Welcome to this update on the work of the NIHR CLAHRC East of England eighteen months into our five year programme of applied health and social care research. This focuses on the needs of people with complex problems, often vulnerable when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway. Service users and carers are at the heart of what we do, in parallel with an ambitious public health programme. Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

Our research themes are described in this brochure but there are many linkages between them. Cross-cutting elements include researching the best ways to involve patients and the public in health research, health economics and patient safety where we enjoy a strong partnership with the Eastern Academic Health Science Network. Our Fellowship Scheme and research training awards are fundamental to capacity building and provide exciting opportunities for early-career researchers, as well as practitioners tasting applied research for the first time. Our regional Showcase events allow their talents to shine.

This time next year we shall have reported on many of our current projects, while we are currently planning new research against the backdrop of a new government and its emerging policy programme.

“We aim to ensure that the findings of our academic studies can be used to make a real difference to front-line care.”
Our values

We are a learning organisation first and foremost.

We tackle complex issues, working to bring benefits to people at risk through better quality care, making a profound difference to their lives.

We are an inclusive organisation; we rely on our stakeholders to help shape research questions, and to work with us in the co-production of peer-reviewed research evidence.

We build trusting relationships with our stakeholders, enabling them to be critical friends.

We use our research funds in the most cost-efficient way, getting the best value for money.

We achieve impact by embedding research, and implementing best evidence, in health and social care services.

The aims of the NIHR CLAHRCs

• To develop and conduct applied health research that is relevant across the NHS, and to translate research findings into improved outcomes for patients.

• To create a distributed model for the conduct and application of applied health research that links those who conduct applied health research with all those who use it in practice across the health community.

• To create and embed approaches to research and its dissemination that are specifically designed to take account of the way that health care is delivered across the local Academic Health Science Network.

• To increase the country’s capacity to conduct high quality applied health research focused on the needs of patients and targeted at chronic health conditions and public health interventions.

• To improve patient outcomes locally and across the wider NHS.

• To contribute to the country’s growth by working with the life sciences industry.
Enduring disability and disadvantage (EDD)

Led by Professor Tony Holland at the University of Cambridge, this theme involves a diverse group of children, young people, and adults ‘at risk’ of mental and/or physical health inequalities.

The EDD theme’s overarching aim is to promote inter-disciplinary, mixed methods, high quality applied health research and implementation projects that will improve the mental and physical health and well-being of a diverse group of children, young people and adults likely to be adversely affected, across a range of situations, by life-long developmental disabilities (learning (intellectual) disabilities (LD)), autism spectrum conditions), acquired disabilities (mental health needs, brain injury (ABI)) and/or extreme disadvantage (young people in care outside their family home). The individuals who fall within the scope of the theme are both especially vulnerable to poor mental and/or physical health and have difficulties in accessing appropriate services. Even where appropriate services are available, it may be hard for these individuals to recognise their mental and/or physical health needs, let alone make contact with and engage with relevant diagnostic services, treatment and support. Often, healthcare will be delivered primarily in collaboration with a third party, such as a carer, support worker, foster parent, or a social care provider. Such arrangements may create additional complexity because the support system(s) may themselves be complex and fragile.

Research projects in this theme are developed from the experiences of individuals and their care-givers and the analysis of legislation and policy (such as the Mental Capacity Act 2005, the Care Act 2014, the UN’s Convention on the Rights of Persons with Disabilities) as well as the relevant academic literature, but they seek always to provide findings that, when implemented, will:

- limit the impact of enduring disability and/or disadvantage on individuals, their carers and paid care-givers, services, and society
- improve the quality of life of an often marginalised group of children, young people and adults and enhance their ability to engage in the activities associated with citizenship.
Current research projects include:

**Winterbourne View Aftermath**

*Responding to Winterbourne View: Developing the design, commissioning, and provision of specialist community-based services for adults with learning (intellectual) disabilities and mental health and/or behavioural needs.*

**Extra-cranial Detection of Seizures**

*The development of a method for acceptable and reliable extra-cranial detection of seizures in adults with intellectual disability and treatment-resistant epilepsy.*

**Family Nurse Partnerships**

*Enhancing resilience and self-efficacy in the families of children with complex health needs and disabilities: sharing the learning and embedding lessons from the Family Nurse Partnership.*

**Evaluation of Interpersonal Counselling (IPC)**

*A pilot study of IPC delivered by family support workers to young people experiencing low mood.*

**Red Flags for Autism Spectrum Conditions (ASC)**

*Follow-up of the CLAHRC Cambridgeshire & Peterborough (CLAHRC CP) Red Flags (adapted AQ (child, adolescent and adult versions and the Q-CHAT) project in primary care or social care settings.*

**Transition from Child & Adolescent Mental Health Services (CAMHS): users and leavers co-produce a transition preparation programme**

*Aims to improve the experience and outcomes for young people leaving CAMHS.*

**Making Safeguarding Personal**

*In partnership with Cambridgeshire County Council’s Adult Safeguarding Service, a project to support the implementation of a new person-centred safeguarding initiative.*

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Find this theme on our website:

http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/enduring-disability-and-disadvantage/
Dementia, frailty and end-of-life care

Led by Professor Carol Brayne of the University of Cambridge, this theme is built upon 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. Modern society has achieved improved health and extended lifespan which, in turn, has led to an ageing population and growing pressures on health and social care services to support older people with increasing physical and cognitive frailty, as well as to address the needs of those approaching the end of their lives. It is clear that the current configuration of services does not take into account how physical frailty, cognitive decline and end-of-life care needs, develop, nor the ways to optimise the individual’s and their families’ experiences during these final stages of life, without being unaffordable to society.

One challenge is to develop a better evidence base for a happier and healthier old age as well as to avoid unnecessary costs in the ‘third age’, and even larger economic, social and human costs that are associated with ineffective and potentially harmful interventions in the ‘fourth age’, which contribute to poor quality of life experience for patients, carers and families.

A second challenge is increasing the public recognition of the importance of dementia which has sparked recent policy initiatives to raise awareness of dementia across healthcare settings, including financial incentives to service providers for case-finding. The so-called fourth age of frailty is strongly associated with increased dementia and is frequently part of terminal decline leading up to death.

A third challenge is to provide good patient-centred end-of-life care which is increasingly recognised in public discourse, policy, commissioning and clinical practice. Building on our CLAHRC CP research and implementation work and the strong academic-service partnerships built over recent years, we will focus on addressing the challenges for patients, carers, clinicians and service providers of avoiding undesired admission, stopping interventions, sharing clinical data and providing bereavement support.
Current research projects include:

**Population Dementia Risk Reduction**
The key aim is to create the capacity to support pilots and trials of promising interventions for dementia that can be rigorously trialled in representative populations with specific targeting for the different types of prevention (primary, secondary and tertiary).

**Eating and Drinking Well In Dementia (EDWINA)**
To increase understanding of the problems around eating and drinking well for people with dementia, and the solutions that may help facilitate people living with dementia in residential care, to eat and drink better.

**Understanding Hospital Admissions Close to the end of Life (ACE) Study**
To review the literature concerning people’s preferences for place of death in order to understand the factors that influence decisions to admit adult patients with a range of potentially life-limiting conditions to hospital, who subsequently die within three days of admission.

**Impacts of Dementia Case-Finding**
To map and describe current practice in dementia case-finding in hospitals across the East of England and its impacts for individuals and services.

**The Cancer Tablets study (CaTS)**
To investigate decision-making concerning the stopping of the newer targeted molecular drugs used to treat cancer. These are taken by mouth, have fewer severe side effects than conventional intravenous chemotherapy but are extremely expensive to the NHS.

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Find this theme on our website:
http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/dementia frailty-and-end-of-life-care/
Patient safety

Led by Professor John Clarkson of the University of Cambridge’s Engineering Design Centre, 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.

Around 10% of hospital admissions are subject to medical error leading to both personal harm and wasted resource (conservatively estimated at £2 billion/year in the UK). The actual rates of harm have not been clearly identified (either in hospitals or community services) and measured, and hence the NHS’s record on patient safety is not well defined. However, it is estimated that the harm rate now is similar to that at the turn of the century (2000) when the first modern estimates were made. Patient safety has been in policy for many years but it really started to become important after An Organization with a Memory (Department of Health 2000) and Building a Safer NHS for Patients (Department of Health 2004). The foundation for improvement in these documents was based on learning from near misses and patient harm. The theme’s aim is to go beyond this reactive approach to safety improvement and apply the best knowledge of design and human factors to prevent harm occurring in the first place.

The work of this theme cuts across all of the other themes in the CLAHRC and maps directly onto the Patient Safety Collaborative in the Eastern Academic Health Science Network (EAHSN). The vision is to have a health service that is supported to be proactive and generative using design approaches, methods and tools to provide services that meet or exceed the standards set for safety and for the services to be sustainable. The theme aims to produce a set of tools that will enable this vision to be realised and for these tools to be in regular use in NHS organisations across the region.

The applied research and implementation (EAHSN) projects support the following 6 objectives:

1. Research the form of a safety management framework needed to embed good systems design processes into the healthcare economy.
2. Develop and deliver a health economics research and implementation capacity in relation to systems approaches to healthcare improvement.
3. Develop and deliver a human factors research and implementation capacity in relation to systems approaches to healthcare improvement.
4. Further research systems design approaches to patient-centric care based on modelling and simulation, with a focus on patient pathways.
5. Further research on risk-based design approaches to be compatible with the framework.
6. Embody the research findings in tools that facilitate good systems design by medical professionals, healthcare managers and patient or their representatives, into the region.

**Current research projects include:**

**Understanding risk**

*Development of a theory of risk management, a picture of risk practice and a new toolkit for assessing risk.*

**Care pathways in the delivery of safe patient care**

*Understanding and evaluating the current designing, documentation and use care pathways in the delivery of safe patient care.*

**How to represent complex healthcare systems?**

*Co-design of a diagrammatic systems modelling language for healthcare.*

**Clinical Innovation**

*To apply design principles to early-stage innovation and develop a design and innovation toolkit to facilitate the process.*

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Find this theme on our website:

http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/patient-safety/
Patient and public involvement (PPI)

Led by Professor Fiona Poland (University of East Anglia), and Dr Jonathan Boote (University of Hertfordshire), this theme focuses 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.

Patient and Public Involvement lies at the heart of current health policy and is seen as an essential element in ensuring patient safety, improving health outcomes and patient experience, and enhancing research quality and outcomes. While there has been a paradigm shift towards partnership working with patients, there continues to be a dearth of evidence about the impact of PPI on health research. The aim of the theme is to improve understanding of how PPI in research can enhance the relevance, quality of experience and impact of NHS research for patients. In the context of the CLAHRC, our core strategic principles for PPI are for it to be “embedded, comprehensive and active” in each CLAHRC project, and for this to be further developed and conceptualised over the duration of CLAHRC East of England.

All NIHR funded research is required to demonstrate good quality PPI and to have a clear pathway to demonstrate “impact”. This has been shown to have a strong relationship to the production of more relevant, feasible and acceptable evidenced interventions and research designs. The implementation of the proposed programme of research and activity will enable a more strongly conceptualised and evidenced effective contribution of PPI to diverse health care research and interventions. This will be achieved by:

- Recognising PPI as an integral part of every CLAHRC East of England project.
- Encouraging all CLAHRC projects to have 5% of the resources to support the project’s PPI activity.
- Including diverse populations in the project design and throughout the research and implementation process to dissemination.
- Encouraging links between PPI stakeholders and initiatives at local and regional levels to support active learning and collaboration.
- Identifying a PPI co-ordinator for each theme.
Current research projects include:

Implementing PPI in an NHS Research Programme

Evaluating the PPI contribution to CLAHRC research implementation.

Patients as partners to improve long-term conditions

What models work best to improve patient experience in long term conditions services? (Patients as Partners to Improve long term conditions services – PIPPIN).

Understanding PPI in research with older people living in residential settings

How best to enable meaningful PPI in research with older people living in residential settings.

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Find this theme on our website:

http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/patient-and-public-involvement-ppi/
Health economics

Led by Dr Garry Barton of the University of East Anglia, the theme provides support to other themes of CLAHRC East of England e.g. in relation to assessing the costs and benefits of alternative treatments. It also leads projects which focus on the application and development of the methods of economic evaluation.

The health economics research theme will work with local health professionals to provide advice regarding the potential implementation of health economic evidence arising from the research of CLAHRC East of England, or as a result of wider research.

Health care budgets are limited and thus choices have to be made about which treatment options to provide and which not to provide. An economic evaluation is often undertaken to inform this decision, where the costs and benefits of alternative treatments are compared in order to assess which represents best value for money. Undertaking the proposed research will enable us to be more certain about the costs and benefits associated with particular health care treatments. This information will increase our confidence as to the cost-effectiveness of these health care interventions. Implementation of this research will also ensure that greater benefits are achieved from scarce health care resources.

Short term objectives:

- To estimate the cost-effectiveness of a particular treatment option (economic evaluation).
- To estimate the value of undertaking further research to provide further evidence as to whether a particular intervention constitutes value for money (value of information analysis).
- To conduct a systematic review of published economic evaluations within a particular treatment area. The data will subsequently be incorporated into an economic model which provides estimates of cost-effectiveness (research synthesis with economic modelling).

Long term objectives:

- To replicate our first three short-term objectives (cost-effectiveness, value of future research and systematic review of economic evaluations) with regard to other treatment options. The specific treatment options will be identified after work with other themes within the CLAHRC.
To use the findings from the aforementioned short-term objectives to inform the design of the economic component of research applications which are submitted to the NIHR for funding.

To ensure the local implementation of research findings.

Current research projects include:

Value of information analysis

_Prevention of long-term social disability amongst young people with emerging signs of severe mental illness_ – estimating the value of further research and what data to collect in a future definitive study (Value of information analysis).

Health resource use measurement in clinical trials

_Health resource use measurement in clinical trials: should we measure general health services or disease-specific resource use?_

Economic evaluation of the EQUIP programme

_Economic evaluation alongside a clinical trial (Equipping Youth to Help One Another Treatment) (Langdon, NIHR Fellowship)._

Economic evaluation of telehealth

_Systematic review and economic model._

A comparison of data collected from GP records versus care home records

_How should we collect health care resource use data in trials conducted in care homes? A comparison of data collected from GP records versus care home records._

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Find this theme on our website:

http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/healtheconomics/
Research capacity development is a major component of CLAHRC East of England’s work. The aim is to equip clinical and non-clinical staff to scrutinise and question the way things are done, to welcome innovation, ensuring more rapid diffusion and adoption of evidence-based best practice. To achieve this, the CLAHRC invests in education and research skills training; supports the dissemination of research findings that are directly relevant to practice; promotes and sustains engagement with, and support for, practitioners, managers and commissioners; has created academic apprenticeships in mental health and primary care; and mentors and supports emergent and future research leaders from health and social care.

The CLAHRC is the national lead for the four recently NIHR-funded Doctoral Training Centres in dementia care research. It is also supporting funded PhD studentships in all the CLAHRC themes and is committed to improving research capacity in applied health and social care research.

CLAHRC Fellowship

Fifty-seven CLAHRC Fellowships have been awarded since 2011. 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. The Fellows are funded by the CLAHRC for one day a week for a year. The key aim of the Fellowship is to make the programme valuable to the individual Fellow and their employing organisation.

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. The taught component of the Fellowship aims to develop an understanding of research and evidence, research methodology, theory of change management, and systems theory applied to healthcare. These skills can be applied in the workplace to effect real change that ultimately brings about improvements in service delivery.

Action learning set: Fellows are allocated to an Action Learning Set (ALS), a small group focused on learning from experience and sharing that experience with group members. The sets meet for a 3 hour session every alternate month and are led by Professor Mike Cook (University of Bedford).

Research project: Putting together a proposal for a research project is part of the application procedure. The project is started at the beginning of the Fellowship and must be completed within the Fellowship year. The Fellow can contribute to a project within one of the CLAHRC East of England themes or may identify a project in their area of interest.
The NIHR CLAHRC East of England is hosted by the **Cambridgeshire and Peterborough NHS Foundation Trust**

**University of Cambridge**  
Department of Psychiatry  
Cambridge Institute of Public Health  
Engineering Design Centre  
Judge Business School

**University of East Anglia**  
Faculty of Medicine and Health Science

**University of Hertfordshire**  
Centre for Research in Primary and Community Care

**Cambridge Biomedical Research Centre**

**Cambridgeshire and Peterborough Clinical Commissioning Group**

**Cambridgeshire County Council - Children, Families and Adult Services**

**Cambridge Learning Disability Partnership**

**Cambridge University Hospital NHS Foundation Trust**

**Eastern Academic Health Science Network**

**East and North Hertfordshire Clinical Commissioning Group**

**East and North Hertfordshire NHS Trust**

**East of England Ambulance Service NHS Trust**

**Health Education East of England**

**Hertfordshire Community Health Trust**

**Hertfordshire Partnership University NHS Foundation Trust**

**NIHR Brain Injury Healthcare Technology Cooperative**

**Norfolk and Suffolk Dementia Alliance**

**Norfolk and Suffolk NHS Foundation Trust**

**Norfolk Clinical Academy for Dementia**

**Rescon Ltd**

**UnitingCare Partnership**
The NIHR CLAHRC East of England reaches throughout the region. Harnessing the strengths of the Universities of Cambridge, East Anglia and Hertfordshire, and working in partnership with health and social care organisations, the CLAHRC aims to improve health through evidence-based innovation.