

NIHR CLAHRC for Cambridgeshire & Peterborough

NHS
National Institute for
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Progress Report
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 UNIVERSITY OF
CAMBRIDGE

Cambridgeshire and Peterborough **NHS**
NHS Foundation Trust

Collaborations for **L**eadership in **A**ppplied **H**ealth **R**esearch and **C**are

OVERVIEW OF ACTIVITIES

Changes to our strategy

There have been no fundamental changes to our local strategy which is built on the NIHR intentions for CLAHRCs: to undertake high quality applied health research and facilitate the implantation of findings, to research the process of implementation, and increase capacity for these activities across the NHS, other providers and universities. Within this overarching framework the strategy of CLAHRC CP remains:

- To improve the care of children and adults with mental ill health, intellectual (learning) disabilities or acquired brain injury, and at the end of life, by applying high quality health research to their needs and those of their families and carers.
- To increase and integrate capacity for applied health research and evidence-based practice into the NHS and social care, ensuring long-term sustainability.
- To increase the application of health and social care research through knowledge exchange.
- To foster a culture of collaboration and develop enduring links between the academic and service delivery sectors to facilitate research translation and inform public health policy.
- To work collaboratively and strategically with our local and national partners, aspiring to international impact.
- To embed design principles and research-led innovation into the NHS and social care culture.

However we remain flexible in terms of our interaction with health leaders and commissioners in the emerging NHS landscape; e.g. we have engaged with GP commissioners and programme leads in all our major projects, and invited GP leads to be part of advisory groups and to attend CLAHRC workshops in order to help us horizon scan ensuring that our work remains relevant and implementable within the redesigned local health economy. We have also tried to extend our reach so that we are not entirely focused on Cambridgeshire and Peterborough, taking a more regional view e.g. by appointing CLAHRC fellows from across the patch. We would like to strengthen the links between academic and local service public health which will be placed in the local authority from 2013, to ensure that future research will remain relevant to the needs of the local population. These relationships will enhance collaborative research in the future and facilitate data sharing for epidemiological and applied health research purposes, so that the output of our research can directly inform CCG and Local Authority decisions.

Significant developments in implementing the strategy

A key achievement of the CLAHRC for Cambridgeshire and Peterborough has been the ability of our individual research teams to respond to the changing health and social care environment, and to develop new initiatives, often tangentially to their original research briefs. This responsiveness has been a key factor in the success that we have had in building strong partnerships with our NHS and social care partners. Our work has had demonstrable positive outcomes of benefit to patients

and clinicians.

In order to performance manage and evaluate the work that we do within the CLAHRC, we have developed a set of key performance indicators (KPIs) which allow us to link our activities to 'process and outcomes-based' metrics. We have **developed a software tool** based on these KPIs, so that we can capture data on an ongoing basis along the timeline of the project. During 2011/12 we reviewed performance of all studies in our portfolio so as to define priority projects and to drive our management and financial targets. The KPI management tool ensures that all the activity within our priority projects is documented and linked to the relevant KPIs. We have shared this new software with NOCRI and all CLAHRCs, two of which are currently implementing it.

Highlights of research and implementation activity supported by the NIHR CLAHRC award during the year

The work of the CLAHRC has enabled outcome data to be looked at in a meaningful way. Much analysis is highly technical but with close cooperation between researchers and our 'customers'- commissioners, clinicians and service managers – we have been able to make sure the findings are rapidly available, and communicated effectively to inform design and implementation. Such co-production is the essence of the CLAHRC. We are able to provide feedback to local services on how to serve patients more effectively and achieve better value for money.

- **Transfer of Care at 17- pilot study (TC17)**. The TC17 project focuses on the transition period from adolescence to adulthood in two potentially vulnerable groups of young people: those in the care of the local authority and those receiving psychological help from the Child and Adolescent Mental Health Service (CAMHS). About one third of young people with mental health difficulties referred from CAMHS to adult services, are non-compliant with the adult service within 6 months. Around 50% of adolescents in care suffer from mental illness and 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 the teenage years. There is little information on early adult wellbeing for either of these vulnerable groups, whether they are compliant or not with the assistance they receive in young adulthood. TC17 focuses on the transitional care pathway in both. From the outset of the study, positive collaborations have been established with Peterborough County Council (CC), Cambridgeshire CC, and the commissioners of NHS CAMHS services in Huntingdon, Cambridge and Peterborough. These collaborations have continued as the study has progressed, and as a result, the findings of the research have been incorporated into care pathways. (See case study 1 for further details.)
- **Specialised service provision for people with complex 'hidden disability' following acquired brain injury**. This work was presented at the SDO SY CLAHRC conference in Sheffield in 2010, winning a best poster award. The collaboration between systems engineering researchers in the process design and change implementation theme, and healthcare practitioners in the adult theme, underpinned the research. A description of conceptually novel work arising from such collaborations will be presented at the forthcoming International Brain Injury Association World Congress.

- **A service design approach to frequent attendance in the Emergency Department.** Dr Mai Wong (CLAHRC fellow 2010/11), won first prize for her presentation of her fellowship project at the inaugural SAS research contest from the Royal College of Psychiatrists.
- **AMBIT collaboration.** Dickon Bevington, (CLAHRC fellow 2011/12) and his CASUS team (young people's substance misuse service) have been awarded the Guardian and Virgin Media "Innovation Nation" Award. This project supports clinical teams throughout the UK. They work with vulnerable, complex and troubled youth by offering cutting-edge therapies supported by wiki technology that makes best practice available to outreach workers "in the field"; likewise, innovations from the field can be shared and developed at speed. Nearly 20 teams from the NHS and the voluntary sector all over the UK are currently using this material.

Examples of effective translation of research findings into improved outcomes for patients, as a result of the NIHR CLAHRC funding

- **Autism Care Pathway.** CLAHRC CP is working with local NHS services (CPFT) to design a new adult autism care pathway integrating existing child and adolescent care pathways. CPFT is developing an adult diagnostic clinic as part of a new service providing follow-up support post diagnosis. This will address an unmet need in the NHS and Social Care.
Transfer of Care at 17. The technical report from this project led to the Director of Children's Services in Peterborough City Council (PCC) prioritising the mental health of children in care. A training programme in mental health is being designed for foster carers in collaboration with all 10 independent fostering agencies in the region. The head of Children's Services for PCC was moved by the results of the TC17 study, specifically by the poor mental health of young people in care. She has said that her involvement with the CLAHRC has had a direct influence on the thinking within Children's Services, specifically the importance of service evaluation, and the need to pay more attention to the mental health (MH) of Looked After Children (LAC), sentiments now backed by her commitment to elevate MH on the LAC agenda, and the decision to incorporate MH clinicians into family units. (See case study 1 for further details.)

Initiation of new research or implementation projects, or new areas of activity

- **Cost evaluation of Improving Access to Psychological therapies in 5 PCTs in the East of England.** New collaborations with the National IAPT team and the University of York have led to a project to develop a Payment by Results (PbR) tariff for IAPT.
- Findings from the **LD-ROME (Management of epilepsy)** study (funded by a grant from the NIHR's RfPB programme) have led to a clinical trial grant application to NIHR HTA examining the role of epilepsy nurses. This will involve a novel collaboration involving NHS commissioners, an epilepsy service user and research sponsoring charity (Epilepsy Action), two academic health economists, a professor of nursing, and specialist clinical trial statisticians, together with members of the original research team.
- **SoF project (the possibility of friendship for people who have profound intellectual disabilities).** CLAHRC CP results that were presented to an

international conference, led to an invitation by a senior academic from another university to be part of a bid for funding for an ESRC seminar series on communication and relationships and people with profound intellectual disabilities, to be held in 2012.

- **Projecting the future prevalence of dementia.** Discussions with Adelina Comas-Herrera from the London School of Economics led to proposals to combine CLAHRC CP dementia projections with the Personal Social Services Research Unit's long-term care model (financed by the Department of Health) to calculate future demand for long-term care of people with dementia, together with associated costs.
- **Hospice at Home developments and evaluation.** NHS and hospice charity funds have recently established a hospice at home service that aims to enable more patients to remain at home at the end of their lives. These developments have in part been stimulated by local dissemination of CLAHRC CP research. In addition, the End of Life Care team are undertaking a formative evaluation as these services come into place.

Grant awards received as a consequence of NIHR CLAHRC funding

Awards are detailed in the spreadsheet (CLAHRC CP ActivityOutputs2011-12) that accompanies this report.

Major research training initiatives or developments in the CLAHRC's training strategy

- **CLAHRC Fellows.** We have recruited 27 fellows from health and social care across the East of England. The aim of the CLAHRC fellowship is to develop future NHS managers and clinicians who will have an understanding of the research environment. The fellows receive training in research methodology, service redesign and change management, and undertake their own research and evaluation projects. They come from a wide range of backgrounds — Consultant Psychiatrists, an NHS manager, Clinical Psychologists and Neuropsychologists, a Consultant Neurologist, a General Practitioner, and Registered Nurses. The NHS organisations where they work are across the East of England (Bedfordshire, Cambridgeshire, Norfolk and Great Yarmouth).

The fellows make a valuable contribution to the CLAHRC, bringing a different set of experiences and perspectives to the research; acting as local 'research champions' and helping the CLAHRC connect with healthcare practitioners in the community. They have already demonstrated, in many cases, direct translation of research into practice, for instance through the restructuring within Norfolk and Waveney Mental Health Trust to introduce a youth service instead of traditional CAMH and Adult mental health services (Dr Jon Wilson CLAHRC Fellow 2010/11), and the training of District Nurses in evidence-based end of life care in Peterborough (Dr Peter Hadfield and Katy Harrison CLAHRC Fellows 2010/11 – see case study 7 for further detail). A project which involved designing a pathway for people with medically unexplained symptoms (MUS) (Ann Mai Wong CLAHRC Fellow 2010/11) led to a report which has generated interest from the local Addenbrooke's Hospital Emergency Dept. as well as a higher level interest from commissioners (see case study 8 for further detail). For her fellowship project, Uju Okereke (CLAHRC Fellow 2010/11) convened

a stakeholder engagement meeting and produced a scoping report on options for research into the impact of dementia on ambulance services; this report has informed a service development bid and will be taken forward through a new project post.

Through these, and other innovative fellows' projects, the CLAHRC Fellowship is building local capacity for evidence informed practice, as well as facilitating networking across the health economy and adding value to NHS organisations.

- **Systems modelling workshops.** The Engineering Design Centre (EDC) (process design and change implementation theme) have run two workshops in the last year 'Systems Modelling of a Children's Brain Injury Service'(with the adult theme) and 'Systems Modelling and Simulation Knowledge Sharing'. The latter event was conceived in April 2011 and organised in collaboration with the PenCLAHRC and the NHS Confederation. The goal of the event was to provide a forum for engagement for members of the NIHR CLAHRCs, NHS Managers and commercial partners involved in using systems modelling and simulation in healthcare. The event was considered successful according to the NHS Confederation's events assessment template that delegates completed. A follow-up event is under discussion to be planned for early next year at Exeter. There were around 50 attendees representing 8 of the 9 CLAHRCs, with both academic and service delivery representation.

Research capacity building:

- Dr Tom Denning, lead of the old age research theme, has been appointed as Professor of Dementia Research at the University of Nottingham. He will develop collaboration between CLAHRC CP and CLAHRC NDL.
- Dr Graeme Fairchild, research associate in the adolescent theme, has been appointed lecturer in psychology at the University of Southampton.
- Dr Jon Wilson, CLAHRC CP Fellow, has been appointed Associate Medical Director for R&D at the Norfolk & Suffolk NHS Foundation Trust.
- Dr Saba Hinrichs and Dr Celine Miani, CLAHRC CP research associates, have been appointed researchers with RAND Europe.
- We continued our programmes of CLAHRC fellowship, summer placements, exchanges and PhD programmes as described elsewhere.
- **LD-ROME (Management of Epilepsy).** The findings from this study were used by Dr Howard Ring to support a successful application for a funded PhD studentship from Epilepsy Action.
- **Healthcare reform.** Professors Eivor Oborn and Michael Barrett of the Judge Business School (process design and change implementation theme), are involved in training new researchers in developing knowledge transfer skills and methodologies in social science health research, with research involvement from an international cohort, including Europe, Middle East, Australia, Asia, and North America.
- **Meeting the needs of adults with intellectual (learning) disabilities: the role of specialist community teams.** One PhD, supervised by members of the EDC, in collaboration with the adult theme, and based in the Cambridgeshire Learning Disability Partnership (LDP) has been awarded.
- **Diagnostic test accuracy (DTA) in dementia:** To foster evidence-based practice surrounding diagnostic tests for dementia we have developed an online

register of DTA studies in dementia (ALOIS), standards for the reporting of diagnostic accuracy studies (STARDem) and dementia DTA modules for authors of systematic reviews.

IMPACT ON HEALTHCARE PROVISION (NICE guidance, health policy and clinical quality guidelines)

- **Comparative Effectiveness of Cognitive Therapies Delivered Face-To-Face Compared with Over the Telephone, in Improving Access to Psychological Therapies (IAPT) programme.** The East of England Strategic Health Authority adopted the research outputs from this project on the effectiveness of over the telephone (OTT) interviews in the delivery of the IAPT service. As a direct outcome, regional training for telephone based sessions has been delivered to 154 people. Delegates included psychological wellbeing practitioners, cognitive behavioural therapists, service managers, counsellors, and partnership colleagues. Two training events have taken place in Norfolk, 1 in Suffolk, 3 in Cambridge, 1 in Hertfordshire, 3 in South Essex and 1 in Luton. (See case study 2 for further details.)
- **A service design approach to frequent attendance in the Emergency Department.** This project's report was cited in the following policy documented published by NHS Confederation– *‘Investing in emotional and psychological wellbeing for patients with long-term conditions: guide to service design and productivity improvement for commissioners, clinicians and managers in primary care, secondary care and mental health.’*
- **Lifestyle Improvement For Everyone (LIFE).** Two local groups for people with learning disabilities and their support workers carried out in partnership with the CLAHRC, highlighted low levels of knowledge and skills relating to nutrition among social care staff. The research team's experiences with the groups led to the design and delivery of a 'healthy lifestyles' programme for Fenland Mencap, and informed the development by Cambridgeshire County Council's workforce and development team, of mandatory training courses for council, independent, and third sector staff delivering social care.
- **Adult Autism Clinical Pathways.** Tools that have been developed by the child theme, have been incorporated into a training course – ‘the Adult Asperger Assessment, a diagnostic method’. The Adult Asperger Assessment (AAA) is a diagnostic method specifically for diagnosing Asperger Syndrome in adults. The AAA was developed by the Autism Research Centre (ARC) and training for clinicians has been conducted in order that they can use this instrument as a diagnostic tool. (See case study 3 for further detail.)
- **End of life discussions in heart failure and COPD - systematic reviews.** This series of systematic reviews generated two papers - one to the British Journal of General Practice, and one invited review for Current Opinion in Supportive and Palliative Care. The former was referred to in the National End of Life Care Programme report, with key findings of the review.
- **GP and DN educational needs assessment: a questionnaire study.** This was a questionnaire study of all General Practitioners and Community Nurses in Cambridgeshire and Peterborough, investigating their training and knowledge in

key areas of palliative care. The data from this survey are informing several educational initiatives which CLAHRC members of the end of life care theme are leading.

- **Health Service Transitions.** The recommendations that came out of this study have been implemented in the mental health service for young people in transition. In this way, the report influenced the standards by which the service providers evaluated themselves and their service, and thus pushed the service level, up. (See case study 6 for further details.)
- **LD-ROME (Management of Epilepsy).** The findings from the LD-ROME study have informed practice in the South Cambridgeshire specialist LD epilepsy clinic. This clinic model has now been extended by the development of a specialist LD epilepsy service in East Cambridgeshire.
- **Meeting the needs of adults with intellectual (learning) disabilities: the role of specialist community teams.** Feedback from the Head of Operations, Cambridgeshire Learning Disability Partnership (LDP), indicated that findings from the study were used as a basis for developments within the LDP e.g. the information about delays in making decisions about entitlement to the service provided by the LDP 'triggered' the development of pathway work involving the LDP and CPFT. (See case study 4 for further details.)
- **Policy Research Programme Review of Schizophrenia.** This CLAHRC research has had an impact on 1) the evidence base for the epidemiology, prevalence and incidence of schizophrenia, 2) delivery of mental health services for service users and carers, particularly early intervention services (EIS) and 3) health policy. (See case study 5 for further details.)

PATIENT AND PUBLIC INVOLVEMENT

How patients and the public have been actively involved in the work of your CLAHRC

There are many different approaches to patient and public involvement (PPI) across the CLAHRC CP that address key challenges for PPI, such as the inclusion of people with learning disability, young people and those with mental illness. Examples of PPI over the reporting period include:

- **Meeting the needs of adults with intellectual (learning) disabilities: the role of specialist community teams.** The adult theme has established a Service User Advisory Group (SUAG) involving nine service users with mild or moderate intellectual disabilities, who work with clinicians, clinical academics and researchers. This unique approach in one of the most challenging areas for PPI has focussed on how integrated community-based specialist teams can best support people with intellectual disabilities and complex behavioural and/or mental health needs. The SUAG was established in 2010 and meets bi-monthly. The work has been presented at two national conferences, and the SUAG will present a workshop at the national INVOLVE conference in November.
- **Cost and benefit analysis of Serious Incident Investigations.** CLAHRC CP held a service user engagement event entitled: '*User and Carer Involvement in Setting Up a Mental Health Research Project*'. The CLAHRC researcher presented an outline of the project to the audience, comprising 20-30 service

users, clinicians and researchers. Feedback from professionals and service users at this event influenced the design of the study, and the methods by which the effectiveness of the serious incident investigation process can be highlighted.

- **Patient choice in End of Life Care: an Anthropological exploration.** Input from several third sector and support groups informed the applied health research design, methods for recruitment and information sheets.
- **A systematic review of screening for dementia.** The management committee for this programme of reviews on screening for dementia includes two lay members from the Alzheimer's Society Research Network who are also part of the management committee for the **Programme of Diagnostic Test Accuracy reviews; updates of intervention reviews in dementia.** CLAHRC CP has also developed a strong collaboration with stakeholders, including the Alzheimer's Society, Dementia Compass, other voluntary groups and DeNDRoN's PPI network. A new work stream focusing on dementia care in the community has been strongly influenced by the voluntary sector partners through, for example, input from people with dementia and their carers at a series of focus groups concerning the exercise programme for people living with dementia.
- **Transfer of Care at 17.** The researchers have continued to work with the 'Just Us' groups of looked after children, in partnership with Cambridgeshire County Council's children's participation service. Members of this group were involved in the design of the TC17 longitudinal study and a follow up foster carer training pilot study. This PPI collaboration, enhanced by the Cambridge Film Consortium, Anglia Ruskin University Department of Music and an independent animator, is now creating a film relating experiences of the care system, something that will form part of the training for foster carers.
- **The teenage and young adult cancer study** continues to work with its advisory group of teenage and young adult patients who have helped to train interviewers, design the measurement process and recruitment methods, including social media, the last of these being led by a young person with cancer, herself.

How do you keep patients and the public informed of the work being undertaken by your CLAHRC.

This happens through a range of mechanisms, both theme-specific and CLAHRC-wide. We have produced a series of accessible information resources (interview podcasts, Q&As, letters) and a related brochure to introduce the public and stakeholders to some of the work at the CLAHRC CP. We publicised these resources widely through our networks and through local media. We have also recently refreshed our website and provided clearer information about the CLAHRC and about each of our main research projects. We work collaboratively with other research networks in order to raise awareness of the CLAHRC's role and its focus on translational, applied research as part of the wider research environment. Some examples are:

- In September 2011 we held a dementia event jointly with DeNDRoN East Anglia entitled '*Dementia Research: Knowledge into Care*'. The event brought together people from different backgrounds and disciplines, including members of the public, to discuss how knowledge from research can improve practice in hospital, care homes and the community. Interactive "marketplaces" allowed participants to contribute comments and ideas about research. The event worked extremely

well and we plan a similar event on end of life care later this year:

- The **Transfer of Care at 17** technical report was disseminated to our research partners, the Prime Minister's office, the Office of the Children's Commissioner and the public, for whom leaflets were also produced.
- **CC75C Study - Informing service planning for an ageing population.** Both MRC-CFAS and the CC75C study collaborated in the Wellcome Trust Public Understanding of Science exhibition in London - '*Mind over Matter: Memory and the search for cures for dementia*' - which received widespread media coverage. The accompanying public talk '*Investigating Brain Donation*' at the Museum's Dana Centre was well-attended by a predominantly young audience very interested in engaging with the issues raised by the exhibition.
- **Autism care pathway.** Public meetings are held by the autism research team where people on the autism spectrum can come and hear about the research. Here, they can give feedback about their experiences of taking part in research and share ideas about future research projects.
- **Concept of friendship for people with profound intellectual disabilities.** The CLAHRC CP provided a joint presentation with a woman with profound learning disabilities and her mother at a conference open to a diverse audience of the public, practitioners, family carers, people with intellectual disabilities and others with an interest in friendship and intellectual disabilities. The person with LD and her mother contributed to both the ongoing analysis of the data and the dissemination of early findings. The abstract for the conference, designed for people with LD, and an audio recording of the presentation were made available to the public via the conference website.
- **Neuropsychological rehabilitation of executive dysfunction and emotional dysregulation following acquired brain injury.** One of the participants involved in the study trialling the effectiveness of computerised Cognitive Behavioural Therapy (cCBT) helped in the presentation of results including her own experiences of using the online self-help tool, and showing her own self-report measures. A poster of this work was presented at the annual British Association of Behavioural and Cognitive Therapies conference in Guildford, July, 2011.
- Representatives of relevant organisations (Cambridgeshire Headway) are members of advisory groups, and a CLAHRC Board member is a service user and regularly advises us on PPI issues.

LINKS WITH NIHR INFRASTRUCTURE

Links with other CLAHRCs, Biomedical Research Centres and Units, Clinical Research Networks

We actively collaborate with other CLAHRCs, the local BRC and BRU and the local research networks. Some specific examples:

- **Creating a dementia register in the East of England (Data4Health, Cambridgeshire).** An up to date list of persons with dementia across primary and secondary care is required for the purpose of improving the quality of care for patients, and supporting medical care for a local population. Such a list would also support service development, the conducting of research, the monitoring of

trends and the planning of future services for an aging population, by linking routine records across services. The CLAHRC old age theme has done a scoping exercise on the feasibility of establishing a dementia register in Cambridgeshire, and the project is being taken forward within the NIHR BRC. Links are being formed with the CLAHRC-led **end of life care register project** that has recently received HIEC funds.

- The Judge Business School (process design and change implementation theme) has been working with the Health Services Research Network, NIHR CLAHRCs and the Health Foundation collaborating on a workshop aimed at developing a **briefing report on challenges of mobilising knowledge**, as well as working with CLAHRC LNR on the challenges related to the commissioning process.
- **Economic Evaluation of early intervention services for psychosis**. A working relationship and collaboration has been achieved between CLAHRCs and the Institute of Psychiatry at Kings College to work on the National Eden Dataset.
- **QIPP for Mental Health, engineering the CLAHRC for the challenge**. The setting up of a special depression service and trial in collaboration/partnership with NIHR CLAHRC NDJ arose out of a learning event that we hosted for all the CLAHRC mental health themes. Recruitment into this project is also supported by the East Anglia Mental Health Research Network.
- The Primary Care Research Network have supported recruitment to the **autism screening study**, and West Anglia CLRN have provided funding for the transitional services for adolescents study, as well as providing GCP training for CLAHRC researchers.
- Close links with DeNDRoN East Anglia have developed from our joint working on the '*Dementia Research: Knowledge into Care*' event, to the extent that for the last year the network is part-funding a consultant old age psychiatrist research lead's time to develop CLAHRC and other research in the mental health trust.

Significant successes and/or any challenges faced during the second award year

We have again been very successful in increasing external funding into the CLAHRC, with large awards this year from Kids Company for the adolescent theme, MRC project grant for the adult theme and an award from Cambridgeshire County Council to the CLAHRC to evaluate their reconfigured social services (undertaken as a result of CLAHRC research). As an inevitable result of this increased activity we are further challenged by our physical environment; we are not able to accommodate our staff in a single location, instead being dispersed across sites. We have been successful this year in appointing to key posts – John O'Brian will take up his post as Professor of Old Age Psychiatry in August 2012.

Please also outline any strategic plans for increasing engagement with other elements of the NIHR Infrastructure.

We are well connected with the other parts of the NIHR infrastructure in Cambridge, including research networks, the Cambridge BRC and dementia BRU. Mental Health has been included as a research theme in the new Cambridge BRC, with explicit links between the research programme and the pull-through of these findings through the CLAHRC. There is also a partnership between the CLAHRC and the BRC in the

development of a population-based dementia register (work that was initiated by the CLAHRC is now part of the informatics programme of the BRC). The University has recruited a new Professor of Old Age Psychiatry to facilitate these interactions and exploit the enormous potential for translational research in neurodegenerative disease presented by the array of NIHR investment. There are plans for closer links with the research networks; in practical terms this will be through shared resources, for instance through PPI coordinators working together, and a joint approach to industry in the region, to offer a unified NIHR infrastructure to support every stage of the research cycle.

Increased involvement by researchers with local policy makers, commissioners and managers.

- **IAPT for 14-19 years old.** The Young IAPT Service is a pilot project that offers timely psychological assessment and interventions for young people with mild to moderate mental health difficulties, and is intended to complement those services that already exist. This project is being led by CLAHRC CP, and the project team has representation from a broad mix of stakeholders from the NHS, social, academic and government offices.
- **The interface between the MCA Deprivation of Liberty Safeguards (DoLS) and the Mental Health Act.** The CLAHRC researchers presented their findings at a dissemination and consultation event attended by senior members of the DH (who funded the research), MCA Leads, and other stakeholders involved in implementing the DoLS. The stakeholders' discussions of our findings are informing our final report to the DH.
- **Meeting the needs of adults with intellectual (learning) disabilities: the role of specialist community teams.** Research findings have been presented at multidisciplinary events; a poster, incorporating our researcher's ideas was shown at the SDO Network/CLAHRC Research Learning and Sharing Event - '*QIPP for mental health - Engineering the CLAHRCs for the challenge?*' in 2011. In February 2012, the findings were used in responding to a telephone call from the Project Manager, Learning Disabilities Services, Southend Borough Council, asking for advice to inform the development of a new service. As part of the same project, joint feedback of our emerging findings by CLAHRC researchers and the Head of Operations (Cambridgeshire LDP) has taken place with each of the 5 community learning disability teams in the service. At least one of these findings has been used as a basis for developments in the LDP. Recently, a CLAHRC multi-agency Implementation Advisory Group for LD has been established with the LDP Head of Operations, to support further translation of the research findings into service redesign and service delivery.
- **Developing and commissioning End of life Care service from evidence-base.** Dr Stephen Barclay, PI of the CLAHRC EOLC theme, continued to chair the Cambridgeshire PCT End of Life Care group and has been appointed Clinical Lead for EOLC in the shadow Cambridgeshire CCG. His recently awarded HEFCE Clinical Senior Lecturer includes a remit to support the development of research activity and capacity within the Palliative Care services and across the Community Trust.
- **CC75C Study - Informing service planning for an ageing population.** Findings on the place of death and transitions in care of very old people in their

last year of life were presented to local health and social service managers, policy-makers and commissioners at the 'Cambridge 2030' event, prompting further dissemination via Addenbrooke's Hospital planning department. These included findings exploring the effects of dementia on end of life transitions presented to the Palliative Care Congress in March 2012.

Knowledge exchange with policy makers and practitioners

- The 'Dementia Research: Knowledge into Care' learning dissemination event, led to colleagues from both DeNDRoN East Anglia and the old age theme/public health implementation themes working closely together. The programme included 'market-place' workshops for the delegates to discuss ongoing projects with the researchers and practitioners. Research projects that were discussed ranged from large-scale long-running population cohort studies, to new pilot studies of service innovations with collaborations between health and social services, primary and secondary care, statutory, voluntary-sector and private-sector providers, academic and service partners based in community, care home and acute hospital settings. Ideas raised at the event, led to subsequent CLAHRC involvement in new developments, for instance, the old age theme provided evaluation advice and data from the CC75C study to inform an acute sector project to better identify dementia, delirium and depression on admission to hospital.
- **Transfer of Care at 17.** The TC17 technical report was distributed to all stakeholders including the Cambridgeshire County Council Service Development Manager who has asked to be invited to future meetings and to be kept in touch of research findings, and possible implementation and impact of findings. This is a significant development as it was initially very difficult to engage the county council, but they have now stated that the CLAHRC's research will be used in future policy development. In addition, a knowledge exchange day was held in May 2011 and a number of collaborations have come out of this with commissioners, Kids Company and YOTS Cambridge.
- **Role of Occupational Therapy with people with learning disabilities.** The CLAHRC supported the preparation of the final report of a study, commissioned by the College of Occupational Therapists (COT), exploring and documenting the nature of occupational therapy with people with learning disabilities across all four countries of the United Kingdom. The report has been cited in the COT's Factsheet - 'The Importance of Occupational Therapy to People with Learning Disabilities (2011)'. It has also promoted collaborations outside the field of LD field, for example, Kent Community Health Trust has asked permission for excerpts to be used as part of a dementia care pathway.
- **Reducing anti-psychotic use in dementia.** Presentations were done by the CLAHRC researchers to over 50 non-medical prescribers who were in attendance at this event. Providing an overview of the rationale for why antipsychotic medication can be inappropriate, was aimed at educating the professionals so that if they were working with a person with dementia who was being prescribed antipsychotics, they would be aware of the issues, and understand that alternative non-pharmacological management strategies can also be effective.

- **Mental Health Act data collection.** Developing the relationship established by the adult theme and the NHS Information Centre through another project, the CLAHRC adult theme were able to give a statistical perspective on the national consultation about changes that are being considered, to the report - '*Inpatients formally detained under the Mental Health Act 1983, and patients subject to Supervised Community Treatment, Annual figures*', which is a key document in monitoring the uses of the Mental Health Act. A researcher from the CLAHRC CP was part of the group of around 10 people (comprising commissioners, psychiatrists and CQC representatives) invited to the single consultation meeting about this report.
- **Meeting the needs of adults with intellectual (learning) disabilities: the role of specialist community team.** Professor Tony Holland and Dr Isabel Clare took part in consultation events convened by the Dept of Health as part of its response to the abuse of people with learning disabilities at Winterbourne View. CLAHRC CP studies have led to Tony Holland being invited to join the newly established local learning disabilities Health and Well-Being Board, and the national advisory group set up by the Department of Health to review services for people with LD. His membership of this group was approved by Paul Burstow MP, Minister of State for Care Services.
- **Professor Simon Baron-Cohen** was elected Chair of the NICE Guideline Development Group for new guidelines on the assessment and diagnosis of autism in adults. He participated in a debate on this subject hosted by the House of Lords.
- **Dr Stephen Barclay**, lead of End of Life theme, is GP member of the NICE Topic Expert Group that developed Quality Standards for End of Life Care. CLAHRC research has informed these descriptions of high quality care to which commissioners must now aspire. Commissioning Standards are now being developed by the group.
- **Dr Eivor Oborn**, co-lead of Judge Business School, process design and change implementation theme, has been promoted to Professor (Chair in Knowledge Translation and Health Organisation). Professor Oborn has been working with Dr Paul Zollinger-Read (Regional Director of clinical commissioning development) on a CLAHRC project **Developing Collaboration and knowledge exchange in clinical commissioning group learning networks.**

LINKS WITH INDUSTRY

- **Neuropsychological rehabilitation of executive dysfunction and emotional dysregulation following acquired brain injury.** The adult theme has developed a collaboration with the company Ultrasis plc, who have allowed them free access to the computerised Cognitive Behavioural Therapy (cCBT) programme '*Beating the Blues*,' which they have developed. The collaborative study will investigate the feasibility, acceptability and effectiveness of this tool as a treatment for depression and anxiety following a stroke.

- **Patient Portals: using new media and Web 2.0 technologies to engage service users.** The Judge Business School are engaging with technology companies on developing social media tools, working with the CEO of the organisations through organisation and tool development.
- **Understanding and improving problems with Self Regulation and Identity following BRain injury and stroke Across the Lifespan (SeRIBrAL).** A paper on the use of SenseCam to support recall of emotionally salient events in people with memory impairment was published in the journal *'Memory'*. This collaboration involved health researchers, the Engineering Design Centre, healthcare professionals and MicroSoft Research Cambridge.
- **Introducing Prospective Quality Assurance Techniques to Mental Health Services.** The event brought together members of the CLAHRCs, affiliated organisations, and a cross section of industry focussing on the use of models and simulation in healthcare. The meeting explored the role of systems modelling and simulation in driving up healthcare research implementation in the CLAHRCs. The programme focussed on practical applications of modelling and simulation in healthcare and included an industrial panel session.
- **Patient Portals: using new media and Web 2.0 technologies to engage service users.** The Judge Business School is working with industry partners to scan new developments in technology innovation, social media use in chronic health management.
- **Developing nutritious finger-foods for patients with dementia** Addenbrooke's Hospital's concern about in-patient nutrition issues has prompted their interest in a collaborative project with local voluntary organisation Dementia Compass and Tiptree (Wilkin & Sons Ltd) to develop a high-calorie biscuit suitable for patients with dementia. The Department of Medicine for the Elderly has sought CLAHRC old age theme involvement to assess acceptability and to advise on research design.

FORWARD LOOK

- **Transfer of Care at 17.** The adolescent theme are currently planning to produce a training film for foster carers. This will involve young people in care speaking about what it's like to enter a foster care placement for the first time; this will give them the opportunity to express themselves through the medium of film and in so doing, learn new skills. The project team will comprise the CLAHRC CP, the Cambridge Film Consortium, the Restorative Justice Coordinator, Cam Youth Offending Service, a final year student of Film Composition at ARU, an animator and Children's Participation Officers at CCC & PCC. The first exchange of ideas resulted in the decision to go with animation as a medium. It is an ideal way of dealing with sensitive issues as young people can distance themselves from their personal experiences, e.g. the group may create characters who create the narrative. We believe it will be appealing to young people - it overcomes confidentiality issues, it's fun to do and young people can be involved in the process. The research team are planning a launch event in Oct 2012 half-term and the public will be invited.

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- **Policy Research Programme Review of the incidence of Schizophrenia.** A commissioning tool to forecast expected rates of psychosis by region was developed and tested by CLAHRC researchers. The tool is based on known evidence of risk factors taken from studies of first episode psychosis (age, sex, urban/rural, migration/ethnicity) and corresponding datasets. There now exists the possibility to apply estimates to any population in the UK, producing expected number of cases over a given amount of time. (Sepea study). The model is being developed as a web-based, interactive tool for commissioning, "PsyMaptic", the first version of which is hoped to be launched in summer 2012. A second version of the model will then be developed, bringing in data from this systematic review in order to strengthen predictions by weighting appropriately to country-wide averages.
 - **Improving Prescribing Practices And Promoting Alternatives To Antipsychotics In Dementia.** Dissemination of the study results is underway. A final report was presented to Dept of Health and a peer-review publication is in preparation in collaboration with Professor Alistair Burns, national Clinical Director for Dementia. The findings were picked up by the local Clinical Commissioning Group to inform their action plan, namely, with regards to training of residential care staff. Findings were presented to a public, health and care audience at the Alzheimer's Research UK day and used as a training case study on the challenges associated with bringing research into policy. (See case study 9 for details)
 - **Screening for dementia.** A suite of reports, briefings and workshops will be rolled out to provide reliable and practical information for policy makers, clinicians and the public on the validity of available screening tools. It will also shed light on the acceptability, cost and unintended consequences of routine screening for dementia.

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