



PenCRU
Childhood Disability Research



University of Exeter Medical School
Annual Report 2014

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Cerebra Chair's reflections on progress in 2014



Welcome to the PenCRU 2014 Annual Report. This year saw our 5th birthday, and further progress in establishing our reputation for involving families as partners in the research process. Meaningful partnership with families in research is what PenCRU is all about and underpins all we do – doing research ‘with’ families, not ‘on’ them, ‘to’ them or ‘for’ them.

For me, the most moving experience of the year was hearing some of the parents who have worked with us talk about their experiences during the annual visit to PenCRU in Exeter by Cerebra staff. Parents described the challenges they face in many aspects of their roles as carers and in dealing with services, and contrasted this with the positivity they experience acting as experts in the research process. Some of these thoughts were captured in the video Cerebra made about our work. For all the staff of PenCRU it is these relationships which make our work feel worthwhile.

On a national level, we completed the project to identify research priorities about treatments and therapies for children and young people with neurodisability. This collaborative research received keen attention from the National Institute for Health Research (NIHR) and we hope will influence the research they commission in future. Do look up the Top 10 priorities, and if you are a researcher then please think about how we can address these issues. These are the issues that young people, parents and clinicians agreed were most important to address to provide essential information to inform decisions.

PenCRU's project highlights this year included the culmination of our study evaluating one-to-one peer support for parents of disabled children, focusing on the Face2Face services in Devon and Cornwall. A striking finding that emerged from this research was the sense of community resilience that Face2Face creates, over and above the benefits for those who use the service in times of need. We were also able to unpack essential components of the service that foster the sense of ‘shared social identify’ necessary for effective peer support.

With funding from NIHR, we were able to work with families and professionals to identify key health outcomes for children and young people with neurodisability. This work has taken on particular importance because of the policy emphasis on improving outcomes for children and young people. The study suggests several specific aspects of health that can be targeted and outcomes that could be measured. The full report was published by the NIHR Library and there are several papers that describe parts of the study in more detail. The work has also been presented at several national meetings and an international conference.

It's fabulous to see how much influence the work we do at PenCRU has, both in terms of the positive impact on families who work with us and the interest in the research findings we produce. I look forward to building on our successes from the first 5 years over the next period in close collaboration with families, and of course Cerebra who provide the core funding that make this work possible.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

Mission statement

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

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.

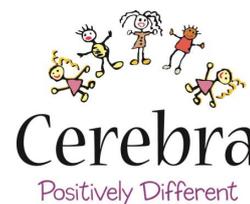
In addition we work in partnership with agencies providing health, social and education services for children across Devon, Plymouth and Torbay. We believe that the partnership between families, service providers and researchers is vital to improving the lives of people affected by disability.

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. A new award was granted for the period 2014-2019. Cerebra also maintain their own in-house research staff and provide direct grants and advice to parents, carers and professionals.



The relationship between Cerebra and the University of Exeter Medical School (formerly Peninsula College of Medicine and Dentistry) 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 University of Exeter Medical School. The views and opinions expressed by PenCRU do not necessarily represent the views of the Cerebra charity.

PenCRU team



**Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPCH Cerebra
Professor of Paediatric Epidemiology**

Stuart is the Director of the Institute of Health Research at the University of Exeter Medical School and Honorary Consultant in Paediatrics in the Royal Devon and Exeter Hospital. His particular interest is the generation of research of direct relevance to policy and practice and useful to practitioners and to families. His major areas of research are the evaluation of complex interventions, and on the effects of social inequalities on child health.



**Chris Morris MSc DPhil
Senior Research Fellow in Child Health**

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



**Katharine Fitzpatrick BSc (Hons) PhD
Family Involvement Coordinator**

Katharine's academic background is in Physical Geography and she also has experience as a learning advisor for young people with learning disabilities and additional needs in a Further Education College. Her main interest of work is widening participation of Family Faculty members in PenCRU's activities and working on the strategy to involve children and young people.



**Sharon Blake LLB (Hons) MA
Associate Research Fellow in Child Health**

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



**Astrid Janssens BSc (Hons) MSc PhD
Research Fellow in Child Health**

Astrid has a Masters degree in Experimental Psychology and Anthropology, and a Doctorate in Medical Sciences. Astrid's research background is in children and adolescents' mental health and the organisation of services taking care of them. Her main area of work has been the CHUMS project.



**Megan MacMillan BSc (Hons) 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 Charles Abraham. Her PhD is titled 'Understanding children's attitudes towards disability and promoting positive attitudes'. This PhD project aims to discover modifiable factors associated with children's attitudes to disability.



**Anna Stimson BA (Hons)
Research Administrator**

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



**Val Shilling BA (Hons) PhD CPsychol
Research Fellow in Child Health**

Val 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 has led an 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. Val moved to Brighton in the summer 2014 after 4 years at PenCRU.



**Meghan McCrory BSc (Hons) MSc PGCE
Family Involvement Coordinator**

Meghan McCrory has a varied background in working with children with disabilities and their families. She is a qualified Primary School Teacher, has a Masters in Psychological Research Methods, and a degree in Psychology. Megan led activities to involve young people in the work of PenCRU whilst the Involvement Coordinator. Megan left PenCRU during summer 2014 to gain experience in clinical psychology.

Team news update

During 2014, Val Shilling and Meghan McCrory left PenCRU. We are hugely grateful for all their contributions to making the unit a success, and wish them all the best for the future. We were joined by Sharon Blake in January 2014 and Katharine Fitzpatrick in June 2014.



Family Faculty and PenCRU team members after an Advisory Group meeting

Family involvement

The ethos of the unit is to involve families in all aspects of our research and related activities.

We understand the amount of time that families have varies, so we are conscious of being flexible and adaptable to accommodate this.



We are examining ways to increase involvement opportunities for those parents who have been working with us for some time, and are interested in getting involved at a deeper level. We have also been looking at ways to involve parents who are unable to physically attend our meetings. You can find out more about this in the 'Engaging remote members' section.

It has been fantastic to work with many parents new to the Family Faculty this year and we look forward to continuing and widening our involvement in 2015.

We regularly request feedback from parents who work with us. Here are some of the things parents have told us this year:

'Thank you so much for the opportunity of a day to meet up. The children had fun and we found it quite relaxing. Robert was safe and happy playing on multiple tractors. I got the opportunity to feel pleased with my goat milking skills, so thank you again.'

'It was so nice to meet you all last week and be a part of the group. Everyone was so nice. I learned quite a bit and also played a useful part I hope.'

'I really enjoyed taking part in the meeting on Tuesday. It was great that I could attend via Skype!'



Families enjoying the annual Family Fun Day

Our unit meetings

Each project holds a number of meetings throughout the year, and families play an important role in these meetings. The table below shows the numbers of parents who attended meetings for each project during 2014.

Project	Number of parents involved
Peer Support	11
Attitudes to Disability	3
Sleep Systems	3
Remote Engagement	10*
Hospital Communication	6
Handbook	5
Healthy Parent Carers	11
Oral Health	5
SEND	6
MeAS URe	3
Wii CPO Active Consoles	5
Children and Young Peoples Involvement	8

*Not all parent attendees of the Remote Engagement meetings physically attended meetings in Exeter.

Note: In addition professionals working in relevant fields have also attended various meetings. Parents unable to attend have forwarded their thoughts to our Family Involvement Coordinator before meetings to then be shared with attendees and included in discussions.

Advisory Group

We use our Advisory Group meetings to consult the Family Faculty on the way that PenCRU runs, and the various operational challenges that arise. It has a strong influence on our programme of work and other activities and meets twice each year. The meetings are usually well attended; 10 parents participated in June, and 9 came in December, despite a plethora of flu bugs and roadworks!

Our most recent Advisory Group was a chance for us to review our PenCRU and Family Faculty Handbook which we have been working on since the summer. The handbook is a clear statement of how PenCRU and the Family Faculty work together as well as containing other useful information such as our policies. We also discussed how we could improve our communications with the Family Faculty and Sharon gave an update about our progress on engaging with social media.

Presenting our activities in the community

Maintaining a presence in the community helps us to understand issues that families are faced with in their day to day lives, and also gives us the opportunity to tell them about PenCRU and what we do. As such, face to face contact helps encourage and support families to come and get involved in research, and is an extremely important part of our family involvement.

This year has been very busy. Families are experiencing many changes in the services that are provided for their children, and there has been much to learn!

We have built up very strong relations with many groups and we are regularly invited to have stands at the events that are put on for families in the community. Katharine, the Family Involvement Coordinator has attended support groups, parent forums and a number of Local Authority events throughout the year.

Listed below are a few of the events that we have attended.

- Devon Parent Carers Voice events across the county
- Exeter Health Fair
- Torbay Fair Play day
- Mayfield School summer garden party
- North Devon Forum for Autism parent support group
- A transitions event at Southbrook SEN school
- Contact a Family sharing event
- Cerebra family fun day
- Visit to Vbranch House



Building a Partnership

PenCRU Stand at a School Summer Fete

This year we ran a Building a Partnership workshop with a difference – the day was organised and run in its entirety by two members of our Family Faculty. Building a Partnership workshops are designed to support parents to be partners in research and are held once or twice a year. This year the workshop focussed on what we mean by involvement, a discussion around ideas of partnership between PenCRU and the Family Faculty and an informal discussion about how PenCRU can improve its working practices further. The workshop featured warm up exercises, a presentation by one of the parents and a quiz. It was a highly successful and fun day!



PenCRU team members enjoying the entertainment at the Family Fun Day

Annual Family Fun Day

The Annual Fun Day is to say thank you to members of the Family Faculty who have been involved in our work and research activities, and to get to know each other better. As a unit we really look forward to the event.

We held our fifth Family Fun day in 2014. After consultation with parents we decided on Pennywell Farm in Buckfastleigh as our venue.



Family Faculty 'helping' Chris's fundraising efforts!

The sun shone (for most of the day), we got to cuddle some tiny 1 day old miniature pigs and saw an owl display among many other things. Vinny the mime artist was also there to entertain us and was a great success as usual. A highlight of the day was when PenCRU's Chris undertook a cream pie and ice bucket challenge to raise money for Cerebra and local support group, A Brighter Tomorrow.

Engaging Remote Members

In conjunction with the work we did this year to focus our digital communications (see 'social media'), we also undertook a mini-project to look at how we can better engage with Family Faculty members who were unable to attend meetings held during the day in Exeter. We trialled different methods of engagement: an anonymous survey monkey poll, a U-tube video, a Facebook forum, FaceTime, Skype and teleconferencing.

By piloting these methods we learnt a lot about the processes of using each approach and this learning has fed into our handbook policies. This mini-project in itself engaged four new members of our Family Faculty and re-engaged a parent carer who had not been involved for over a year.

Children and Young People's involvement

This year saw the development of our project to involve children and young people (CYP) in PenCRU.

Meghan piloted some engagement with two special schools in the local area. This focussed around finding out CYP's ideas for research that PenCRU may carry out around oral care and dentistry.

We have carried out a systematic review of published research which brings together information about how disabled children & young people have been 'involved' in health-related research. The review is published in the journal 'Child: Care, Health and Development' and members of our Family faculty were involved with the writing and review of a Plain Language Summary for the article.



Logo designed by a young person from South Devon College.

With the arrival of the new Family Involvement Coordinator in June we have continued to build networks with local organisations that work with CYP including meeting with representatives from Young Devon. We visited Exeter College to discuss potential future collaboration with groups of young people there. We also had some great involvement from a group of young people at South Devon College who came up with ideas for posters to advertise involvement opportunities for CYP. We will continue to build links in 2015 and work with young people to create an accessible resource for young people explaining the outcomes of an existing PenCRU research project.

Handbook

This year PenCRU and parents from the Family Faculty worked on the production of a Handbook. The handbook is a clear statement about who we are and how PenCRU and the Family Faculty work together. Initial ideas for the handbook were discussed in the advisory group meeting in June, and we held a meeting with five parents to discuss the first draft in October. The handbook was 'signed off' at the advisory group meeting in December and we look forward to publishing it in early 2015!

Conferences

2014 was an exciting year for conferences. Chris and Katharine from PenCRU attended the Cerebra conference with four parents from the Family Faculty. This was an excellent 1 day conference in London. The conference was about 'Problem Solving: accessing decent services and support'. This was also a great opportunity to meet other parents. The Family Faculty members who attended shared their opinions with us:



Chris with parents from our Family Faculty at the Involve conference.

'Nice treat to have time away – don't underestimate the value of that. We feel valued by PenCRU as they have covered the cost of the conference, travel, hotel and food for us to be there.'

'I thoroughly enjoyed being part of the Cerebra conference. I thought the speech given by Alison was both powerful, emotive and inspirational reminding me of why it is so important to bring parent's views to the forefront of all professionals minds. Although I missed my own family terribly it was really nice to have a break away from the stresses and strains of home.'

'It was brilliant that there was a whole segment on the agenda for the parent voice – it enhanced the full programme of invited speakers and added value to the day.'

'Thoroughly enjoyed the conference agenda, it was interesting, informative and thought provoking. I feel privileged to have been sat in an audience of professionals and parents. I appreciate the opportunity of being able to attend.'

In November we attended the Involve conference which was a great opportunity to meet colleagues and other groups who are working in this area. Three Family Faculty members attended and we really enjoyed the time at the conference as well as a spot of Christmas shopping in Birmingham!

'Really enjoyed Birmingham and the conference did provoke some thoughts on parent engagement especially from the presentations on involving young people.'

Programme of research

The following pages describe our programme of research, and the progress we made in 2014.

[James Lind Alliance \(JLA\) Childhood Neurodisability Research Priority Setting Partnership](#)

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



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

The work involved a national survey, bringing together similar topics, framing representative research questions, checking the questions were uncertainties not already answered by research, and prioritising them with young people, parent carers, charity representatives and clinicians from different professions. [The Top 10](#) represents the 'shared priority' topics selected by participants at the final workshop.

An academic paper describing the project in detail has been accepted for publication in BMJ Open. The project was supported by a grant from the Paul Polani Fund administered by the Royal College of Paediatrics and Child Health.

[The CHUMS study](#)

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



This study funded by the NIHR examined what outcomes of NHS care should be measured for children with neurodisability using questionnaires completed by children and/or parents. The research was completed last year and [the report published in the NIHR Library](#) in 2014. A paper reporting on the qualitative work with children and young people and parents is available [here](#), and plain language summary [here](#). A paper describing the series of surveys to identify which aspects of health professionals target is available [here](#) and plain language summary is available [here](#).

We presented the findings of this study at the national and regional meetings of the British Academy of Childhood Disability (BACD) & British Association of Community Child Health (BACCH), and also at the COMET (Core Outcome Measures in Evaluative Trials) Initiative meeting in Rome. This project was funded by the National Institute for Health Research Health Services and Delivery Research (NIHR HS&DR) programme (project number 10/2002/16).



[Eating and Drinking Classification System \(EDACS\) for cerebral palsy](#)

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

Children with cerebral palsy have difficulties with movement and some have difficulty biting, chewing and swallowing. Children who have these difficulties are likely to have problems with eating and drinking enough to stay healthy.

PenCRU are part of a team of researchers led by Diane Sellers at Chailey Heritage Clinical Services (Sussex Community NHS Trust) who developed an [Eating and Drinking Ability Classification System for children with cerebral palsy](#) (EDACS). You can hear and see, Diane talking about the EDACS [here](#). As part of this research we carried out a [systematic review](#) to establish that there was no existing classification system, and this paper has been published [here](#).

The research is funded by the NIHR [Research for Patient Benefit \(RfPB\) programme](#). The next stage will involve evaluating the 'clinical utility' of EDACS, such as - how is EDACS used?

[Hospital communications](#)

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

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

We completed a [qualitative](#) analysis of interviews with parents of children that had recently stayed in hospital, and interviews or focus groups with hospital staff working on children's wards. The findings identify barriers and facilitators to effective communication. The article is published [here](#) and a [plain language summary](#) of the paper is also available.

We used the information from the review and qualitative study to develop a training package for health professionals. Parents from our [Family Faculty](#) have been involved in designing and delivering the training package. The training has been delivered on five occasions, and refined each time based on feedback and reflections. Once we are satisfied with the training, we will document the content and delivery strategy to enable it to be replicated by others in different locations. The research is funded by NIHR through [PenCLAHRC](#) and a 'small grant' from the Royal Devon and Exeter NHS Foundation Trust held by pediatricians Dr Eleanor Thomas and Dr Rebecca Gumm.

[Benefits and costs of peer support for parents of disabled children](#)

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

This study evaluated the benefits and costs of providing one-to-one peer support to parents of children with disabilities. The project was an evaluation of the peer support service offered by Face2Face in Devon and Cornwall. [Face2Face](#) is a national network which offers peer support to parents of disabled children from trained befrienders. The work was completed in 2014. In the qualitative study we conducted interviews with parents who had given or received support through Face2Face and a group of relevant health and social care professions who might refer to the service. We wanted to understand more about whether people think peer support works and how; who might benefit from support and what those benefits might be. In the costing study we investigated what resources are needed to provide the service in terms of time, resources and money. Two papers describing the qualitative research have been accepted for publication in the journal *Child: Care Health and Development*. This research is funded by NIHR through [PenCLAHRC](#).

[Promoting children's positive attitudes towards disability](#)

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

This study sought to identify modifiable factors that affect children's attitudes towards disability. The work is based on concepts of social contact and identity. A survey, with over 2,000 children was conducted across 20 mainstream schools in Devon to further our knowledge on factors associated with attitudes to disability. The analysis also examined the robustness of a scale that measures children's attitudes towards disability. Several papers are submitted to academic journals and we hope the findings will be published in 2015. This research is funded by NIHR PenCLAHRC through a PhD studentship held by Megan MacMillan.

[Sleep positioning in cerebral palsy: Cochrane review](#)

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

This systematic review is appraising evidence of whether commercially available night-time postural management systems reduce hip deformity in children with cerebral palsy. Although there is a biomechanical basis for such this treatment, the equipment may create other problems for the child and family, such as affecting sleep. This will also be considered in the review. We worked with three members of our [Family Faculty](#) to develop the protocol for this review, which published online [here](#). Our early searches the review did not identify any high quality evidence regarding the effectiveness of sleep systems. A second wave of searching was completed in 2014. A report has been drafted and will hopefully be published in the Cochrane Library in 2015. The work is supported through our core funding from the charity, Cerebra.

[Sleep systems for children with cerebral palsy: a pilot randomised controlled trial](#)

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

The aim of this research was to find out if using a 'sleep system' to control posture helps children with cerebral palsy to be more comfortable in bed, reduces pain, improves sleep, prevents deformity, and avoids the need for surgery. This was an 'exploratory' pilot study to help in the development of a [protocol](#) for a larger clinical trial. It will help to identify whether clinicians and families will participate in the trial; whether families find such systems acceptable; and are able to use them as prescribed; and a preliminary examination of any effects on sleep. PenCRU is part of a team led by Dr Donna Cowan at [Chailey Heritage Clinical Services](#) (Sussex Community NHS Trust). The research is funded by the NIHR [Research for Patient Benefit \(RfPB\) programme](#).

[The MeASURE study](#)

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

PenCRU were part of a large team of researchers around the UK, led by Professor Helen MacConachie at the University of Newcastle, who carried out a [systematic review](#) to answer the research 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?" This research was commissioned by the NIHR Health Technology Assessment (HTA) programme. The full report will be published in the NIHR Library in 2015.

School based interventions for ADHD

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

This systematic review examined non-drug interventions for children with ADHD delivered in schools. The review is completed and the report will be published in the NIHR Library in 2015. A parent from our Family Faculty was involved in this research from the application for funding through to the production of the report. This research was commissioned by the NIHR Health Technology Assessment (HTA) programme. The full report will be published in the NIHR Library in 2015.

Supporting Teachers And childRen in Schools (STARS): a cluster randomised controlled trial

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

The STARS study is examining whether the Incredible Years Teacher Classroom Management (TCM) course can enhance teachers' skills in promoting socio-emotional well-being among their pupils; and improve academic attainment and child enjoyment of school. The study is funded by the NIHR Public Health Research programme and will be completed by June 2017.

Involving disabled children and young people as partners in research

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

This methodological research is working to involve disabled children and young people as partners in PenCRU research and activities. Contacts have been made with several local schools. We have also liaised with local and national organisations to build our networks. We carried out a systematic review to bring together published and unpublished information about how disabled children have been involved as partners in health-related research. The paper is published in the journal *Child: Care, Health and Development* which you can see [here](#) and a plain language summary is [here](#). This work is supported by the Exeter Catalyst public engagement scheme, PenCLAHRC and Cerebra.

Active console games

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

This research theme pertains to evaluating using active console games (such as WiiFit) as therapy for children and young people with motor impairments. We collaborated with colleagues in Oxford and Sussex on an application for funding for a study to evaluate Wii games in children with cerebral palsy. This pilot study has been recommended for funding by the NIHR Research for Patient Benefit programme and will commence in 2015.

Other projects we have worked on

There are several other lines of research that we have pursued in 2014 that are not featured above. These are research themes where we are developing ideas and/or seeking funding. Examples include our 'Healthy Parent Carers' research focusing on health promotion for parent carers, and ideas to enable more cross-disciplinary research with our colleagues in the SEND group in the School of Education. A decision is pending on an application for research relating to transition for adolescents with ADHD. We continue to pursue these activities. PenCRU also retains a keen interest in oral health and dental issues for disabled children with colleagues at Plymouth Dental School. Lastly some good news was funding from the charity SPARKS for research we are involved with, led by Tim Adlam in Bath, developing a novel seating system for children with dystonia.

Communicating about research

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

What's the Evidence?

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

During 2014 we produced eight new What's the Evidence? summaries:

- *Is equine-assisted therapy* effective to reduce symptoms and improve functioning for children with disabilities, particularly children with ADHD?
- Is there an association between having a child with complex care needs and a parent in the *armed forces*?
- What are the outcomes of using *yoked prism lenses* for children with neurodisabilities such as cerebral palsy and autism?
- Are *noise generators* an effective treatment for hyperacusis in children, and how long should they be worn for?
- To what extent does the use of *Makaton Sign & Symbol* support the communication of children who have neurological conditions?
- Is there any evidence that *Conductive Education* is effective to improve functioning for children with Cerebral Palsy and Brain Injury and Motor Disorders?
- Does *Cocoa* have a calming effect for children with Tourette Syndrome?
- Is there any evidence that *probiotics* have positive benefits for children with ASD (Autistic Spectrum Disorder)?



Team members working on a project

We also checked and updated two existing What's the Evidence? summaries to see if there was any new information available:

- Auditory Integration Training – what is the evidence for *Tomatis* treatment; is it simply a calming therapy or does it have some medical benefits?
- Are the therapies provided by *Brainwave* and *Footsteps* effective?

By posing the question, or providing feedback on the written report, 14 parent carers were involved in producing What's the Evidence? summaries this year.

During 2014 findings from two of our research projects were included in publications produced by other organisations: 1) our 'What's the Evidence?' summary on special care dentistry was referenced in a new [Sturge Weber UK leaflet on dental care](#) and 2) findings from our CHUMS project were incorporated into a tool produced by the Council for Disabled Children to help professionals and parents [identify outcomes for children and young people with special educational needs](#).

Our summaries on a range of therapies and approaches were also praised by a Consultant Paediatric neurologist during [a speech he made at a Chartered Society of Physiotherapy event](#), and when contacted later he replied: *'I think your evidence summaries are a good place to start with families looking for strategies to help their children, and will direct them towards your website in clinic.'*

Plain language summaries



Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

Research Summary
Tips to involve disabled young people as partners in health research

Key messages

- A small number of examples describe how disabled children and disabled young people have been involved in research, and provide helpful good practice recommendations to guide researchers.
- Investing adequate resources, planning activities tailored to people's ages and abilities, offering choices, and supporting people who use non-verbal communication are important.
- Involving disabled children and disabled young people in research can have positive impacts when done well, but can potentially have negative impacts if done poorly.
- Methods to involve disabled children and disabled young people meaningfully in research should be further developed, and reported so that the research community can share good practices.

This year our plain language summaries were recognised by NIHR ['make it clear'](#) campaign as an example of good practice.

Four new summaries were coproduced with parent carers from our Family Faculty:

- 1) [Involving Disabled Children and Young People in Research](#) PDF 664 KB
- 2) [How could communication on hospital wards be improved?](#) PDF 689 KB
- 3) [Families views on key outcomes for neurodisability](#) PDF 592 KB
- 4) [What are professionals trying to achieve?](#) PDF 712 KB

Social media

We have both a Twitter account and a Facebook page to communicate our news and raise awareness of our work. In 2014, we started working on a digital communication strategy to focus and streamline this work. This has been rolled out in respect of Twitter and the intention is to direct more attentions on the use of Facebook next year.

Twitter

Currently our audience on Twitter is largely organisations (charities and research units) and activists (e.g. disabled & carer rights bloggers). We use Twitter to both disseminate our research findings and network within our field, e.g. by following conferences & tweetchats. During 2014, we increased the number of our followers on Twitter from 106 (January) to 363 (December).



www.pencru.org

Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

TWEETS 1,388 FOLLOWERS 459 FOLLOWING 363 FAVORITES 120 LISTS 2

PenCRU (@Pen_CRU)
PenCRU carries out a broad programme of applied health services research that aims to improve the health and wellbeing of disabled children and their families.
Exeter, Devon, England
@pencru.org
Joined June 2012

Interest in #disability research? There are many ways for families to be involved & no research experience necessary
[ow.ly/z7wNA](#)

Who to follow: NHS Confederation, BMJ, HealthServiceJournal, HSJ



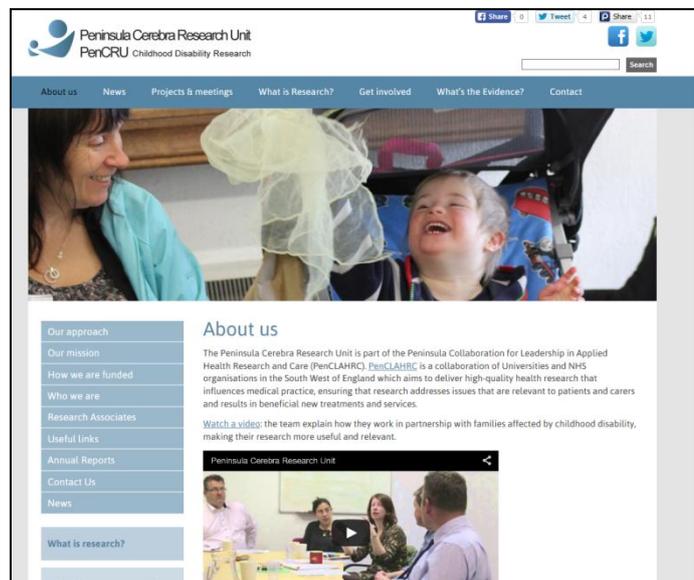
Facebook

During 2014, we have also grown our Facebook audience from 53 'likes' in January to 107 in December. Our audience on Facebook is currently more individual families, so we use a more personal style of communicating. As well as posting our news, we post information we think will be helpful from other organisations such as Cerebra. Our intention in 2015 is to further this engagement by connecting more with parent forums through our Facebook page.

Website

The PenCRU website is often families and professionals' first point of contact with the unit. It provides information about research and our programme of work at the unit. There are sections giving information on how families can get involved and a full list of the evidence summaries we produce.

This year we have added social sharing buttons to each page, so that content can be shared on social media more easily. We have also added a comments box on each page, so that users can report information they have found particularly helpful or less useful.



So far two website users have provided feedback through the comment box, both were positive. One reported that they found the applied behavioural analysis evidence summary useful and another reported that the website was *'Easy to move around and clear headings, regular format and colour. Language and chunks, easy to read and understand; not off putting to me.'*

We set up Google Analytics reports in June 2014 and, according to their figures, since then on average 541 individual IP addresses have hit on our website each month. Around half of these users were returning to the site and the other half were new visitors. We will be reviewing the analytics reports regularly to see what website content is being accessed and what may need to be revised.

This year our [searching for evidence on the internet guide](#) available on our website has proven to be popular. [SENDirect](#) (an online directory of services) have featured it on their website and it reached 670 people when shared on our Facebook page. One person commented *'I have shared this link to a couple of forums I am active on, very helpful piece thank you.'*

Newsletter



PenCRU produce a quarterly newsletter with up to date information about our programme of work, activities, upcoming meetings, recent publications and other items of interest.

The newsletter is circulated to families and professionals who have expressed an interest. Under advice from the Family Faculty we continue to produce both electronic and hardcopies which we email and send by post to all families registered with the Family Faculty (currently 340 contacts). We also publish all new editions of the newsletter on our website, as well as maintaining an historical list.

Our aim is make the newsletters visually appealing as well as informative, to encourage people to pick them up and share with friends and relatives too. We find parents love to see pictures of their own children featured, at the Family Fun Day for example!



There were lots of different activities on offer at the Family Fun Day at Pennywell Farm this year.



Collaboration with Cerebra

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

This year we worked with Cerebra to produce a video capturing the way PenCRU seeks to work in a true partnership with families that you can watch. If you are viewing this report online, click on the picture to run the video. Alternatively, you can find it at <http://www.pencru.org/aboutus/>

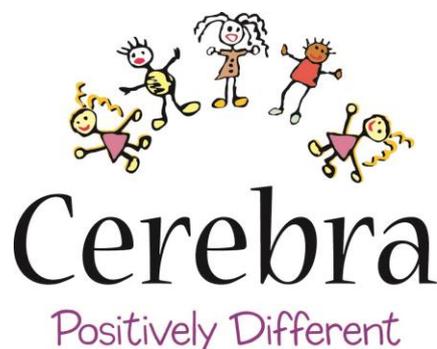
The video may be used for fundraising by the charity, but also portrays well the approach PenCRU take to research, where families feel empowered to truly influence our work.



Cerebra were involved in all stages of the JLA Childhood Disability Research Priority Setting Partnership that was led by PenCRU, including representation at the final priority setting workshop. This was another example of successful partnership between families, charities and support groups, clinicians and researchers – it seems obvious that working together provides the best chance of finding ways to improve the health and wellbeing of children and families.

PenCRU staff and parents from our Family Faculty enjoyed participating in the 2014 Cerebra Research Conference; our display stand received lots of attention and provided us with new contacts and an opportunity to tell people about our work. It was also a useful opportunity to meet up with the other Cerebra funded centres and hear about their work.

The annual visit to PenCRU in Exeter by Cerebra staff and trustees was once again an enjoyable event. Several parents expressed movingly what they get out of working with PenCRU, and how they appreciate the opportunity to be valued for their experience as parent carers.



Who we work with

We collaborate with a large number of colleagues at the University of Exeter Medical School and the University of Exeter; also NHS clinicians and people in other universities and organisations. The list below recognises some of the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2014.

Professor Katrina Wyatt BSc (Hons) PhD

Senior Lecturer in Health Services Research

Dr Wyatt advises the unit on methods for involving children, families and members of the public in research; and also research methods for promoting health.

Professor Tamsin Ford MRCPsych PhD

Clinical Senior Lecturer in Child and Adolescent Psychiatry

Dr Ford is a child psychiatrist and collaborates closely with 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.

Kate Boddy BA MA MSc

PenCLAHRC Associate Research Fellow for Patient and Public Involvement

Kate has expertise in systematic reviews and involving patients and members of the public in research.

Jo Thompson Coon BSc PhD

PenCLAHRC Senior Research Fellow (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's interests span both psychology and health economics approaches. Annie has worked 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 worked on the systematic review and conducted interviews for the 'Communication in Hospital' study. She has also led on the STARS project with Dr Ford.

Brahm Norwich MA MSc PhD

Professor of Educational Psychology and Special Educational Needs

Professor Norwich's broad area of interest is special needs and inclusive education. He is part of the team for the systematic review of school-based interventions for ADHD.

Helen Evans and Jenny Brent

Web Marketing Officers

Hannah and Jenny have advised on the development and evolution of the PenCRU website.

Local Authority and NHS staff

Dr Richard Tomlinson B Med Sci MB BS MSc MRCPCH

Consultant Paediatrician

Dr Tomlinson is a member of our advisory group and has been involved in several previous and current projects including the CHUMS project.

Dr Eleanor Thomas BSc (Hons) MRCPCH

Consultant Paediatrician

Dr Thomas specialises in community child health and has been involved in the 'Communication in Hospital' study.

Dr Rebecca Gumm BMBS MRCPCH

Paediatric Clinical Trials Research Fellow

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

Dr Alice Martin BMBS MRCPCH BMedSci

Paediatric Registrar & Academic Clinical Fellow

Dr Martin is a specialist trainee in paediatrics and has been involved in the study about communication when disabled children are inpatients.

Diane Sellers BA MA PhD MRCSLT

Research Fellow & Speech and Language Therapist, Chailey Heritage Clinical Services

Diane is a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex. Diane led the development of the eating and drinking classification system for children with cerebral palsy.

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 has collaborated with PenCRU on the CHUMS project.

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. He has collaborated 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 has collaborated with PenCRU on the CHUMS project, and been 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; her work at CDC is developing the health and participation services. Amanda has been 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.

Helen McConachie MA MPhil PhD

Professor of Child Clinical Psychology, University of Newcastle

Professor McConachie's research focuses broadly on the health and wellbeing of children affected by disability and their families. Helen leads the MeASURe project about appropriate outcomes for young children affected by autism.

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

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

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

Academic publications

Shilling, V., Bailey, S., Logan, S. and Morris, C. (2015), Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health and Development*. doi: 10.1111/cch.12222

Shilling, V., Bailey, S., Logan, S. and Morris, C. (2014), Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health and Development*. doi: 10.1111/cch.12223

Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C. (2014). Communicating with disabled children when inpatients: Barriers and facilitators identified by parents and professionals in a qualitative study. *Health Expectations* doi: 10.1111/hex.12254.

Bailey, S., Boddy, K., Briscoe, S., Morris, C. (2014). Involving disabled children and young people as partners in research: a systematic review. *Child Care Health Dev* doi: 10.1111/cch.12197

Camden, C., Shikako-Thomas, K., Nguyen, T., Graham, E., Thomas, E., Sprung, J., Morris, C., Russell, D.J. (2014). Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disability and Rehabilitation* doi:10.3109/09638288.2014.963705.

Morris, C., Janssens, A., Allard, A., Thompson-Coon, J., Shilling, V., Tomlinson, R., et al. (2014) Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting. *Health Serv Deliv Res* 2(15)

Janssens, A., Williams, J., Tomlinson, R., Logan, S., Morris, C. (2014). Health outcomes for children with neurodisability: what do professionals regard as primary targets?. *Arch Dis Child*. doi: 10.1136/archdischild-2013-305803.

MacMillan, M., Tarrant, M., Abraham, C., Morris, C. (2014). The association between children's contact with people with disabilities and their attitudes towards disability: a systematic review. *Developmental Medicine and Child Neurology*, 56(6), 529-546.

Allard, A., Fellowes, A., Shilling, V., Janssens, A., Beresford, B., Morris, C. (2014). Key health outcomes for children and young people with neurodisability: qualitative research with young people and parents. *Bmj Open* 4:e004611.

Sellers, D., Mandy, A., Pennington, L., Hankins, M., Morris, C. (2014) Development and reliability of a system to classify eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology*, 56(3), 245-251.

Cowan, D., Smith, M., Gardiner, V., Horwood, P., Morris, C., Holsgrove, T., Mayhew, T., Long, D., Hillman, M. (2013). Mechanical and electromechanical devices in Taktak A, Ganney P, Hegarty F, Long D, White P (eds.) *Clinical Engineering*, Academic Press.

Martin, A., Ford, T., Goodman, R., Meltzer, H., Logan, S. (2014). Physical illness in looked-after children: a cross-sectional study. *Arch Dis Child*, 99(2), 103-107.

Williams, A.J., Wyatt, K.M., Williams, C.A., Logan, S., Henley, W.E. (2014). A repeated cross-sectional study examining the school impact on child weight status. *Prev Med*, 64, 103-107.

Martin, A.E., Newlove-Delgado, T.V., Abbott, R.A., Bethel, A., Thompson-Coon, J., Nikolaou, V., Logan, S. Dietary interventions for recurrent abdominal pain in childhood. *Cochrane Database of Systematic Reviews* 2014, Issue 2. Art. No.: CD010972. DOI:10.1002/14651858.CD010972.

Martin, A.E., Newlove-Delgado, T.V., Abbott, R.A., Bethel, A., Thompson-Coon, J., Nikolaou, V., Logan, S. Pharmacological interventions for recurrent abdominal pain in childhood. *Cochrane Database of Systematic Reviews* 2014, Issue 2. Art. No.: CD010973. DOI: 10.1002/14651858.CD010973.

Anderson, L.J., Henley, W., Wyatt, K.M., Nikolaou, V., Waldek, S., Hughes, D.A., Lachmann, R.H., Logan, S. (2014). Effectiveness of enzyme replacement therapy in adults with late-onset Pompe disease: results from the NCS-LSD cohort study. *J Inherit Metab Dis*, 37(6), 945-952.

Anderson, L.J., Henley, W., Wyatt, K.M., Nikolaou, V., Hughes, D.A., Waldek, S., Logan, S. (2014). Long-term effectiveness of enzyme replacement therapy in adults with Gaucher disease: results from the NCS-LSD cohort study. *J Inherit Metab Dis*, 37(6), 953-960.

Anderson, L.J., Henley, W., Wyatt, K.M., Nikolaou, V., Waldek, S., Hughes, D.A., Pastores, G.M., Logan, S. (2014). Long-term effectiveness of enzyme replacement therapy in children with Gaucher disease: results from the NCS-LSD cohort study. *J Inherit Metab Dis*, 37(6), 961-968.

Anderson, L.J., Wyatt, K.M., Henley, W., Nikolaou, V., Waldek, S., Hughes, D.A., Pastores, G.M., Logan, S. (2014). Long-term effectiveness of enzyme replacement therapy in Fabry disease: results from the NCS-LSD cohort study. *J Inherit Metab Dis*, 37(6), 969-978.

Presentations

Shilling V. and Morris C. on behalf of the Study Stakeholder Group. Peer Support for Parents of Disabled Children. British Association of Community and Child Health West Midlands Regional Meeting.

MacMillan M. Understanding children's attitudes towards disability. University of Exeter SEND research group, Graduate School of Education, University of Exeter.

MacMillan M. Contact interventions aiming to improve children's attitudes towards disability: a meta-analysis and systematic review. University of Exeter Medical School Annual Research Event.

Morris C. Meaningful health outcome measures for children with neurodisability. British Academy of Childhood Disability (BACD) Annual Scientific Meeting.

MacMillan M. Children's contact with disabled people and their attitudes towards disability: a cross-sectional study' [poster]. European Association of Social Psychology.

Morris C. Meaningful health outcome measures for children with neurodisability. British Association of Community and Child Health Annual Scientific Meeting.

Morris C. Meaningful health outcome measures for children with neurodisability. COMET (Core Outcome Measures in Effectiveness Trials) Initiative IV meeting.

Pearson M, Gibson A, Shilling V, Whear R. Patient and Public Involvement in systematic reviews: Why bother? What's the way forward? [poster] NIHR INVOLVE conference.

Logan S. Applied Health Services Research. Somerset Partnership NHS Foundation Trust Research Seminar

Logan S. Using evidence in medical education. 2nd International Conference on Evidence Based Education System - EBESCON 2014, India.

Logan S. Reducing Paediatric Admissions, Lyngford House Conference Centre, Taunton

Logan S. Why do I get out of bed in the morning? INSPIRE Medical Students' Research Conference, University of Exeter Medical School.

Professor Logan also contributed a series of lectures for University of Exeter medical students:

- Lecture to Year 1 BMBS students for UEMS Introduction to clinical decision making.
- Lecture to Year 2 BMBS students for PCMD Introduction to Diagnostics.
- Making sense of evidence: using research to inform clinical decision making.

Lecture to Year 1 BMBS students for UEMS 'Using research to inform clinical decision making.

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