little boy full-time.

Kath Wilkinson started her maternity leave in December and her little girl was born just before Christmas.

Astrid Janssens has moved to Denmark to take up a position and exciting opportunity as Associate Professor at the University of Southern Denmark in Odense.

Beth Cuffe-Fuller joined PenCRU in November to work predominantly on the Healthy Parent Carers project.

Helen Eke will join the team in January. Helen has been working on the CATCh-uS study evaluating transition to adult services for young people with ADHD and will work on the Improving Continence in children with Neurodisability (ICoN) project.

Family and Community Involvement

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

Family Fun Day 2018

We had a brilliant day out for our Annual Family Fun Day in September. This year we visited Crealy Adventure Park. The purpose of the day is to say thank you to members of the Family Faculty who have been involved in our work, to keep in touch with some of the members who we haven't seen in a while and to welcome new members. As usual the amazing Vinny was there to entertain us (supported at times by many budding apprentices!) and he got us juggling and spinning plates, and a great day was had by all.

Community Involvement

Our Family Involvement Coordinator Katharine has been attending events in the community, such as Plymouth Parent Carer Voice Conference, to raise awareness of PenCRU and encourage new members to sign up to our Family Faculty mailing list. We currently have 170 Family Faculty members and 95 Professional members.

Visitors from the Netherlands!

In April we welcomed a group of researchers from BOSK, the Dutch association for people with disabilities. Researchers from BOSK were joined by three people from ZonMW, The Netherlands Organisation for Health Research and Development, the Dutch equivalent of our UK National Institute for Health Research. The purpose of their visit was for them to learn about how PenCRU and the Family Faculty work together. Some Family Faculty members joined us and gave presentations on how they had been involved in PenCRU research. BOSK would like to set up something similar to our Family Faculty in the Netherlands, and appreciated the opportunity to talk to us about best practice and challenges. We had a great day – thank you to all who contributed!

Accessible dissemination of research

PenCRU aims to provide accessible information for professionals, families and people with brain injury and neurological disorders. We try to help families obtain the best current evidence to help them in making decisions. Our '*What's the Evidence?*' summaries are designed to summarise existing research about specific questions. New Summaries in 2018 included:

- Colourful Semantics for children with Autism Spectrum Disorder
- Cannabis-based products to treat childhood epilepsy
- Tools and strategies to support children and young people with dyscalculia
- Is Selective Percutaneous Myofascial Lengthening an effective treatment for children with cerebral palsy?
- Omega-3 and omega-6 supplements to improve speech in children with dyspraxia
- Family Hope Center

Updated What's the Evidence? summaries

- Therapies based on sensory integration in autistic spectrum disorder
- Hyperbaric Oxygen Treatment for children with cerebral palsy
- Is G Therapy an effective treatment for Cerebral Palsy?
- Stem Cell Therapy for Cerebral Palsy
- Can Omega 3 supplements reduce symptoms in children with ADHD?

We also produced plain language summaries:

- Healthy Parent Carers: a peer-led programme to improve health and wellbeing

With help from a gifted graphic artist CookieScience @ScienceofCookie we produced a fabulous illustrated plain language summary for the paper describing our project on Core Health Outcomes In Childhood Epilepsy (CHOICE): protocol for the selection of a core outcome set

One of our Family Faculty worked with PenCLAHRC's public involvement and communications teams to produce a fantastic video explaining her personal journey being involved as a partner in research and expressing clearly and colourfully how anyone could get involved in health research. The video was used to celebrate the NHS 70th Birthday

NHS at 70: Celebrating public involvement in health research

On Thursday 5th July 2018, the National Health Service (NHS) turned 70 ...

youtube.com

Programme of research

The following pages describe our programme of research, and progress made in 2018.

Healthy Parent Carers programme

C. Morris, G. Bjornstad, A. Borek, M. Fredlund, A. McDonald, V. Berry, M. Tarrant, A. Hawton, J. Lloyd, O. Ukoumunne, S. Logan.

This randomised controlled trial is a feasibility study to see whether the peer-led group-based programme can be delivered in the community and whether we can test to see whether it improves health and wellbeing using our trial design for evaluating effectiveness and cost-effectiveness.

The research is funded by the NIHR Research for Patient Benefit 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, J, D Hughes, L. Wiggs, J. Currier, D. Roberts, C. Tudor-Smith, H. Hickey, F. Gibbon, L. Smith, H. Hiscock, H. Gillard.

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

PenCRU is leading a study with children, parents, doctors and nurses to choose a core outcome set and the best ways to measure health and quality of life for children with rolandic epilepsy.

The research is funded by a NIHR Programme Grant

Focus on Early Eating Drinking & Swallowing (FEEDS)

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

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

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

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

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

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

The research was funded by the NIHR Research for Patient Benefit 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 is testing feasibility of using patient reported outcome measure questionnaires in outpatient clinics with children who have survived brain tumours as a way of shifting the focus of consultations towards families' priorities for quality of life. Professor Colin Kennedy at the University of Southampton leads the study.

This research is funded by The Brain Tumour Charity

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

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

This project is the first national study examining the level of need, as well as practice and processes, around the transition of young people with ADHD into adult services. The study is led by Astrid Janssens and Tamsin Ford, in the Child Mental Health Research Group, and Cerebra Chair Stuart Logan. Parent carers from our Family Faculty have helped to shape the design of this project and are meeting throughout the project to discuss and influence the processes. The surveillance study, qualitative interviews, and the first round of the mapping study were completed in 2017. The second round of the mapping study will be launched in early 2018.

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

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

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

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

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

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

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

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

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

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

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

Research to evaluate ways to promote continence for children with neurodisability was ranked number 7 in a top 10 of research topics prioritised by young people with neurodisability, parent carers, charity representatives and clinicians. Subsequently NIHR commissioned a survey of practice and a systematic review of interventions to improve continence for children with neurodisability.

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. In 2018 we tested the training in several hospitals around England.

The research is supported by **NIHR PenCLAHRC**.

Unfortunately not all our applications for funding are successful. In 2018 we were pleased to work with colleagues from around the UK on two applications to NIHR that were subsequently rejected:

- Foot orthoses for children with symptomatic flat feet commissioned by Health Technology Assessment Programme, led by Mr Tim Theologis in Oxford.
- The delivery of therapy in school settings for children with physical impairment: what works, for whom and in what circumstances? led by Dr Sarah Crombie in Sussex was submitted to the Health Services and Delivery Research Programme.

Research capacity building - NIHR funded 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 pleased to share our experiences of childhood disability research and involving families as partners in research, and build capacity for more research in future.

- Jen McAnuff, NIHR / HEE Clinical Doctoral Research Fellow, University of Newcastle & Clinical Lead Occupational Therapist, Leeds
  Supporting participation in leisure in children aged 8-12 years with communication and mobility difficulties
- Lesley Katchburian NIHR / HEE Clinical Doctoral Research Fellow, University College London & Clinical Specialist Physiotherapist in Neurodisability, Great Ormond Street Hospital
  Use of Botulinum Toxin A in Ambulant Children with Cerebral Palsy
- Rachel Rapson NIHR / HEE Clinical Doctoral Research Fellow, Plymouth University & Clinical Manager Children and Learning Disability Physiotherapy Teams, Torbay
  A novel interactive training device to improve walking Ability and quality of life for Children with CErebral Palsy Trial (ACCEPT study): A multi-centred feasibility RCT with an embedded qualitative study
- Marilyn Poole, NIHR / HEE Clinical Doctoral Research Fellow, University of Birmingham Senior Community Paediatric Physiotherapist, Birmingham
  Developing interventions to reduce sedentary behaviour in non-ambulant children with long term disabilities
- Phillip Harniess, NIHR / HEE Clinical Doctoral Research Fellow, University College London & Senior Research Physiotherapist, Great Ormond Street Hospital
  Optimising Parent Engagement with Early Intervention Physical Therapy for Their Infants with Emerging Cerebral Palsy

Academic publications in 2018

Borek A, McDonald B, Fredlund M, Bjornstad GJ, Logan GS, Morris C (2018). Healthy Parent Carers programme: development and feasibility of a novel group-based health-promotion intervention. BMC Public Health, 18, 270-270. https://doi.org/10.1186/s12889-018-5168-4

Thomas N, Blake S, Morris C, Moles DR (2018). Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. Int J Paediatr Dent, 28(2), 226-238. https://doi.org/10.1111/ipd.12345

McConachie H, Livingstone N, Morris C, Beresford B, Le Couteur A, Gringras P, Garland D, Jones G, Macdonald G, Williams K, et al (2018). Parents Suggest Which Indicators of Progress and Outcomes Should be Measured in Young Children with Autism Spectrum Disorder. J Autism Dev Disord, 48(4), 1041-1051. https://doi.org/10.1007/s10803-017-3282-2

Crudgington H, Morris C, Rogers M, Dunkley C, Gibbon FM, Currier J, Roberts D, Carter B, Bray L (2018). Core Health Outcomes in Childhood Epilepsy (CHOICE) - Development of a Core Outcome Set. EPILEPSIA 59: S93-S93, Meeting Abstract: p193

Hunt H, Whear R, Boddy K, Wakely L, Bethel A, Morris C, Abbott R, Prosser S, Collinson A, Kurinczuk J, et al (2018). Parent-to-parent support interventions for parents of babies cared for in a neonatal unit-protocol of a systematic review of qualitative and quantitative evidence. Syst Rev, 7(1). https://doi.org/10.1186/s13643-018-0850-2

Kandiyali R, Hawton A, Cabral C, Mytton J, Shilling V, Morris C, Ingram J (2018). Working with Patients and Members of the Public: Informing Health Economics in Child Health Research. *Pharmacoecon Open* 10.1007/s41669-018-0099-7 https://doi.org/10.1007/s41669-018-0099-7

Humphreys G, King T, Jex J, Rogers M, Blake S, Thompson-Coon J, Morris C (2018). Sleep positioning systems for children and adults with a neurodisability: A systematic review. British Journal of Occupational Therapy. doi: 10.1177/0308022618778254

Axford N, Lowther K, Timmons L, Bjornstad GJ, Brook L, Webb L, Sonthalia S (2018). Rapid review on safeguarding to inform the Healthy Child Programme 5 to 19. London, Public Health England. https://www.gov.uk/government/publications/healthy-child-programme-rapid-review-on-safeguarding

Axford N, Warner G, Hobbs T, Heilmann S, Raja A, Berry V, Ukoumunne O, Matthews J, Eames T, Kallitsoglou A, et al (2018). The effectiveness of the Inspiring Futures parenting programme in improving behavioural and emotional outcomes in primary school children with behavioural or emotional difficulties: study protocol for a randomised controlled trial. BMC Psychology, 6, 3-3. https://doi.org/10.1186/s40359-018-0214-7

Whybra L, Warner G, Bjornstad GJ, Hobbs T, Brook L, Wrigley Z, Berry V, Ukoumunne O, Matthews J, Taylor R, et al (2018). The effectiveness of Chance UK's mentoring programme in improving behavioural and emotional outcomes in primary school children with behavioural difficulties: study protocol for a randomised controlled trial. BMC Psychology, 6, 9-9. https://doi.org/10.1186/s40359-018-0220-9

Eke, Helen & Janssens, Astrid & Ford, Tamsin. (2018). Review: Transition from children's to adult services: a review of guidelines and protocols for young people with attention deficit hyperactivity disorder in England. Child and Adolescent Mental Health. 10.1111/camh.12301. https://doi.org/10.1111/camh.12301

PenCRU
University of Exeter Medical School
St Luke’s Campus
Heavitree Road
Exeter, EX1 2LU

Email: pencru@exeter.ac.uk
Tel: +44 (0)1392 722968/6046
Website: www.pencru.org

Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

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Family Faculty
designed by Matt aged 14