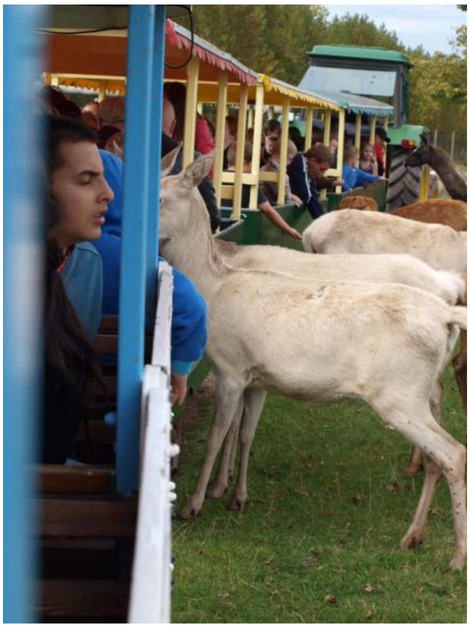
Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research



Deer ride at Annual Family Fun day

Peninsula Medical School

Childhood disability research based in Devon

Annual Report 2011

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Cerebra Chair's reflections on progress in 2011


Professor Stuart Logan

In this report we largely reflect on the progress PenCRU has made in the last year. Nevertheless I want to take the opportunity to reflect more broadly on the extent to which we have made progress against the goals that we first proposed to Cerebra in 2006/7. At the heart of that proposal was the aim of involving families of disabled children in setting the research agenda and shaping how we worked. This active engagement of families is the aspect of our work of which we are most proud. Our Family Faculty has grown considerably, now numbering over 150 families, and also in the depth of their involvement in every aspect of the unit. I am particularly delighted that over this year we have had members of the Family Faculty as joint applicants on a number of grant applications. Family involvement means that we are led to addressing the questions that really matter, thinking about the outcomes that are important in their lives, that the way in which we set up the studies is ethically sound and has a high chance of successfully recruiting participants. In addition to these practical benefits it also makes the work much more fun for the researchers.

A key objective was to evaluate the effectiveness of interventions, both by systematically reviewing existing evidence and by carrying out primary studies. Doing this work is very expensive, so our aim has always been to use the core support Cerebra has given us as a way of unlocking grants from other organisations. Success in winning big grants requires building collaborative teams and we have been fortunate in being able to draw on the growing group of health services researchers within our medical school interested in childhood disability, and in developing links with groups in other institutions. Recent highlights include a grant of £308K from the National Institute for Health Research (NIHR) Health Technology Assessment Programme to systematically review the effects of non-drug treatments for Attention-Deficit Hyperactivity Disorder (ADHD), led by Tamsin Ford, and a grant of £247K from the NIHR Health Services Research Programme for a study which aims to determine which 'health outcomes' should be measured in services for disabled children, led by Chris Morris.

This latter grant is also helping us to deliver on another of our key objectives, developing a better understanding of the effect of interventions on the life experience of children, their families and carers, so that we can improve the design and delivery of interventions. For this study PenCRU brought together an expert team including several parents as well as clinicians and esteemed research methodologists. As the UK Department of Health continues to be focused on assessing NHS performance from the patients' perspective, it is fantastic that PenCRU is leading research to inform how the impacts of NHS care affect the health of disabled children. Collaborating with the Council for Disabled Children means that we will ensure that children themselves will have their say, and also that the study will gather views from parents and young people from across England.

A further objective was to systematically review the evidence for treatments and therapies in response to questions raised by families, and to make summaries of the research evidence available to families and clinicians in an accessible format. The PenCRU website provides our platform for publishing evidence summaries, and we have covered a range of mainstream and complementary and alternative therapies. Inevitably, these reports have sometimes received a mixed response when evidence of effectiveness of therapies is not available or is unconvincing, though we are reassured by the many positive comments we have received. It is entirely understandable that families may be keen to try a range of therapies, especially when the NHS is offering little or less help and/or hope. We see our role as providing a balanced representation of the evidence for the effectiveness for therapies to inform families' decision making alongside other factors. Just because evidence of effectiveness is not available does not mean a therapy doesn't work, it is simply a fact that we cannot be certain that the treatment works and/or do not know which children are likely to benefit.

We also tasked ourselves with trying to build capacity in the area of childhood disability research. Therefore It is great to see our first PenCRU PhD student, Megan McMillan, making a promising start to her research about children's attitudes towards disability; and especially as the idea for this topic came from parents in our popular 'social inclusion' working group. We note with pride that Stuart Read who worked with us at undergraduate and during his Masters studies was recognised with a Dean's Commendation for his MSc dissertation that was supervised by PenCRU staff. Stuart is continuing in disability-related research, studying for his PhD based in the Psychology Department at the University of Exeter.

The number of projects that PenCRU is involved in has grown hugely in 2011, and will continue to expand next year with two new staff joining us in February and March. I am confident that we are making a significant contribution to the field of childhood disability research, and sincerely hope that the information that we provide translates to improvements in the health and wellbeing of children and families. Most of all I am delighted at the enthusiastic participation of so many children and families who continue to teach me about what matters in life and remind of why I enjoy coming to work.

I hope you enjoy reading this report and look forward to further close collaboration with families and Cerebra over the coming years.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

Our Mission

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

Fundamental to the ethos of the unit is the meaningful involvement of families affected by childhood disability in all aspects of our research and related activities. This includes setting our research agenda and deciding how to carry out specific research projects. We achieve this involvement through our ‘Family Faculty’. You can read more about how families are involved in our work in this report.

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

We also pursue research with colleagues engaged in childhood disability research across the UK and worldwide.

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. The charity also maintains their own in-house research and provides direct grants and advice to parents, carers and professionals.

The relationship between Cerebra and the Peninsula Medical School evolved from the conception, design and completion of a randomised controlled trial evaluating the effectiveness of osteopathy for children with cerebral palsy. Professor Stuart Logan was subsequently awarded the title of Cerebra Chair in Paediatric Epidemiology and the charity provided funding to establish the research unit.

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 schemes operated by the National Institute for Health Research, Medical Research Council and charitable agencies that fund research.

PenCRU is an independent academic research unit at the Peninsula Medical School, University of Exeter. The views and opinions expressed by PenCRU do not necessarily represent the views of the Cerebra charity.

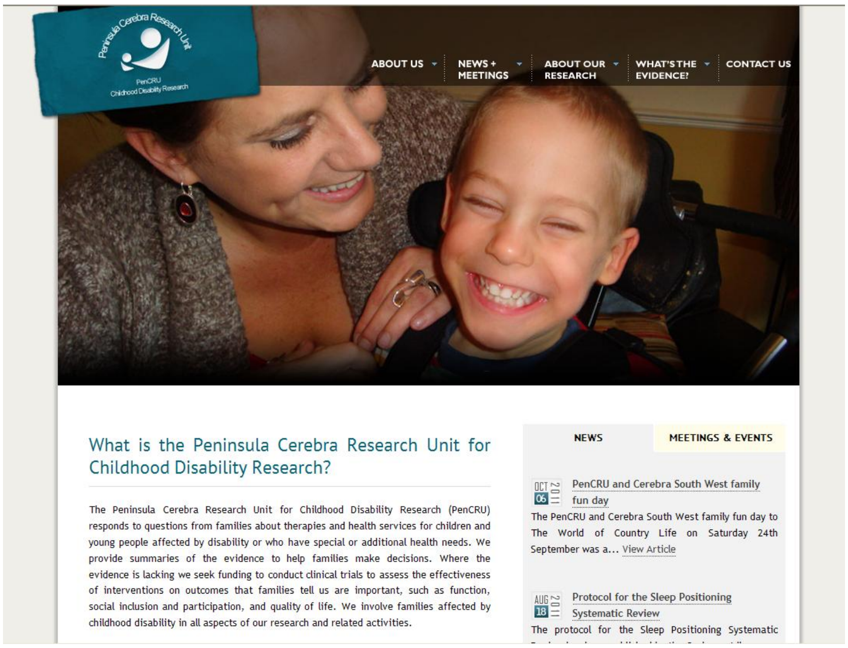
New name: PenCRU

This year we renamed the unit PenCRU, which stands for the Peninsula Cerebra Research Unit. The reason for the change of name was that we were often confused with Cerebra the charity. While we collaborate closely, it is important that we remain distinct organisations. For instance, if someone doesn't like what we say about a particular therapy then we do not want it to be assumed that this is the view of Cerebra. There is also a need for PenCRU to be seen as an independent academic research unit.

We ran a competition with our Family Faculty to come up with our new name; and the winner received a £20 Amazon voucher. At the same time we had a competition for the children of our Family Faculty to design a logo for the Family Faculty and again the winner received a £20 Amazon voucher, see page 7 for the winning logo.

New Website

In May of this year we successfully launched our new website with our personalised domain name www.pencru.org at the same time as we publicised the new name. The new website was designed with the Family Faculty, many of whom supplied all the lovely photos of the children and which we feel makes the website particularly special. We have received lots of compliments about the website; Julia and Harrison in the photo below will feature on the front cover of a new handbook on cerebral palsy being published by Mac Keith Press. The website is a growing and important resource of information for families and professionals.



What is the Peninsula Cerebra Research Unit for Childhood Disability Research?

The Peninsula Cerebra Research Unit for Childhood Disability Research (PenCRU) responds to questions from families about therapies and health services for children and young people affected by disability or who have special or additional health needs. We provide summaries of the evidence to help families make decisions. Where the evidence is lacking we seek funding to conduct clinical trials to assess the effectiveness of interventions on outcomes that families tell us are important, such as function, social inclusion and participation, and quality of life. We involve families affected by childhood disability in all aspects of our research and related activities.

PenCRU and Cerebra South West family fun day

The PenCRU and Cerebra South West family fun day to The World of Country Life on Saturday 24th September was a… View Article

Protocol for the Sleep Positioning Systematic Review

The protocol for the Sleep Positioning Systematic

Regular communications

We produce a quarterly newsletter which is sent to all our Family Faculty, the professionals that we have made contact with, and all special schools in the region. The newsletter keeps people up to date with our work and informed of upcoming meetings, seminars or events. We also publish notes from our meetings on the website once approved by those people who participated.

Involving Families in Research

The ethos of the unit is to involve families in all aspects of our work. There are many ways that families can get involved and we are always trying to find new ways to make research more accessible. Some of the ways that families can get involved currently are: to become a member of the Family Faculty, which does not commit members above being informed about the work that we are doing; to take part in the Advisory Group, which oversees the strategic management of the unit; take part on committees or review information leaflets for specific studies; work with us to design new studies; review PenCRU publicity documents; assist with the dissemination of results of studies; come with us to attend conferences and make presentations. We appreciate that the amount of time that families have varies so we understand when our families want or need to dip in and out of being involved.

This year we secured funding from PenCLAHRC to 'acknowledge' families for their time in accordance with INVOLVE guidelines for paying patients and public involved in research. We have published our payment policy on our website.

Parents from our Family Faculty took part in the following activities this year; although many other members of our Family Faculty often feedback to us via email or telephone:

We had three PenCRU advisory group meetings with three to four parents attending each.

The Peer support project had a stakeholder meeting in July at which seven parents attended; these parents also reviewed the information sheets as well as four who participated in a meeting to design the systematic review protocol.

The CHildren's oUtcome Measurement Study (CHUMS) project held a co-investigator's meeting to which four parents came; these parents have also attended two follow up meetings to design the topic guide for focus groups. Nine parents in total reviewed and provided feedback on the content of information sheets for this project.

So far the Computer Games working groups has met twice and we have four parents who are able to come to meetings, but several others who are interested in this topic sent us their contributions via email.

The Social Inclusion working group has met once this year and six parents were able to make the meeting; several others are keenly interested in the development of this piece of work.

Many members of the Family Faculty voted on the doodle poll for the choice of venue for the Annual Family fun day and two parents came along to check out the facilities to make sure they were suitable and helped us plan the day.

'I have always found Peninsula Cerebra Research Unit very professional to work with. They are always helpful, interested and keep me well-informed. I am unable to attend meetings but I have still been able to have some involvement, mainly through e-mail. My only suggestion is that it would be good to see even greater involvement in the future for those parents, like myself, who are unable to get to meetings.' Liz

About our Family Faculty

Family Faculty
designed by Matt aged 14

We have continued to build up the numbers in our Family Faculty; currently we have 158 families who are interested in our work. Members are parents of disabled children in Devon, with a few from farther afield around the UK. We recruit families by various methods and by continuing to build links with local support groups, special schools and local authorities.

This summer we were invited by Mayfield special school to have a stall at their summer fete; we had some PenCRU balloons which were a huge success with the children. They proved very popular at the Millwater special school Christmas fete too, which we were also invited to attend.

Mayfield Special School fete with PenCRU balloons

Annual Family Fun day

Due to the success of last year's Family Fun day Cerebra in the South West and PenCRU co-hosted our second annual event in September. It was held at *The World of Country Life* near Exmouth, and celebrated and thanked families for being involved with us over the year.

The event was organised with the input of parents who voted for the venue and some parents visited the site to check it would be appropriate for our needs. We were pleased to welcome 114 people. The goat walking, deer-train ride and especially Vinny the mime artist, an all-round entertainer were definite highlights. It was a fantastic family day and a great opportunity for the families and Cerebra members to get together.

Vinny – the mime artist

Learning to work together

The 'Building a Partnership' group has developed over the past year and the group has been thinking of ways to support families in how we can work together. At a previous event we hosted in October 2010 a parent explained her frustration of not being able to find reliable information about her child's condition on the internet in a timely manner.

We took this as an opportunity to plan a 'shared learning' event in May offering hands on experience to Family Faculty members. The day was a great success and was co-hosted by PenPIG (Patient Involvement Group of the Peninsula Collaboration for Leadership in Applied Health Research & Care) researchers Andy Gibson and Kate Boddy alongside Sue Abbott, PCMD Academic Support Consultant. Due to its success we repeated the training in November.

Kate Boddy in action in the IT suite

Some of the questions that were generated from the morning session were:

- *Expressing emotions* - Comprehension and 2-way understanding
- *Fine motor skills* -How to strengthen these? Outside of school, Physical problems – aches/joints
- *Transition* - Child to adult services – involvement of parents post 18, How to choose the right service/provider, Person centred planning – what is it? How to be involved? Information. Who makes the decision? Legal info
- *Sensory processing in Downs Syndrome*- Early intervention now standard but what about children who were not screened early? Is there benefit to testing later or is it crucial to test early?
- *Downs Syndrome* - Learning profile; Specialist or mainstream, not doing what is known to work; Individuals – not all situations are the same!
- *How can children feel more at ease* - e.g. loud noises
- *Labels are not helpful*! -They can unlock some doors and close others
- *Cleft palette* - Choices of treatment. What works? Information; What are the alternatives; Communication of information about treatments/consultation
- *Medication* - Reduction of medicines; Safety of intense medication use; effects on organs such as liver and kidney; alternatives to drugs? Individualised drug treatments; homeopathy.

Here are some of the comments from the 16 parents who attended the training:

'I will be putting it into practice'
'Brilliant'
'It was really interesting'
'I found it all new and very informative and a tool that can be used and individualised for one's own use'
'The event was well organised and highly informative; I really enjoyed myself, too!'
'very informative, very friendly and useful'
'a really useful opportunity to meet other parents'
'very good organisation, was able to participate within group and all relevant information'

Plans for 2012

We have prepared a 'recruitment and retention' strategy with goals for involving more families in 2012. This is to help us focus on particular areas where we are less known and to think about new and more flexible ways for involving families that will suit them. We are planning to host working group meetings in Barnstaple, Plymouth and Torbay so that those people who find it difficult to come to Exeter are not excluded. We hope to be invited and attend more special school fetes or fairs, taking our balloons with us. We also hope to develop more training as part of our 'Building a Partnership' group in areas that parents from our Family Faculty request.

We plan to set up a working group to explore how we will go about involving children and young people in research, we have several contacts who are interested in coming to help us plan so that this is a rewarding experience for children and young people. We plan to have our first meeting in March.

We have been invited to have an information stall at several Devon County Council parent information events and will be presenting a workshop on 'finding reliable information on the internet'. We will also attend the bi-annual INVOLVE conference. At both of these events we hope to co-present with members of our Family Faculty.

Developing ideas into research projects

PenCRU responds to questions from families about therapies and health services. We provide summaries of the evidence regarding specific treatments to help families make informed decisions, or signpost families to existing summaries written by others. Where the evidence is lacking we seek funding to conduct clinical trials to assess the effectiveness of interventions. Our focus is on outcomes that families tell us are important, such as function, social inclusion and participation, and quality of life.

Questions received from families or health professionals enter a process of prioritisation as detailed in the flowchart in the appendix at the end of this report. The first step is to clarify the question, where possible specifying this in a 'PICO' format (detailing the type of Patients, Intervention, Comparison, Outcomes). Research questions are then divided into those topics that have already been researched elsewhere, in which case the proposer is directed to the appropriate resources, or we produce a 'What's the Evidence?' summary. Issues that are identified as potential projects and felt to be important to members of our Family Faculty are carried forward to a working group and developed as research protocols.

PenCRU benefits from being part of the NIHR Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC). PenCLAHRC is a collaboration of Universities and NHS organisations in the South West of England which aims to deliver high-quality health research that influences medical practice, ensuring that research addresses issues that are relevant to patients and carers. Several research topics that have been prioritised by PenCRU have been funded by PenCLAHRC.

Goat walking!

'I've been involved with PenCRU for about one and a half years. During this time PenCRU have encouraged me to use the knowledge, both positive and negative, I've gained in raising my disabled daughter and put it to positive use in helping them find research questions that hopefully will make a difference to other children in similar situations in the long term. The team at PenCRU have made me feel very welcome and a valued member of the team; since attending their meetings my confidence has really grown.

Just recently they asked if I'd consider being a co-investigator on the CHUMS study, a research project that PenCRU is under taking. The confidence that I have in PenCRU to help me, help them meant it was easy to say yes! I've now attended a couple of the CHUMS meetings and it's been so good to be involved in a project that although there are many professional people involved they really want to hear and value what parents have to say. Thus making some sense of all I've been through with my daughter and giving much more to my life.' Kim

Vinny working his magic

Involving Service Providers

We seek to work in partnership with agencies providing health and education services for disabled children across Devon, Plymouth and Torbay. This is no easy feat as there are three Local Authorities and several NHS Trusts in our region, and the frontline staff are all exceptionally busy people. However, it is fundamental to the 'applied' nature of our research that we are aware of the issues professionals are dealing with, and have an entry route for disseminating findings to influence policy and practice in the 'real world'.

The Local Authorities we seek to work with are the services supporting disabled children at Devon County, Torbay and Plymouth City Councils.

In Plymouth we have established a good working relationship with Jo Siney, the Children's Integrated Disability Service Manager. We contributed ideas for the evaluation of the new Plymouth Disabled Children's Strategy. We also liaise with Plymouth Parent Partnership and presented at the 'Your Voice, Your child' meeting.

The Devon County Council (DCC) headquarters is very close to our base in Exeter and we have attended several meetings over the last year. We liaise with Beryl Perrin, the Children with Special Needs Commissioning Officer, and participate in the DCC Aiming High Family Consultation Days and Conversation Events. We are pleased to be included in the strategy Support to Parents & Young People Design Group, which is part of the Special Educational Needs (SEN) & Disability Green Paper Pathfinder Project. We liaise with DISCPlus, Devon's family information service for disabled children. We have good relations with DCC Parent Carer's Voice and attend meetings with the East, North and South groups.

To date our links with service providers in Torbay have been less strong and making contact with their integrated disability services is a key objective for us in 2012. However, several parents in our Family Faculty live in Torbay and are active in Torbay Parent Partnership Forum and we are participating in their meeting early in 2012.

As part of our research theme on social inclusion we have engaged with people running Devon's Inclusion Services and Out of School Inclusion, the Torbay Inclusion Project and Inclusion Works in Plymouth.

In terms of the NHS, we have always had good links with paediatricians in Exeter but this year have had contact with more paediatricians and increased awareness of our activities across the region. We have worked with the Children's Wards at the Royal Devon and Exeter, and North Devon and District, Barnstaple, Hospitals. We maintain contact with various Allied Health Professionals, and twice each year we host the South West Orthotics Group, which brings together all the orthotists working in the South West region.

Historically PenCRU has fostered excellent relations with Special Schools in the region. As we go forward we are keen to understand the issues faced by disabled children in mainstream schools. Our research, notably a survey examining children's attitudes towards disability, will increase our contact with primary and secondary schools as we go forward in 2012.

Who We Are

Unit staff

Professor Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPCH Cerebra Professor of Paediatric Epidemiology
Stuart Logan is the Director of Health Service Research at the Peninsula 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 has 20 years clinical experience as an orthotist and 12 years experience in childhood disability research. He has been awarded Masters and Doctoral degrees by the University of Oxford for research about children with cerebral palsy. His main research interests include epidemiology, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

Camilla McHugh BA
Family Involvement Co-ordinator
Camilla has experience of working closely with children and their parents in a variety of settings; she has worked in a research setting for the past five years. She has taken on the role of liaising with our Family Faculty to provide information and support for families working with the unit.

Claire Lloyd BSc (Hons) MSc
Associate Research Fellow in Child Health
Claire is an Associate Research Fellow in Child Health. She has experience in research with children with disabilities and their families. Claire works closely with families developing and carrying out several projects.

Val Shilling BA (Hons) PhD CPsychol
Research Fellow in Child Health
Val Shilling has a background in psychology and a Bachelors degree and Doctorate from the University of Manchester and is a Chartered Psychologist. Her research interests include patient and particularly parent experiences and communication in healthcare. She is currently working on a pilot evaluation of the peer support service offered by Face2Face (F2F) in Devon and Cornwall to explore the benefits and costs of offering peer support to parents of disabled children.

Rebecca Taylor BA (Hons) PGCE MSc MSc
Research Fellow in Child Health
Rebecca Taylor has over 10 years experience working on a variety of health services research projects within the fields of clinical trials, systematic reviews and health policy. With a Bachelors Degree from the University of Exeter, Masters Degrees from the Universities of Exeter and Birmingham and as a qualified teacher, her research interests span the field of child health.

Postgraduate students

Stuart Read BSc
MSc Student, Psychology, University of Exeter
Stuart carried out a survey for his Masters Dissertation entitled “Do adults with cerebral palsy have differing general and social self-efficacy to non-disabled adults?” supervised by Chris Morris. Stuart was awarded a distinction for his dissertation and the Master of Science degree, and also received the Dean's Commendation as well!

Megan McMillan BSc MSc
PhD Student, Institute of Health Service Research, University of Exeter
Megan is a psychology graduate studying for a PhD supervised by Mark Tarrant, Chris Morris and Professor Abraham. Her PhD is titled “Promoting positive attitudes towards childhood disability”. The PenCRU Family Faculty suggested that one of the problems they encounter having a disabled child was from other people’s negative attitudes. This project aims to discover what factors influence attitudes amongst children/young people towards their disabled peers, through surveys in mainstream schools around Devon, Torbay and Plymouth. The aim is to develop and test an intervention, to be implemented in schools, which will seek to modify attitudes in a positive direction.

Research Associates

We collaborate with a large number of colleagues at the Peninsula Medical School and the University of Exeter; also NHS clinicians and people in other universities and organisations. The list below recognises the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2011.

Katrina Wyatt BSc (Hons) PhD
Senior Lecturer in Health Services Research
Dr Wyatt was involved in managing the osteopathy trial and continues to advise the unit on methods for involving children, families and members of the public in research.

Tamsin Ford, MRCPsych PhD
Clinical Senior Lecturer in Child and Adolescent Psychiatry
Dr Ford is a child psychiatrist and provides advice and support to the unit for studies relating to child mental health topics, specifically Autistic Spectrum Disorders and ADHD.

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

Andy Gibson BA (Hons) MA PhD
PenCLAHRC Research Fellow for Patient and Public Involvement
Dr Gibson manages the involvement of patients and members of the public in research conducted by PenCLAHRC. He has worked closely with the unit on several projects.

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. Kate led the ‘shared learning’ workshops to help parents find information.

Jo Thompson Coon BSc PhD
PenCLAHRC Senior Research Fellow (PenTAG)
Dr Thompson Coon has expertise in evidence synthesis and has been working with us on several systematic review projects.

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.

Siobhan Sharkey BA (Hons) PhD
PenCLAHRC Research Fellow in Qualitative Methods
Dr Sharkey is a qualitative health researcher with a background in anthropology. She leads on the analysis of the transcripts for the 'Communication in Hospital' study.

Colin Green MSc PhD
Associate Professor in Health Economics, Head of Health Economics Group
Professor Green has collaborated with us to provide specialist input regarding economic evaluations and also in the CHUMS project.

Annie Hawton BSc MSc
Research Fellow in Health Economics
Annie has worked in health and social care research for over 15 years using both psychology and health economics approaches. Annie is working with PenCRU on the costing component of the peer support evaluation study.

Vanessa Edwards RGN BA (Hons) MPH
PenCLAHRC Research Fellow in Child Health
Vanessa was the trial manager for the osteopathy trial, and also worked on the systematic review and conducted interviews for the 'Communication in Hospital' study.

Sarah Dean PhD CPsychol MCSP MSc Grad Dip Phys BSc (Jt Hons)
Senior Lecturer in Health Services Research
Dr Dean has expertise in qualitative research and developing outcome measures, and has been involved in our work developing ways to measure children's inclusion/participation.

Rod Taylor BSc (Hons) MSc PhD
Professor of Health Service Research
Professor Taylor helped to develop the protocol for a clinical trial of Lycra-based orthoses.

Hannah Parsons BSc (Hons)
Analyst Programmer
Hannah is part of the website and database team at Peninsula College of Medicine and Dentistry. She designed and maintains our website.

Local clinicians

Dr Richard Tomlinson B Med Sci MB BS MSc MRCPCH
Consultant Paediatrician
Dr Tomlinson is an integral member of our advisory group and has been involved in the development of several projects including the Lycra study and the CHUMS project.

Dr Eleanor Thomas BSc (Hons) MRCPCH
Consultant Paediatrician
Dr Thomas specialises in community child health and having recently moved to Exeter is keen to become involved in research with PenCRU.

Ginny Humphreys Grad Dip Phys MSc DPT
Head of Therapy at Vranch House School and NHS Centre, Exeter, NHS Devon, Head of Profession for Paediatric Physiotherapy
Ginny is a member of our advisory group and has been involved in the development of the Lycra trial and also research about postural management and sleep.

Other universities and organisations

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, the evaluation of patient experiences of medical care, and methodology. He is collaborating with PenCRU on the CHUMS project.

Alan Tennant BA PhD
Professor of Rehabilitation Studies, University of Leeds
Professor Tennant has extensive expertise in developing outcome measures, and is one of the leading exponents of Rasch measurement methods. He is collaborating with PenCRU on the CHUMS project, and involved in discussions about measuring inclusion/participation.

Amanda Allard BA BSc MSc
Principal Research Officer, Council for Disabled Children
Amanda has worked in children's policy both as a researcher and campaigner for the past 19 years; her work at CDC is developing the health and participation services. Amanda is a key collaborator in the CHUMS project appraising NHS outcomes for disabled children.

Professor Bryony Beresford BSc (Hons) PhD
Director, Children and Families Team, Social Policy Research Unit, University of York
Professor Beresford has a strong track record in applied childhood disability research. Many of her projects have used qualitative research methods and she has been at the forefront of developing methods/supporting the inclusion of disabled children directly in research.

Dr Jane Williams MB BS Dip Child Health FRCPH
Consultant Paediatrician, Nottingham University Hospitals NHS Trust
Dr Williams has expertise in childhood neurodisability and is a former Chair of the British Academy of Childhood Disability. She is collaborating with PenCRU on the CHUMS project

Terry Pountney MA MSCP
Head of Research, Chailey Heritage Clinical Services
Terry is a research physiotherapist well known for her work related to postural management systems. She has fostered collaboration with PenCRU on studies relating to cerebral palsy.

Work experience visitors

This year we had three requests from people wanting to gain work experience with the research unit during the summer. Each of them was a different stage in their education and career. They tell in their own words below of their experience with us.

Chloe Tremlett-Williams is 14 years old and goes to the local Isca College of Media Arts.
‘I came to PenCRU for my work experience we. I originally heard about the Peninsula Cerebra Research Unit through my parents and when deciding where to go for work experience. I thought I would try here as it is relevant to me as I have an 8 year old brother who has cerebral palsy. I am glad I came here, because although it is too far ahead for me to really think about what job I would like to have, this has certainly showed me an area to consider. I think I would like to go into medicine, whether in research or something else I don’t know yet. Being here has also given me the chance to learn more about things I am interested in such as cerebral palsy; I was able to do a small amount of research into massage as a treatment for children with cerebral palsy and cerebral palsy itself. Giving me a greater understanding of what affects my brother.”

Jay Wittram is a 2nd year biochemistry student at Bath University.
“I thoroughly enjoyed the four days experience at PenCRU. The skills learned were invaluable and will be very useful going into the third year of university. The researching experience, especially, will certainly help me in my end of year project, which is a large percentage of my overall degree. The staff at PenCRU made me feel very welcome and were very helpful, so a huge thanks for them for putting up with me.”

Nicola Jeffries starting a degree in clinical sciences at Exeter
“In the past I have taken an active interest in PenCRU’s Family Faculty, even sharing our experiences by taking part in research into some of the important questions that had been raised by parent carers. We have two daughters, aged 15 and 10 years, who both have additional needs. Our eldest daughter unfortunately has a lot of medical problems and this has led me to decide on a complete career change. So, with a lot of excitement and quite a bit of trepidation I am about to embark on a degree in clinical sciences, which will hopefully result in a career where I can make a positive difference to patient care. This made me think again about PenCRU and the valuable work that they are doing in raising important questions about patient care, so I contacted Camilla and asked if I could do some work experience. They were very happy to put up with me in August for two days and I learned a great deal. I am very grateful to everybody at PenCRU for letting me get a glimpse of the important research they are carrying out and giving me an insight into what a difficult and time consuming task their work is. This is a real opportunity for parent carers to have a voice as well as the chance of being involved in research that could have real and practical benefits for our children.”

Collaboration with Cerebra Team

We liaise closely with the team at Cerebra, sharing details of queries raised by families and using this information to steer our activities. This year we produced three reports that were published by Cerebra in the 'Monthly Briefs' series:

Finding and appraising information and evidence on the Internet
Families of children with disabilities are often keen to look for more information about their child's condition, therapies and treatments, or other services that might be available, and the legal rights that they and their child have. This guide outlines suggestions to help you search efficiently on the Internet, and to appraise whether the websites you find present reliable and unbiased information.

'What's the Evidence?' Compilation
The PenCRU 'What's the Evidence?' reports are an ongoing series of short reports that seek to summarise what is known about the effectiveness of a particular treatment or therapy. They are written in response to queries from families about specific therapies and treatments. This brief described four topics that families had queried: Selective Dorsal Rhizotomy (SDR), Lycra Orthoses, Brainwave and Footsteps, and the Scotson Technique.

Cranial osteopathy for children with cerebral palsy: a randomised controlled trial of the effects of cranial osteopathy on the health and wellbeing of children with cerebral palsy.
The Osteopathy for Children with Cerebral Palsy Trial (OCP Trial) examined the effectiveness of cranial osteopathy on movement, overall quality of life, sleep patterns, pain and fits in children with CP. This is a summary of the trial methods and results. The brief describes how the design of the trial was influenced by involving families so that the procedures were acceptable and the outcomes measured were those that families would think important.

Cerebra Annual Conference

In November 2011, Professor Logan presented at 'Brighter Futures' the Cerebra Annual Conference for health professionals involved in preventing and reducing the impact of brain injury in children and young people. Professor Logan's talk was titled 'Clinical trials and the parents' perspective' in which he argued for greater involvement of families in research.

Cerebra seminar 'Carers and their rights'

PenCRU also provided a venue for the Cerebra seminar 'Carers and their rights' facilitated by Luke Clements, Professor of Law at Cardiff University.

Cerebra in the South West

We also liaise closely with Cerebra staff working in the Devon area. In 2010, Angela Dawe took over the role of Regional Officer for the South West. Angela collaborated with PenCRU to organise the Annual Family Fun Day which was a great success.

Bird of prey display

Our Programme of Work

Projects in progress

Improving communication with disabled children when they have to spend time in hospital

C. Lloyd, S. Sharkey, C. Morris, V. Edwards, A. Martin, R. Tomlinson, J. Choules, B. Hart, S. Logan

This study, funded by PenCLAHRC, will assess whether a parent-delivered programme of training for paediatric ward staff improves the effectiveness of communication with disabled children and their parents in hospitals. There are three stages:

- A structured review and synthesis of qualitative studies reporting children's, parents and professional views of disabled children's experience as inpatients
- Qualitative research with parents of children with communication difficulties and ward staff to understand their experiences of communication
- Developing & evaluating a training package for staff to enhance communication with disabled children when they have to stay in hospitals

This year we completed the review of the literature; this has been accepted for publication in a peer reviewed journal and will be published early in 2012.

Interviews were conducted with parents of children with communication difficulties that had recent experience of staying on the ward, and also with health professionals who work on children's wards in Exeter and Barnstaple. The aim was to identify good and poor practices and opportunities for improvement from both parent and professional perspectives. The analysis of the qualitative data is at an advanced stage, and will be completed by the spring.

Once we have completed the 'qualitative' analysis we will use the findings from the review and qualitative work to develop the training package. Parents will be involved both in designing and delivering the training package to health professionals.

What are the benefits and costs of providing peer support to parents of disabled children?

V. Shilling, C. Morris, A. Hawton, S. Logan

This project, funded by PenCLAHRC, is a pilot evaluation of the peer support service offered by Face2Face (F2F) in Devon and Cornwall. It will explore the benefits and costs of offering peer support to parents of disabled children. We will undertake three streams of research:

- Systematic review of the existing literature on peer support for this group
- Costing study of the F2F service provided in Devon and Cornwall
- Qualitative research comprising interviews with parents who have given or received support through Face2Face and relevant health and social care professionals

Information gathered from this study will help us to understand more about the benefits and costs of this particular service and will also help us to design a larger more definitive evaluation of the effectiveness and cost effectiveness of providing peer support to parents of disabled children.

This study has been developed from a suggestion from a member of our Family Faculty. A number of parents and related professionals have been involved in the design and development of the project and will continue to be involved at a management level throughout the course of the project.

The systematic review is in progress and will be completed early 2012. The study received ethics approval in January 2012. The qualitative research and costing study will begin in the spring, once work with the families and professionals in our stakeholder group to develop appropriate topic guides is complete.

***CH**ildren's o**U**tcome **M**easurement **S**tudy (CHUMS): Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability?*

R. Taylor, C. Morris, A. Allard, B. Beresford, J. Williams, R. Tomlinson, S. Logan, A. Tennant, C. Jenkinson, J. Thompson Coon, V. Shilling, C. Green, K. Antonio

The **CH**ildren's o**U**tcome **M**easurement **S**tudy (CHUMS) will capture the views of children with neurodisability and their families, to measure the outcomes of the NHS care they receive. This study comes at an important time for the healthcare of children with neurodisabilities as the NHS changes how it delivers care and measures outcomes. Patient-reported outcome measures (PROMs) are included in the NHS Outcomes Framework as one way of assessing whether the NHS is working effectively and efficiently for patients. These are carefully designed questionnaires that measure health. The CHUMS project has been designed specifically to investigate how well these outcome measures perform for children with neurodisability.

CHUMS is a collaborative project, involving co-investigators from the Council for Disabled Children, academic colleagues from the Universities of York, Leeds and Oxford, NHS paediatricians, and parents of disabled children.

The following three streams of research will be undertaken: a systematic review of literature, a qualitative study of children and parents, and an on-line Delphi survey of healthcare practitioners.

The systematic review will identify and appraise generic PROMs which have been used with children with neurodisability. The CHUMS team at PenCRU at PCMD are developing the protocol for the review and literature searches will be undertaken in the coming few weeks.

Having received approval in December 2011 from the National Research Ethics Service, recruitment to the qualitative study and Delphi survey can now begin in 2012.

Sleep Positioning for Children with Cerebral Palsy: Cochrane Review

C. Lloyd, S. Logan, C. McHugh, G. Humphreys, S. Parker, D. Beswick, M. Beswick, C. Morris, K. Wyatt

This research is a systematic review to determine whether commercially available night-time postural management systems, compared with usual care, reduce hip migration in children with cerebral palsy. The evidence appears inconclusive as to whether the provision of night-time postural management helps to prevent hip deformity and it will be interesting to look at the existing literature to determine what is known. Although there is a biomechanical basis for such intervention, the equipment can create problems for the child and family.

We worked with 3 members of our Family Faculty to develop the protocol for this review, which was recently published in The Cochrane Library. The protocol can be accessed at: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009257/full.

The review can now get underway and we hope to continue to work with the families who were involved in writing the protocol.

Non-pharmacological interventions for Attention-Deficit/Hyperactivity Disorder (ADHD) delivered in school settings; a systematic review of quantitative and qualitative research

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

Attention Deficit Hyperactivity Disorder (ADHD) can have many negative impacts on the life of a child and the people around them. Children with ADHD are less likely to fulfil their academic potential than their peers and are more likely to be involved in anti-social behaviour. ADHD continue to affect young people into adulthood, and the impact of the difficulties with focusing attention, restlessness and impulsivity can dramatically affect their life-course and the lives of those in contact with them. Children at risk of ADHD are often unable to remain seated to eat, travel or study, are extremely fidgety and distractible, and struggle to focus attention and carry out complex instructions. These patterns of behaviour often lead to secondary difficulties, such as defiance and disobedience, aggression, problems with peer relationship, an inability to react to their environment in an age-appropriate way, and difficulty in keeping strong emotions in check.

This project is a 'systematic review' of ways of supporting children with ADHD that do not involve drug treatment and that can be provided in school settings, such as classroom management programmes or psychological therapies. A systematic review means that we will carefully search all the available literature and put the findings of many studies together to try and find out which ways of supporting children work better at reducing symptoms of ADHD and other related problems, and which provide the best value for money. We will also look at factors that may help or hinder the successful delivery of these interventions and how the interventions impact on parents, carers and teachers.

__S__upporting __T__eachers __A__nd child__R__en in __S__chools (STARS): a cluster randomised controlled trial with parallel economic and process evaluations.

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

Poor social and emotional adjustment in childhood may compromise mental health and academic attainment and can adversely impact on life chances of all the children in a classroom, particularly children living in deprived circumstances. Disruptive behaviour is a common source of stress among teachers, and a common reason for many leaving the profession. Despite the research and guidelines available, there is no specific guidance on how social and emotional well-being should be promoted in primary schools.

The Supporting Teachers And childRen in Schools (STARS) study will examine whether the Incredible Years Teacher Classroom Management (TCM) course may enhance teachers' skills in promoting socio-emotional well-being among their pupils. If effective, TCM could transform the classroom from an environment where many children currently struggle to cope, particularly boys from low socio-economic backgrounds, into one where many more children can thrive. Enhancing teachers' skills potentially benefits all children that come into contact with that teacher over subsequent years, so TCM may be a particularly cost-effective way to assist the most vulnerable children in our society.

Projects we're involved in that are being led elsewhere

Development of a Functional Classification System of Eating and Drinking for Children and Young People with Cerebral Palsy

D. Sellers, T. Pountney, L. Pennington, C. Morris, A. Mandy, M.Hankins

This research is developing and testing a classification system to describe the eating and drinking ability of children with cerebral palsy (EDACS). Similar systems for classifying movement and manual ability have been widely adopted, and improve communication between clinicians and families, between clinicians, and between researchers and others. The project is funded by the NIHR *Research for Patient Benefit* programme and led by Diane Sellers, a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex. Chris Morris is a co-investigator and member of the project team.

A series of 'nominal groups' were held around the UK in 2011, including one group hosted by PenCRU in Exeter that involved two parents from our Family Faculty. These events and much work by Diane have enabled us to devise a description of children's functioning in five levels. The next stage is to see whether a wider group of parents and professionals find these descriptions meaningful. This is done through an online 'Delphi' survey, which is a process for seeking broad agreement and consensus.

The effects of night positioning on sleep, postural deformity and pain in children and young people with cerebral palsy - an exploratory study

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

The aim of this programme of research is to find out if using commercially available night-time postural management systems makes children more comfortable in bed, reduces pain, improves sleep, prevents deformity and avoids the need for surgery. This is an exploratory 'pilot' study to help in the development of a protocol for a larger clinical trial. The trial is funded by the NIHR *Research for Patient Benefit* programme and led by Dr Terry Pountney at Chailey Heritage Clinical Services in Sussex. Chris Morris is a co-investigator on the team.

The project started mid 2011 and the first stages have been to identify regions of the UK which are willing and able to take part in recruiting children and families. The team have established two sites which will enable recruitment to begin, and other sites should be agreed early in 2012. We hope to recruit 50 children; half of them will be allocated a sleep system and half will not use a system. Factors relating to the children's sleep, pain and other outcomes will be assessed at intervals for two years.

Projects we are developing

Social inclusion

We are developing a research programme to promote the social inclusion of disabled children. Several meetings have been held with parents and health and social care professionals to outline potential lines of research activity.

We want to promote positive attitudes towards disability. Parents working with us prioritised focusing on promoting positive attitudes of school-aged children and young people towards disabled children. We have secured funding for a PhD student to lead this work, and Megan McMillan began with us in October 2011, supervised by Dr Mark Tarrant, Chris Morris and Prof Charles Abraham.

We are looking at ways of defining and measuring inclusion of children and families using the libertarian values of 'equality of opportunity' and 'freedom to choose' to be involved in key life situations. The first steps are reviewing existing definitions.

We are interested in 'social identity' experienced by disabled children, parents and siblings. Parents working with us and previous research suggest that there are both positive and negative effects associated with the 'social identity' of being part of a family with a disabled child.

We are also working with social care professionals employed by local authorities in Devon, Plymouth and Torbay who deliver individualised services to promote inclusion of disabled children. Such services are a valuable resource for families, and we are interested in evaluating how they are effective in promoting social inclusion.

Safety and efficacy of complimentary & alternative therapies for children diagnosed with Attention Deficit Disorder with hyperactivity (ADHD)

C. Morris, J. Thompson-Coon, C. Shotton, J. Margetson, R. Tomlinson, T. Ford, R. Marlow, A. Richards, E. Ernst

This year we carried out a scoping review to ascertain the evidence base (published trials) for the use of various complementary therapies for the treatment of children diagnosed with ADHD. No critical appraisal of any studies was undertaken but the scoping review identified a number of trials of a range of complementary and alternative therapies. We shortlisted those for which evidence is available, considered which of these may potentially be beneficial or harmful, and sought the views of parents in our Family Faculty. From this we have prioritised 'elimination diets', where certain foods are omitted from the diets of children and young people with ADHD in the belief this will reduce symptoms. Next we will carry out a systematic review of the literature to better inform families about the evidence as to whether these dietary modifications are effective in reducing symptoms. We will also use the scoping review to guide further work on this topic.

Virtual reality & computer games

Following a suggestion from a parent that 'Dance Mats' had been helpful in increasing her child's concentration, we have begun to explore the possibility of a project to look at the positive impacts that playing computer games might have on children with disabilities.

An initial meeting with parents and professionals generated a lot of discussion about the types of computer games that we might be interested in, and the improvements that we might look for in children who had played them regularly. We also discussed comparing playing computer games to more traditional types of therapy, i.e. Physiotherapy and Occupational Therapy.

The next steps for this project are to carry out more detailed searching of the existing literature and talk to some groups of children about the types of computer games that they enjoy playing. We hope to be able to use this information and continue to work with families and professionals to start to narrow down and develop our ideas.

Previous projects

Continence services

Some parents from our Family Faculty raised the topic of continence services. They discussed their experiences of the continence services and in some cases, raised concerns. They asked us to consider this as a topic for research. The PenCRU team understands that this is a very important issue; nevertheless it was not one that we could readily turn into a research project. There appears to be a high level Government commitment to delivering a high quality service. Those with responsibility for delivering services need to be lobbied to deliver to the required standard. We believe that the issues are better addressed by organisations that campaign for high quality services on behalf of disabled children and their families. We recommended that parents experiencing difficulties with continence services contact Every Disabled Child Matters (www.edcm.org.uk) to lobby on the issue.

Evaluating the effectiveness of Lycra-based orthoses

Lycra-based orthoses (splints) are popular with some therapists and families but not available widely as there is limited evidence that they are an effective treatment.

Working with parents and a physiotherapist, paediatrician, orthopaedic surgeon and statistician we designed a clinical trial that would be the first stage in testing whether Lycra-based sleeve/glove orthosis improves the manual ability of children with hemiplegia. We applied to the National Institute for Health Research's programme Research for Patient Benefit, and subsequently a charity called Action Medical Research, for funding to carry out the trial. Unfortunately, although these funders appreciated that this was an important topic for research, the trial was not selected for funding. We have decided not to pursue the trial further at the present time. We have published the protocol for the pilot study on our website as it may be useful to others interested in research on this topic.

Navigators

Parents of disabled children tell us that it is difficult to find their way around the different services and to find out what services are available. This point is also emphasised in major reports, for instance in “Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs” published by the Department of Health.

We tried to develop this as a research idea but have not made progress over the last year. While we remain interested in the issue and recognise the importance of finding out what services are available, the project is currently ‘on hold’ to enable us to pursue other work.

PenCRU team relaxing at the 2011 Family Fun Day

External Grant Funding

Grants awarded

As described earlier in our annual report we use the core funding from Cerebra to support involving families and apply to major research grant agencies to fund major projects. The following studies are funded by the National Institutes for Health Research (NIHR), which is the body responsible for commissioning NHS, social care and public health research. All studies funded by NIHR are extensively peer-reviewed and closely managed. Details of each of these studies are described in our programme of work.

- Morris C, Beresford B, Shilling V, Allard A, Thompson Coon J, Williams J, Tomlinson R, Jenkinson C, Tennant A, Logan S. (16 months starting 2012) Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? NIHR Heath Services Research Programme, £247,419
- Ford T, Stein K, Thompson Coon J, Norwich B, Taylor E, Logan S, Shotton C, Pritchard W, Garside R, Morris C. (15 months starting 2012) Non-pharmacological interventions for Attention-Deficit/Hyperactivity Disorder (ADHD) delivered in school settings; a systematic review of quantitative and qualitative research. NIHR Health Technology Assessment Programme, £308,000
- Ford T, Shotton C, Norwich B, Logan S, Okoumunne O, Byford S, Pritchard W, Jones P. (60 months starting 2012) Supporting Teachers and childRen in Schools (STARS): a cluster randomised controlled trial with parallel economic and process evaluations. NIHR Public Health Research Programme, £1.7 million.
- Pountney T, Porter D, Morris C, Khan Y, Cowan D, Underhill J, Humphreys G. (36 months from 2011) The effects of night positioning on sleep, postural deformity and pain in children and young people with cerebral palsy - an exploratory study. NIHR Research for Patient Benefit Programme, £178,478
- Sellers D, Pountney T, Pennington L, Morris C, Mandy A, Hankins M. (36 months from 2011) Development of a functional classification system of eating and drinking abilities for children and young people with cerebral palsy. NIHR Research for Patient Benefit Programme, £163,116

Decisions pending

MeASURe: Measurement in autism spectrum disorder.

This project was designed in response to a competitive commissioned call for research by the National Institute for Health Technology Assessment programme. The brief asked for research to address the question "what is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder (ASD); and how well do these reflect and measure issues of importance for patients and carers?" We are part of a large team of researchers around the UK, led by colleagues at the University of Newcastle, which proposes to carry out a systematic review to answer the research question.

Academic Publications

Published in 2011

Wyatt K, Edwards V, Franck L, Britten N, Creanor S, Maddick A, Logan S. (2011) Cranial osteopathy for children with cerebral palsy: a randomised controlled trial. Arch Dis Child. 96(6):505-12.

Edwards V, Wyatt K, Logan S, Britten N. (2011) Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy. Health Expect. 14(4):429-38.

Morris C, Shilling V, McHugh C, Wyatt K. (2011) Why it is crucial to involve families in all stages of childhood disability research. Dev Med Child Neurol. 53(8):769-71.

Lloyd C, Logan S, McHugh C, Humphreys G, Parker S, Beswick D, Beswick M, Morris C, Wyatt K. (2011) Sleep positioning for children with cerebral palsy. [Protocol] Cochrane Database of Systematic Reviews Issue 7. CD009257

Morris C, Bowers R, Ross K, Stevens P, Phillips D. (2011) Orthotic management of cerebral palsy: recommendations from a consensus conference. NeuroRehabilitation. 28(1):37-46.

Jenkinson C, Dawson J, Morris C. (2011) Aspects of methodology. In Jenkinson C, Peters M, Bromberg M. (Eds) Quality of Life Measurement in Neurodegenerative and Related Conditions. Cambridge: Cambridge University Press.

Wyatt K, Lloyd J, Creanor S, Logan S. (2011) The development, feasibility and acceptability of a school-based obesity prevention programme: results from three phases of piloting. BMJ Open doi:10.1136/bmjopen-2010-000026

Shilling, V. Wiliamson P.R. Hickey, H. Sowden, E. Smyth, R.L. Young, B. (2011) Processes in recruitment to randomised controlled trials (RCTs) of medicines for children (RECRUIT): a qualitative study. Health Technol Assess 15:15

Shilling, V. Wiliamson P.R. Hickey, H. Sowden, E. Beresford, M.W. Smyth, R.L. Young, B. (2011) Communication about children's clinical trials as observed and experienced: qualitative study of parents and practitioners. PLoS ONE 6(7): e21604. doi:10.1371/journal.pone.0021604

In Press

Morris C, Shilling V. What is the role of parent and community organizations in child health promotion? (In press) In Ronen G & Rosenbaum P (Eds) Health, Participation and Quality of Life in Young People with Neurodevelopmental Conditions: Theory, concepts, evidence and practice. Clinics in Developmental Medicine, Mac Keith Press: London.

Morris, C. (In press) Orthotic management of neurodisability. In Gada, S. (Ed) Oxford Handbook of Community Paediatrics. Oxford University Press

Morris, C. Majnemer, A. (In press) Activity and participation: An overview of generic measures. In: Majnemer, A. (Ed) Measures of outcomes for children and youth with developmental disabilities. Clinics in Developmental Medicine, Mac Keith Press: London.

Shilling, V. Edwards, V. Rogers, M, Morris C. (In press) The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting children's, parents' and professionals' views. *Child: Care, Health and Development*.

Published on PenCRU website

Listed below are the treatments and topics we have been asked about in 2011, and subsequently provided summaries of the evidence on our website. You can read these summaries at www.pencru.org/evidence_main.php

- I am writing to find out if you know if there are any stem cell trials for children with cp in this country?
- Is TEACCH an effective treatment for children with ASD (Autistic Spectrum Disorder)?
- Has there been any research about the effectiveness of 'Meditouch' rehabilitation systems, in particular the HandTutor™?
- Does having a child with special needs incur health problems in the main carer?
- Hyperbaric Oxygen Treatment for Cerebral Palsy
- G Therapy for Cerebral Palsy
- Sensory integration in ASD (Autistic Spectrum Disorder)
- What is the impact of having a disabled sibling and support for siblings?
- One to one versus group SALT (Speech and Language Therapy)?

In May 2011 we reviewed and, where appropriate updated, the summaries and responses that we have posted previously.

- Brainwave and Footsteps
- Scotson Technique
- Audio Integration Therapies
- Selective Dorsal Rhizotomy
- Lycra Orthoses

Major Presentations

Morris C, Shilling V, McHugh C, Wyatt K, Logan S. (2011) Involving families of disabled children as meaningful partners in all stages of childhood disability research. American Academy for Cerebral Palsy and Developmental Medicine 65th Annual Meeting.

Bates J, McCahill J, Stebbins J, Theologis T, Morris C. (2011) Correlation between Oxford Foot Model kinematics and Oxford Ankle Foot Questionnaire. European Society of Paediatric Orthopaedic Surgery 30th Annual Meeting. Journal of Children's Orthopaedics 5, Supp:13.

Logan S. "From Jim to the HTA: Service users in research" Seminar for Development and Disability Group, Institute of Health & Society, Newcastle University.

Logan S. "RfPB – reflections of the outgoing Chair" NIHR Research Design Services Residential Research School.

Logan S. ‘Evidence base for models of acute paediatric and ambulatory care, including Paediatric Assessment Units’ South West Paediatric Club

Logan S. ‘Partnerships in Prevention, Cure and Care’. European Society for Social Pediatrics and Child Health, 2011 Annual Meeting.

Logan S. 'Implementation and decision making' Seminar at the University of California and San Francisco

Logan S. ‘Opportunities for Health Research in the New NHS’ (workshop) NIHR Senior Investigators’ meeting “Rising to the Challenge: Turning Good Ideas into Practice”.

Morris C. ‘The work of the Peninsula Cerebra Research Unit’ (seminar) Special Educational Needs (SEN)/Disabilities in Education Group, University of Exeter.

Logan S. ‘Clinical trials and the parents’ perspective’ Cerebra Annual Conference.

Other Major Meetings Attended

Chris Morris attended

- British Academy of Childhood Disability (BACD) Annual Meeting.
- European Academy of Childhood Disability (EACD) Annual Meeting.
- Mentoring & Befriending Foundation (MBF) National Conference 2011.

Media & Publicity

The work of PenCRU has been featured on local radio stations and in news publications.

- Chris Morris appeared on BBC Radio Devon as part of the ‘Interactive Lunch’.
- The Osteopathy Study results were featured in a range of newspapers and journals.
- Stuart Logan was featured on ITV and local radio opening the new NIHR Paediatric Clinical Research Facility which is based at the Royal Devon & Exeter Hospital

Editorial, Peer Reviews and Committee Work

Editorial work in 2011

Stuart Logan continued as Editor in Chief for *Child: Care, Health and Development*.

Chris Morris continued as Associate Editor and Editorial Board Member for *Developmental Medicine and Child Neurology*, and Director/Trustee of the publishers *Mac Keith Press*. Chris is also on the Editorial Board for *Physical & Occupational Therapy in Pediatrics*.

Peer reviews for academic journals in 2011

Stuart Logan	NIHR Public Health Research programme (2 applications)
Chris Morris	Child: Care Health and Development Journal of Intellectual Disability Research Physical & Occupational Therapy in Pediatrics
Val Shilling	Child: Care Health and Development PLoS ONE

Specialist Committees

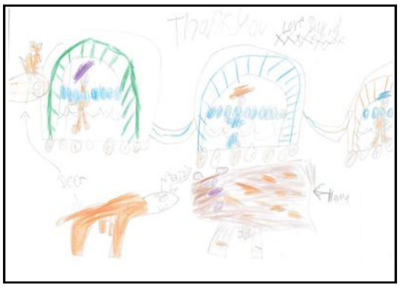
Stuart Logan is a member of the NHS Evidence advisory Committee (NICE) and Chair of the NIHR Research for Patient Benefit Programme South West Regional Funding Committee. He is also:

- Chair of MENDS Trial Steering Committee (HTA funded trial)
- Member of the NIHR carbon guidelines committee
- Member of the NPEU (National Perinatal Epidemiology Unit) Advisory Committee
- Chair of the SMILE external advisory group (SMILE is a feasibility trial investigating the Lightning treatment for CFS/ME)
- Member of 'Why don't children take their medicine' initiative (MCRN)
- Chair of the UoE Science Strategy Translational medicine, personalised healthcare and public health committee
- Member of the Child Health Independent Health Advisory Committee (HQIP – Healthcare Quality Improvement Partnership)
- Chair, NIHR HTA Newborn Screening Programme
- Participant in COMET (Core Outcome Measures in Effectiveness Trials)
- Participant in NIHR HS&DR Programme half-day seminar to identify the broad themes which will go to form the agenda for our future programme of research focused on quality, access and delivery of health services.
- Member of the Neighbourhood Health Watch steering group (partnership with Devon Partnership NHS Trust, Devon & Cornwall Police and Health Innovation and Education Cluster).

Chris Morris served on a number of committees

- Member of the Strategic Research Group, British Academy of Childhood Disability
- External expert advisor to the NICE Clinical Guideline Development Group for 'Spasticity in children and young people: the management of children and young people with a non-progressive brain injury.'
- Trustee for the Orthotic Education and Training Trust.
- Member of the External Advisory Group for SPARCLE (Study of Participation of Children with Cerebral Palsy Living in Europe)

Kieran



David

Sophie

Thank you drawings following the 2011 Family Fun Day at The World of Country Life.

PenCRU
Peninsula Medical School
Veysey Building
Salmon Pool Lane
Exeter, EX2 4SG

Email: pencru@pcmd.ac.uk
Tel: +44 (0)1392 722968/2901
Website: www.pencru.org

Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

PenCLAHRC
The NIHR CLAHRC for the South West Peninsula

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