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Making the case for health literacy: East Midlands national demonstrator site 2016 - 17 Strategic report

**Prepared by Health Education England, NHS England,
Public Health England, and the Community Health and
Learning Foundation**

About Health Education England

Health Education England (HEE) exists for one reason and one reason only: to support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place.

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About NHS England

[NHS England](http://www.nhs.uk) leads the NHS in England. We set the priorities and direction of the NHS and encourage and inform national debate to improve health and care. We want everyone to have greater control of their health and wellbeing, and to be supported to live longer, healthier lives by high quality health and care services that are compassionate, inclusive and constantly-improving.

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About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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About Community Health and Learning Foundation CIC

Our purpose is the reduction of health inequalities throughout the UK by increasing the health literacy of individuals and communities. Our aim is that everyone has the ability to make informed decisions about their own health and wellbeing.

We approach this in a number of ways, such as:

- delivering health literacy training to Health and Social Care professionals
- delivering Community Health Development Programmes around health literacy
- developing and reviewing resources and training
- providing expert advice on Health Literacy to both providers and commissioners of health and care information and services
- supporting research and evidence based practice around health literacy
- providing expert advice to support national and local policy around Health Literacy by working with national partners including NHS England and Public Health England

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Background

The report, [Health Literacy Toolkit for Low and Middle-Income Countries](#) defines health literacy as:

‘Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions’

Health literacy is a two-sided issue, comprising both an individual’s ability to understand and use information to make decisions about their health and care, and a ‘systems issue’, reflecting the complexity of health information and the health care system. Those with low levels of literacy and numeracy, and therefore those likely to be most affected by health inequalities, also have a lower level of health literacy.

Being able to understand health information (and make subsequent decisions based on this understanding), and engage with health care structures and systems, is therefore vital to a person's wellbeing and their ability to take positive action. Evidence suggests that health literacy interventions at both system and practitioner level can impact positively upon health behaviours and health outcomes in those with low health literacy.

The impact for individuals with low levels of health literacy include:

- significantly more negative outcomes across a range of health indicators
- higher likelihood of developing negative health behaviours
- less likely to make informed lifestyle choices and engage with preventative programmes
- higher levels of morbidity and premature mortality
- less able to manage long term conditions
- less likely to adhering to medication regimes effectively.

A Public Health England commissioned report , [‘Improving health literacy to reduce health inequalities’](#) highlights the extent of the health literacy challenge, identifying that up to 61% of the working age population, in England, finds it difficult to understand health and wellbeing information.

The pilots described in this report ran in the East Midlands from April 2016– March 2017. These pilots were established in recognition of the need to develop and test system wide approaches to tackle the issues around health literacy. A suite of practical resources, the [Health Literacy Toolkit](#), has also been developed as a result of learning arising from the East Midlands work, to support adoption of similar approaches in other areas.

Evaluation data was collected prior to and immediately after the training sessions that formed part of the East Midlands work and again three months later, with the

aim of measuring the impact of training. A report highlighting key findings from this data will be available at the end of 2017 on [the CHLF website](#).

Introduction: the East Midlands demonstrator site

To address the challenges set out previously in this report, Health Education England (HEE), Public Health England East Midlands (PHE EM) and NHS England worked together during 2016 – 17 to fund a health literacy demonstrator site in the East Midlands. The delivery partner was Community Health and Learning Foundation (CHLF), a Voluntary Community and Social Enterprise Sector organisation.

The aim was to develop, test and evaluate a range of health literacy interventions, building approaches and a suite of practical resources, the [Health Literacy Toolkit](#), for dissemination across the country to support adoption elsewhere.

Activities fell under four strands:

- **Strengthening the system:** delivery of health literacy awareness training to staff in a variety of health, care and wider workforce settings, to increase health literacy awareness and skills and enhance practice.
- **Enabling supported self-care:** delivery of the national, evidence based health literacy programme, '[Skilled for Health](#)' to individuals with low health literacy, living with diabetes and identified as not managing the condition effectively.
- **Building the case for system efficiency:** utilising raw data produced as part of the demonstrator site implementation to identify the potential for health literacy interventions to deliver economic benefits to the system.
- **Embedding health literacy into professional development:** exploring the feasibility for development of an undergraduate Health Literacy module.

What we did

Strengthening the system

- Delivery of 15 Health Literacy Awareness training sessions to 239 staff in a variety of organisations and sectors including primary and secondary care; Fire and Rescue Service; JobCentre Plus; community and voluntary; local authorities and social care.

The aim of the sessions was to increase knowledge of what health literacy is, the impacts of low levels of health literacy on individuals and to support practitioners are aware of tools and techniques help to enhance health literacy approaches in their day to day delivery.

- Delivery of three [Royal Society of Public Health \(RSPH\) Level 1 Understanding Health Improvement](#) qualifications to 57 staff, to enable participants to feel more confident when talking with service users about their health and wellbeing.

Enabling supported self-care

- Delivery of the national, evidence-based health literacy programme, [Skilled for Health](#) to 56 individuals identified to have low health literacy, living with diabetes and not managing it effectively.

Skilled for Health was developed in 2003 as a cross-government / voluntary-sector initiative, with the aim of developing literacy, language and numeracy skills of adults alongside a better understanding of their health. It aims to enhance health literacy and reduction in [health inequalities](#).

Building the case for system efficiency

- Development of a set of metrics to measure impact of the training participation and provide some early indications of the efficacy of health literacy interventions in delivering system efficiencies. Evaluation had a longitudinal element, with a three month follow up planned for all participants.

Embedding health literacy into professional development

- Identification of a university to co-develop and trial a health literacy module for the clinical pharmacy and inter-professional education undergraduate programme. Development will be taken forward by CHLF during 2017-18.

Outcomes

Strengthening the system

Health Literacy Awareness training

Evidence from evaluations completed by participants in both the Health Literacy Awareness and RSPH sessions demonstrates that this type of training is relevant to a wide range of sectors, including 'traditional' health organisations – for example, GP surgeries, trusts – as well as to local authorities, voluntary and community organisations, Fire and Rescue Service and JobCentre Plus.

Participants reported:

- a greater understanding of health literacy, and of the way low levels of health literacy impact the people they provide services to
- a greater understanding of how health literacy is relevant to their particular roles
- enhanced confidence in speaking to others including colleagues, peers and patients/ clients about health literacy
- knowledge about – and commitment to - the changes needed to enhance practice and service delivery to those with low levels of health literacy
- knowledge of, and confidence in, incorporating the practical approaches and techniques taught as part of the sessions, to enhance practice or service delivery to those with low levels of health literacy

Additionally, participants attending the RSPH level 1 Award in Health Improvement training reported:

- increased knowledge across all five topic areas (healthy eating, physical activity, hydration, alcohol and smoking) and enhanced confidence in talking about these issues with service users
- Increased awareness about the services they could refer or signpost service users to.

Enabling supported self-care

This was the first time that Skilled for Health had been delivered exclusively to a group of patients with a long term condition. Evaluation showed that this was effective in improving participant's knowledge about leading a healthier lifestyle and ability to self-manage; enabling better medication management; and in accessing NHS services more appropriately.

Building the case for system efficiency

The raw data generated through delivery and evaluation of health literacy awareness and RSPH training will be utilised to provide some early indications about the extent to which health literacy interventions might support system efficiencies. Due to the scope of the pilot, it was not intended that the East Midlands work would develop fully fledged Return on Investment (ROI) tools. The need to build upon the East Midlands work to build the evidence base, and contribute to ROI approaches, is therefore reflected in the [Conclusion and recommendations](#) section.

Embedding health literacy into professional development

Following discussions with the clinical pharmacy and inter-professional education pharmacy postgraduate team at De Montfort University, Leicester, CHLF will develop an optional Health Literacy module for post-graduate students. The module will consist of 150 learning hours and will be aimed at post-graduate students taking courses in pharmacy, nursing and General Practice.

Toolkit

A suite of resources to support the development of effective approaches to health literacy in other areas was a key outcome of the national demonstrator site work. These [resources](#) can be readily adapted for local use.

Added Value outcomes

The work associated with the project generated significant interest in, and demand for, Health Literacy Awareness training from colleagues within Arm's Length Bodies (ALBs). Colleagues identified potential for such training to support transformational activities such as New Care Models, supporting self-management for people with long term conditions, Making Every Contact Count, care and support planning,

patient and public involvement, and the delivery of Sustainability and Transformation Plans.

To further scope and define this need, CHLF delivered two workshops during May 2017 to ALB audiences. These consisted of a short Literacy Awareness taster session, followed by focus group activity. Participants identified a number of areas for potential development and this forms a key recommendation under the heading of 'System Leadership', below. More detail about this particular work stream is available by [emailing NHS England](#).

Conclusion and recommendations

Whilst the numbers participating in the East Midlands Health Literacy pilot are relatively small, evaluation demonstrates the positive impact of health literacy interventions, and supports the case for further development and action. A series of recommendations for consideration is thus included below.

Training: practitioners

It is clear from the evaluation results that health literacy awareness training has the capacity to support practitioners in recognising the impacts of low levels of health literacy on those accessing and using services. The East Midlands work demonstrates that health literacy awareness training can support practitioners to make changes to their practice, thereby enabling more effective approaches that better support patients or service users – for example by providing information to patients in a more appropriate way, thereby helping individuals to manage their condition, or to make positive lifestyle changes.

To address issues of sustainability, and effectively scale up approaches that have been shown to be effective in the East Midlands, it will be important to consider how implementation can be achieved at scale and pace, whilst retaining the quality assurance aspect that contributed to the success of the East Midlands work.

Recommendations:

- Development of a Train the Trainer programme provided by appropriately experienced and qualified providers
- Development of an audit and quality assurance framework for health literacy training

Supporting self-care

Attendees to the Skilled for Health sessions improved their knowledge about leading a healthier lifestyle. They also felt more confident about their ability to self-care, manage their medication and access NHS services appropriately. This suggests that Skilled for Health has the capability and utility to significantly contribute to supporting people with / at risk of long-term or fluctuating conditions to both take action on

primary prevention but also to support self-care, management and secondary prevention.

Recommendations:

- Roll out the Skilled for Health Train the Trainer programme
- Test the Skilled for Health approach with other long-term condition patient groups for example mental health, musculo-skeletal (MSK) and within an Accountable Care System.
- Review and update the Skilled for Health resources so that it reflects current policies and practice.

Embedding Health Literacy into key national work programmes

Health Literacy is a key underpinning element of many health and wellbeing programmes. It can enable Empowerment, Patient Choice, Shared Decision Making, Making Every Contact Count and other programmes to meet key deliverables. The East Midlands demonstration work has “proved the concept” and now needs to be embedded into existing programmes.

It is also important to note that NHS England has recently published [“Next Steps on the Five Year Forward View”](#). This outlines objectives for the NHS to achieve in meeting its mandate and fulfilling the strategic vision of the [Five Year Forward View](#), and explores at a high-level how those objectives might be delivered. It also sets out the vision for [Accountable Care Systems](#) – an evolved form of STP – which will take on clear collective responsibility for resources and population health. They will comprise of hospital trusts, local authorities and CCGs and are seen as the future model for all health and social care organisations. Consequently, it is suggested that embedding health literacy into programmes in one of the emerging Accountable Care Systems would be a useful next step in scaling up the demonstration activity.

Recommendations:

- To further strengthen collective ownership around delivery of person centred approaches to support self-management and adoption of healthy lifestyle behaviours via interventions for those with low levels of health literacy, it is recommended that consideration is given, by the national [Health Literacy Collaborative](#), to embedding health literacy into work programmes such as [NHS Health Checks](#), Person Centred Care, Health Coaching, and [Making Every Contact Count](#). It is also recommended that this, initially, takes place in an [Accountable Care System](#).
- Consideration could also be given to embedding health literacy into other behaviour change interventions utilising the learning and [resources](#) in Skilled for Health.

Building the case for system efficiency

The raw data generated through delivery of health literacy awareness training to practitioners, and to patients, has demonstrated that such approaches are effective in enabling and supporting more effective practice, and in supporting behaviour change and enhanced ability to manage a condition.

There is a need to build upon the East Midlands work to develop more robust Return on Investment approaches, testing the efficacy of such training interventions to contribute to health and care system efficiencies and economies more widely, and developing an evidence base for such interventions.

Recommendation:

- That the national [Health Literacy Collaborative](#) considers how further multi partner research to develop Return on Investment approaches might be supported

System Leadership

The East Midlands work demonstrated that improving health literacy approaches has potential to contribute to the success of many transformation programmes. Effective health literacy approaches are also absolutely central to the delivery of person centred care, the MECC initiative and in supporting people to navigate the health and social care system. The workshops delivered to Arm's Length Body colleagues demonstrated there is an appetite to understand more about the potential of health literacy in this context.

Recommendation:

- That the national [Health Literacy Collaborative](#) considers how best to ensure that key ALB staff with a system leadership role can benefit from increased health literacy awareness

Dissemination

As demonstrated throughout this report, the learning arising from the East Midlands Demonstrator site has clear system wide applicability. There is a need to share the learning across the whole system.

Recommendation:

- That the national [Health Literacy Collaborative](#) considers how best to disseminate the learning from this pilot across the entire health and care system.