World class research making a difference

Collaborations for Leadership in Applied Health Research and Care
Foreword

In 2008, the National Institute for Health Research (NIHR) created Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). They have a specific aim: to bridge the gap between the world class research conducted by academics and its implementation on the NHS frontline, where it can impact on patient lives and the quality of service provided to them. In 2013, following the success of the pilot CLAHRCs, it was decided to fund a second wave of 13 CLAHRCs for a five year period commencing 1 January 2014.

CLAHRCs bring together local NHS providers and commissioners with academics, other relevant local organisations, industry partners and health research infrastructures together with our local Academic Health Science Network (AHSN). The CLAHRCs we lead undertake high quality applied research and evidence based implementations that are responsive to and in partnership with our collaborating organisations, patients, carers and the public, the outcome being an improvement in both the health and wealth of our population.

All CLAHRCs conduct world-class applied health research across the NHS and then translate research findings into improved outcomes for patients. We focus on research targeted at chronic disease and public health interventions. The 13 CLAHRCs in England work together as a college ensuring that we share our learning across the country and work in a cohesive and collaborative way. We know that our success will be judged by the impacts we have not only on patient outcomes but on practice.

We are well aware that there are a number of pressures on the NHS, including:

- people living longer, often with long-term conditions and multiple co-morbidities
- greater financial pressures
- health inequalities.

We also understand that this is an era of enormous technological change evidenced by the Information and Communications Technology revolution going on around us.

All of us at CLAHRCs want to focus our research to address those challenges and, wherever possible, provide solutions to the issues of our age whilst taking advantage of this era of change. We know that our success will be judged by the impacts we have not only on patient outcomes but on practice and policy changes locally and nationally.

This brochure introduces you to the highlights of our CLAHRC programme to date. It details successful examples of our work and the impact it has had and will continue to have. Combined, we are saving the NHS millions and are helping to save and improve the lives of patients across England and further afield.

We would like to thank all of the CLAHRCs for sharing their hard work and the staff who supported the development of this brochure.

We would particularly like to thank CLAHRC East Midlands who led the development of this brochure and Professor Kamlesh Khunti and Dr Kevin Quigley who coordinated the work.

All of us at the NIHR CLAHRCs are looking forward to continuing our work with the aim of reducing the gap between research and practice, and significantly improving patient access and outcomes.

CLAHRC Directors
“Bridging the gap between research and the frontline NHS”
CLAHRCs in numbers

Since 2008, CLAHRCs have conducted a range of innovative research studies leading to improved outcomes for patients, better and more cost-effective services and challenge health inequalities nationally. Alongside that, CLAHRCs engaged in innovative capacity development work with NHS partners, running courses in research, evaluation and implementation of the latest evidence.

In broad numbers, the CLAHRCs as a whole have:

• generated more than £130 million in external income
• published 1,777 articles in peer-reviewed publications
• carried out 2,144 research and implementation projects
• awarded 2,058 higher degrees to students
• recruited 3,221,707 participants* to projects.

* The total figure of 25,343 participants recruited in 2014/15 (incorporated in 3,221,707 above) excludes any studies recruiting > 1,000 subjects not individually consented.
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Early detection and prevention

Leicester Self-Assessment (LSA) and Walking Away from Diabetes - CLAHRC East Midlands

Short questionnaire revolutionises early identification of diabetes – just seven questions that assess your risk

Diabetes UK, Tesco and Boots amongst those using tool

820,000 have taken the test online with an estimated 50,000 successfully diagnosed
Early detection and prevention has formed part of the biggest diabetes awareness campaigns, also widely used by Boots and Tesco chemists and recently replication by the Leicester Diabetes Centre (LDC) and Diabetes UK has shown that an estimated 1 in 16 people who have taken the questionnaire and received an initial high score have been subsequently diagnosed with type 2 diabetes. As such, approximately 51,250 people have been successfully diagnosed after taking the test.

Recent research
Recent research conducted by the Leicester Diabetes Centre (LDC) and Diabetes UK has shown that an estimated 1 in 16 people who have taken the questionnaire and received an initial high score have been subsequently diagnosed with type 2 diabetes. As such, approximately 51,250 people have been successfully diagnosed after taking the test.

Walking Away from Diabetes
The next stage of this pipeline of projects was to develop the Walking Away from Diabetes study, which is a structured education programme encouraging and supporting physical activity in those at-risk from diabetes. The Walking Away programme is recommended for use in the National Institute for Health and Care Excellence (NICE) Guidelines for Early Intervention and Prevention of Diabetes. It has been commissioned by 16 CCGs in England, and is used in health services in Ireland, Gibraltar and Western Australia.

Project summary
• **What?** - LSA and Walking Away are two linked studies looking into identifying those at-risk from type 2 diabetes, and helping to prevent its onset.
• **Why?** - Type 2 diabetes represents a major health challenge with a large increase in the numbers with the condition and in the cost of treating it.
• **How?** - The study works by allowing both health workers and patients to identify the level of risk through taking a short questionnaire and then, if necessary, the patient begins a walking programme to improve their fitness.

Result
An estimated 50,000 have been identified as having type 2 diabetes and have commenced treatment which will save the NHS money and improve the health of those receiving treatment.
Case study: Walking Away from Diabetes

A woman from Leicester has turned her life around after participating in a programme to help people avoid diabetes.

At the age of 61, Christina Brennan went to see her GP. She was told that because of her age, being slightly overweight and having high blood pressure, she was a prime candidate for developing type 2 diabetes.

Being a grandmother of five meant Christina was keen to do all she could to avoid getting diabetes and allowing her health to decline. Christina said:

“My GP suggested doing the Walking Away From Diabetes project in Leicester. The team did some health tests, asked about my lifestyle and offered advice.”

The aim of Walking Away from Diabetes, which was funded by CLAHRC East Midlands, was to investigate the impact a structured education programme has on walking activity in those with a high risk of developing type 2 diabetes.

The aim of the programme is to promote physical activity by targeting perceptions and knowledge of impaired glucose tolerance, physical activity self-efficacy, barriers to physical activity and self-regulatory skills, using a person-centred approach to patient education.

High-risk patients are identified by GPs using a specialist ‘risk-score’ calculation.

Once Christina had been deemed a high-risk patient, she attended a group-based interactive education session and was given a pedometer to encourage her to increase her physical activity.

“I gradually built up my walking and cut down on certain food. I didn’t do anything drastic.”

After a few weeks, Christina noticed her waistband felt looser and after weighing herself, she discovered she had lost about half a stone.

Now aged 64, Christina tries to walk as much as she can every day and has even joined an aqua-aerobics class. Christina said:

“My blood pressure has come down, my BMI has improved and I’m no longer in the high-risk category. I feel great.”
“Grandmother Christina ‘walks away’ from diabetes”
CLAHRC Greater Manchester (GM) and Salford Diabetes Care created an impaired glucose tolerance (IGT) care call project, which aimed to delay or reduce the risk of people with IGT developing type 2 diabetes. IGT is a condition where patients have a blood glucose level that is above normal but not high enough for a diagnosis of diabetes.

Development of service

The CLAHRC team worked with Salford Diabetes Care’s existing care call service to develop and implement a telephone-based lifestyle intervention, delivered by trained health advisors for patients diagnosed with IGT. The IGT care call service developed evidence-based scripts to provide educational messages, specifically for people with IGT, offering them lifestyle advice from a dedicated health advisor. Rather than teaching in a directive manner, health advisors engaged the patients in motivational discussions, identifying key areas of their lifestyle that could be improved, such as weight loss and healthy eating.

Research shows that without lifestyle or medical intervention, about 50 percent of people with IGT will develop type 2 diabetes within five to ten years. Intensive lifestyle interventions, such as IGT care call, can reduce the risk of developing type 2 diabetes by up to 58 percent in people with IGT. Our research shows that 75 percent of patients who were supported in this way lost weight, and 65 to 75 percent of patients saw improvements in oral glucose tolerance tests, demonstrating the positive effect of their lifestyle changes.

National recognition and awards

The project has also been nationally recognised. IGT care call won the Quality in Care (QiC) award for ‘Best Type 2 Diabetes Prevention Initiative’ in 2011 and NICE consider the IGT project an exemplar for the prevention of diabetes in its 2012 guidelines. Salford CCG have commissioned care call for all patients with IGT.

Future partnerships

Building on this success, CLAHRC GM is now working with Hitachi, Salford Royal NHS Foundation Trust, NHS Salford Clinical Commissioning Group and NorthWest EHealth to engage with general practices across Salford as part of the Comparison of Active Treatments for Impaired Glucose Regulation (CATFISH) trial.

Project summary

- **What?** - This is a telephone support service to assist those at-risk from type 2 diabetes in developing and maintaining a healthy lifestyle in order to prevent onset of the condition.
- **Why?** - Type 2 diabetes represents a major health challenge with a large increase in the numbers having the disease and in the cost of treating it.
- **How?** - The project worked with Salford’s existing care call service to develop a telephone-based lifestyle intervention.

Result

The study shows that the vast majority of those involved in the study lost weight and saw their oral glucose tolerance levels improved saving the NHS thousands and helping people maintain a healthier life.
Early detection and prevention
Management of long-term conditions

Greater Manchester Stroke Assessment Tool (GM-SAT) - CLAHRC Greater Manchester

Innovative stroke assessment tool developed to streamline care

Over 4,000 assessments already carried out
Management of long-term conditions

CLAHRC GM created a tailored assessment tool to help determine the specific care needs for individual stroke patients, six months after their stroke. The project team worked with health care, social care and voluntary sector staff, stroke survivors and their carers to develop and evaluate a structured assessment tool which identified the specific needs of individual patients, and signposted them to relevant support.

The Greater Manchester Stroke Assessment Tool (GM-SAT) is a free, evidence-based assessment tool designed specifically for a six month post-stroke review. GM-SAT identifies a wide range of potential post-stroke care needs, from medication management and secondary prevention, through to mood and fatigue problems. Together with its supporting materials, it provides everything needed to undertake a six month review, from the questions to ask within the review and the algorithms to guide care, through to the documentation for recording and communicating review outcomes to other professionals involved in an individual’s care. The team also developed an easy-access version of GM-SAT to be suitable for people who have aphasia following their stroke, created in collaboration with stroke survivors from Speakeasy, a communication support charity based in Bury.

GM-SAT integrates the needs analyses set out in the Care Quality Commission’s ‘Supporting Life after Stroke’ report and fulfils aspects of the Department of Health’s Accelerating Stroke Improvement Programme and the NHS National Stroke Strategy. The flexibility of the tool enables it to be tailored to local services and voluntary sector provision.

Use of the assessment tool

It is now used across the country and is the only tool used for post-stroke assessment by the Stroke Association, who have carried out more than 4,000 assessments to date. It is able to highlight the needs of the local patient population and areas for targeted professional or service development, leading to service improvement. For example, the integration of the tool into the IT system used by primary and community care providers in Yorkshire and Humber made care more consistent across the whole area.

Project summary

- **What?** - GM-SAT is a free assessment tool designed to support a six month post-stroke review.
- **Why?** - Recovery from stroke is a vital part of preventing relapse and maintaining the patients’ quality of life.
- **How?** - CLAHRC GM worked with stroke teams in the Greater Manchester area to implement the tool.

Result

The assessment tool is now used across the country, where it has helped make stroke support services much more effective.
Improving the identification and care of patients with kidney disease - CLAHRC East Midlands and CLAHRC Greater Manchester

CKD software tool and CKD support website developed for GPs which is set to save the NHS millions

Research Studies identified over 3,000 cases of early onset Chronic Kidney Disease and now being used in over 200 GP Practices

Evaluation estimates savings of £1.3 million over four years for one CCG

A guide to using IMPAKT™ to improve diagnosis and care for people with chronic kidney disease
Excess cardiovascular disease related to CKD is thought to cost the NHS in England £175 million per annum. With end stage CKD growing at an estimated six percent per annum, diagnosing and treating CKD effectively as early as possible is hugely important. Researchers at CLAHRC EM (formerly CLAHRC LNR) developed a software tool IMPAKT (IMProving Patient Care and Awareness of Kidney disease progression Together) which analysed pre-existing general practice data more efficiently to identify patients at risk from CKD.

CLAHRC GM also identified early diagnosis of CKD as a key priority and as a consequence collaborated on projects helping GPs identify cases of early stage CKD, using manual MiQuest queries run on general practice IT systems. This identified 1,863 additional patients with CKD across 30 GP surgeries, and led to a large increase in the percentage of these patients treated to recommended NICE guidelines blood pressure targets. There is strong link between CKD and high blood pressure which leads to other conditions such as heart attacks and strokes.

The synergy between the CLAHRC EM and GM projects, developed from common clinical interests and complementary skills in both teams resulted in a collaborative project to bring together the IMPAKT software tool and the improvement package used with GM practices in the initial projects. This collaboration resulted in the development of a CKD improvement support website: Improving Patient Care and Awareness of Kidney disease Together (IMPAKT): www.impakt.org.uk which includes the software tool and a range of supporting resources, including those developed by CLAHRC GM through related research.

**Impact and current use**

Over 4 years, 2,729 additional patients with CKD across 61 GP surgeries in Greater Manchester were identified. Of those, 77% now have had their blood pressure controlled to NICE recommended guidelines. IMPAKT has also been used to support a cluster randomised trial of primary care CKD management in Northamptonshire including 48 practices and >30,000 CKD patients.

The tool is now used by more than 200 GP practices across the UK, especially in Greater Manchester, the Midlands, North Wales and West Yorkshire. CLAHRC GM in partnership with GM AHSN is set to have analysed data for over 400 GP practices by the end of 2015. A further 60 practices are being supported by CLAHRC GM to improve care and increase those with blood pressure managed to NICE targets.

The tool continues to evolve and has been updated to incorporate latest CKD NICE guidance. It is also being developed to support the identification and management of acute kidney injury.

**Evaluation of the tool**

Work has begun by CLAHRC EM to evaluate the impact of the software tool and the level of savings likely. A programme entitled “Making an IMPAKT” has been commissioned by West Leicestershire CCG supported by a CKD specialist nurse. An evaluation of its first year in 30 GP practices showed that it led to a 2.7 percent increase in recorded CKD prevalence and large increases in CKD patients treated to NICE blood pressure targets. Extrapolating the data across the whole of the CCG area would lead to an additional 314 patients identified with CKD and 1,797 patients with CKD treated to appropriate BP targets. Recent meta-analysis shows that treating 19 people with CKD and high blood pressure over four years prevents an estimated one cardiovascular event (e.g. myocardial infarction or stroke) from occurring. Research estimates that the average cost of a cardiovascular event to the NHS is £24,857. Based on our research the tool is likely to prevent 52 cardiovascular events and save West Leicestershire CCG £1.3 million. CLAHRC GM has also been carrying out evaluation of the tool which is already showing similar positive results.

CLAHRC EM will be carrying out further economic evaluation work of the IMPAKT tool and the likely levels of savings to the NHS that this highly innovative piece of software will bring. The Intellectual Property for the IMPAKT tool is held by the University of Leicester.

**Project summary**

- **What?** - IMPAKT is a software tool for use in General Practice that identifies patients at risk from early onset Chronic Kidney Disease (CKD) and provides a range of support resources for their management of patients with CKD.
- **Why?** - Identifying and managing CKD at early stages reduces the risk of it progressing, and of patients having heart attacks and strokes. The costs of treatment at later stages are extremely high and growing.
- **How?** - IMPAKT grew from clinical interest in how to identify early onset CKD and was developed into a package to support improved diagnosis and care, and can be supported in general practices.

**Result**

Early identification of CKD has allowed for early treatment, which reduces the risk of cardiovascular disease and has the potential to reduce costs. Results show that NICE indicators of excellent care for CKD such as blood pressure control were improved dramatically by use of the IMPAKT package.
Stroke pathways - CLAHRC South West Peninsula

Pilot simulation work carried out to improve stroke management

Series of key changes made to improve effectiveness of stroke care

Process being rolled out throughout the South West Peninsula (Devon, Cornwall and Somerset)
CLAHRC South West Peninsula (PenCLAHRC) has been instrumental in carrying out simulation modelling work with acute trusts in order to improve stroke management. In 2011, a CLAHRC project team carried out a pilot simulation modelling project with the Royal Devon and Exeter Foundation NHS Trust to explore the potential impact of a wide range of ‘what if’ scenarios on the detailed steps involved in managing an acute stroke from arrival at hospital to thrombolysis.

Key changes
A key change identified in the project was the benefit of ambulance staff alerting the hospital of the condition of the person with the suspected stroke, so that relevant resources for example stroke specialists, nurses and radiologists, could be prepared for their arrival, thus managing their care with minimal delays. The model also supported the use of thrombolysis.

Latest results
This initial project resulted in significant changes to the Trust’s performance in managing acute stroke. The latest quarter’s figures for the Royal Devon and Exeter Foundation NHS Trust show that since implementation of the study’s findings, patient access to thrombolysis services has increased by 14 percent, which is in line with the predictions of the computer model. Average door-to-treatment times have fallen from 109 to 49 minutes, with an increase in treatment rates from 4 percent to 16 percent. In real terms, this equates to 100 people with a stroke receiving treatment per year compared to 25 at study commencement – a fourfold increase in the population benefit from an evidence-based intervention.

The research demonstrates the potential for computer simulation modelling to predict the likely outcomes of change to complex pathways and for the process of engagement in modelling to act as a catalyst for change across the different elements of a service. The initial research is being extended with the South West Academic Health Science Network (AHSN) and South West Specialist Clinical Network across all the hospitals in the region. Each collaborative project is leading to specific local proposals for changes in the acute stroke pathway. The methodology is generalisable and transferable to acute hospitals across the UK.

Project summary
- **What?** - A process of simulation modelling of emergency stroke care management is used to identify ways to improve care.
- **Why?** - The period straight after a stroke is vital to survival and recovery.
- **How?** - PenCLAHRC worked closely with Royal Devon and Exeter Foundation NHS Trust to assess their emergency stroke care processes and identify ways of improving care.

Result
The study identified ways of improving care as well as discovering that computer simulation processes can be utilised by any NHS trust where it has the potential to dramatically improve stroke services.
Characteristics of general practices associated with emergency admission rates to hospital: a cross-sectional study - CLAHRC East Midlands

Key research study influences government policy

Named GP for everybody over 75 decided following study evidence
Emergency care and acute illness

A CLAHRC EM (formerly CLAHRC LNR) project: ‘Characteristics of general practices associated with emergency admission rates to hospital: a cross-sectional study’ was referenced by Secretary of State for Health Jeremy Hunt when he announced changes in November 2013 to the GP Contract for 2014 to 15. The change was that every general practice patient over 75 would be allocated a named GP. A number of projects within CLAHRC LNR’s Implementation Theme looked at the issue of rising care admissions into NHS hospitals. Its partnership work identified this as a priority, and CLAHRC researchers worked closely with primary and secondary care in looking at ways to reduce emergency admissions. One of the main findings was the association between patients reporting being able to see a particular GP and admission rates. Researchers found that, as the proportion of patients able to consult a particular GP increased, emergency admission rates declined. CLAHRC researchers were delighted to be able to directly influence government policy.

Project summary

- **What?** - A suite of studies that looked at reducing acute admissions in hospitals.
- **Why?** - Emergency admissions are extremely costly to the NHS and have risen in recent years.
- **How?** - CLAHRC LNR worked with local partners to identify ways of reducing admissions.

Result

The Coalition Government adopted the project finding that every over 75 should have a named GP as policy, citing the study.
Complaints of back pain are the most common reason why middle-aged people visit their GP, and the second-most-common reason for sickness absence from work. To assist the management of lower back pain, CLAHRC West Midlands has developed a brief screening tool for use in clinical practice: STarT Back. The tool was developed after initial analysis of data identified distinct back pain trajectories.

STarT Back is an example of stratified care for low back pain, whereby patients are initially screened for the type and likely duration of back pain and are then matched to pathways that ensure the right patient gets the right treatment. STarT Back has been shown to be both clinically and financially effective, by reducing over-treatment of low-risk groups. This is achieved through ensuring the management of this group is maintained in primary care, with more effective and efficient matched and targeted treatment for medium- and high-risk groups, provided by physiotherapists in community and secondary care settings. A linked study demonstrated that the application of the STarT Back approach provided a 40 percent reduction in the referral of low-risk groups, while medium- and high-risk groups gained earlier access to therapy, with improved outcomes and significant reduction in time lost from work.

Regional roll-out

In early 2014, the West Midlands Academic Health Science Network (WMAHSN) supported a funding application to extend the STarT Back approach to care management across the west midlands, in order to support GPs in using the tool and train physiotherapists in treatment approaches so that patients are managed according to need. To date, 109 physiotherapists have been trained in STarT Back matched treatments, spanning 12 NHS providers within the west midlands.

Evaluation

An audit tool was also developed for NHS leads to evaluate the impact on services. Evidence from early audit data suggests:

- increased utilisation of the STarT Back tool within general practice settings. For example, a 30 percent increase has been reported in Stafford and Surrounds CCG
- STarT Back tool completed by physiotherapists 100 percent of the time
- a reduction in physiotherapy waiting times after STarT Back matched treatments have been applied. For example:
  i. pre-intervention, 52 percent of patients were seen within the target waiting time, compared to 80 percent post-intervention (Staffordshire and Stoke-on-Trent Partnership NHS Trust)
  ii. Telford and Wrekin CCG and Shropshire Community Trust waiting times reduced from 10 to 4 weeks
- 100 percent patient satisfaction rates
- a reduction in the number of patients being referred on for second opinion (1 percent to IMPACT pain service).

Beyond the west midlands the project has developed industry partnerships with EMIS (Egton Medical Information Systems) and www.patient.co.uk. These partnerships have allowed the tool to be integrated into the GP clinical system, allowing automated completion and access to high-quality patient information and auto-referral to appropriate matched treatments.
National roll-out

The project team have also established links with other AHSNs to facilitate the eventual roll-out of the tool elsewhere across the country, making considerable savings for the NHS and reducing the number of work days lost to lower back pain.

Finally, the project team have created new partnerships with national professional groups, such as Public Health England and NICE, to make the StarT Back toolkit and educational resources available at a national level.

CLAHRC WM believes this tool can dramatically improve the quality of care for those suffering with back pain.

Project summary

- **What?** StarT Back is an audit tool that supports GPs in identifying the most appropriate care for patients with back pain.
- **Why?** Back pain is the most common reason why middle-aged people visit their GP and the second-most-likely reason for sickness absence from work.
- **How?** CLAHRC WM developed the tool and has worked with local GP practices and the WMAHSN to roll it out.

Result

The tool is being used across the west midlands and is likely to be rolled out to the rest of the country where it can be a valuable support tool for GPs dealing with patients who suffer from back pain.
Tranexamic Acid (TXA) in trauma - CLAHRC South West Peninsula

Research implemented to save lives in emergency care

Use of tranexamic acid is shown to improve life chances

Results adopted in national guidelines
PenCLAHRC has taken the lead in supporting the use of tranexamic acid (TXA) by paramedics and others involved in emergency care for trauma patients, saving approximately 400 lives a year in the UK (CRASH-2 trial data). Previous research had shown that, if used within three hours after trauma, TXA reduces the risk of death from bleeding by as much as 30 percent. Despite the costs being low and there being virtually no side-effects, there had been little implementation within the NHS. After an initial review of the evidence, it was decided that an effective way of delivery would involve the drug being administered by paramedics as well as in A&E, using a protocol that has been agreed upon with emergency departments.

PenCLAHRC worked with the South West Ambulance Service NHS Foundation Trust (SWAST) and the acute trusts to support all emergency services in the south west in carrying TXA. As a result of this work, all emergency ambulances across Devon, Cornwall, the Isles of Scilly, Somerset and Dorset started to carry TXA and all hospital trusts introduced it into their emergency departments as well as developing local guidelines and protocols for its use.

As a result of this successful implementation, the use of TXA was incorporated into the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) National Guidelines for use across the UK. All emergency ambulance services across England now carry TXA, saving lives in the most extreme cases of injury.

**Project summary**

- **What?** - PenCLAHRC looked at ways of broadening emergency care workers’ use of TXA when treating trauma patients.
- **Why?** - Previous research has shown that the use of TXA reduces the risk of death from bleeding by as much as 30 percent.
- **How?** - PenCLAHRC worked with South West Ambulance Service NHS Foundation Trust (SWAST) and local acute trusts to support the use of TXA on trauma patients.

**Result**

The use of TXA is incorporated into national guidelines where it is used across the UK and is already saving lives.
Children

Expanded Newborn Screening (ENBS) - CLAHRC Yorkshire and Humber

Newborn screening extended to cover four new conditions

Estimated 20 to 30 lives saved per year
Identifying metabolic diseases at birth is crucial to early treatment and the ability to save lives.

The Expanded Newborn Screening (ENBS) project funded by CLAHRC Yorkshire and Humber (formerly CLAHRC South Yorkshire) involved screening 430,000 infants for five metabolic disorders in addition to the five conditions that are currently usual practice. Health economic analysis of the project predicted that national screening for these conditions would be cost-effective. During the project, 12 patients were detected as having one of the inherited metabolic diseases, thus allowing for treatment to start sooner than otherwise would have been possible and improving the life and wellbeing of these children and their families.

**National Screening Committee**

Clinical and health economic evidence was submitted to satisfy the National Screening Committee that expanding the existing national screening programme was appropriate. As a consequence, children born since January 2015 are now screened for a further four conditions. Around 700,000 children are born in England each year and expanded screening is estimated to offer significant health benefits as well as potentially saving the lives of 20 to 30 children per year.

**Project summary**

- **What?** - Expanded Newborn Screening (ENBS) is a study that looked into expanding tests at birth to identify five metabolic disorders in addition to the five conditions currently tested.
- **Why?** - Expanding the newborn screening saves infant lives as well as being cost-effective.
- **How?** - The project involved screening 430,000 infants to justify a national screening.

**Result**

Project presented clinical and health economic evidence to the National Screening Committee, who then expanded the national screening programme. It is estimated that this health benefit will save approximately 20 to 30 infant lives each year.
‘Second chance’ for baby treated for life-threatening illness picked up by screening process
Case study: Expanded Newborn Screening

A baby has been given a second chance after a newly introduced newborn screening process successfully diagnosed her with a life threatening illness early.

Habul, from Birmingham, became the first baby in the country to be identified with Maple Syrup Urine Disease (MSUD) during the pilot project of the Expanded Newborn Screening (ENBS), which was funded by CLAHRC Yorkshire and Humber.

MSUD is an inherited disorder in which the body is unable to process certain protein building blocks properly. The condition gets its name from the distinctive sweet smell of affected infants’ urine. MSUD is one of five metabolic diseases which can affect newborn babies. Detecting and diagnosing early is crucial to providing the right treatment, which will help save lives. The ENBS involves screening 430,000 babies for the five metabolic disorders, as well as the five conditions that are already standard practice.

Habul’s life was saved because of the fast diagnosis and the speed with which the healthcare team reacted to the screening results. Habul’s mother Fahmeeda had noticed her baby had been sleeping more and not feeding as much, but her GP had been unable to work out what was wrong. But Louise Simmons, a Newborn Screening Nurse Specialist at Birmingham Children’s Hospital NHS Foundation Trust, said they moved very fast once they received the results. She said:

“We were at the house within an hour. Habul was on her way to becoming poorly. We called an ambulance to bring her into hospital because we wanted her in as soon as possible.”

Diagnosing a condition such as MSUD can take hospital staff a few days, as they normally try to eliminate more common conditions first, such as infection. Dr Anupam Chakrapani, a Consultant in Inherited Metabolic Diseases at Birmingham Children’s Hospital NHS Foundation Trust, said:

“The danger of that is, with this condition, if there’s a delay in diagnosis, it can cause permanent brain damage.

“So children who are not treated promptly will often go on to develop learning difficulties. Because of the ENBS screening we already had the diagnosis, so we immediately started Habul on treatment.”

The little baby spent several days in intensive care and underwent a period of dialysis for 48 hours. Within just four days she was much better and continues to thrive, growing stronger every day. Fahmeeda said:

“She’s smiling and she’s moving. She is very active and God-willing she will remain active and in good health for the future.

“To this day we have felt that we are a family member of the metabolic team, and they have continued to help caring for my child and looking after her.”
Key tool developed to identify autism

GPs able to use Red Flags tool to spot autism in all age groups

Red Flags recommended in NICE guidelines
Children and young people

CLAHRC East of England (EoE) (formerly CLAHRC Cambridge and Peterborough) has helped lead the development and implementation of the Red Flags system of screening instruments for autism spectrum conditions (ASC). There is one each for four age groups: toddlers, children, adolescents and adults. The checklists provide a quick and accurate tool for GPs to determine if a patient needs referral to a specialist centre for a full diagnosis of ASC. NICE have recommended the short ‘Autism Spectrum Quotient (AQ-10)’ in their guidelines for the management of ASC in adults, which were published in June 2012.

Diagnosis of ASC can be a lengthy process with many individuals going undetected even into adulthood. A CLAHRC EoE research study addressed the need for a tool which would assist primary care professionals in making decisions about referrals to specialist services for a full diagnostic assessment for ASC.

Study results

The aim was to assess four screening instruments: the Autism Spectrum Quotient (AQ) in the Adult, Adolescent and Child versions, and the Quantitative Checklist for Autism in Toddlers (Q-CHAT), and identify 10 items on each instrument that had a good test accuracy. A case sample of more than 1,000 individuals with ASC and a control sample of 3,000 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 of the checklists.

The study has produced much-needed screening measures for frontline clinicians, and toddlers, children, adolescents and adults with possible ASC have a faster route to assessment and will be facilitated in accessing the support they require.

Project summary

• What? - This project is the development of a system of Red Flags to help GPs identify autism, with separate flags for toddlers, children, adolescents and adults.
• Why? - Autism spectrum condition (ASC) represents a major challenge for the NHS, with GPs finding it a challenge to diagnose and some incidences not being spotted before adulthood.
• How? - The project tested signs of autism in four separate groups: toddlers, children, adolescents and adults. The 10 most common signs were adopted as screening measures.

Result

The study has produced much-needed screening measures for frontline clinicians helping identify autism, ensuring early treatment and dramatically improved outcomes for patients.
Supporting

Transfer of Care at 17 – an investigation of factors which influence two groups of young people facing transitional care - CLAHRC East of England

- Training film for young adults wins documentary award
- Films used to support care for 17 year olds
- Study shows vulnerable people not receiving enough support in the 16 to 18 age group
The transition from childhood to adulthood is a challenging time for all. For the most vulnerable of children, that challenge is even greater. The CLAHRC EoE project ‘Transfer of Care at 17’ focused on two of the most vulnerable groups of 16 and 17 year olds: young people in local authority care (YPiC) who face moving to independent living, and the young people who are NHS Child and Adolescent Mental Health Service Users (CAMHSu) who face either discharge or transfer to an adult service. The project looked at how they made this transition and the quality of the support they received.

Study design
The project team worked with Cambridgeshire County Council, Peterborough City Council and Cambridge and Peterborough Foundation Trust (CPFT) to identify young people for the trial. Participants were interviewed by trained researchers on two separate occasions, a year apart. The interviews covered service use, and lifetime and current psychiatric diagnoses. Additionally, computerised self-report questionnaires assessed their state of mind, access to support and overall wellbeing.

Study conclusions
The study concluded that these young people needed greater support in identifying and treating their poor mental health, which had an impact on their transition into adulthood. As a consequence of these findings, three films have been commissioned and made, and are currently being used all over the UK for training by the British Association of Adoption and Fostering (BAAF), as well as local authorities, fostering agencies, colleges and universities. More specifically, ‘My Name is Joe’ has been incorporated into The Fostering Network’s ‘The Skills to Foster’ national training for prospective carers, used by the majority of local authorities and agencies in the UK. Another film ‘Finding My Way’, about leaving care, won the documentary award at the BFI Future Film Festival.

Result
Three films have been made to support the passage into adulthood and CLAHRC EoE researchers are now developing a mental health training course for foster carers, in collaboration with Cambridgeshire County Council and independent foster agencies in the region.

Next stage
This work is helping promote understanding for these vulnerable young people and help them at this crucial juncture in their lives. CLAHRC EoE researchers are now devising and piloting a new mental health training course for foster carers, in collaboration with Cambridgeshire County Council and independent foster agencies in the region.

Project summary
- **What?** A project looking at the challenges facing vulnerable young adults through interviewing 16 to 18 year olds.
- **Why?** Vulnerable adolescents aged 16 to 18 need support in making the transition to adulthood, which can have a major impact on their wellbeing.
- **How?** 16 to 18 year olds were interviewed on two occasions a year apart with problems identified.
A ground-breaking early intervention service in Birmingham to offer mental health services for young people from 0 to 25 years - CLAHRC West Midlands

Research highlights need for new services for young adults

Government commends new Mental Health Care pathways
Supporting vulnerable people

Research led by CLAHRC West Midlands (WM) looking at early intervention in psychosis has led to the introduction of a ground-breaking early intervention service in Birmingham for young people covering the ages of 0 to 25. The service has been positively commended in the recent government policy paper published in March 2015: ‘Future in Mind’.

Research findings

Research evidence generated through CLAHRC WM showed that young people who exhibit initial symptoms of psychosis face long delays in receiving treatment, partly due to bottlenecks within the specialist mental health services. In particular, research showed significant numbers of young people being ‘lost’ and becoming ‘disengaged’ at the period of transition between child (0 to 16) and adult mental health services (16 years onward), when they are at their most vulnerable. Findings also showed that ‘Did Not Attend’ rates were highest in the 16 to 24 age group in the Birmingham population, especially among Black and Minority Ethnic (BME) groups.

New youth pathway introduced

An experimental youth pathway (‘YouthSpace’) was co-produced and implemented with service users in Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT). The new service included a dedicated website to signpost people to services more effectively. In parallel, a public health campaign aimed at increasing mental health awareness was carried out to encourage vulnerable people to put themselves forward. At the end of the project the new 0 to 25 pathway was taken over by Birmingham Children’s Hospital and the project team then evaluated the new service. The evaluation showed that appropriate intervention led to a drop in the delay from treatment from 285 to 104 days.

Outcomes

These findings by CLAHRC WM led to the introduction of a new service in Birmingham, based around early detection and intervention in mental health, covering an individual’s first 25 years. A prospective evaluation of the new service will be completed and led by CLAHRC WM’s youth mental health team based at the Universities of Warwick and Birmingham.

Project summary

- **What?** - This project represented the development of a care pathway service for Birmingham, to support young mental health service users from 0 to 25 years old.
- **Why?** - Research had indicated that many vulnerable 16 to 18 year olds were being lost in the transition from adolescence to adulthood.
- **How?** - An experimental youth pathway (‘YouthSpace’) was co-produced and implemented with service users in Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT). This service was then evaluated.

Result

A new service was introduced in Birmingham that covered 0 to 25 year olds, removing the bottlenecks and lost service users in the 16 to 18 age group.
Case study: Youthspace

A teenager has been saved from a life on the streets and deep depression, thanks to the help and support she received from a mental health service called Youthspace, which is supported by the Prince’s Trust.

Youthspace was an experimental pathway created by researchers at CLAHRC WM as part of their ground breaking work on early intervention in psychosis. Youthspace is part of the Birmingham and Solihull Mental Health NHS Foundation Trust and has been providing clinical services, support and training to help young people aged between 16 to 25 cope with their mental health conditions. Vicky from Birmingham began to self-harm at the age of 14 after she was moved to a special needs school. She said:

“*It affected my confidence and also made me question whether I was normal or good enough. During this time I started to self-harm, this was something I could release my pain on and also something I could control.*”

Things got worse for Vicky, who was given medication for depression, which she said didn’t work. She said:

“I *still felt hopeless and low. I ended up being excluded from college and I felt discriminated against for my health problems.*”

Vicky’s living situation became very unsettled and her temper became worse, which resulted in a hospital stay for six months.

Through no fault of her own, Vicky found herself homeless after she was discharged. Moving around hostels and having no job, meant she began to feel even worse and attempted several overdoses.

“At this time something clicked in my head, and I asked the authorities for help for the first time. This was something that was really hard for me to do because I didn’t really trust them and also I thought things would just go wrong, but they referred me to Youthspace and the Prince’s Trust.”

Over the next few months she secured her own flat and started to volunteer for several organisations, which helped Vicky’s confidence to grow. She went on to join the Youth Board, which is a group of service users who directly inform the Youthspace services, and now she is a full-time project support worker.

“*Taking part in Youthspace has made me turn my anger into a positive to create change for other young people. Youthspace has given me the opportunity to develop my skills and grow as an individual.*

“I *have finally been able to use my skills and experiences to make that change. If it wasn’t for the Prince’s Trust and Youthspace giving me these opportunities I wouldn’t be here today.*

Youthspace’s innovative care pathway is being taken over by Birmingham Children’s Hospital who will ensure that the care pathway remains allowing other teenagers to have the same level of support as Vicky.
Individual placement and support
- CLAHRC East Midlands

Innovative support getting vulnerable people into employment

Those with mental health disability helped to get fulfilling work

Service being implemented across the east midlands region
Supporting vulnerable people

There are 500,000 people of working age with a mental health condition in the UK and only 19 percent of them are in employment. Mental health experts acknowledge that there are considerable individual benefits to being in work for these vulnerable people. The Individual Placement and Support (IPS) project supported by CLAHRC East Midlands (formerly CLAHRC Nottinghamshire, Derbyshire and Lincolnshire) found a positive impact from the implementation of IPS for people with severe mental health conditions within Nottingham who were seeking employment. The project looked at the barriers preventing personalised support being delivered and proposed ways in which they could be overcome.

Study results

Employment specialists within mental health agencies worked directly with clients with mental health conditions to explore jobs that they were interested in doing, and then provided support, coaching, CV development and interview training as well as on-the-job support. As a result, 57 percent of the people with a mental health condition provided with personalised support gained employment compared to 12 percent of those who were offered usual care. 74 individuals were recruited into the study and received IPS: 25 started a new job; 11 achieved voluntary work and eight began studying for a long-term professional qualification.

Roll-out of service

The East Midlands Academic Health Science Network (EMAHSN) have agreed to lead the implementation of the IPS project across the east midlands and have appointed an IPS Development Manager. So far, the project has been implemented in three of the region’s acute mental health trusts: Nottinghamshire, Derbyshire and Northamptonshire. In addition, EMAHSN are working with Lincolnshire, who already used IPS, to look at extending the service. In addition, a team from the University of Nottingham is working with employers in the region to develop guidance to help support them when employing people with mental conditions. IPS is now internationally recognised as the most efficient way of supporting people who experience mental conditions to gain employment.

Project summary

- **What?** - This study looks at the effectiveness of individualised support to help people with mental health conditions into employment.
- **Why?** - There are over 500,000 people with a mental health condition and only 19 percent of them are in work despite the acknowledged benefits of employment.
- **How?** - The project provided individual support to people with a mental health condition to help them to get fulfilling jobs, by identifying the barriers they may come up against.

Result

The project showed that individualised support dramatically increased the chances of people with mental health conditions getting employment. The service is currently being rolled-out across the east midlands.
Electronic Frailty Index (eFI) - CLAHRC Yorkshire and Humber

Screening tool developed in collaboration with Industry to support frail patients

Tool used by a third of GP practices covering 25 million
It is estimated that one in ten people over 65, and one in four over 85, are frail. Frailty is associated with adverse outcomes including a need for long-term care residence, hospitalisation and mortality caused by events such as falls. The Care Act of 2014 legislates for a preventative approach to the management of older people, especially the frail.

To help identify the frail elderly in primary care, so that they can receive more proactive support, CLAHRC Yorkshire and Humber has developed an electronic frailty index (eFI) in conjunction with industry partners TPP and SystmOne. The eFI is made up of 36 indicators and produces an overall score to allow the GP to identify the frailest people within their practice.

The eFI has been embedded into SystmOne, the predominant clinical software system in Yorkshire and Humber, and which is used by over a third of UK GP practices for over 25 million patients. It has also been recognised nationally by the British Geriatric Society’s ‘Fit for Frailty’ Commissioning Guidelines.

Project summary

- **What?** - The Electronic Frailty Index (eFI) is a screening tool that allows GPs to identify their frailest patients.
- **Why?** - It is estimated that one in ten people over 65 and one in four over 85 can be categorised as frail and that frailty causes falls, hospitalisation and long-term residential care.
- **How?** - The eFI was developed in partnership with industry partners, and highlighted 36 pointers that identify the most-frail patients.

Result

The eFI is now used in over a third of GP practices nationally covering more than 25 million patients.
My Medication Passport (MMP) - CLAHRC Northwest London

My Medication Passport (MMP) is a small, easy-to-read, user-friendly booklet or app designed by patients for patients to hold a comprehensive record of their medication and related information including demographic information, a photo (if desired), full details of current medication, allergies and sensitivities, adverse drug reactions, medical episodes, dates of vaccinations and screenings, home treatments and medication aids. Its aim is to help the patient to inform healthcare professionals about their medications and healthcare needs.

Patient involvement
The development of the MMP was a triumph for the ability of patient involvement to drive health innovation. At an early CLAHRC Northwest London public focus group assembled to explore patient empowerment in medication management, the idea of a passport was born. CLAHRC researchers worked with the patients and professionals to transform the idea into a booklet entitled My Medication Passport. This process was supported through extensive consultation with patient reading groups, patient focus groups, discussions in patient forums and input from professional designers.

Passport success
Since its launch in April 2013, 100,000 pocket booklets have been ordered by pharmacies, hospitals, charities, GP practices, nursing homes and patients across the United Kingdom. Additionally, over 5,000 iPhone and 4,263 Android apps have been downloaded in at least 37 different countries worldwide.

My Medication Passport is used as a good practice example in the Royal Pharmaceutical Society’s ‘Keeping patients safe when they transfer between care providers – getting the medicines right.’ ‘My Medication Passport’ has been of particular value to vulnerable patient groups including those with multiple long-term conditions and learning disabilities, and for people using a wide range of health and social care services.

Initial qualitative research has been carried out amongst 133 patients from three Acute Trust sites and one GP site about four to six weeks after passport issue:
- 70 percent said that they carried the MMP out with them
- 60 percent reported having used their MMPs
- For those who had shared their passports, the most common people they shared it with were their GP (n=24) or a hospital doctor (n=24).

Media coverage and award
The launch of My Medication Passport received extensive media coverage and it has been endorsed by Simon Denegri, the Chair of INVOLVE and the NIHR National Director for Public Participation and Engagement in Research. It has also won awards, such as the National Pharmacy Forum award for the Best Industry-NHS Partnership in 2013. The dissemination of the MMP has involved Boots, the London Ambulance Service, Mencap, Carers UK, Age UK, The Metropolitan Police and the Terence Higgins Trust.

Project summary
- **What?** - This project represents the creation, design and distribution of an easy-to-use passport for patients to carry, outlining their medication profile.
- **Why?** - Patients identified the need for an easy-to-carry document that could be used in all dealings with health professionals.
- **How?** - The MMP was developed in conjunction with patients and was tested on patient groups before distribution.

Result
Over 100,000 My Medication Passport booklets have been ordered by pharmacies, hospitals, charities, GP practices, nursing homes and patients across the United Kingdom and the MMP won a National Pharmacy Forum award.
Supporting vulnerable people
New wave of CLAHRCs

As part of the second wave of funding, the NIHR agreed to fund 13 CLAHRCs. All of the original CLAHRCs were re-funded, either individually or as part of new, larger merged CLAHRCs, and are continuing their programme of innovative research, building on previously successful projects as well as developing new, innovative areas of focus. Alongside those already in existence, six new CLAHRCs were funded and commenced their work in January 2014. Already, these CLAHRCs have begun to show promising signs of major breakthroughs in research.

Emergency Multidisciplinary Unit (EMU) - CLAHRC Oxford

Study points the way to a revolution in acute care

New Emergency Multidisciplinary Units to be rolled-out as a means of preventing emergency hospital admissions

Study team developing commissioning models
A major challenge for the NHS is reducing acute admissions to hospitals, particularly amongst the frail elderly. The Emergency Multidisciplinary Unit (EMU) treats patients with acute medical illness without using hospital beds. The EMU won the Guardian Healthcare Innovation Award for Service Delivery in 2013 and it is hoped that it will become the national model for the future of emergency care for older people. Patients can be referred to the EMU by their GP, a community nurse or an ambulance paramedic.

Study aims
The aim of the EMU is to provide assessment and treatment for adults with sub-acute care needs, as close to patients’ homes as possible. Providing medical, nursing and therapist assessments and treatments, the units are designed to offer patients a faster and more convenient alternative to admission to an acute hospital.

Partnership working
CLAHRC Oxford has been collaborating with NIHR Oxford Biomedical Research Centre, the NHS England Pricing Unit, the health service regulator Monitor and Deloitte Consulting to develop a commissioning model that supports the setting up and running of acute ambulatory care units. This work will provide decision support for commissioners and providers as they develop services. The Project lead Professor Daniel Lasserson has been invited to an ‘Early Insights Workshop’ hosted by Monitor, to further develop the simulation models that will support commissioning acute ambulatory care.

In addition, CLAHRC researchers are undertaking projects to investigate the impact of community-based acute ambulatory care on patient and carer experience, clinical outcomes, provider activity and combined health and social care costs.

The outcomes of this work could help revolutionise the delivery of acute care, as well as potentially save the NHS millions in the costs of acute admissions to hospitals and help deliver the NHS Five Year Forward View.

Project summary
- **What?** The Emergency Multidisciplinary Unit (EMU) are units set up to assist the care of acutely ill patients in a way that prevents unnecessary hospital admissions.
- **Why?** Reducing acute admissions of frail elderly patients is a priority for the NHS.
- **How?** The project involves working in partnership with other agencies to develop a commissioning model that supports the roll-out of the EMUs.

Result
We expect the result to revolutionise the delivery of acute care as well as potentially save the NHS millions.
Evaluating the impact of early intervention in psychosis services - CLAHRC Oxford

Considerable savings probable, as a result of study improving quality of care for psychosis patients

Research likely to lead to new national guidelines

Working in collaboration with Janssen Healthcare Innovation (JHI), CLAHRC Oxford have provided clear evidence that treatment of psychosis patients aged between 16 and 35 under Early Intervention in Psychosis (EIP) services will save considerable amounts compared to the non-EIP treatment. CLAHRC estimates the savings at £5,200 per patient per year, with significantly fewer mental health bed days and reduced attendance at A&E, as well as better employment and educational opportunities for those being treated under EIP services.

In recent years EIP services have been lost or downgraded. Using Janssen Healthcare Innovation’s own method for case identification and data linkage, CLAHRC Oxford used a combination of routine mental health system (MHMDS) and secondary care Hospital Episode Statistics (HES) data, collected over a three year period, to gain an accurate map of health service utilisation by psychosis patients across Thames Valley’s population of 2.2 million. Researchers identified 4,643 patients with psychosis aged 16 to 35 in the area, and found 947 (20 percent) were treated under an EIP service during that time. Comparisons were made between the rates of admission to mental health hospitals, length of stay, employment outcomes and A&E attendances between those who were treated in an EIP service and those who weren’t. In addition to the considerable cost savings identified, researchers found that occupational outcomes were also significantly improved, with 38 percent of young people under EIP in employment or education, compared with 25 percent of those not under EIP. These findings are leading to the development of new national guidelines.

The project lead, Professor Belinda Lennox, is a member of the NICE guideline development group (hosted by the National Collaborating Centre for Mental Health) that is further developing the Referral to Treatment and accompanying guidance. CLAHRC researchers were also invited by NHS England to organise a national expert reference group and take the lead on drafting the first mental health Referral to Treatment Time for EIP, submitted to the Health and Social Care Information Centre (HCSIS) in December 2014.

Project summary

- **What?** - This project has looked at the cost savings of using Early Intervention in Psychosis (EIP) in treatment of psychosis patients aged between 16 and 35.
- **Why?** - The treatment of psychosis represents a major challenge for the NHS.
- **How?** - Data was collected on psychosis patients, comparing the outcomes of those who used EIP and those who didn’t.

Result

The research estimated that the use of EIP saved the NHS £5,200 per patient per year, as well as improved the outcomes for patients.
New wave of CLAHRCs
Evaluation of Haringey welfare hubs - CLAHRC North Thames

Study shows value of welfare hubs at GP surgeries

Evaluation work supporting the roll-out of welfare support at surgeries
New wave of CLAHRCs

CLAHRC North Thames has been working with Haringey Council to evaluate a welfare hub service within GP surgeries which supports patients with low income and debt. Haringey CCG had noticed a large volume of GP consultations were related to benefit claims and social problems arising from low income and debt. During 2013 and 2014, Haringey CCG established ‘Welfare Advice Hubs’ in five GP surgeries, where benefit advisors from Haringey Citizens Advice Bureaux provided one-to-one advice sessions to the most deprived residents in Haringey. Clients were either referred by GPs or were self-referred. In total, during the financial year 2013 to 2014, the advisors saw nearly 850 individual clients.

Haringey Council then approached CLAHRC North Thames and asked them to carry out an evaluation of the project. The evaluation calculated that over a five month period in 2014, £137,748 of additional income was generated for clients. This figure didn’t include the value of debts that were rescheduled or removed, or avoided fines or repossessions, so it is likely that the actual savings were even greater. The cost of providing the service over the evaluated period was £41,000. The evaluation identified areas of improvement for the service, including increasing awareness of the service amongst GPs, and improving communication between benefit advisors and GPs.

Next steps

Following the evaluation, Haringey CCG continued to fund the Welfare Advice Hubs Service project and Haringey Council agreed to support a larger, summative evaluation of the project. This evaluation is now underway and involves a CLAHRC researcher, who is embedded within the Public Health Team at the London Borough of Haringey, co-developing the framework and carrying out the evaluation.

Project summary

- What? - This project is an evaluation of the value of welfare advice service placed at GP surgeries.
- Why? - Haringey CCG discovered that a large volume of GP consultations were to support patients with low income and debt.
- How? - CLAHRC North Thames carried out an evaluation of a pilot welfare advice service at Haringey GP surgeries to assess their value.

Result

CLAHRC North Thames estimated that over a five month period in 2014, £137,748 in additional income was generated for clients with low-income and debt. This finding secured ongoing funding for the service from the CCG, which will help continue to generate income for those most in need. This valuable service can be rolled out across the UK.
Outcome Assessment and Complexity Collaborative (OACC) - CLAHRC South London

Study taking lead in developing outcome measures for end of life care

Team working closely with Hospice UK and NHS England to standardise care
Researchers at CLAHRC South London, based at the Cicely Saunders Institute at King’s College London, are taking a lead role in introducing a standardised set of outcome measures into the day-to-day work of palliative and end of life services. This means that patients, the public, commissioners, funders and policymakers can, for the first time, quantify the difference palliative and end of life services make. This is particularly relevant when there are increasing numbers of people who have advanced illness and multiple long-term conditions.

The Outcome Assessment and Complexity Collaborative (OACC) comprises six short outcome measures, each one taking just a couple of minutes to complete. These evidence-based outcome measures capture information about physical symptoms such as pain and breathlessness, emotional issues such as anxiety and depression, and other patient prioritised concerns such as information needs, practical needs and family support needs.

Two end of life care nurses known as Quality Improvement Facilitators (QIFs) have worked with provider organisations in south London to help them implement the OACC measures. So far, eight provider organisations in south London are now routinely using the OACC outcome measures. The two QIFs are continuing to work with south London organisations, to help them become OACC-registered.

The CLAHRC South London team are now working with Hospice UK, provider organisations across England, Public Health England and NHS England to help facilitate the widespread adoption of palliative and end of life care outcome measures into routine practice.

Project summary

- **What?** - This project is the creation and evaluation of a standardised set of outcome measures in palliative and end of life care.
- **Why?** - End of life care is a critical element in general NHS health and social care, where sensitivity is essential.
- **How?** - The Outcome Assessment and Complexity Collaborative (OACC) is a set of six short outcome measures. Two end of life care nurses have been working with provider organisations in south London to help them implement these OACC measures.

Result

Eight provider organisations in south London are now routinely using the OACC outcome measures and the research team are working with Hospice UK, provider organisations across England, Public Health England and NHS England to help implement OACC into regular practice.
CLAHRC Wessex is leading a revolutionary change in the capacity to assist people in managing long-term conditions through the use of support networks. In recent years it has been recognised that social support and the effective use of resources can help patient self-management and reduce isolation. Researchers at CLAHRC Wessex have shown how networks can be effectively used as a substitute for formal care and can produce substantial savings. This led to the development of GENIE: a web-based tool which aims to connect people with long-term conditions to local resources, helping them to live healthier lives.

The GENIE tool has been implemented in the north-west of England across 24 GP practices. More recently, the tool has been implemented across the Isle of Wight and Dorset, as well as by Solent NHS Trust where it is being used by mental health services. Further afield it is being implemented in community and primary care settings in Norway, the Netherlands, Greece, Bulgaria, Spain and Canada.

Alongside this implementation, CLAHRC Wessex, in collaboration with CLAHRC Greater Manchester, has evaluated the tool’s impact on NHS costs and patient outcomes. The evaluation found that the tool saved £175 in the cost of treating the average patient with long-term conditions, primarily in reduced overnight hospital stays. There is also evidence of significant improvement in patient outcomes, such as better blood pressure control. Finally, GENIE is shown to significantly improve the quality of life for those using it.

These findings are informing the next phase of work on the GENIE tool at CLAHRC Wessex, where the project team are working with NHS England and the Coalition for Collaborative Care to use GENIE to strengthen existing individual and community networks and improve patient engagement.

Project summary

• What? - The GENIE tool is a web-based networking tool that uses social support and targeted resources to assist people with long-term conditions.
• Why? - There has been a dramatic increase in the numbers of people with long-term conditions, with further projected increases of people who live alone trying to manage one or more long-term condition.
• How? - Researchers at CLAHRC Wessex have shown the importance of support networks in helping manage long-term conditions.

Result

Evaluation work has shown that use of the tool reduces patient costs by an average of £175 per patient and improves patient outcomes and the tool is currently being rolled out to a number of sites across the world including sites in mainland Europe and North America.
New wave of CLAHRCs
There are 13 CLAHRCs.

- NIHR CLAHRC East of England
- NIHR CLAHRC East Midlands
- NIHR CLAHRC Greater Manchester
- NIHR CLAHRC North Thames
- NIHR CLAHRC North West Coast
- NIHR CLAHRC Northwest London
- NIHR CLAHRC West Midlands
- NIHR CLAHRC Yorkshire and Humber
Greater Manchester Stroke Assessment Tool (GM-SAT)
Project contact: Katy Rothwell (Katy.Rothwell@nhs.net)

Stoke pathways
Project contact: Jo Shuttleworth (j.shuttleworth@exeter.ac.uk)

Characteristics of general practices associated with emergency admission rates to hospital: a cross-sectional study
Project contact: Richard Baker (rb14@le.ac.uk)

Regional implementation of STarTBack – an approach to manage and treat people with back pain according to the patient’s prognosis
Project contact: Nathalie Mailliard (N.Maillard@warwick.ac.uk)

Tranexamic Acid (TXA) in trauma
Project contact: Jo Shuttleworth (j.shuttleworth@exeter.ac.uk)

Expanded Newborn Screening (ENBS)
Project contact: Jim Bonham (jim.bonham@sch.nhs.uk)

Detection of autism spectrum conditions
Project contact: Angela Browne (angela.browne@cpft.nhs.uk)

Transfer of care at 17 – An investigation of factors which influence two groups of young people facing transitional care
Project contact: Angela Browne (angela.browne@cpft.nhs.uk)

A ground-breaking early intervention service in Birmingham to offer mental health services for young people, 0-25 years
Project contact: Nathalie Mailliard (N.Maillard@warwick.ac.uk)

Individual placement and support
Project contact: Justine Schneider (justine.schneider@nottingham.ac.uk)

Electronic Frailty Index (EFI)
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My Medication Passport
Project contact: Sue Barber (s.barber@imperial.ac.uk)

Emergency Multidisciplinary Unit (EMU)
Project contact: Daniel Lasserson (dan.lasserson@phc.ox.ac.uk)

Evaluating the impact of early intervention in psychosis services
Project contact: Belinda Lennox (Belinda.lennox@psych.ox.ac.uk)

Evaluation of Haringey welfare hubs
Project contact: Charlotte Woodhead (c.woodhead@ucl.ac.uk)

Outcome Assessment and Complexity Collaborative
Project contact: Jane Stafford (jane.stafford@kcl.ac.uk)

GENIE: Network tool revolutionising support for long-term condition management
Project contact: a.e.rogers@soton.ac.uk
Further recommended reading on our studies

CLAHRC East of England

Detection of autism spectrum conditions


Transfer of Care at 17 – An investigation of factors which influence two groups of young people facing transitional care


CamFilmConsortium. *My Name is Joe.* [video file] 2012. Available from: https://www.youtube.com/watch?v=ArBjWe3IWs0 [Accessed 12th August 2015]


CLAHRC East Midlands

Leicester Self-Assessment (LSA) and Walking Away from Diabetes


Improving the identification and care of patients with kidney disease


CLAHRC Greater Manchester

**Improving the identification and care of patients with kidney disease**


**Greater Manchester Stroke Assessment Tool (GM-SAT)**


**CLAHRC South West Peninsula**

**Stroke pathways**


**CLAHRC Wessex**

**GENIE: Network tool revolutionising support for long-term condition management**


**CLAHRC Northwest London**

**My Medication Passport**


Further recommended reading on our studies

**CLAHRC West Midlands**

**A ground-breaking early intervention service in Birmingham to offer mental health services for young people, 0 to 25 years**


**CLAHRC Yorkshire and Humber**

**Expanded Newborn Screening (ENBS)**


**Electronic Frailty Index**


**Regional implementation of STarT Back – an approach to manage and treat people with back pain according to the patient’s prognosis**


