The National Institute of Health Research (NIHR) established nine Collaborations for Leadership in Applied Health Research and Care (CLAHRC) in 2008 to undertake high quality applied health research focused on the needs of patients and service users, and to support the translation of research evidence into practice in the NHS and social care.

The Cambridgeshire and Peterborough CLAHRC (CLAHRC CP), hosted by the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), has been a five-year collaboration between the University of Cambridge and a wide range of Cambridgeshire and East Anglian health and social care providers.

CLAHRC CP has been one of nine CLAHRCs around the country. Their common aim has been the translation of evidence from applied health research into the design and implementation of services, and into policy, planning and practice so to benefit patients, their families, carers and society. They also study the process of this knowledge translation at the, so called, T2 gap that prevents health and social care services actually doing what is known to be best practice. Finally, CLAHRCs have a remit to increase the capacity of the health and social care workforce to create and use such evidence. CLAHRC CP has had a particular interest in mental health and learning disability.

Matched-funding by partner organisations, usually in the form of staff time aligned to the CLAHRC, and good communication, is the engine of co-production. On the university side, unusual marriages of academic disciplines – systems engineers and psychiatrists, psychometricians and management scientists – create additional energy.

CLAHRC CP’s research has focused on people with mental illness, intellectual (learning) disabilities, acquired brain injury, and care for those approaching the end of life. CLAHRC CP is a multi-disciplinary and multi-agency project with three clinical research themes; Adult, Child and Adolescent, and Old Age and End of Life Care cross cut by two implementation themes; Public Health, and Design and Implementation. Many strands of research are being undertaken, and all members of CLAHRC CP work in a collaborative manner across the themes in a ‘virtual’ organisation. While the primary goal of the CLAHRC is the translation of research evidence into practice, in achieving this goal we aim to enhance the capacity of health organisations to do and use research, and to develop and establish robust and enduring links between the academic and service delivery sectors. We are doing this by providing opportunities, through collaborative partnerships and through programmes such as the CLAHRC Fellowship scheme for NHS managers and clinicians.
The Cambridgeshire and Peterborough CLAHRC Core Team

Professor Peter Jones
CLAHRC CP Director

Peter Jones is Director of the NIHR CLAHRC for Cambridgeshire and Peterborough. He is Professor of Psychiatry and head of the department of psychiatry at the University of Cambridge. His research interests as an epidemiologist are at the interface between biological and social models of mental illness, particularly concerning early developmental, adolescent and adult life. He was the clinical lead for the East Anglia Hub of the mental health research network, 2005-2009, is the national lead for the Royal College of Psychiatrists early intervention network, and a director of the Cambridge University Health Partners, the academic health sciences centre for Cambridge.

Angela Browne
CLAHRC Manager

Angela joined the CLAHRC in April 2012 from the East Anglia Hub of the Mental Health Research Network which she managed for four years. Her background is in social care, where she worked as a care manager, and as a team leader for home care in community-based services for older people, run by Huntingdonshire Primary Care Trust. Angela gained a first degree in Psychology from the University of York, has an MSc in Psychology, and a Professional Diploma in reading abilities.

Dr Christine Hill
CLAHRC Deputy Director

Dr Christine Hill is Consultant in Public Health Medicine in the Cambridgeshire and Peterborough CLAHRC, based at the Cambridge Institute of Public Health (CIPH) with Professor Carol Brayne’s research team. Christine has worked in clinical medicine and in healthcare management at executive director level in the acute hospitals sector. Christine’s special interests include translation of research into policy and practice, health policy and management, and screening in disease prevention. Christine holds Masters degrees in Business Administration, Law, Public Health and is a Fellow of the Faculty of Public Health of the Royal College of Physicians.

Capacity Building in CLAHRC CP

The CLAHRC Fellowship is aimed at clinicians, health and social care practitioners, and managers, who would like to work at the interface of research and practice, develop an understanding of the research environment, and develop skills in research methodology, service redesign and change management. The focus within the Fellowship programme is on local applied research and evaluation projects, building local capacity for evidence-informed practice, and facilitating networking across health and social care.

Our CLAHRC Fellowship programme provides an opportunity to increase capacity for applied health research in the NHS and social care, laying the foundations for developing a culture of collaboration between the academic and service delivery sectors. Thirty three Fellowships have been awarded since 2011; our Fellows have come from a wide range of backgrounds: Consultant Psychiatrists, NHS managers, Consultant Clinical Psychologists, Neuropsychologists, Occupational Therapists, General Practitioners, Registered Nurses; they have come from across the East of England (Bedfordshire, Cambridgeshire, Suffolk, Norfolk and Great Yarmouth).

The fellows carry out a project during their fellowship year under the supervision of one of Cambridge University’s senior researchers. This can be a specific project chosen by the fellow or they can contribute to a project within one of our CLAHRC themes. Examples of CLAHRC Fellows’ projects can be found on our website.

In addition to the research project, we hold a programme of monthly half day teaching workshops and half day action learning sets (ALS). The main aim of the Action Learning Set is to learn from experience and sharing that experience with others, being open to the challenge of colleagues and listening to alternative suggestions, all in a non-judgemental atmosphere. The research time, workshop and ALS sessions are protected time for the fellow. The key aim of the Fellowship is to make the programme valuable to the individual fellow and their employing organisation.

The CLAHRC Fellowship programme taught component Making sense of the research world and promoting the use of research-based evidence in healthcare organisations are the main aims of the Fellowship programme. With this in mind, the educational component of the fellows programme aims to develop an understanding of research and evidence, research methodology, theory of change management, and systems thinking. These skills can be applied in the workplace to effect real change that ultimately brings about improvements in service delivery.

CLAHRC Fellowship programme taught component

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CLAHRC Fellows

Mark Hall
CLAHRC Fellow 2012

“As a Service Manager for Learning Disabilities & Neurodevelopmental Needs in CPFT, the opportunities secured from being part of the Cambridgeshire and Peterborough CLAHRC, in particular the learning from the Fellowship award, was truly uplifting and beneficial to my leadership and practice. On both a professional and personal level I consider myself a better manager as a consequence of this unique learning experience, making me more mindful of the need to drive forward better care in partnership, based on the evidence all around us and the opportunities to consistently search for stepped improvement and a better patient experience.”
the way individuals at risk of developing major mental health problems access and receive their care” says Jon. Jon’s CLAHRC project ‘Designing and implementing a Youth Mental Health Service’ was through a review of the current literature, then taken forward through an iterative consultative process with local stakeholders, patient groups, commissioners and senior management in the NHS Foundation Trust. Through this process, an evolving vision and proposed service model was developed which gained widespread agreement and common ownership.

A briefing paper on Jon’s fellowship project can be found on the CLAHRC CP website.

Dr Mai Luen Wong
CLAHRC Fellow 2011

Mai Luen’s CLAHRC project was done under the supervision of the Cambridge Engineering Design Centre, and looked at the frequent attenders to the Addenbrooke’s Hospital Emergency Department, in particular, the design of services for patients who may benefit from assessment and early intervention for medically unexplained symptoms and psychological co-morbidity as a consequence of long term conditions. Frequent attenders have been associated with a number of characteristics including: male, out-of-hours attendance, vulnerability, high rates of addiction, mental health problems, somatiform disorder and chronic medical problems. This variation makes it difficult to study this population and in this case, to design appropriate services.

A briefing paper on Mai Luen’s fellowship project can be found on the CLAHRC CP website.

Dr Fergus Gracey
CLAHRC Fellow 2011

Fergus is a Consultant Clinical Neuropsychologist who works with both adults and children following acquired brain injury. He has worked at the Oliver Zangwill Centre for Neuropsychological Rehabilitation for 10 years and has specialised in understanding and rehabilitating self-regulation, emotional adjustment and social-emotional processing problems. Fergus has published book chapters and papers in peer reviewed journals on topics relating to his interests in social and emotional aspects of brain injury, especially relating to cognitive behaviour therapy, identity and adjustment. His research is currently supported by successful grant applications and he works part time as a practitioner researcher within the CLAHRC CP where he is involved in research relating to service improvement and service design for adults and children with brain injury.

Alison Watson
CLAHRC Fellow 2013

Alison is responsible for evaluating the effectiveness of psychological therapies and the efficiencies of changes in mental health service delivery resulting from the implementation of the IAPT programme across the East of England. Since graduating in 2001 with a MSc in Forensic Psychology, Alison has worked as a Researcher & Analyst for the Police Service, Fire Service and Local Authority providing strategic guidance to senior officers and partnership managers on the allocation of resources to reduce crime and disorder. Alison then became the Police Authority Lead in Communications, working closely with the Home Office and Association of Police Authorities to secure public and stakeholder engagement. Immediately prior to joining the CLAHRC, Alison worked as an Assistant Psychologist in a low-secure Mental Health Unit specialising in child protection referrals and delivering rehabilitation programmes to community and in-patients. She also worked as an Advocate with Young Offenders providing support to people under the age of 18 years who had either been charged with an offence or had been identified as ‘at risk’ of committing an offence.

Alison’s CLAHRC Fellowship project is Filling the Void: an evaluation of non-attendance to scheduled appointments within East of England Improving Access to Psychological Therapies (IAPT) Services.

Using PCMS data extractions spanning a 3-year period from 1st January 2010 - 31st December 2012 from 9 IAPT services across the East of England, descriptive statistics and correlation analysis will be used to explore patterns and trends relating to service and patient variables with a view to identifying indicators that could be used to help increase engagement with treatment and reduce resource waste.

“The CLAHRC Fellowship has given me a valuable opportunity as a busy NHS clinician to undertake clinically relevant research in my service, and also to support my development as a clinical researcher. The teaching provided interesting and highly relevant knowledge and learning experiences not only of direct use in carrying out my project but also to understand the diverse disciplines and fields that contribute to understanding the integration of clinical practice, service delivery and research. The programme also provided great networking opportunities and a chance to share stories and learning with other fellows from very diverse aspects of the NHS”.

Fergus’ CLAHRC project ‘Mental health problems of children with acquired brain injury’ set out to improve understanding of the presenting needs of children with acquired brain injury (ABI) and to explore service design issues via a new service for children with acquired brain injury serving the East of England region (Cambridge Centre for Paediatric Neuropsychological Rehabilitation, CCPaNR). The research question – What are the presenting cognitive, emotional, behavioural and social problems of these children compared with matched non-ABI Child and Adolescent Mental Health Services (CAMHS) referrals? The work has raised awareness of the needs of children with ABI in the Trust. Screening for presence of brain injury as a diagnostic category has been added to the CAFMHS Outcomes Research Consortium (CORC) referral checklist. A brief ABI screening tool is now being used by the Youth Offending Team in Cambridgeshire.

A briefing paper on Fergus’ fellowship project can be found on the CLAHRC CP website.
Sara Simblett
Sara graduated from the University of Bristol in 2007 with a BSc in Experimental Psychology, and in 2008, with an MSc in Neuropsychology. During her Masters degree and for six months after graduating, she worked as a Research Assistant in the Department of Experimental Psychology at the University of Bristol, with Dr Christine Mohr. She worked on a project exploring individual differences in cognition, personality and creativity. Funded by the CLAHRC for Cambridgeshire & Peterborough, to work with Dr Isabel Clare, she has been awarded a CLAHRC Funded PhD Studentship and is currently working with Dr Andrew Bateman at the Oliver Zangwill Centre, Ely, and Dr Howard Ring, on a project exploring new interventions for the rehabilitation of acquired brain injury, in particular executive dysfunction.

Rianne Van Der Linde
Rianne is a PhD student at the Department of Public Health and Primary Care in Cambridge, funded by the NIHR CLAHRC for Cambridgeshire and Peterborough. She started her project in October 2010 under the supervision of Professor Carol Brayne and Dr Tom Dening. Rianne studies the course, causes and impact of Behavioural and Psychological Symptoms of Dementia in the older population. She uses mainly population-based cohort studies, including the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). In 2009 Rianne completed her MSc in Epidemiology (Biomedical Sciences) at the Radboud University Nijmegen in The Netherlands.

"CLAHRC has a wide range of people including psychiatrists, general practitioners, epidemiologists, psychologists and nurses. I learned a lot from talking with them about my work and it was good to think about what the implications of my findings are for clinical practice. My experience with CLAHRC has prepared me well for my new job as a Public Health Intelligence Analyst at a local authority."

Angela Aristidou
Angela holds a Masters degree from Harvard University in Technology, Innovation and Education, and a Masters in Information and Communication Technologies. Angela has also worked for the Veterans Health Administration, where she evaluated and re-designed an interactive online program that aimed at creating an online community of practice for VHA psychologists. Also, on a project of the NASA Biomedical Research Institute, she assisted with the research and development of software-based training material for astronauts on conflict management and mental health management. Angela is a doctoral candidate at Cambridge Judge Business School, specialising in Operations, Information and Technology and her CLAHRC research is about: The Contribution of Open Source Software to Knowledge Sharing and Organisational Change in Healthcare.

Ruth Spence
Ruth’s research involves investigating the development of temperament and personality in adolescents. In particular, how different temperamental styles might be associated with later personality functioning, and how personality may interact with symptomatology to inform and engage with mental health provision in adolescents.

The adoption and implementation of this CLAHRC CP research has involved our researchers doing extensive work with young people in care, including the making of a short animated film by 11 young people in foster and residential care in Cambridgeshire. This film is currently being piloted as part of a new training course for foster carers and social workers being developed as a result of this research. The film, called ‘My Name is Joe’, gives a powerful insight into how it feels to enter the care system as a young person. It is freely available on YouTube and has been very well received - the young people involved in its making received an Outstanding Achievement Award at the Children’s Service Annual Awards.

The training programme to help foster carers to recognise mental health problems in children in their care will better equip foster carers to detect the early signs of emotional and behavioural disorder in children. This would help reduce placement breakdown, improve mental health and emotional wellbeing and enhance the future life chances for these young people. This is currently being developed and piloted with our Local Authority partners. The partnership with the local authority, developed through the CLAHRC, has been key to the success of the TC17 project.

Erica Borgstrom
Since January 2010, Erica has been working on her CLAHRC-funded PhD about choice and end of life care in the UK. She is a trained anthropologist (BA, MA research methods) and uses social science methods and theories in her work. Her past research interests have been wide ranging, including studying issues around advocacy and ethics in research of sensitive topics (using infanticide in Ghana and female circumcision as examples) as well as social networks and the spread of information in a small American town.

"Doing my PhD as part of CLAHRC has helped me successfully complete independent research whilst still being part of a larger team working on different projects. Through this I’ve been exposed to lots of different ideas and approaches to research and implementation – more so than I would have been without CLAHRC. It has helped me think more broadly about the research process and prepare for a career in health services research."

Main CLAHRC CP projects
Case Study One
Transfer of Care at 17 (TC17)

The “Transfer of Care at 17 (TC17)” research study, led by Prof Ian Goodyer and colleagues found that transition into adult life may be compromised by poor mental health, particularly in the Young people in Care (YPiC) group, where poor mental health is often accompanied by other potent negative factors. This research has changed the way our local authority partners think about the mental health of young people in their care. Estimates suggest that around one third of young people who are referred to adult mental health services from Children and Adolescent Mental Health Services (CAMHS) do not take up regular appointments even though around 50% of adolescents in care suffer from mental illness. Their relatively poor social, economic and health outcomes in early adult life may be due in part to the absence of collaborative psychiatric management in their teenage years, but there is very little data on early adult wellbeing for either of these vulnerable groups.

A briefing paper on the TC17 project can be downloaded from the CLAHRC CP website.

This research has been published as
Dunn, V., Goodyer, I., Memarzia, J., Owens, M., St Clair, M., & Thand, J. (2013). Transfer of Care at age 17 (TC17)-an investigation of factors which influence young people in CAMHS facing transitional care at 17.

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Case Study One
Continued

ENGAGING YOUNG PEOPLE THROUGH ANIMATION

Valerie Dunn
University of Cambridge and CLAHRC CP researcher, scientific co-ordinator for this project

“The young people, supported by the adults, have co-produced a unique, raw, honest and insightful film which is a resource for use by multiple audiences, and has been used to train social workers and foster carers, and we’ve formed a strong link with a group of young people for future work.”

Feedback from carers who have been involved with the foster carers training course includes the following comments:

“positive, useful, informative”
“everything about the course was interesting”
“This course is very useful, from Skills to Foster [initial training for new carers] to foster carers that have been fostering for years. For new carers it would give them a better understanding and for us that have been carers for years, very helpful – we never stop learning”

As a direct result of seeing the film, The National Fostering Agency (NFA) committed to producing family profiles of all foster carers which will be given to all young people coming into care.

At the suggestion of the young people who made the first film, there is another film in the pipeline on leaving care. Workshops and an animation summer school took place in August 2013, with the film launch planned as part of Cambridge Film Festival, October 2013.

Val Dunn said “We will run workshops which introduce variety of animation styles, play with sound equipment, consider the issues, as well as introduce the research and practicalities of the project”.

The young people commented on their involvement in the film:

“I did My Name is Joe last year and really enjoyed it, particularly the stop-frame animation, sound and scripting. I find it really useful … I don’t have any work at the minute and its really good to get into something I actually enjoy. Having a go on camera was really good and the clapper was pretty good as well.”

“I did My Name is Joe last year and it had very successful results and helped a lot of people and got a message across really well … I enjoyed seeing my creations and everyone’s efforts come to life in picture form. It’s a great way of doing things”

“I did [the film] helps young people feel less alienated and it helps service provided provide a better service because they have some knowledge of the emotions and things young people are going through”

“It was a once in a lifetime’s opportunity” [referring to the film project]

“I believe it will help in the future. Not many people know much about the system … people don’t get young people’s point of view. Our emotions and the way we think about different things really comes out”

“the message from the film is very diverse … the worries, the reasons why, different scenarios, from good to bad, from loneliness to money problems to parties”

Professor Ian Goodyer
Lead for the Adolescent Theme in CLAHRC CP

Professor Goodyer is a Child and Adolescent Psychiatrist pursuing research into the connections between human development and psychopathology. His studies are centred on children and adolescents in the community as well as current patients and their relatives. Professor Goodyer’s research team has completed a prospective study of adolescent development from 14 through to 18 years of age. This study is known as ROOTS (www.roots-group.org.uk) and involved 1200 young people and their families.
IAPT promotes access to talking treatments based on cognitive behavioural therapy (CBT), which are approved by NICE (the National Institute for Health and Clinical Excellence). There are two tiers of IAPT therapy, depending on clinical severity, and corresponding to NICE steps 2 and 3 for the treatment of depression and anxiety. More intense therapy is delivered by more experienced clinicians in the higher tier; the lower tier provides treatment for the majority of referrals from primary care and other sources. Telephone-mediated psychological interventions are convenient for patients and therapists, with a 40% reduction in treatment time and removal of barriers to treatment initiation, especially for patients receiving low intensity therapy. Services are no longer constrained by working hours or treatment space. However, the evidence for these benefits relies on small samples in specialised settings, and may not be relevant to the relatively brief interventions (fewer than six sessions) delivered in the lower tier of IAPT. To address this uncertainty, we assessed the clinical and cost effectiveness of low intensity talking therapies, delivered face-to-face (FTF) versus over the telephone (OTT) in the IAPT programme in East of England.

Background
Patients who are accepted onto the IAPT programme complete a number of disorder-specific outcome measurement tools at every contact with the therapist, which is usually over 6-8 sessions. Under the aegis of NHS East of England (now Midlands and East Anglia), IAPT services have been commissioned by seven primary care trusts (PCTs) in the East of England since 2008 and have achieved over 90% geographical coverage. The aim of this project, in partnership with the East of England SHA, was to develop a PCT-specific evaluation of IAPT services and, for the recommendations arising out of the research to be used as the basis for a best practice guide that will support the SHA in its performance management.

Methods
This was an observational study looking at routine patient-reported clinical outcomes collected at each session for individuals being treated using CBT-based psychological therapies. Patients were asked to complete questionnaires about their depressive symptoms, anxiety and ability to function in terms of work, home management, social leisure, private leisure and personal or family relationships. In addition, the cost per session for OTT (over the telephone) was compared with that for F2F (face to face).

Results
Outcomes improved under both interventions, regardless of symptom severity, except in the most severe cases. Improvements in social functioning were also observed. The per-session cost for OTT was cheaper than F2F, remaining so when assumptions were varied in a sensitivity analysis.

Implications
Findings revealed that talking therapies delivered OTT are more cost-effective than seeing patients F2F, and as clinically effective. Delivering interventions OTT has opened up the IAPT service to groups of people who might otherwise be unable to access the IAPT service either through transport problems, physical disability, work commitments, or perhaps a reluctance to talk face to face about their about personal issues. The research team has been working in close partnership with the SHA to improve services based on research results. On the back of these findings, the SHA has instigated a regional training programme to ensure the East of England therapists are competent at telephone contact with patients and that the service is standardised across the region.

This research has now been published as: Hammond GC, Crundace TJ, Radakrishnan M, Lafortune L, Watson A, et al. (2012) Comparative Effectiveness of Cognitive Therapies Delivered Face-to-Face or over the Telephone: An Observational Study Using Propensity Methods. PLoS ONE 7(9): e42916.

A brief paper on the IAPT research can be downloaded from the CLAHRC CP website.

Dementia is a progressive degenerative syndrome characterised by cognitive and non-cognitive symptoms that increase in frequency and severity with advancing disease. The progression from mild cognitive impairment to dementia is typically accompanied by progressive loss of the ability to perform activities of daily living (ADL) and is also often marked by the emergence of neuropsychiatric and challenging behaviours of varying type and severity. Multiple diseases can cause the dementia syndrome and, to date, research has produced no effective approach for primary prevention. Secondary treatments are also of limited effectiveness and there is no available disease modifying treatment. In light of the high personal, societal and economic costs associated with dementia-related disability, it is no surprise that the rise in the incidence of dementia associated with the global demographic change has become a prime source of public health concern.

Our research within the CLAHRC aims to characterise the mental health of older people and to improve preventative and treatment interventions, with a focus on dementia, frailty and ageing. Our programme of work is carried out in collaboration with a range of NHS bodies, but also with charities such as the Alzheimer’s Society. The theme is based in the Institute of Public Health, University of Cambridge, and at Fulbourn Hospital, Cambridgeshire and Peterborough NHS Foundation Trust. The theme has a wide portfolio of projects including population based studies and therapeutic trials.

Evidence synthesis and research dissemination are important elements of our translational work.

Our main projects are:

- A systematic review of screening for dementia
- A programme of diagnostic test accuracy reviews
- Alternatives to anti-psychotic use in dementia
Systematic review of screening for dementia

One of our most important studies is a series of 3 complimentary systematic reviews into screening for dementia which is being undertaken to answer the following key questions regarding screening for dementia:

- What tools are available to screen people for dementia, and how good are they?
- How do patients, carers and doctors feel about screening?
- What would be the benefits and costs of a screening programme for dementia?

Despite more than a decade of policy and research efforts supporting early intervention in the care and treatment of people with dementia, the well-documented difficulties in achieving its early recognition in clinical practice persist. There are complex reasons for this ‘gap’ which include lack of effective treatments to alter the natural history, an absence of suitable validated instruments that can detect with accuracy at the individual level, limited training in screening, mixed availability of specialist services and unclear referral pathways. However, they also reflect the insidious and highly variable development of dementia syndromes that renders recognition problematic and there are also wide differences in physician’s, patient’s and caregiver’s attitudes towards dementia and dementia screening.

Dementia screening may provide a suitable mechanism to decrease the individual and social burden of dementia by identifying the disease earlier and thus allowing timely diagnosis and early deployment of treatment and support strategies, however, a clear distinction must be made between the clinical recognition of symptoms of dementia on the one hand and population screening on the other. For over a decade researchers have sought ways to improve the early detection of dementia. Yet still a large proportion of patients who meet the criteria for dementia do not receive a formal diagnosis or receive it too late to be clinically useful. One possible approach to improving detection of dementia could be to screen older people in the population to identify the disease sooner and allow earlier treatment and support.

Many researchers are dubious about the benefits this would bring. Routine screening for dementia is not currently considered to be clinically or cost effective. However, the pressure for faster diagnosis and for population screening may increase as the burden of dementia increases and as new therapies emerge. We do not currently have a clear view of the advantages and drawbacks of this approach.

Our research will provide reliable evidence and practical information for policy makers, health professionals and the public on the validity of available tools, and the acceptability, cost and benefits of dementia screening. It will also help further our understanding of how to improve early detection of dementia in the community.

Partners

This project is a collaboration between the Public Health and Old Age themes of the CLAHRC CP, the BUFA Foundation and the Alzheimer’s Society. Two members of the Alzheimer’s Society are part of the management committee and contribute a public perspective to the project.

The work on dementia research will continue into the CLAHRC East of England and will be led by Professor Carol Brayne.

Primary Care is central to the provision of End of Life Care (EOLC). Most of the last year of life is spent at home under the care of General Practitioners (GPs) and Community Nurses (CNs). Nationally, 19% of deaths occur at home and 18% in care homes, under the care of GPs and CNs. Local and national strategies emphasise the importance of increasing EOLC provision at home: the involvement of GPs and CNs in the care of patients approaching the EOL is set to increase over the coming years. However, medical and nursing student training in EOLC is limited. This leaves many clinicians feeling unprepared when providing care for people near the end of their lives and feeling that they lack the training and knowledge required to deliver high quality EOLC. Previous studies have investigated the education and knowledge of GPs, while CNs have been little studied in this regard.

This study investigated the knowledge and prescribing habits of Peterborough and Cambridgeshires GPs and CNs to identify training and educational needs. It also gathered information on their views on the out of hours services in their area and their preferences for further EOLC education.

Methods

A questionnaire study of all general practitioners and community nurses in Cambridgeshire and Peterborough, investigating their training and educational needs. It also gathered information on their views on the out of hours services in their area and their preferences for further EOLC education.

Outcomes

Generally a high level of knowledge was found amongst responders, with key areas for improvement identified. These include: educational needs and awareness of the side effects of some medicines; specific training and practice to increase competency; and the need to increase awareness of night and evening services for end of life patients.

Presentations have been requested by different groups (community nurses, Peterborough out of hours service and local palliative care teams) to inform them of the results and facilitate discussion. In addition, data from this survey are informing several educational initiatives with which the CLAHRC team is associated, in particular the HEC Initiative. This study has been published in the Journal of Pain and Symptom Management.

Dr Stephen Barclay
End of life care theme lead

“The NHS is increasingly recognising the importance of care for people as they approach the end of their lives; it is also increasingly recognised to be an under-researched area. In order to address this need for an evidence base, the CLAHRC End of Life care theme, jointly funded by the Arthur Rank House Charity, undertook an evaluation of the Cambridge Hospice at Home service; this has helped shape the service as it expanded and informed the successful bid to the Clinical Commissioning Group for an additional £250,000 per annum for the service. I am Clinical Lead for End of Life Care in the Cambridge and Peterborough CCG, a role in the research of the Theme that is frequently used to inform commissioning decisions. The Theme have also undertaken a suite of systematic literature reviews concerning End of Life Care conversations in heart failure, chronic obstructive airways disease, dementia and the frail elderly: are conversations taking place and what are the views and preferences of patients and clinicians concerning talking about the end of life. I have also been involved in developing the NICE Quality Standards for End of Life Care and Department of Health review of the national End of Life Care Strategy which has been shaped by the Theme’s research.

Future research to be undertaken in CLAHRC East of England, includes studies of patients who die in hospital shortly following admission and of the sharing of clinical data across the health care system for patients nearing end of life. Additional studies are planned of decision-making concerning withdrawal of treatment towards the end of life in cancer and motor neurone disease and of bereavement care.”

Partners

Our partners include NHS Cambridgeshire and NHS Peterborough. Both of these Primary Care Trusts are using the information from the study to help tailor the content of training courses for health practitioners.
Applied research in autism

Autism and Asperger Syndrome are part of a range of developmental conditions known as autism spectrum conditions (ASC). They affect how a person communicates with others and how they make sense of the world around them. Individuals with ASC have difficulties in social interaction and adapting to change, alongside unusually narrow interests and strongly repetitive behaviour.

Autism Spectrum Conditions (ASC) are characterised by difficulties in social interaction, communication, and adapting to change, alongside unusually narrow interests and strongly repetitive behaviour. Diagnosis of ASC can be a lengthy process because it varies greatly across individuals, and the age at which symptoms first appear differs. Diagnosis is often delayed because it can be difficult to detect in very young children or in later life when ASC can be masked. Parents may raise concerns about their child as early as 18 months, but there is frequently a delay between the point of first concern and an eventual diagnosis.

The average age of a diagnosis for individuals with Asperger Syndrome (AS) is 11 years, however, it is clear that there are many individuals with ASC in the population who go undetected even into adulthood and who are struggling and would benefit from support. In addition, awareness and expertise about how to recognise ASC within primary care is highly variable.

The ‘Red Flags’ research study by CLAHRC researchers led by Professor Simon Baron-Cohen, addresses the need for a ‘red flag’ tool for primary care professionals and specialist diagnostic services to aid their decision-making about whether to make a referral for a full diagnostic assessment for ASC. The aim was to identify 10 items from each of 4 screening instruments (the Autism Spectrum Quotient (AQ), the Autism Quotient (AQ)-10 child, the Autism Quotient (AQ) adult, and the Childhood Autism Rating Scale (CARS)) and on the Quantitative Checklist for Autism in Toddlers (Q-CHAT) to balance validity and reliability.

A case sample of more than 1,000 individuals with ASC and a control sample of 3,000 controls with no ASC diagnosis participated. Participants completed full-length versions of the measures. The 10 best items were selected on each instrument to produce short versions.

Findings

At a cut-point of 6 on the AQ-10 adult, sensitivity was 0.88, specificity was 0.91, and positive predictive value (PPV) was 0.85. At a cut-point of 6 on the AQ-10 adolescent, sensitivity was 0.93, specificity was 0.95, and PPV was 0.86. At a cut-point of 6 on the AQ-10 child, sensitivity was 0.95, specificity was 0.97, and PPV was 0.94. At a cut-point of 3 on the Q-CHAT-10, sensitivity was 0.91, specificity was 0.89, and PPV was 0.58. Internal consistency was > 0.85 on all measures.

Conclusion

These short measures have potential to aid referral decision-making for specialist assessment and should be further evaluated in the context in which they are intended to be used.

Impact

This piece of research has provided a much needed screening measure where one has not been previously available. The AQ-10 will be available for front line clinicians, and adults with possible ASC will have a faster route to assessment, and consequently obtaining the support they require.

At national policy level, the National Institute for Health and Clinical Excellence (NICE) has recommended the short Autism Spectrum Quotient (AQ-10) in their guidelines for the management of ASC in adults, which was published in June 2012, and in the Evidence Update on autism diagnosis in children and young people was published by NICE in April 2013.

The adult theme of the CLAHRC has established a Service User Advisory Group (SUAG), which involves nine service users with mild or moderate intellectual disabilities (ID). The Advisers, who were identified from across Cambridgeshire through our collaboration with the integrated NHS and LA teams managed by the Cambridgeshire Learning Disability Partnership, work with the clinicians, clinical academics and researchers in the CLAHRC CP on a study examining how integrated community-based specialist teams can best support people with intellectual disabilities and complex and enduring needs. Our Advisers bring a range of relevant experiences to the group, including different histories of contact with the specialist community teams, severe physical health problems and/or additional physical disabilities, communication difficulties, mental health problems, and aggressive or sexually inappropriate behaviours that have led to their exclusion from specialist ID services and/or contact with the criminal justice system. All of them experience or have experienced loneliness, unemployment, social deprivation, exploitation, discrimination and marginalisation; none has been involved in self-advocacy activities before.

The group met every two months. In our meetings, we used accessible materials to carry out a range of activities. These started from the experiences of our Advisers and have included both general team-building and skills in working together, and more specific training in quantitative and qualitative research methodologies. For example, Advisers have carried out research within the group and seen how this can be presented visually as bar or pie charts. They have also been involved in experiences, such as travelling by train in order to attend the meetings more independently, and presentations to increase their skills and confidence. We have also worked together to explore visual methodologies.

We try hard to support the Advisers, using phone calls and home visits, and encourage them to attend the meetings, even when they feel overwhelmed by their difficulties. So far, we have been successful, and all of those who came to the initial ‘information event’ have remained active members of the SUAG and attended regularly.

Case Study Five

Red flags tool for the detection of ASD

Case Study Six

Service user advisory group

Professor Tony Holland
Theme Lead, Adult Theme

Tony Holland trained in medicine at the University of London, UK, and later trained in psychiatry at the Institute of Psychiatry and Maudsley Hospital, London. As a clinician he specialises in the assessment and treatment of psychiatric and behavioural problems of people with intellectual disability. He leads a research group that has undertaken many published studies on Prader-Willi Syndrome investigating the nature of and reasons for the eating disorder and other behavioural, psychiatric, and physical problems associated with the syndrome. He is psychiatric adviser to the UK PWS Association and also their President. He is the scientific representative for the UK PWS Association on the Board of the International PWS Organisation (IPWSO). Two main areas of Professor Holland’s research interest include; first, investigating the relationship between particular genetic syndromes and associated psychiatric and behavioural disorders (e.g. Prader-Willi Syndrome and over- eating, and Down’s Syndrome and Alzheimer’s disease) and, secondly, clinic–legal studies, including studies investigating the capacity of people with learning disabilities to make particular decisions.

Professor Holland leads the adult clinical theme of CLAHRC CP.

This theme is specifically concerned with the needs of adults with intellectual disabilities and those with acquired brain injury. Professor Holland will also lead the Enduring Disabilities and Disadvantages theme in CLAHRC EoE.

What is research? A question and answer session with Professor Tony Holland
Case Study Seven
Development of older people’s primary care mental health services

There is a critical need for innovation in the NHS both now and in the future. With an ageing and more demanding population, the current health service models will not be able to meet rising demand at an affordable cost. A broad outline for what changes are required in both health and social services is emerging. Nevertheless there is a need to make these changes happen. The Engineering Design Centre were particularly interested in understanding better how healthcare providers make decisions about the design of the new services that they develop. The idea of developing an older people’s primary care mental health service for came from the NHS Cambridgeshire Mental Health Commissioning Team as part of a decision to redesign older people’s mental health (OPMH) services. Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) had already piloted a primary care service for working age adults in Huntingdon and, with the advent of the UK Government’s programme of Increasing Access to Psychological Therapies (IAPT), this adult service was rolled-out across Cambridgeshire, which became a pathfinder site for IAPT nationally.

The NHS Cambridgeshire Mental Health Commissioning Team were keen to develop a similar primary care mental health service model for older people and discussions started between OPMH management and NHS Cambridgeshire in 2006 to enable this. The Professional Lead for Older Peoples Psychology (Psychologist A) took on the project management role of the pilot study and one of the aims was to influence national guidance around the development of an IAPT/Primary Care MH service for Older People to provide therapies for those older people with mild or moderate mental health needs who would not previously have been considered for secondary care interventions. This would not just be a standalone psychological therapies service based on Adult IAPT. Instead it would be seamlessly integrated with secondary care and work closely with community services, social care and voluntary organisations. Moreover, although the adult primary care model would provide the starting point, there would need to be differences in the service to make it accessible to older adults and address their unique needs. Psychologist A explored these differences with the various OPMH service managers, the commissioners, local GPs and the people running the Adult IAPT service in CPFT. She also gathered information on the evidence base and national good practice using her contacts in other trusts and through her involvement in national healthcare bodies. Based on this research and her 30 years of experience as a clinician she was able to propose a model for how the new service would work.

Prior to this reorganisation, the Older People’s Mental Health service (OPMH) provided a range of community and in-patient services, primarily to people over the age of 65 years old who suffer from cognitive (mainly dementia) or functional (e.g. depression and/or anxiety) mental health problems. The Primary Care service was developed by OPMH to improve access for older people to psychological interventions and provide therapies for those with mild or moderate mental health needs who would not previously have been considered for secondary care interventions.

This required the service to be developed in a way that makes it accessible to older adults and meets their unique needs. The service is intended to work seamlessly with the other CPFT services, particularly the community teams providing secondary care to older people, as well as GPs, community services, social care and voluntary organisations. Its focus is on early diagnosis, intervention and support and signposting for patients and carers in the community.

The activity data gathered from the pilot project did not unequivocally demonstrate the financial benefits of a primary care service for older people’s mental health across the whole of Cambridgeshire, however the pilot was considered a great success by those involved i.e. OPMH, the commissioners, GPs, patients, carers etc. The clinical outcomes were good and there was lots of very positive, qualitative feedback from the patients and GPs about the service. Moreover the commissioners had enjoyed the experience of a very positive, close collaborative working relationship with the pilot team.

Consequently the commissioners decided in late 2010 that they would like OPMH to prepare a business case and plan for a full roll-out of OPPCMHS to the whole of Cambridgeshire. In the meantime the pilot team continued to provide the primary mental health service to the six GP surgeries in St Ives throughout 2011. They were eventually subsumed into the full roll-out when that took place in November 2011.

In 2012, CPFT’s new chief executive reviewed and reprioritised service improvement activities across the Trust and the pilot project, which had been running since January 2009, and now had a caseload of 80 patients across the six GP surgeries in St Ives, was absorbed into the Huntingdonshire community mental health team in 2012.

Professor John Clarkson
CLAHR CP Design theme lead

John Clarkson was appointed director of the Engineering Design Centre in 1997 and became a Cambridge University Professor in 2004. John is directly involved in the teaching of design at all levels of the undergraduate course. His research interests are in the general area of engineering design, particularly the development of design methodologies to address issues, for example, process management, change management, healthcare design and inclusive design. As well as publishing over 400 papers, he has written a number of books on medical equipment design and inclusive design.
Patient and public involvement (PPI) in CLAHRC CP

CLAHRC CP has involved patients and public in research in many ways, some examples of which are detailed below:

- CLAHRC CP has a PPI Coordinating group which meets bimonthly with representatives of each research theme and a lay representative who is actively involved in the group’s activities. Part of the group’s remit is to ensure that patient/service users and the public are informed about research and have the opportunity to engage where appropriate.

- The Adult theme has developed a successful process of including people with learning disabilities and additional mental health and/or behaviour needs, in the research process in a meaningful way through the Service User Advisory Group (SUAG). Four of the ‘Advisers’ (service users), supported by CLAHRC researcher members of the SUAG, represented their experience of research involvement at the National INVOLVE conference in November 2012, in Nottingham.

- The researchers of the adolescent theme have worked with a group of young people in care from the beginning of the TC17 research project which has been described previously in this report. Producing this film gave the young people an opportunity to give their views first-hand, and given me a better understanding of how PPI can be included at each stage of the research process and how it plays a part in a wide range of projects, from systems modelling to the evaluation of PPI itself."

- We produce patient information leaflets when required so that they can be distributed at learning events and focus groups, for example our PPI leaflet ‘Applied Research in Dementia’ was distributed at a workshop for service users, carers and the public as part of a scoping exercise for the Old Age theme project ‘Improving emergency care in the community for people with dementia.’

- CLAHRC CP in collaboration with the Cambridgeshire and Peterborough Foundation Trust (CPFT) have provided a four day research training programme to patients and the public who have shown an interest in being involved in research. The training was facilitated by service users and carers as well as CLAHRC CP researchers and the CPFT PPI Lead. The feedback was positive and the intention is to develop this training further in line with other NIHR organisations.

- The End of Life Care theme held a Knowledge and Practice Showcase event in March 2013 that was well attended by professionals, patients and the public.

- Researchers from the Engineering Design Centre, which forms part of the Design and Implementation Theme, worked in collaboration with PenCLAHRC to jointly lead a PPI workshop which formed part of a modelling and simulation event held in November 2012.

- The SUAG, represented their experience of research involvement at the National INVOLVE conference in November 2012, in Nottingham.

Looking Ahead to CLAHRC East of England

In August 2013, it was confirmed that the National Institute of Health Research (NIHR) has awarded CLAHRC East of England £9.97 million over five years. Projects that are funded by the money could be making a difference to people’s lives within three years. CLAHRC East of England will begin operating in January 2014, developing from the CLAHRC for Cambridgeshire and Peterborough which was formed in 2008.

At the core of CLAHRC East of England will be a new academic partnership between the Universities of Cambridge (UoC), East Anglia (UEA) and Hertfordshire (UoH), as well as a wider collaboration of partners ranging from NHS provider Trusts, local authorities, CCGs, Public Health England (PHE), third sector organisations and SMEs.

Researchers in the new CLAHRC will need to demonstrate how their work will make a difference to patients within three to five years, and how their projects will fit into one of a number of research themes including dementia and patient safety.

The NIHR CLAHRC East of England works in partnership with a wide range of health and social care providers across the region.

Sara Rae
Lay Advisor

“As Lay PPI Advisor in CLAHRC CP I have contributed at board level and attended PPI coordinating group meetings, locally and nationally. I worked closely with the PPI Lead and was involved in developing the PPI strategy and evaluating PPI content in research studies across CLAHRC CP. I contributed to the PPI pages on our website and have given talks to researchers emphasizing the importance of good PPI. This role has greatly increased my understanding of the breadth and depth of the subject and given me a better understanding of how PPI can be included at each stage of the research process and how it plays a part in a wide range of projects, from systems modelling to the evaluation of PPI itself."

Professor Peter Jones
Director of CLAHRC East of England and Head of Department Psychiatry
at the University of Cambridge

“I am delighted that NIHR has awarded this funding to our new CLAHRC. “The aim of the CLAHRC is to ensure the findings of academic studies can be used to make a real difference to front-line patient care as soon as possible. The work around dementia and how we care for older people is especially important because they are such major challenges facing healthcare and social care providers.”

David Edwards
Chairman of Cambridgeshire and Peterborough NHS Foundation Trust

“The award of this funding is very welcome. It will be used to fund vital research and will continue to build on our commitment to place patient care at the very top of our priorities.”
NIHR CLAHRC East of England focuses on improving the health and wellbeing of vulnerable people in complex health systems while retaining a population health view. Research themes concern: enduring disability and disadvantage, dementia, frailty and end-of-life care; patient safety; health economics and patient and public involvement. It will focus world-class applied health research onto the priorities of the Eastern Academic Health Science Network (EAHSN), accelerate innovation and act as a national resource.

These are alloyed with knowledge management, a public health skills collaboration, industry engagement and research capacity development. Partner organisations committing matched funding include the full gamut of those planning, commissioning and delivering health and social care, as well as industry. Through on-going prioritisation and peer-review, NIHR funds will be used to support applied health researchers and fund high quality priority research projects, to develop strong, region-wide applications to NIHR and other national funding bodies, and to align other NIHR investments in the region. This will ensure high quality research, maximise value and support the CLAHRC East of England legacy.

Our strategy for CLAHRC East of England is designed to meet our objective of improving patient care, health outcomes, and wellbeing through the execution of high quality applied health research on questions that matter to the partners and to the nation, the efficient implementation of results, and through increasing the capacity for these activities beyond the life of CLAHRC East of England. We see the CLAHRC as a catalyst for change and NIHR funding as a multiplier leveraging other resources, including external funding and the workforce. The step change comes from more, high-quality applied health projects in our enhanced collaboration yielding evidence consumed by a more sophisticated, informed workforce that is also amenable to supporting research.

The far larger, regional, footprint of CLAHRC East of England, encompasses a more complex set of health and social care economy and harnesses the research power of the 3 universities. We believe that this wide collaboration of organisations will enhance our ability to undertake a more ambitious applied health research programme, and further will allow us to be a highly productive strategic partner of the Eastern Academic Health Sciences Network (EAHSN). We have developed the research themes and research infrastructure of CLAHRC East of England to support the EAHSN clinical priorities of 1) Dementia and mental health, 2) Long term conditions and 3) Patient safety.

Our overarching ambition is to undertake world-class applied health research using NIHR funds as a multiplier to develop top quality proposals that can be funded through other sources to answer questions relevant to our partners, thus providing evidence that has regional as well as national and international impact. Through this step-change and the strategy outlined below, CLAHRC East of England will provide the infrastructure for the region to become a national resource for applied health research well beyond the current funding round.

**Dementia, frailty and end-of-life care**

Led by Professor Carol Brayne (UoC), this theme continues highly successful applied health research involving established collaborations between universities, commissioners and provider organisations. The overall aim of this theme is to develop the evidence base that will support the efficient delivery of safe, timely and coordinated patient-centred services to the older population transitioning to the fourth age of life and at the end of life. The theme also covers key EAHSN priorities regarding these ubiquitous concerns, and incorporates Dr Stephen Barclay’s work on EoL (end of life) care across diagnostic groups and the life course.

**Patient and public involvement research**

Led by Dr Fiona Poland (UEA), this theme will focus not only on implementation of current best practice but also on applied research that defines and develops optimal approaches to PPI in applied health research, implementation science and the process of innovation.

**Enduring disabilities and disadvantage**

Led by Professor Tony Holland (UoC), this theme involving children, young people, and adults ‘at risk’ of mental and physical health inequalities develops the inter-disciplinary applied research in learning (intellectual) disabilities in the universities and strong connections with health commissioners and providers and social care commissioners in the East of England. The theme includes research projects on developing monitoring for seizures in people with epilepsy and learning disabilities, specialist community teams for people with learning disabilities, the implementation of findings relating to early screening and diagnosis for autism spectrum conditions and the mental health needs of young people, including those in local authority care.

**Health economics research**

Led by Dr Garry Barton (UEA), this work cuts across all themes and is closely linked with the EAHSN. The theme will provide technical support to the research themes of CLAHRC East of England as well as exploring methodological developments and undertaking applied research in health economics.

**Patient safety**

Led by Professor John Clarkson, Engineering Design Centre (UoC) and incorporating the Judge Business School (Professor Stefan Scholtes), this theme brings design principles into complex health and social care systems with many immediate applications, particularly in the light of the Francis Report. The work cuts across all themes in the CLAHRC and maps directly onto the patient safety clinical priority of the EAHSN where the engineers have already been closely involved in the design approaches to improving patient safety in several foundation trusts in the region.

NIHR CLAHRC East of England evolves from the CLAHRC for Cambridgeshire & Peterborough. Reaching throughout the East of England, the new, extended collaboration harnesses strengths in the Universities of East Anglia, Cambridge and Hertfordshire, it aims at international impact.

Looking Ahead to CLAHRC East of England

Continued

Professor Cath Sackley

CLAHRC EoE Deputy Director

“This research will substantially benefit patients in East Anglia particularly some of the most vulnerable groups – people with dementia, frailty and mental health problems. CLAHRC East of England will support the best research into treatments and care and provide resources for world leading research based at UEA. The opportunity has arisen through our collaboration with the Universities of Cambridge and Hertfordshire, NHS Trusts and other organisations such as the Norfolk and Suffolk Dementia Alliance.”