Collaboration for Leadership in Applied Health Research and Care
Celebrating 10 years of NIHR

IMPROVING HEALTH AND WEALTH OF THE NATION
Foreword

The National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), are delighted to be part of the NIHR’s tenth anniversary celebrations. The NIHR’s mission is: “To provide a health research system in which the NHS supports outstanding individuals working in world-class facilities, conducting leading-edge research focused on the needs of patients and the public”. The NIHR CLAHRCs are proud to contribute to this mission through our research and research capacity building within the NHS.

In 2008, the NIHR agreed to fund 9 CLAHRCs across England with a specific aim: to develop and conduct applied health research relevant across the NHS, and to translate research findings into improved outcomes for patients. Each individual CLAHRC does this by creating linkages and partnerships between the applied health researchers who conduct the research, and those who use the research in the community. The implementation of world-class research in the NHS and the community, will have an impact on patients’ lives and the quality of health and care services provided to the population. 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. These 13 CLAHRCs work together as a college ensuring that we share our learning across the country, working in a cohesive and collaborative way.

CLAHRCs bring their academics together with NHS providers and commissioners, local health and social care organisations, industry and third sector partners, health research infrastructures, and local Academic Health Science Networks (AHSNs). The CLAHRCs 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. All of the CLAHRCs conduct applied health research that is focused on chronic disease and public health interventions.

The projects described here introduce you to some of the highlights of the CLAHRC research programme. These projects have been selected for their excellence and their current and likely future impact. The selection includes examples of CLAHRCs working individually with their local partners, as well as examples of cross-CLAHRC collaboration. A recent review showed that CLAHRCs have collaborated on 71 projects/major pieces of work. We anticipate that these collaborations will grow exponentially in the future, building upon successful research production and implementation across the country. NIHR CLAHRC research is saving the NHS millions and helping to save and improve the lives of patients, carers and the public across England and further afield.

We would like to thank all of the CLAHRCs for sharing their work, and the staff who supported the development of this brochure. We would particularly like to thank Professor Kamlesh Khunti, Dr Kevin Quigley and Michael Bonar of CLAHRC East Midlands for co-ordinating, development and production of this work; Professor Richard Hobbs of CLAHRC Oxford and Professor Ruth Boaden of CLAHRC Greater Manchester for helping review the projects.

All of us at the NIHR CLAHRCs are looking forward to continuing our work and significantly improving patient access and outcomes.

CLAHRC Directors
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
CLAHRC South West Peninsula (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.

CLAHRC South West Peninsula 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?** CLAHRC South West Peninsula 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?** CLAHRC South West Peninsula 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.
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 up to £750,000 over four years for one CCG
Cardiovascular disease related to Chronic Kidney Disease (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 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. The first project 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 a 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 230 GP practices across the UK, especially in Greater Manchester, the Midlands, North Wales and West Yorkshire. A further 60 practices are currently being supported by CLAHRC GM to improve care and increase those with blood pressure managed to NICE targets.

In addition to its original use, the IMPAKT tool has recently been utilised to conduct an audit across Greater Manchester and Eastern Cheshire (with a 60% coverage rate), in collaboration with the Greater Manchester Academic Health Science Network (GM AHSN). The audit showed that across the region there were 16,483 patients not coded as having CKD despite their clinical status, that could be diagnosed with CKD immediately, and 43,207 who warranted further investigation for CKD based on previous low eGFR readings. Furthermore, of the 312 practices audited, 28-35% of coded cases of CKD (stages 3-5) were not managed to NICE CKD guidelines. CLAHRC GM is currently in consultation with Clinical Commissioning Groups across the region to explore options for potential future improvement work in light of these findings.

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 study

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. The latest evaluation work estimates that treating 35 CKD patients to BP targets over four years would result in one cardiovascular event being prevented. The cost to the NHS of managing a stroke, for example, was estimated to be £35,868 in 2008. Therefore, given that 345 extra patients reached BP targets during this project, 9 cardiovascular events may have been prevented. If these were all strokes, then a cost saving of circa £320,000 would be achieved. It is also estimated that if the findings of the project were replicated in all the practices of WLCCG this saving could be as high as £750,000.

CLAHRC GM plan to do a similar analysis of economic impact across GM in the next stage of their work, which is likely to be ten times the size of that already identified from the work in West Leicestershire because of the number of people identified as having CKD who are not being treated to guidelines.

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).
- **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.
Short questionnaire revolutionises early identification of diabetes – just seven questions that assess your risk

Diabetes UK, Tesco and Boots amongst those using tool

1,100,000 have taken the test online with an estimated 67,000 successfully diagnosed
The identification and management of type 2 diabetes represents one of the greatest challenges facing the NHS, with the numbers developing the condition rising over the last few years. In 2010 an estimated 3.1 million in the UK had diabetes, and on current projections that figure will rise to 4.6 million by 2030; 90 percent of which will be type 2 diabetes. Therefore identifying those at risk from developing diabetes is a key priority for the NHS. CLAHRC East Midlands (EM) (formerly CLAHRC LNR) has developed a number of projects focusing on the identification of those at-risk from the disease, as well as prevention programmes to try to prevent the onset of full type 2 diabetes.

The Leicester Self-Assessment (LSA) is a short questionnaire of seven questions which provides a quick and easy way for people to see how at-risk they are of developing type 2 diabetes, taking into account factors like family background and ethnicity. The LSA was developed with support from CLAHRC EM, in partnership with Diabetes UK. The questionnaire is available both in paper form and online at the Diabetes UK website, where it has been taken by more than 1.1 million people. It is also widely used by Boots and Tesco chemists and has formed part of the biggest diabetes awareness campaign to date, run by Diabetes UK.

Building on this success CLAHRC EM in collaboration with the East Midlands Centre for Black and Ethnic Minority Health has begun a programme of translating the LSA into a range of languages to assist south Asian communities who are particularly susceptible to developing type 2 Diabetes. The project has already been translated into Guajarati and Bengali and work has commenced on a Punjabi translation. This will allow people from those communities to access the Questionnaire and assess their personal risk of developing type 2 diabetes.

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 begin a walking programme to improve their fitness and reduce their level of risk.

**Result**

An estimated 67,000 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.

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

Innovative stroke assessment tool developed to streamline care

Over 12,500 assessments already carried out
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

GM-SAT is now used across the country and is the only tool used for post-stroke assessment by the Stroke Association. They have carried out more than 12,500 assessments to date in areas where they are commissioned to do so, with the number of assessments having grown year on year since its introduction as shown in the table across.

In addition, in 2016, the GM-SAT is known to be used by providers other than the Stroke Association in twelve of the fifteen CCGs that commission six month post-stroke reviews in North West England.

The GM-SAT 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.

Finally, CLAHRC GM is developing the tool in partnership with the Stroke Association for use in care homes.

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 across England 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.
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
Autism Spectrum Conditions (ASC) are characterised by difficulties in social interaction, communication, and adapting to change, alongside unusually narrow interests and strongly repetitive behaviour. Diagnosis of ASC can be a lengthy process as it varies greatly across individuals, including the age at which symptoms first appear. This CLAHRC East of England (formerly CLAHRC Cambridge and Peterborough) research study addressed the need for a brief screening tool for primary care professionals to aid their decision-making about whether to refer a patient to a specialist autism centre for a full diagnosis of ASC.

Study results

The aim of the study was to identify 10 items with good test accuracy, on autism screening tools for four different age groups: the Autism Spectrum Quotient (AQ) in the Adult, Adolescent and Child versions, and the Quantitative Checklist for Autism in Toddlers (Q-CHAT). 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 screening tools. Ten items were selected in each screening tool for each age group to produce the AQ-10. At a cut-point of 6 on the AQ-10 adult, sensitivity was 0.88, specificity was 0.91, and positive predictive value (PPV) was 0.85. At a cut-point of 6 on the AQ-10 adolescent, sensitivity was 0.93, specificity was 0.95, and PPV was 0.86. At a cut-point of 6 on the AQ-10 child, sensitivity was 0.95, specificity was 0.97, and PPV was 0.94. At a cut-point of 3 on the Q-CHAT-10, sensitivity was 0.91, specificity was 0.89, and PPV was 0.58. Internal consistency was > 0.85 on all measures. These short measures have potential to aid referral decision-making for specialist assessment and should be further evaluated in the context in which they are intended to be used.

Project summary

- **What?** - The Red Flags are brief checklists/screening tools for Autism Spectrum Condition. There is one checklist for each of four age groups: toddlers, children, adolescents and adults.
- **Why?** - The diagnosis of Autism spectrum condition (ASC) can be a lengthy process so a tool that can help speed up diagnosis will enable patients to access the support they require earlier.
- **How?** - The research identified 10 items with good test accuracy in each screening tool for each of four age groups to produce a short version or a ‘red flag’ screening tool.

Result

The study has produced much-needed screening measures for frontline clinicians where one has not previously been available. The AQ 10 will enable a faster route to assessment and consequently enable those with a full diagnosis of ASC to obtain the support they require.
GENIE: Network tool revolutionising support for long-term condition management - CLAHRC Wessex

Radical networking tool improving patient outcomes and saving costs

GENIE networking tool already implemented over multiple sites across the UK, Europe and Canada

CLAHRC Wessex working with NHS England to extend the GENIE tool’s functions and reach

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 with users taking up new activities identified through the tool.

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.
Expanded Newborn Screening (ENBS) & Non-Invasive Prenatal Testing (NIPT) for trisomies - CLAHRC Yorkshire & Humber and CLAHRC West Midlands

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 and using Non-Invasive Prenatal Testing (NIPT) for detecting trisomy disorders is safer, more accurate and will reduce the risk of test-related miscarriage.

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 was 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.

A review and meta-analysis, supported by CLAHRC West Midlands, was completed to consider the accuracy of Non-Invasive Prenatal Testing (NIPT) to assess the risk of the three trisomy disorders in first trimester pregnancies. NIPT uses a sample of cell-free foetal DNA (cffDNA) from the pregnant mother’s blood to assess the risk of Down’s, Edwards and Patau syndrome. These syndromes are all caused by the presence of an extra copy of a chromosome, a trisomy, which can be detected by the test. Findings from this study, published in BMJ Open, demonstrated that NIPT has high sensitivity and very high specificity and can contribute to national screening programmes, but they cannot be considered diagnostic.

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.

Recently the National Screening Committee has endorsed the new NIPT test to screen for Down’s syndrome. The test is used widely across the world, for example it has been rapidly adopted in the USA, with a corresponding decrease in combined test and invasive testing, such as amniocentesis or chorionic villus sampling. A parallel economic evaluation model suggests that the addition of this test was ‘cost neutral’, but that the introduction of the test would result in a reduction in number of test-related miscarriages. This is because fewer women would be offered an invasive test since the accuracy of the NIPT is higher than that of the traditional combined tests.

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. Non-Invasive Prenatal Testing (NIPT) is a safer, more accurate way of screening for Down’s, Edwards and Patau syndrome in the first trimester of pregnancy.

- **Why?** - Expanding the newborn screening saves infant lives as well as being cost-effective and introducing the NIPT is ‘cost neutral’ and would result in a reduction in number of test-related miscarriages.

- **How?** - The project involved screening 430,000 infants to justify a national screening and the NIPT project involved an evidence synthesis to provide information on the accuracy of the test to inform the National Screening Committee decision to introduce in to the NHS.

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.

The NIPT final report was presented to the National Screening Committee, who have now endorsed the uses of the test to screen for Down’s syndrome.
**My Medication Passport (MMP) - CLAHRC Northwest London**

**Patients lead the development of a Medical Passport**

Over 1,000 pocket book passports distributed after design

Passport won National Pharmacy Forum award

---

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 124,000 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.
Encourage patients to take control of their medications with My Medication Passport.

It has been developed by patients for patients.

It is available as a paper booklet and also as an app for smartphones and tablets.

In order to encourage the most appropriate patients to access the passport, we would like your help in disseminating the passports.

For information on how the passport can be downloaded, please visit: [Passport Website URL]
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.

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).

Regional roll-out

In early 2014, the West Midlands Academic Health Science Network (WM AH SCN) 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. 14 CCGs in the west midlands have adopted the STarT Back approach. STarT Back has also been implemented by the private healthcare provider AXA PPP.

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.
First episode psychosis affects over 8,000 people in England each year; most of them are teenagers and young adults on the cusp of independent lives. The Early Intervention in Psychosis Access and Waiting Time Standard was introduced by NHS England in April 2016: half or more of all patients with first episode psychosis must be assessed and taken on by a specialist early intervention in psychosis service within two weeks of referral. This is the first access and waiting time standard introduced in mental health.

Widely undertaken by several CLAHRCs has been instrumental in informing the standard and ensuring its national implementation. CLAHRC project leads have been on the NICE guideline development group (hosted by the National Collaborating Centre for Mental Health), the NHS England Expert Reference Group for Early Intervention, and have led preparedness programmes in NHS Midlands and East, and South regions.

NIHR CLAHRC West Midlands demonstrated that the target and standard are needed. The longer the duration of untreated psychosis (DUP) the worse the outcome for patients. The principle is no different from cancer where access and waiting time targets have improved outcome. Young people who present with first psychotic symptoms experience long treatment delays due to bottlenecks within specialist mental health services. Even when people with psychosis are seen by mental health services there can be delays during which their psychosis is untreated by antipsychotic medication. This is why the Access and Waiting time standard starts the clock as soon as the referral is received anywhere within a mental health trust, rather than when the referral reaches the EIP service. CLAHRC WM went on to show that treatment delay could be reduced using a youth care pathway within adult services for those up to 25yrs. This inspired a complete redesign of services for young people in Birmingham between 0 and 25 years of age to improve access for all diagnoses. The model has also been adopted by Norfolk and Suffolk, again stimulated by CLAHRC work.

NIHR CLAHRC East of England have developed the on-line PsyMaptic prediction tool (www.psymaptic.org), derived from epidemiological studies in London, Bristol, Nottingham and East Anglia. PsyMaptic provides psychosis incidence prediction for each locality across England and is the basis of Public Health England’s www.Fingertips.phe.org.uk health indicators gazetteer entry on first episode psychosis. Health Education England is currently using these predictions in their Workforce Planning Guidance. PsyMaptic and Fingertips have been included in the NHS England Access and Waiting Time Standard Implementation Guide and has directly informed commissioning and workforce development plans across England.

But is this good value for money? CLAHRC Oxford, in collaboration with Janssen Healthcare Innovation (JHI), have undertaken a health economic analysis of cost savings associated with Early Intervention in Psychosis (EIP) services as implemented in the Guide. Those in EIP services spent an average of 15 fewer days admitted to hospital each year; they were 117% more likely to become employed, and 52% more likely to be housed in independent accommodation compared with those cared for by standard services.

The annual cost saving to the NHS per person currently treated with EIP is £4,031. If all eligible patients in England were treated by EIP services, the NHS would save £33.8m per year. Further savings would also be gained from reduced welfare payments and productivity gains, resulting in total cost savings to the economy of £57.5 million per year if EIP were fully implemented.

The Early Intervention in Psychosis Access and Waiting Time Standard should ensure these savings are realised while improving the lives of thousands of people.
Project summary

- **What?** - These NIHR CLAHRC projects have supported the development and implementation of new Access and Waiting time standards for Early Intervention in Psychosis (EIP) in England.
- **Why?** - Improving access to Early Intervention in Psychosis services is a health and economic priority for the UK; early identification and treatment improves outcomes and saves money.
- **How?** - Clinical and epidemiological research, and health economic evaluation.

Result

Improved health and social outcomes for over 8,000 people in England each year, and associated cost savings of £57.5M per year.

Example of PsyMaptic output included in the Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence (Chapter 7, p122; figure 7.5)  
Introducing standardised outcome measures for palliative and end-of-life care – 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.

What does this mean in practice?
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.

How do the new outcome measures work?
Known as the Outcome Assessment and Complexity Collaborative (OACC), the project has selected/developed six short outcome measures, each one taking just a couple of minutes to complete. These evidence-based outcome measures capture information about patients’ physical symptoms, such as pain and breathlessness, emotional issues, such as anxiety and depression, and other concerns which people with advanced illness have indicated are a priority, such as information needs, practical needs and family support needs.

Implementing the measures in south London
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, nine provider organisations in south London are now routinely using the OACC outcome measures. The two nurses are continuing to work with south London organisations, to help them become OACC-registered. These organisations collect outcomes data and return it to the central research team for analysis. This enables providers to better understand their patient population and to improve care.

Achieving impact: in the UK and internationally
The CLAHRC South London team are also now working with national organisations such as Hospice UK, provider organisations across England, Public Health England and NHS England as well as other healthcare organisations from countries abroad (New Zealand, Australia, Sweden, Canada and the USA), in order to help facilitate the widespread adoption of palliative and end-of-life care outcome measures into routine practice. Working with Hospice UK, the team has produced more than 200 OACC outcome resource packs to support palliative and end-of-life services to implement the outcome measures, which have been taken up across the UK. Since June 2015, they have also been running monthly national webinars to support the implementation of outcome measures, with a total of 306 participants to date (this figure does not include multiple attendees within a meeting room and so is likely to be even higher). They have also launched a series of ‘Train the Trainer’ workshops in conjunction with Hospice UK, to prepare other professionals across the sector to become trainers in using the OACC measures.

Finally, CLAHRC South London is working with CLAHRC North West London to roll out OACC in their area.

Project summary
- **What?** - This project is the creation and evaluation of a standardised set of outcome measures in palliative and end-of-life care services for the first time.
- **Why?** - End-of-life care is a critical element in general NHS health and social care, where sensitive and responsive care is essential for patients and their families.
- **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
Nine provider organisations in south London are now routinely using the OACC outcome measures. The CLAHRC South London team are working with national organisations such as Hospice UK, Public Health England and NHS England.

Study points the way to a revolution in acute care

Considerable savings probable, as lower back pain costs the NHS an billions per annum.
Low Back Pain (LBP) is one of the most common ailments and is the second most common cause for work place absence. Suffering can be long lasting and impact on people’s ability to work, function and enjoy life. In 2009, the direct costs of LBP were estimated at £2.8 billion, caused by the high volume of consultations in the NHS and pain relief medications.

The Back Skills intervention is a group-based intervention that teaches patients with low back pain cognitive behavioural skills to improve physical activity and reduce disability. General physical activity, and inactivity induced by back pain can actually prolong the lower back pain. Therapists undergo additional training in order to deliver the intervention, and whilst many use motivational techniques in their day to day practice, the cognitive behavioural skills used are novel.

The treatment is based on delivering treatments in groups as opposed to the more expensive option of individual treatment, and helping people to “undo” many of the unhelpful and unfounded beliefs people have about LBP, and to provide skills and motivation to become more active despite pain. This approach is based on rigorous clinical trials.

CLAHRC Oxford is leading the implementation of the programme nationally and internationally. The research is being directly translated into the NHS and wider healthcare community in the following ways:

- The development of an evidence-based training method that is targeted to overcome identified barriers to implementation;
- The national dissemination of a scalable training strategy that is evidence-based and enhanced to support implementation in clinical practice to a wide range of clinicians in the NHS;
- The dissemination of the patient perspective of receiving the Back Skills Training within the NHS; and
- To inform producers of clinical guidelines about the scalable training method that could be used as a tool to aid the implementation of their guideline-based recommendations for combined psychologically-informed and physical therapy services.

Evaluation work carried out by RAND Europe on behalf of the NIHR estimate that the potential cost savings to the NHS of this approach is over a £1 billion per annum in reduced waiting lists and NHS expenditure on physiotherapy and primary care.

**Project summary**

- **What?** - This project is a group based intervention to support patients in managing and recovering from Lower Back Pain.
- **Why?** - Lower Back Pain costs the NHS an estimated £2.8 billion per annum.
- **How?** - The project is working both directly with patients and therapists to introduce the group based model across the country.

**Result**

The project is currently being rolled out nationally across the NHS and RAND Europe have carried out an independent evaluation of the intervention and estimate that it could save the NHS more than £1 billion per annum.
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
- NIHR CLAHRC South London
- NIHR CLAHRC South West Peninsula
- NIHR CLAHRC Wessex
- NIHR CLAHRC Oxford
Project contact information

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

IMPAKT (IMProving Patient Care and Awareness of Kidney disease progression Together)
Project contacts: Nigel Brunskill (njb18@le.ac.uk) and John Humphreys (john.humphreys@srft.nhs.uk)

Leicester Self-Assessment (LSA) and Walking Away from Diabetes
Project contact: Laura Gray (lg48@le.ac.uk)

Greater Manchester Stroke Assessment Tool (GM-SAT)
Project contact: Katy Rothwell (Katy.Rothwell@nhs.net)

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

GENIE: Network tool revolutionising support for long-term condition management
Project contact: a.e.rogers@soton.ac.uk

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

Non-invasive prenatal testing (NPT) for trisomies
Project contact: Nathalie Mailliard (N.Maillard@warwick.ac.uk)

My medication passport
Project contact: Sue Barber (s.barber@imperial.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)

Improving outcomes for people with first episode psychosis
Projects Contacts: Nathalie Mailliard (N.Maillard@warwick.ac.uk), Angela Browne (angela.browne@cpft.nhs.uk) and Belinda Lennox (Belinda.lennox@psych.ox.ac.uk)

Introducing standardised outcome measures for palliative and end-of-life care
Project contact: Jane Stafford (jane.stafford@kcl.ac.uk)

Back Skills Training (iBest): Implementation of improved pathways of care for sub-acute and chronic back pain
Project contact: Alex Gardiner (alex.gardiner@phc.ox.ac.uk)