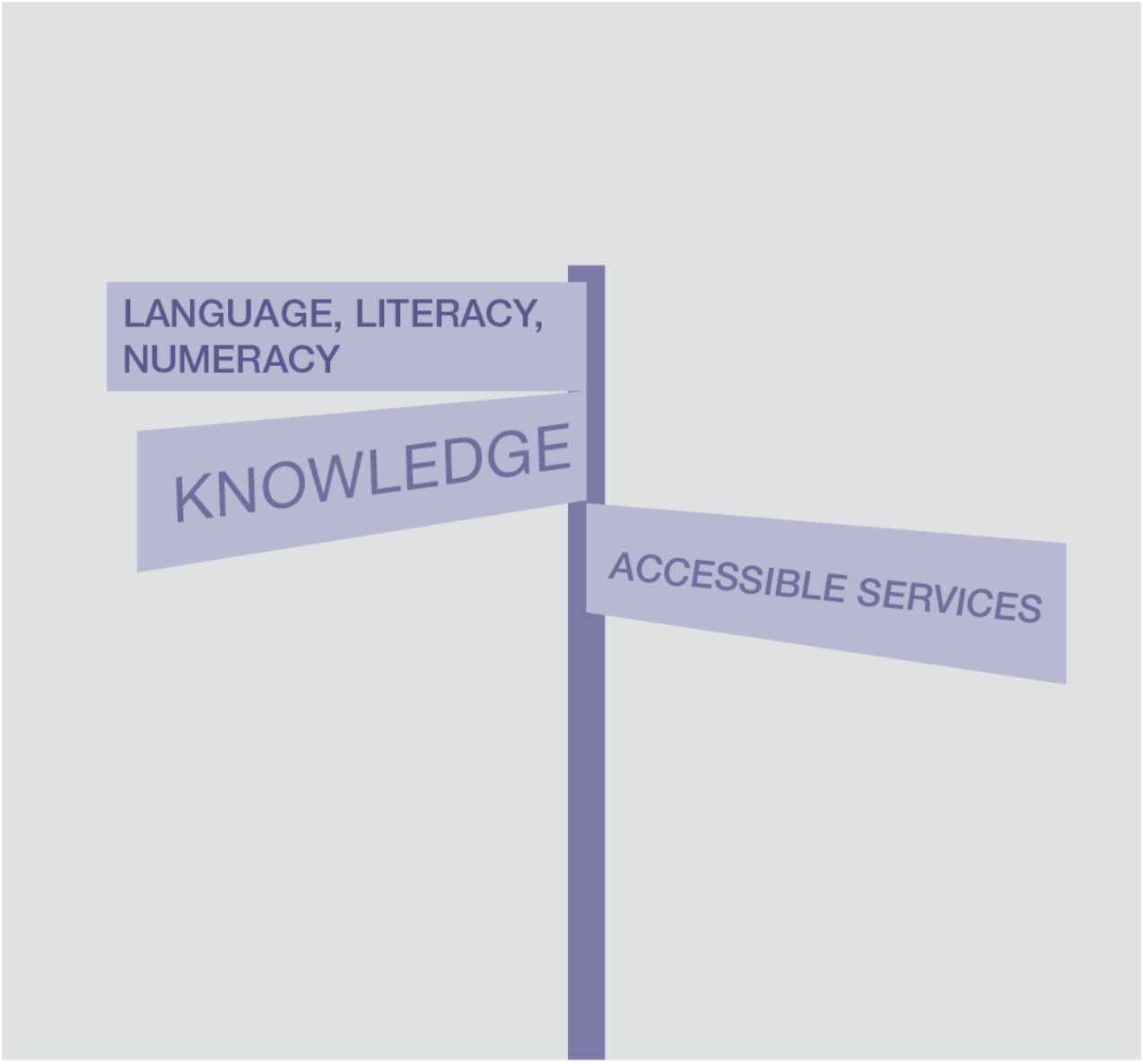
Public Health England

UCL Institute of Health Equity

Local action on health inequalities

Improving health literacy to reduce health inequalities

Practice resource: September 2015



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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.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

About the UCL Institute of Health Equity

The UCL Institute of Health Equity (IHE) is led by Professor Sir Michael Marmot and seeks to increase health equity through action on the social determinants of health, specifically in four areas: influencing global, national and local policies; advising on and learning from practice; building the evidence base; and capacity building. The Institute builds on previous work to tackle inequalities in health led by Professor Sir Michael Marmot and his team, including the Commission on Social Determinants of Health, Fair Society Healthy Lives (The Marmot Review) and the Review of Social Determinants of Health and the Health Divide for the WHO European Region.
www.instituteofhealthequity.org

About this practice resource

This practice resource was written for PHE by Jill Roberts of the UCL Institute of Health Equity. The author is grateful to PHE and to all of those who contributed and commented on the report:

Diederik Aarendonk, European Forum for Primary Care (EFPC), and its member Pharos, Dutch national centre of expertise on health disparities
Bola Akinwale, Public Health England
Jonathan Berry, Community Health and Learning Foundation
Laura Bolland, NHS England
Jennifer Cabe, Canyon Ranch Institute
Dr Ann Marie Connolly, Public Health England
Bob Gann, NHS England

Chloe Johnson, Public Health England
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Marie McWilliams, Older People's Advocacy Alliance (OPAAL)
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Professor Richard Osborne, Deakin University, Australia
Kath Parson, CEO of Older People's Advocacy Alliance (OPAAL)
Dr Joanne Protheroe, on behalf of Health Literacy Group UK
Professor DK Theo Raynor, University of Leeds
Blythe Robertson, Healthcare Quality and Strategy, Scottish Government
Professor Gillian Rowlands, International Union of Health Education and Promotion Global Working Group on Health Literacy, and on behalf of Health Literacy Group UK
Janet Solla, Community Health and Learning Foundation
Tim Warren, Healthcare Quality and Strategy, Scottish Government

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Contents

Key messages

1. The term ‘health literacy’ refers to people having the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services. Levels of health literacy are also influenced by the provision of clear and accessible health and social care services and information for all (service responsiveness).
2. Limited health literacy is linked with unhealthy lifestyle behaviours such as poor diet, smoking and a lack of physical activity and is associated with an increased risk of morbidity and premature death. People with limited health literacy are less likely to use preventive services and more likely to use emergency services, are less likely to successfully manage long-term health conditions and as a result incur higher healthcare costs.
3. An individual’s health literacy tends to be related to their social circumstances. Educational attainment strongly predicts good health literacy and people with limited financial and social resources are more likely to have limited health literacy. In turn, limited health literacy limits opportunities for vulnerable and disadvantaged groups to be actively involved in decisions about their health and care over the life course. This can undermine people’s ability to take control of their health and the conditions that affect their health.
4. Efforts to improve health literacy can have a range of benefits. They can increase health knowledge and build resilience, encourage positive lifestyle change, empower people to effectively manage long-term health conditions and reduce the burden on health and social care services.
5. The available evidence suggests that strategies to improve health literacy are important empowerment tools which have the potential to reduce health inequalities because the most vulnerable and disadvantaged people in society are at risk of limited health literacy and are known to have the poorest health outcomes.
6. Further large-scale, robust and clearly defined research is needed to better understand the effect of health literacy interventions on health inequalities. This should include research focused on how best to improve the health literacy of disadvantaged or vulnerable people, the effects of such initiatives on clinical and health outcomes over time and more research on cost-effectiveness.
7. Promising health literacy strategies to support people to take control of their, their families’ and their children’s health include:
    - health and social care service use of the simple and effective teach-back method to check service user understanding
    - an early intervention approach to health literacy – ensuring that promoting health literacy is fully integrated into early years and school curriculums, as well as in health and social care professional training

- community-based, peer-support approaches to health literacy that help to distribute health literacy among social networks
- empowering professionals through training, continued education and inter-disciplinary initiatives to improve health literacy and strengthen public–professional communications

8. Integrated, cross-sector working is needed to promote health literacy with professionals from health and social care services supported by those from other sectors such as child and adult education services and the third sector. Employers, communities and families also have a role to play in implementing successful health literacy initiatives.

Introduction

Literacy is the ability to read, write, speak and listen to a level that enables a person to communicate effectively, understand written information and participate fully in society.[1] Health literacy is people having the skills (language, literacy and numeracy), knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services. Levels of health literacy are also influenced by the provision of clear and accessible health and social care services and information for all (service responsiveness).[2]

In England, 42% of working-age adults (aged 16-65 years) are unable to understand or make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension.[3] Additionally, many health information producers say that they lack the tools and skills to develop appropriate resources and initiatives to meet the needs of people with low literacy.[4]

Limited (functional)[1] health literacy predicts poor diet, smoking and a lack of physical activity, independent of risk factors including age, education, gender, ethnicity and income[5-10], and is associated with an increased risk of morbidity and premature death in older adults independent of age, socioeconomic position, cognitive ability and pre-existing illness.[11-13] People with long-term conditions including depression, diabetes, stroke, and heart, kidney and musculoskeletal disease are also more likely to have limited health literacy.[6 10 14-20]

Health literacy is associated with people's social circumstances, in other words, the social determinants of health. Although anyone (including highly literate individuals) could have limited health literacy, people with limited financial and social resources – such as low educational attainment,[9 21-24] poor quality jobs,[22 25-27] and weak social connections[28] – are more likely to have limited health literacy. In turn, limited health literacy can reduce opportunities for people in vulnerable and disadvantaged groups to develop the capabilities needed to be actively involved in decisions about their health and care over time, and in changing circumstances. This can undermine their ability to take control of their health and the conditions that affect their health.[3 29]

The social and economic impacts of limited health literacy are considerable. Limited (functional) health literacy independently predicts poor diet, smoking and a lack of physical activity,[5-10] and is associated with an increased risk of morbidity and premature death in older adults even when age, socioeconomic position, cognitive function and pre-existing illness are accounted for.[11-13] The economic cost of poor

[1] A person's ability to read and comprehend information and instructions in health settings

health literacy in England is crudely estimated to be between £2.95bn and £4.92bn per year.[30]

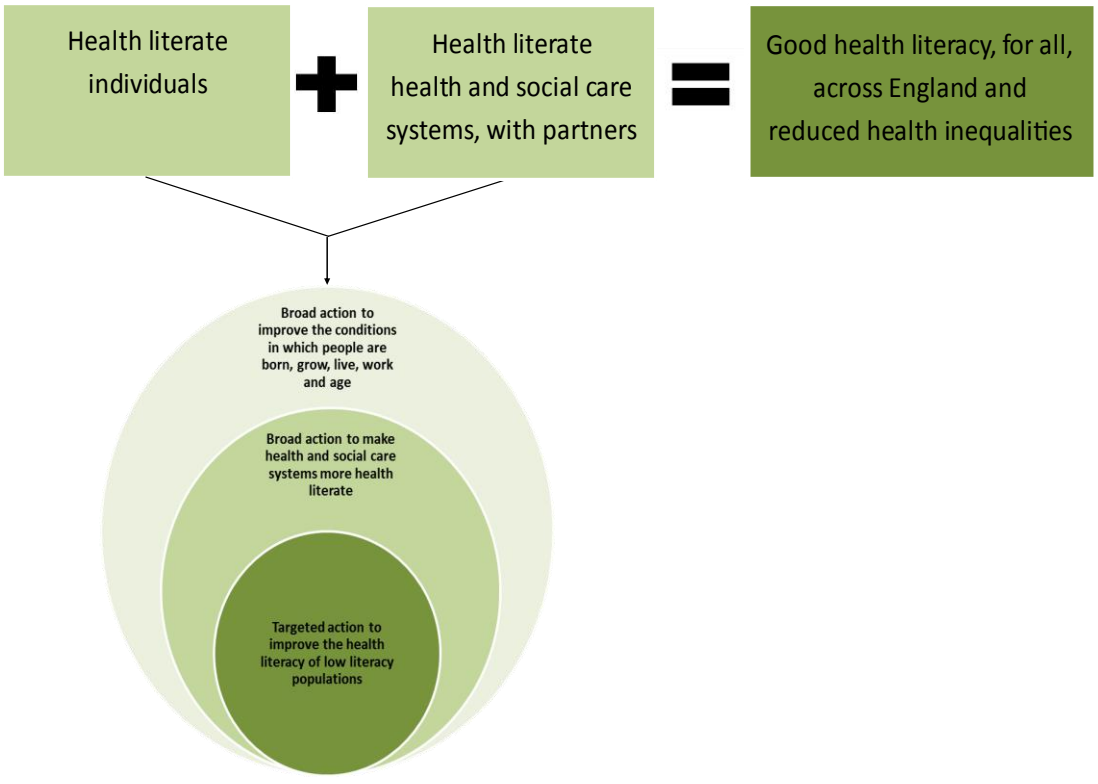
Strategies to improve health literacy are important empowerment tools which have the potential to reduce health inequalities. This is because people most at risk of limited health literacy are also known to have the poorest health outcomes.[3 29 31 32] Health literacy also plays a larger role in influencing the health outcomes among people with lower levels of education than among those with higher education.[33]

Efforts to improve health literacy have been shown to impact on some health outcomes, including being linked with reduced disease and depression severity[16], and improved health knowledge and health behaviours.[34-37] Further research, however, is needed to determine:

- whether improving the health literacy of disadvantaged or vulnerable groups and health and social care services can positively affect health outcomes over time
- how best to improve the health literacy of disadvantaged or vulnerable groups, and health and social care systems
- the cost effectiveness of health literacy initiatives

At the local level, a targeted approach, to improve the health literacy of disadvantaged or vulnerable groups within a broader strategy to improve health literacy and the conditions in which people are born, grow, live, work and age, can contribute to strategies to reduce health inequalities (Figure 1).

Figure 1. Local action to improve health literacy and reduce health inequalities



Policymakers, public health agencies, schools, adult education services, employers, health and social care professionals and community groups, among others, all play a role in addressing health literacy and improving health outcomes. Health and wellbeing boards are well placed to enable collaboration locally between the NHS, public health, education, social care, and community and voluntary stakeholders to improve health literacy in the local community.

Promising strategies to improve the health literacy of vulnerable or disadvantaged groups, and improve the accessibility of health and social care systems, are presented in section 6 of this report.

Public Health England (PHE) commissioned the UCL Institute of Health Equity (IHE) to examine whether improving health literacy can help to reduce health inequalities. This report:

- explains what health literacy is and how it contributes to health inequalities
- provides information, guidance and examples of effective and promising strategies to inform local action across England

This report is part of a series of practice resources commissioned by PHE and written by the IHE. The series is designed to help local authorities, health and wellbeing boards, and health and social care professionals when devising local programmes and strategies to reduce health inequalities. It is intended to provide practical information and examples that can be applied locally.

This practice resource is based on analysis of research and service literature on health literacy including statistical evidence, primary evaluations of interventions, review-level studies of interventions, and descriptions of interventions. Literature on associated issues, such as health promotion and health education, was also examined to identify appropriate engagement strategies for underserved, disadvantaged or vulnerable groups. We consulted experts on the draft report to help refine the final messages. The report draws on the evidence base and examples of local practice to illustrate notable approaches for local action. It is beyond the scope of this report, therefore, to systematically review all general and targeted health promotion and education initiatives that might impact on health outcomes.

Throughout the document, selected evidence and resources are highlighted in boxes such as this one. These are labelled in the following ways:

Initiative – An example of a strategy, programme or initiative that may contribute to improving the health literacy of individuals in one of the following ways: strengthening individual skills; simplifying and clarifying health information and health systems; or engaging underserved, disadvantaged or vulnerable groups through

general literacy or health literacy initiatives. It has either been evaluated and shown to be effective or is considered to be an example of promising action.

Key messages – Summaries of the key findings or action proposed in this paper.

Key literature – Overview of key findings from the literature.

1. What is health literacy?

Literacy is the ability to read, write, speak and listen to a level that enables a person to communicate effectively, understand written information and participate fully in society.[1] In the UK, 43% of adults have literacy skills lower than Level 2[2] and 15% have skills equivalent to Entry Level 3 or below[3], which indicates a poor mastery of basic skills.[38] Adults with skills below Entry Level 3 may not be able to understand labels on pre-packaged food or pay household bills.[39]

Health literacy is the bridge between people and health settings. Having the skills (language, literacy and numeracy), knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care systems can empower people to be active partners in their own health and social care, and in the care of their children, families and communities.

Health literate individuals

An adequate level of literacy is necessary for people to navigate often complex health system, which involves:

- communicating with health professionals – voicing their own health needs and clarifying information
- finding, understanding and using the health materials (in a variety of formats) that they need to stay healthy
- getting the services and support they need
- applying health-related knowledge to healthcare and decision-making, so that they are able to make healthy choices
- having more control over the things that make them healthy[3 40]

Health literate organisations

Inaccessible and unduly complicated systems and information can limit a person's health literacy. It is critical to acknowledge that people's health literacy depends on not only individual ability but also the responsiveness of health and social care systems: the efforts of health and social care providers (and linked agencies) to ensure that services and information are clear and accessible, removing barriers to access, engagement and understanding for all people.[2]

[2] Level 2 literacy skills are equivalent to GCSE grade C

[3] Entry Level 3 skills are equivalent to Key Stage 2 levels

The Scottish government, for example, has shifted "the problem" of health literacy away from people who have difficulty understanding and accessing health and social care resources towards providers delivering easily accessible information and services for all.[28] The programme is supported by 'health literacy place', a knowledge network which aims to share existing evidence, good practice, techniques and tools.

Box A. Examples of barriers to health for a person with low health literacy

Navigating unfamiliar health information, services and terminology – which can range from nutritional guidance to specialist medical instructions – can be challenging and daunting for anyone, but particularly for a person with limited literacy. Some people may feel embarrassed or humiliated because they do not understand the information being given to them by medical professionals and will try to hide their ill-health or concerns. People may also struggle to communicate their health needs effectively to health professionals; health professionals often assume a higher level of understanding by the service user and public than is the reality. A 'mismatch' can occur between individual ability and the level of education and confidence needed to access and understand health information and services.

People with limited health literacy may, for example:

- struggle to comprehend instructions on prescribed medicines and consequently may take the wrong dosage at the wrong time or mix up medicines
- have difficulty understanding signage and navigating their way around healthcare sites such as hospitals

People with limited health literacy may have less control over their health – particularly if they lack the skills to easily access health information. This means they are less informed and are less likely to choose the healthy option for themselves and their families. Limited health literacy can therefore become entrenched over generations.

Health literacy is a complex and evolving concept with no universally accepted definition or measure. For example, a systematic review published in 2012 identified 17 different definitions of health literacy and multiple conceptual models.[41] There are also more than 50 health literacy measurement tools in the literature[42] and the term is sometimes avoided completely. Nevertheless, there are many overlapping features used in different definitions, models and measures. In this practice resource, we adopt a three-level definition of health literacy – functional, interactive and critical health literacy – drawn from the literature.[43] This is outlined in Box B.

Box B. Definitions used in this paper

Literacy – The ability to read, write, speak and listen to a level that enables a person to communicate effectively, understand written information and participate fully in society.[1]

Health literacy – The ability to engage with health information and services. This incorporates language, literacy and numeracy skills that are used in health settings and for managing health, as well as the ability to access, understand, evaluate, use and navigate health and social care information and services.[41] A person's health literacy depends both on their own abilities and on the efforts of health and social care systems to make their services and information clear and accessible for all.[2] Health literacy is often broken down into:

Functional health literacy – a person's ability to read and comprehend information and instructions in health settings.

Functional health literacy is linked to educational attainment[9] and general literacy.[44] [45] People with inadequate skills in reading and numeracy will have less exposure to universal health information, and the skills needed to comprehend and act upon health information will be less developed.[46]

Functional health literacy is not always equivalent to level of education, despite the correlation. [33] Having adequate or good general literacy and numeracy skills does not necessarily equip a person with the skills and confidence to deal with the complicated literacy demands of healthcare settings.[29] A well-educated and literate person can have low health literacy when required to understand and act upon unfamiliar terminology and concepts in unfamiliar healthcare settings[47] and when navigating health information online,[48] especially when illness makes them more vulnerable.

Basic literacy and numeracy skills are therefore fundamental necessities for adequate health literacy, but they are not sufficient.

Interactive health literacy – a person's ability to be actively involved in decisions about their health and care over time, and in changing circumstances.

Interactive health literacy is defined as people having more advanced cognitive and literacy skills, as well as confidence, and therefore being able to discuss and actively participate in their health and treatment options with health professionals.[46] This also necessitates health systems removing all complexity and barriers to access, engagement and understanding. Interactive health literacy is believed to enable people to be actively involved in decisions about their healthcare over time and in

changing circumstances.[2]

Critical health literacy – a person's ability to take control of the wider determinants of health.[46]

The highest level cognitive skills are required for critical health literacy, which, with social skills, enables people to take control of the wider determinants of their health. This includes identifying barriers to health in their environment – such as a lack of accessible green space – and then taking appropriate action.[43]

Health inequalities and health equity – health inequalities are differences in health between different populations. Such differences in health status are described as 'inequitable' where they are unfair or avoidable.

Patient activation – The knowledge, skills and confidence a person has in managing their own health and care.

Empowerment – Empowering people to make decisions about their health and healthcare that are right for them. Health literacy without empowerment may result in dependence on health professionals while a high degree of empowerment without health literacy might mean that a person is less able to make suitable health choices.[49]

Self-efficacy – The belief in one's capabilities to achieve a goal or outcome.

Although the concepts of health literacy, patient activation, empowerment and self-efficacy are distinct, the impacts are often intertwined.[50-52]

2. The scale of limited health literacy

Key messages

- almost half the population are thought to have limited health literacy
- 42% of working-age adults in England are unable to understand and make use of everyday health information
- 61% of England's working-age population find health materials containing both text and figures too complex to understand
- 43% of working-age adults in England struggle to understand instructions to calculate a childhood paracetamol dose

In the European Health Literacy Survey (EU-HLS), which includes measures of all three levels of health literacy – functional, interactive and critical health literacy – nearly every second respondent showed limited health literacy.[53]

A study on functional health literacy levels across England reports that 42% of working-age adults (aged 16-65 years) in England are unable to understand and make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension.[3] Furthermore, 43% of working-age adults will struggle to understand instructions to calculate a childhood paracetamol dose.[3]

The Community Health and Learning Foundation estimates that 15–21 million people in the UK might not have the level of skills needed to live a healthy life.[30] These estimates do not factor in the number of people who have low interactive and critical health literacy skills as this is not yet known; overall numbers are likely to be even higher.[54]

Limited health literacy is most common in people with low basic education[55] and poor information and communication technology (ICT) skills, the two of which frequently overlap.[38] It is highly unlikely that people with poor general literacy will have good health literacy.

Key literature: measuring health literacy

A number of direct measures of functional health literacy are used in the UK, including the Short Test of Functional Health Literacy in Adults (STOFHL-UK) and the Newest Vital Sign (NVS-UK) measure.

Self-reported measures include the Health Literacy Management Scale (HeLMs) and the Health Literacy Questionnaire (HLQ), both of which have recently been identified as valid and reliable health literacy instruments that measure a range of

health literacy elements.[56]

The health literacy measurement instrument HLS-EU-Q was used in the EU-HLS survey and was derived from the health literacy model and definition developed by the survey consortium.[41]

The recent health literate healthcare organisation 10 item questionnaire (HLHO-10) was developed to represent the ten attributes of health literate healthcare organisations as identified by the Institute of Medicine.[57] The instrument has been found to have satisfactory reliability and validity, and can help assess the degree to which healthcare organisations help people to navigate, understand and use health and social care information and services[57]. This instrument is discussed in more detail in section 6. A US review also identified 12 tools that measured five or more attributes of organisational health literacy, as identified by the Institute of Medicine.[58] (see Table 1) Two of these cover all ten relevant attributes – the Enliven Organisational Health Literacy Self-Assessment Resource (85 items)[59] and the AHRQ Health Literacy Universal Precautions Toolkit (over 100 items).[60] (See the case study “health literacy universal precautions toolkit” in section 6.)

The Media Health Literacy (MHL) measure has been found to be effective in identifying groups of adolescents at increased risk of poor health literacy.[61]

3. The effects of limited health literacy on health

Key messages

Limited (functional) health literacy predicts poor diet, smoking and a lack of physical activity independent of risk factors including age, education, gender, ethnicity and income, and is associated with an increased risk of morbidity and premature death in older adults independent of age, socioeconomic position, cognitive function and pre-existing illness. People with long-term conditions including depression, diabetes, and heart, kidney and musculoskeletal disease are also more likely to have limited health literacy.

People with low health literacy, compared with the general population:

- are 1.5-3 times more likely to experience increased hospitalisation or death, and are more likely to have depression
- are more likely to struggle with managing their and their family's health and wellbeing, and are thus at increased risk of developing multiple health problems
- use fewer preventive and health promotion services, such as cancer screening and flu vaccinations, and have less recall and adherence to medical instructions and healthcare regimes
- find it more difficult to access appropriate health services, make more use of accident and emergency services and have longer in-patient stays
- have less effective communication with health and social care practitioners and are less likely to engage in active discussions about their health options, potentially leading to their health needs being hidden

Impact on clinical outcomes and use of healthcare services

Limited (functional) health literacy is associated with an increased risk of morbidity and premature death in older adults independent of age, socioeconomic position, cognitive function and pre-existing illness.[8 31 62-66] It is also more common among people with diabetes,[10 14 15] depression,[16] stroke,[6] and heart,[10 17] kidney[18] and musculoskeletal disease.[19 20] People with low health literacy are less likely to successfully manage long-term conditions[67] and 1.5-3 times more likely to experience increased hospitalisation or death than more health-literate people.[68]

Strategies to improve health literacy can help to build resilience among individuals and communities.[29] For example, community members can benefit from community

support and resources, such as social networks and peer support, to distribute good health literacy and, in turn, improve health and reduce health inequalities.[29] Furthermore, combined with good social resources, health literacy can help support people to: recover despite adversity or changing circumstances; adopt healthier behaviour; advocate on their own behalf, or take action to improve health in their community – all of which can impact clinical health outcomes and use of services.

Recent research suggests that stress resilience in adolescence – how susceptible the child or young person is to stress and how well they cope with it – predicts mental and physical health in adult men.[69] Low stress resilience in adolescence is found to be associated with stress and anxiety in males aged 50 and is likely to have a similar effect for women.[69] Building resilience in childhood through improved health literacy might therefore have a positive impact on health and wellbeing across the life course. There is also evidence to suggest that literacy interventions might lessen the severity of depression.[16]

Furthermore, limited health literacy is associated with reduced knowledge and uptake of prevention services such as immunisation and cancer screening programmes,[66 70-72] and with less recall and adherence to medical instructions and self-care regimes.[73-75]

A systematic review found that people with lower literacy had less appropriate patterns of health service use and were not always able to secure appropriate treatment.[76] When compared with people with adequate health literacy, people with limited health literacy generally enter the health system when they are sicker,[77] are more likely to use emergency services, are more likely to be hospitalised with longer hospital visits, are less likely to use preventive services, and incur higher healthcare costs.[66]

There is also evidence that parental health literacy impacts on dependents' health. For example, children with long-term health conditions who have care-givers with low literacy are twice as likely to use more health services than those whose care-givers have good health literacy.[78]

People with limited health literacy are more likely to report a sense of shame about their skill level,[79] which is likely to reduce interaction with health and social care services. In addition, limited health literacy has been found to be predictive of greater physician distrust[80] and more general negative attitudes towards health and healthcare.[81] For example, limited health literacy has been found to be associated with more negative beliefs about medication, such as a fear of medicines.[82]

Impact on healthy lifestyle behaviours

A health-literate person is better able to understand and carry out instructions for self-care, more likely to plan and achieve healthy lifestyle change, make informed

health decisions, share health-promoting messages with others and know how and when to access healthcare, including emergency healthcare when appropriate.[29]

Limited health literacy is independently associated with unhealthy lifestyle behaviours such as smoking, drinking, insufficient exercise and fruit and vegetable consumption – all of which are major risks for premature morbidity and mortality.[6-10]

The European Health Literacy Survey (EU-HLS) also found that across all participating countries[4] except Spain the amount of physical exercise people undertook was consistently and strongly associated with health literacy.[53]

Good childhood health literacy has also been found to be positively associated with a healthier diet. For example, a 2014 study found that young people with good health literacy are more likely to use food nutritional labels.[83]

Key literature: Measuring the impact of health literacy initiatives

Overall, trials examining the relationship between health literacy and health outcomes tend to focus on health knowledge and health behaviours. A 2009 systematic review of complex interventions to improve the health of people with limited literacy found that nearly half of the identified reviews (seven out of 15) had not reported any clinical outcomes.[84] Instead, knowledge and self-efficacy – the belief in one's capabilities to achieve a goal or outcome – were found to be the classes of outcome most likely to improve with increased health literacy skills.[84] It is acknowledged that although improvements in factors such as knowledge and confidence are important, they do not necessarily translate into changes in health.[84]

However, a study examining interactive and critical health literacy skills in the European Union replicated functional health literacy findings in England and found that people with low skills in these areas also made more use of hospital services, were less likely to get involved in preventive activities and were more likely to die at a younger age[85] than those with better skills.

Although we can infer that the associations between functional health literacy and health outcomes are likely to persist when interactive and critical health literacy skills are taken into account, more evidence, based on the UK population, is required to provide firm evidence of this association.

[4] The eight participating countries in the EU-HLS are Austria, Bulgaria, Germany (state of North-Rhine Westphalia), Greece, Ireland, the Netherlands, Poland and Spain.

The economic costs of limited health literacy

The World Health Organisation reported that there is a case to be made for viewing inadequate or problematic health literacy – as defined by the EU-HLS – as "a key determinant of health, a high-prevalence problem, a drain on human and financial resources and an obstacle to development".[29] The existing research literature on health literacy research in England and Europe however, does not address the issue of costs or include good economic evaluations.

Estimating the costs of poor health literacy is clearly a complex area which requires some assumptions to be made. US research suggests that the annual cost of poor health literacy is 3–5% of the health budget.[86] Based on these estimates, the cost of poor health literacy in England could be £2.95–4.92bn (based on the NHS England budget for 2014-15 being £98.4bn).[30] However, it is difficult to accurately transfer US cost implication findings to the English health system.

4. Population groups most at risk of limited health literacy

Some population groups have been identified as experiencing disproportionately low or inadequate health literacy. These are:

- more disadvantaged socioeconomic groups
- migrants and people from ethnic minorities
- older people
- people with long-term health conditions
- disabled people (including those who have long-term physical, mental, intellectual or sensory impairment)[3 46 53 87-90]

Health literacy therefore contributes to health inequalities because the population groups most at risk of low health literacy are also known to have the poorest health outcomes.

Each of the low literacy populations is considered in turn in the remainder of this section.

More disadvantaged socioeconomic groups

There is consistent evidence to show that health outcomes are correlated with social position in nations across the developed world. People from disadvantaged backgrounds[32 91 92] and with lower education[93] are known to have a lower disability-free life expectancy and to die prematurely.

Rates of inadequate functional health literacy have been shown to be higher among lower income adults[22 25-27] and adults with lower levels of educational attainment.[21-24] A person's social background has a strong influence on education and skills[94] and on health outcomes.[32 95] The OECD's Survey of Adult Skills showed that the relationship between parental background and adult literacy and numeracy among young adults is stronger in England than in all other OECD countries except the Slovak Republic.[96]

Recent research has found that health literacy interventions in mainland Europe are potentially not adequately focused on disadvantaged people from more disadvantaged socioeconomic groups.[97] Additionally, these groups are under-represented in health literacy research.[98]

People in disadvantaged socioeconomic groups are less likely to seek information or help for their health problems than more advantaged people[88], are less likely to

receive patient-centred care and more likely to be affected by morbidity and mortality from cardiovascular disease.[99-102]

A study by the Department of Business, Innovation and Skills (BIS) found that people with low adult literacy and numeracy skills had worse health-limiting conditions and were more likely to report deteriorating self-rated health.[62] For example, women with lower literacy and numeracy skills[5] are three times and twice more likely, respectively, to have worsening health-limiting conditions than women with higher skills.[62]

Migrants and ethnic minority people

Evidence shows that people from migrant communities and some ethnic minority groups have lower literacy, health literacy and poorer health outcomes than the general population.[29 66] Low health literacy and poor health outcomes among migrant and ethnic minority groups is thought to be due to greater difficulties in obtaining, understanding and act on health information than the general population.[66 103] For example, language can be a major barrier for people from some ethnic groups – people from ethnic minority groups who are asylum seekers or refugees are particularly affected.[104]

The Office for National Statistics (ONS) report Focus on Inequalities found that 41% of people who speak English as a second language receive no interpretation support when visiting a GP or health centre.[105] A lack of access to health information and inappropriate health information are seen as key drivers of risky behaviour, as well as inappropriate use of health services and generally poorer health outcomes among migrants and some ethnic minority groups.[106] For example, health and health inequalities are experienced by the Gypsy and Traveller community partly because they are at an additional disadvantage due to a lack of internet and broadband access.[107] Migrants and ethnic minority groups are also at disproportionate risk of more disadvantaged socioeconomic position.[29]

Additionally, a general lack of affordable English as a Second Language (ESOL) courses have been reported,[29] despite being promising settings for health literacy interventions.[108] A lack of information provided in a range of languages in many hospitals outside large urban areas[109] and often a lack of adequate social support[110] are other factors thought to partly explain why health and education information does not always adequately serve and engage disadvantaged or vulnerable groups.[29]

Recent research has found that health literacy interventions in mainland Europe potentially under-target disadvantaged ethnic minority groups.[98] Disadvantaged

[5] Measured using an objective indicator of basic skills. Questions were adapted from the 2002 Skills for Life survey. Adults operating at Entry Level (Levels 2 and 3) suggest a poor mastery of basic skills.

ethnic minority communities are also generally under-represented in health literacy research.[98]

Migrants and some ethnic minority people have poorer access to and use of health information, disease prevention and healthcare services compared with the general population. For example, take-up of interventions such as cancer screening, smoking cessation and diabetes programmes is lower among migrant and minority ethnic groups compared to the general population.[29]

Older people

Older adults have been found to be disproportionately affected by poor health literacy[11]: older adults (65 years-plus) were over four times more likely to have limited functional health literacy than the general population.[111] Adults over the age of 65 years have the lowest levels of health literacy compared with younger age groups[112-114] and health literacy skills have been found to decline rapidly from age 55.[22] In the UK, a third of adults aged over 65 are unable to comprehend basic usage instructions on medicine labels, indicating low health literacy. Older adults (over 50 years) with inadequate health literacy are also less likely to participate in cancer screening than those with adequate health literacy – 48% and 58% respectively.[111]

Additionally, e-literacy (computer and internet literacy) skills are lower among older adults compared with the general population. Disability, illness or impairments can make technology difficult to use.[115] This digital divide is likely to disadvantage older adults as health communications and access to health services are increasingly delivered online, so as technology changes so do the requirements for health literacy skills. Poor literacy skills, including e-literacy, among older people can directly impact on ability to manage effectively in the evolving health system.

Lower levels of health literacy among older people may be due to a number of factors, including a decrease in mental processing skills due to advancing age,[116] having more long-term health conditions,[113] and less participation in formal education than subsequent generations.[117 118]

Limited health literacy among older adults is associated with increased risk of long-term illness, disability and premature morbidity. For example, after adjusting for measures of cognitive function, low health literacy significantly predicts an earlier death for older people,[9] although a person's health literacy might decrease as part of a general decline in cognitive capabilities with age.[119 120]

People aged 65 years or older, with fewer years of education, are also more likely to report worse perceived health, have higher levels of disability, make more visits to health services, have higher rates of hospitalisation, engage in less activity and be less likely to obtain and adhere to medicines than those with more years of

schooling.[118 121] Research suggests that older people with cognitive dysfunction have the greatest need for health literacy interventions.[122]

People with long-term health conditions

Limited health literacy is more common among people with long-term health conditions, including diabetes,[10 14 15] heart disease,[10 17] stroke,[6] kidney disease[18] and musculoskeletal disease.[19 20] Health literacy is an important factor in preventing long-term conditions because low health literacy is correlated with unhealthy behaviours, including smoking, drinking alcohol, a sedentary lifestyle and eating an unhealthy diet,[6-10] as well as lower use of preventive services such as health risk screening.[66 70-72] Health literacy is also crucial to empowering people to effectively manage long-term conditions, including making behaviour and lifestyle changes.[29]

Disabled people

Disabled people are at increased risk of limited health literacy.[29] Limited health literacy among intellectually disabled people[6] is explained by limited communication skills and reduced capacity to access and comprehend health information and to express health needs effectively to health professionals and carers.[89]

Health and social care systems that do not adequately serve disabled people contribute to the disproportionate effect of limited health literacy on disabled people.[123-125] Research has found that only 30% of GP surgeries have information that is accessible to people with learning disabilities.[126] Furthermore, where initiatives aimed at strengthening the health literacy of people with intellectual disabilities do exist, they can inadvertently reinforce low health literacy skills by adopting a narrow definition of health literacy (functional), and neglect to offer people with intellectual disabilities opportunities to develop capabilities to interact with health information in a more critical manner.[127]

A number of organisational barriers to people with disabilities accessing healthcare services have also been identified in the literature.[89] These include a “failure by health professionals to make reasonable adjustments in light of the literacy and communication difficulties experienced by many people with learning disabilities”.[89] For example, people with a disability are three times more likely than those without to never have used the internet, and four million people with a disability have never been online.[38] Yet many health services promote online GP appointment bookings, which may have the unintended consequence of widening health inequalities by

[6] The WHO defines intellectual disability as a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

easing access to health information and services for only the more advantaged in society.

5. Improving health literacy and health outcomes

Key messages

Health literacy is an important empowerment tool that has the potential to reduce health inequalities. This is because:

- the population groups most at risk of low health literacy are also known to have the poorest health outcomes
- health literacy plays a larger role among those with lower education than among those with higher education, in terms of health outcomes

There is also evidence that improved health literacy can:

- build resilience
- reduce disease severity
- improve mental health
- increase health knowledge
- improve adherence to medical instruction
- promote healthy lifestyle changes
- improve engagement and involvement in health
- improve confidence and self-esteem
- empower people to effectively manage long-term conditions

At the local level, a targeted approach to improve the health literacy of disadvantaged or vulnerable groups, within a broader strategy to: a) improve the health literacy of health and social care systems, and b) address the conditions in which people are born, grow, live, work and age, can therefore contribute to strategies to reduce health inequalities.

Further large-scale, robust and clearly defined research, however, is needed to determine:

- whether improving the health literacy of disadvantaged or vulnerable groups and health and social care systems can positively impact clinical and other health outcomes over time
- how best to improve the health literacy of disadvantaged or vulnerable groups, and health and social care systems
- the cost effectiveness of health literacy initiatives

The idea of promoting health literacy to improve health and reduce health inequalities is growing in the UK with, for example, the development of the health literacy group, led by the Royal College of General Practitioners, and recent briefings published by the Patient Information Forum,[4] the Community Health and Learning Foundation[30] and the Association for Young People's Health.[128] All of these have sought to draw attention to the issue of limited health literacy, with suggested priority actions.

Health literacy is widely regarded as an important empowerment tool with the potential to reduce health inequalities. This is because the groups most at risk of limited health literacy are also known to have the poorest health outcomes. For many vulnerable or disadvantaged people, a lack of financial and social resources – such as education, good quality work or strong social connections – as well as stress linked to ill health and limited resources, can reduce opportunities to develop the capabilities needed to be actively involved in decisions about health and the conditions that affect health (critical and interactive health literacy).[3 29]

Health literacy plays a larger role in influencing health outcomes among people with lower educational attainment than among those with higher.[33] A recent review affirmed that "disadvantaged groups may benefit from shared decision-making interventions more than higher literacy/higher education groups".[129] Increasing health literacy therefore has the potential to help reduce health inequalities.

Health inequalities are estimated to account for over £5.5bn in healthcare costs to the NHS in England each year.[32] Engaging groups that are at risk of limited health literacy in enabling them to become more literate has the potential for positive social and financial impacts. For example, costs to the NHS can be saved if people are enabled to seek out information to help them better manage their own health and wellbeing, and if re-admissions or repeated GP visits are reduced because people know the correct course of treatment or health strategy that is right for them. Improving the health literacy of vulnerable or disadvantaged groups through targeted health literacy strategies can also address broader social determinants of health such as social inclusion and employment, by potentially reducing loneliness and isolation, and developing skills to enable people to access good quality work.[130]

Broad action to improve health literacy and reduce health inequalities

Focusing solely on the most disadvantaged or vulnerable groups will not reduce health inequalities sufficiently. To reduce the steepness of the social gradient in health, health literacy initiatives and actions must be aimed broadly (universally), but with a scale and intensity that is proportionate to the level of disadvantage – known as proportionate universalism – that is, with a particular focus on those most at risk.[32]

Therefore, at the local level, strategies that aim to improve health literacy and reduce inequalities might incorporate a targeted approach to improve the health literacy of disadvantaged or vulnerable groups, within a broader strategy to: a) improve the health literacy of health and social care systems, and b) address the conditions in which people are born, grow, live, work and age.

Improving the conditions in which people are born, grow, live, work and age

Fair Society, Healthy Lives (the Marmot Review) laid out six areas in which action is required to create the social conditions needed to reduce avoidable and unfair inequalities in health including giving every child the best start in life; education and lifelong learning; employment and working conditions; and a social determinants approach to disease prevention.[32] As health literacy is associated with the social determinants of health, efforts to improve health literacy which support action on the key social conditions are likely to have more impact.

Community-based peer-support programmes are likely to promote health literacy and health equity where peer-support workers have things in common with participants, allow participants to engage in discussions about topics wider than health and encourage participants to be involved in social networks where problems, concerns and tips can be shared.[131]

Such community peer-support programmes have the opportunity to reduce health inequalities because they aim to change perceptions of social status by workers nurturing a common bond with vulnerable or disadvantaged people. This, in turn, has the potential to promote positive social networks and interaction, which has been linked to improved health literacy and health outcomes.[131]

Initiative: Bolsover Community Learning Champions

Bolsover Community Learning Champions (CLCs), Derbyshire, are volunteers who use signposting, mentoring and buddying to encourage people from disadvantaged wards to take part in informal learning to improve their health and wellbeing. The target learner groups are adults without formal qualifications and who are not currently engaged in learning, adults with learning disabilities and/or physical disabilities, and mental health service users. Adult Community Education Centres are used as meeting places and participants are reached via community settings such as children's centres. All CLCs go through an induction programme and are encouraged to undertake training in skills other than literacy for health that might prove helpful, such as CV writing and communication skills. There is informal evidence that the CLCs are effective at engaging typically underserved, at-risk adults, and participants report a new enthusiasm for learning.

For further information see:

www.communitylearningchampions.org.uk/sites/default/files/downloads/Bolsover_CLCs_draft_vFINAL.pdf

There is evidence that CLCs are also cost-effective. For example, a one-year course of antidepressants to address mental ill-health costs the NHS £365 per person, compared with the average cost of £64 of involving someone in learning through a CLC[132].

Building health literacy during early years and school years

Measures to strengthen health literacy among children are key to reducing health inequalities.[29] Poor childhood health literacy, with associated negative health behaviours, can compound or accumulate over the life course, leading to worse lifelong health and wellbeing. A stakeholder child literacy workshop facilitated and reported by the Royal Society for Public Health concluded that health inequality could be reduced if children learned how to understand the impact of poor health behaviours in order to make informed, healthier choices.[133] Early years services have an important role to play, therefore, in potentially increasing the health literacy, and associated skills such as self-efficacy, of both children and their parents/carers.

School, community and family-based interventions to promote childhood health literacy have shown promising results. For example, the Adult Education Trust's 'Talk about Alcohol' intervention, delivered in English secondary schools, has reported an effect on health behaviours – specifically, a statistically significant delay in the age young people start drinking alcohol, as well as increased knowledge about the effects of alcohol. Students were also found to be better engaged during their personal, social and health education (PSHE) lessons.

Headstrong – a school-based intervention to improve mental health literacy – has been found to improve health literacy and reduce the stigma around mental health more than traditional PSHE lessons[134].

Initiative: Healthy Eating for Young Children (HEY!)[135]

The HEY! Programme is an early years community health improvement project led by Danone Baby Nutrition UK (DBN) and the Community Health and Learning Foundation (CHL Foundation). The aim of the programme is to improve the health outcomes and life chances of local children aged 1–3 by engaging their parents in healthy eating and promoting Skills for Life learning. The course is based on learning resources from Skilled for Health (see case study). The pilot project ran for seven weeks with a weekly three-hour session comprised of practical activities and group discussion, and was delivered through the children's centres, targeting families living in the most disadvantaged areas.

In April 2013, HEY! Was accredited by the Royal Society for Public Health (RSPH). An evaluation of the HEY! Programme based on participant and partner feedback found that parents and carers are making positive changes as a result of attending HEY!, such as checking food labels, understanding portion sizes and saving money on their food shopping. Overall, parents and carers reported increased knowledge about health, positive health behaviour change, as well as a social impact. For example, 98% of parents reported knowing how to eat and drink healthily, compared with 66% at the start, and 61% of parents now involve their toddler in food preparation and activities, compared with 21% before the intervention. Behaviour change was continuing at 6-8 weeks after the Hey! programme had ended.

Public Health England, working with the Association for Young People's Health (AYPH), has produced a series of summaries on key issues affecting young people's health and wellbeing, one of which summarises the more in-depth AYPH research on health literacy.[128] This research found that much of the literature in this area is described as "health promotion". Where such health promotion takes place, predominantly in schools, there is evidence that this can translate into better educational attainment,[128] which is associated with good health literacy.

As young people with good health literacy are more likely to adopt healthy lifestyle behaviours, such as taking heed of food nutritional labels,[83] children and young people have the opportunity to become "health champions" and can in turn help to improve their family, friends' and community's health literacy.

Daily reading has the single strongest effect on health-literacy.[136] Educational attainment is also known to be a strong factor explaining health literacy skills (independent of reading practices).[136 137] Broad strategies to promote health literacy should therefore remain tied to more general strategies to promote literacy, language, numeracy and ICT skills in the population.[138]

Initiative: Bookstart

Bookstart, run by Booktrust, is a universal programme, which provides free books to families of children before they start school. The aim of the programme is to engage children and families with daily reading practices. Bookstart is delivered via local public service professionals, including library staff, health visitors and early years professionals. A key benefit of such a multi-agency approach is that families are encouraged to engage with wider services that can advise about health checks and learning opportunities, such as basic skills courses.

Longitudinal research has found that children who had received Bookstart packs were ahead of other children in both literacy and numeracy upon entering school and that this advantage was maintained through Key Stage 1. Bookstart children were

found to outperform their non-Bookstart peers by between 1 and 5%.

In the long term, it is suggested that Bookstart will demonstrate considerable savings as a result of educational and health gains, economic success, reduced criminal activity and reduced demand for social services.

For more information see: www.bookstart.org.uk/

Health literate health and social care systems

Efforts to improve people's health literacy without addressing the responsiveness of services will have limited effect; health literacy also depends on the provision of clear and accessible information and services for all.[31 84 139-142]

Health information that only reports essential information is associated with improved comprehension among the general public (an increase of 0.3 on a three-point health literacy scale), although the improvement is more marked among populations with low numeracy skills (an increase of 0.7 on a three-point scale).[143] Furthermore, positioning the essential information at the start of the communication has been found to increase comprehension for people with low numeracy skills (an increase of 0.6 on a three-point scale).[143]

A number of studies have also found that using icon arrays – pictographics representing, for example, the proportion of people at risk of dying of a heart attack when the drug was and was not taken – is a promising method for communicating medical risk reduction.[144 145] With the use of such icons, one study found that the percentage of low numeracy participants who estimated the treatment risk reduction incorrectly decreased from 74% to 42%, and from 26% to 15% in participants with high numeracy.[144] This indicates that using icons in health materials has the potential to reduce inequalities in health outcomes and certainly improves comprehension of health information.

Presenting comparative information on the harms and benefits of two different drugs in tables, as opposed to just text, has similarly been found to improve understanding, especially for low literacy populations (an increase of 2.36 on a five-point literacy scale for understanding essential information, and an increase of 2.78 on a seven-point scale for understanding the exact meaning of the entire communication).[145]

Furthermore, medicine labelling that states the exact dosing times, as opposed to how many times a day medicine should be taken, has been found to improve understanding of correct medicine use.[146] A recent intervention similarly found that for cardiovascular patients, having health professionals enter medication information into calendars for them, including graphics that showed dosage and the exact dosing

times, improved medicine adherence and resulted in a decrease in patients' average blood pressure (between 0.5 and 1.5mmHg) and body weight (3.6 pounds), six months later.[147]

In an intervention where adults with low literacy received verbal medicine dosage instructions from a pharmacy dispenser, participants reported greater understanding of their medication dosage regime than those who did not receive verbal instructions (88% of people who received the intervention correctly described their regime, compared with 70% of those who did not receive additional verbal counselling).[35]

A review of the literature found that multimedia, such as video, appears to be a promising medium for educating the population, when compared to printed information.[148] For example, one study found that interventions that included a video on self-care for cancer patients resulted in an improvement of self-care behaviours for all participants, regardless of their health literacy level (no effect size reported).[34]

Health experts that have contributed to this report believe that empowering professionals about health literacy through training, continued education and inter-disciplinary initiatives can help to strengthen public–professional communications, and thus improve health literacy and health outcomes.

A working group sponsored by the Institute of Medicine Health Literacy Roundtable identified ten attributes of a health literate organisation:

1. Has leadership that makes health literacy integral to its mission, structure and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation and evaluation of health information and services.
5. Meets needs of populations with a range of health literacy skills while avoiding stigmatisation.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audio-visual and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications and medicines.

10. Communicates clearly what health plans cover and what individuals will have to pay for services.[40] [7]

Initiative: health literacy universal precautions toolkit

The universal precautions approach to health literacy is gaining ground in the US. The idea is to make all health information and health systems as easy as possible to understand and navigate. The toolkit is designed to help health professionals and partner services take a systematic approach to reducing the complexity of health information and ensure that people can successfully navigate the healthcare system.

The toolkit includes a number of strategies to use with all populations, including the much lauded teach-back method, which involves asking people to repeat back to health professionals what they have just heard as a way of confirming understanding. Other strategies include advocating follow-up with service users via telephone or written materials between appointments, and a number of approaches to designing easy to understand communication.

For further information and examples to replicate and test, see: www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf

Initiative: The Ophelia approach (Australia)[149] [150]

The OPtimising HEalth LIterAcy (Ophelia) study in Victoria, Australia involved the collaboration of community leaders, members and health professionals to identify evidence-based health promotion approaches and develop health literacy interventions based on the needs of local communities. A response framework was developed that outlines the sort of strategies required across the different levels of the health system – regional, organisational and practitioner level – to optimise the health literacy of individuals and communities, as follows:

- regional level – an integrated service system
- organisational level – effective marketing of services; an appropriate mix of services; high level of service accessibility; effective partnerships with local services
- practitioner level – effective professional development; effective professional networks; practice guidelines; effective management and mentors; tools, aids and resources

[7] For insurance-based and/or private healthcare

The study has recently collaborated with the World Health Organisation to produce a health literacy toolkit for professionals working in low- and middle-income countries.[151]

Next steps for the study are for the framework to be confirmed and validated, and for tools and resources to be developed to support providers, organisations and governments. Ophelia case studies are soon to be tested in the UK.

Community-based initiatives delivered by multi-disciplinary teams

A few studies have provided strong evidence that having more intensive interventions in community settings reduces the number of hospital visits as well as disease severity.

For example, an evaluation of an intensive disease management intervention delivered by a multi-disciplinary team, involving eight hours of teaching supported by pharmacist adjustment of medication dose, reported a significant decrease in haemoglobin (a protein in red blood cells that carries oxygen) and blood pressure for low literacy participants.[36] In higher literacy groups, only blood pressure was lowered.[36] After 12 months, 42% of those who had received the intervention achieved their haemoglobin level goals, compared with 15% of those who had not received the intervention.[36]

Another intervention, the Stanford Nutrition Action Programme, involved six sessions of low fat nutrition group education specially designed for adults with limited literacy, delivered by nutrition professionals, and used an activity-based approach with less emphasis on written materials and a focus on links with heart disease.[37] The group-based intervention was supported with follow-up telephone calls on eating patterns, with low-fat-related problem solving and goal setting and follow-up mailings that included nutrition and goal-setting cards. Adults involved in the intervention reported significantly reduced percentage calorie intake from total fat (-2.3%) and saturated fat (-0.9%) compared with general intervention participants. Nutritional knowledge, attitudes and self-efficacy also increased.

An intervention for adults with symptoms of depression involved referral to an adult education programme on literacy.[16] This involved an interview with an adult education teacher to determine learning style, followed with literacy and employment skills training via computer assisted or text-based instructions. Participants could also choose whether they worked individually, in small groups or one-to-one with tutors. Participants, after 12 months, reported lower scores on the Patient Health Questionnaire (PHQ-9), indicating improved mental health, compared with those involved in a general intervention (down to an average score of 6 from 12.5 for those involved in the intervention, as opposed to 10 from 14 for those not involved).[16]

Initiative: Health literacy in Ashton, Leigh and Wigan

NHS Ashton, Leigh and Wigan has worked to engage a wide range of local services to help promote the health literacy of its local communities – including the voluntary and community sector, social care, criminal justice, sports clubs and businesses. A network of health champions engages people in community settings, such as in community centres, sports clubs, voluntary organisations and private companies, and provides health information and knowledge via informal chats, leaflet distribution and posters. They can also instigate activity programmes and support environmental change such as installing bicycle racks. Health champions are trained using the Royal Society of Public Health awards.

Qualitative evaluations suggest that course participants have embraced the health champion roles and are successfully engaged with members of the local community with low health literacy skills to promote healthy behaviours.

Initiative: MindEd programme

MindEd is a portal that provides free e-learning to help adults to identify, understand and support children and young people with mental health issues. The learning materials were written and edited by leading experts from the UK and around the world.

As part of the MindEd programme, the National Collaborating Centre for Mental Health (NCCMH) was commissioned to carry out a systematic review of e-mediated therapies and computer-based applications for the prevention and treatment of mental health problems and substance misuse among children and young people.[152] The review reported that such e-learning applications and computer-based applications, such as computerised cognitive behavioural therapy (cCBT), show promise to provide effective treatments and therapy. The design and presentation of programmes, and user-acceptability, however, were also found to be important. The review concluded that e-therapies should be delivered in a way that encourages people to have some control over their treatment and should be integrated with their use of other mental health services.

For further information see: www.minded.org.uk

Initiative: NHS England – Digital Strategy

NHS England has been working with the Tinder Foundation, a social enterprise, to deliver a programme of digital skills training so that people with limited digital literacy skills, regardless of income, location, age, gender or ethnicity, can get online and

access the support and information they need to improve their health, make informed choices and manage their own health more effectively. The project was developed in response to the fact that those most in need of NHS services are those least likely to have the skills they need to access online services.

Nearly 150,000 people who lack the relevant digital skills have been trained in digital skills for health to date. Evaluations have shown positive impacts in terms of use of health and social care services, and health behaviours. 93% of users who were trained with the 'Staying healthy with NHS Choices' course agreed or strongly agreed that the course helped them understand how NHS Choices can help them to manage their own health. More than three in four users reported feeling more confident about using online tools to manage their health, and nearly one in five users reported reducing their use of offline NHS services as a result of using online resources.

Further information about the strategy, with individual case studies, can be found at: http://nhs.tinderfoundation.org/

Targeted action to improve health literacy

When considering strategies to improve health literacy it is important to bear in mind that some groups at greater risk of limited health literacy, such as disabled people and people from ethnic minority groups, are protected by the public sector equality duty. The equality duty requires public bodies to have due regard for advancing equality of opportunity between people who share a protected characteristic and those who do not. This includes removing or minimising disadvantage and taking steps to meet the needs of people with certain protected characteristics where these are different from the needs of other people.[153]

A one-size-fits-all behaviour change or education strategy will rarely be successful for serving and engaging certain population groups.[154] There are a number of major reviews of the literature on interventions intended to improve health outcomes for people with low health literacy.[31 84 139-142] More evidence, however, is needed to identify the best strategies to improve the health literacy of specific disadvantaged or vulnerable groups, that is, appropriately adapting information and services, and strengthening people's skills and capabilities – and to reduce health inequalities. Some promising practice is, however, emerging. A summary of the best available evidence is presented, supplemented with information about the current best known strategies to serve and engage at-risk groups.

Disadvantaged socioeconomic groups

People from disadvantaged backgrounds are less likely to seek information or help for their health problems, including using the internet[88] and less likely to receive patient-centred care.[100-102 155]

Key literature: Promising initiatives for serving disadvantaged socioeconomic groups

Making further education more accessible: Research has found that making further education more accessible for those whose parents did not have the opportunity to access it themselves will help promote social mobility and indirectly promote public health.[156] For further information, see the IHE/PHE report Local action on health inequalities: adult learning services.[157]

Combining lifelong skills training with health: A number of studies have found that combining general literacy, language and numeracy skills training with empowerment strategies to increase self-efficacy and attitudes towards health may be beneficial in terms of influencing health behaviours of families with lower socioeconomic status and thus reducing inequalities.[92 158-161]

Specific health literacy strategies for disadvantaged socioeconomic groups: Effective interventions include the limiting of teaching objectives and the facilitating of health goal setting – for example, cutting back on tobacco – with people from disadvantaged socioeconomic groups.[162]

Demonstrating medical instructions: Demonstrating instructions such as measuring dosages and counting pills is known to be a more effective strategy than providing written materials or reading out instructions. Repeating health information in different ways also helps to mitigate low health literacy levels, but even better is to involve the service user in learning, through the use of techniques such as teach-back, whereby the service user is asked to repeat back the information they have just heard to the health professional. This will enable the health professional to check for understanding (see the health literacy universal precautions toolkit, above).

Using trained community workers or health champions to relay health messages: Relaying messages in this way has been found to be an effective strategy to serve people from lower socioeconomic backgrounds, who are less likely to seek out health information, particularly from formal sources. Health professionals should also seek to involve family members or other care-givers in health decisions, and in general and health literacy initiatives. [163 164] This has been found to be an effective way of engaging this particular population group in health discussions and decision-making, and for disseminating key health information more widely. [163 164]

Ensuring that health materials are clear and concise [165-169]: Health information and messages should be presented in a number of different ways to take into consideration the varied ways people learn. Health material providers should also use a range of different media to present health information, such as leaflets, the internet and different technologies, to take into account the fact that people from lower socioeconomic backgrounds are less likely to seek out health information online than higher socioeconomic groups.

Writing health materials in plain English: Simple and short written information, ideally avoiding the use of passive voice and medical jargon, has a positive effect. As mentioned above, any written material should be combined with demonstrations and repeated oral instructions.

Initiative: Skilled for Health

Skilled for Health was a national, government-funded programme that ran from 2003 to 2009. The programme combined Skills for Life learning with health improvement topics and aimed to address both the skills deficit and the health inequalities prevalent within disadvantaged communities. Skilled for Health classes took place in community settings such as schools and used general health topics relating to health and healthy living as a lever to engage adult learners and develop their literacy, language and numeracy skills.

The national evaluation of Skilled for Health involved 3,500 people across 157 settings in England. As well as improving community engagement, participants demonstrated increased health knowledge, particularly in the areas of healthy eating, exercising, smoking, drinking and looking after their mental health. By the end of the course, 88% of participants reported to be eating more healthily and 65% reported exercising more. Furthermore, the literacy, language and numeracy skills of participants were found to increase and 80% of participants said they intended to take up further education courses (with 29% already having done so).

Migrants and people from ethnic minority groups

Effective communication between health professionals and migrants or people from some ethnic minority populations can be challenging due to language barriers and cultural differences. Economic and social barriers can also prevent health materials and education programmes from serving migrant and ethnic minority groups.[29] Simply accessing information is not enough to improve health outcomes, as once information is received, it needs to be accurately understood and acted upon appropriately.[170]

There is limited evidence about the clinical or cost effectiveness of cultural adaptations of health materials and interventions compared with non-adapted initiatives[171] because the outcome measures used in studies tend to vary extensively.[171 172] Furthermore, most studies have been conducted in the US among African Americans and Hispanics and it may not be possible to generalise findings to other population groups or to other countries.[173]

However, there is evidence of promising strategies to help identify migrant and ethnic minority populations with low health literacy within communities, and engage them with healthcare and their own health and wellbeing. These strategies will help overcome the difficulties migrant and some ethnic minority groups face in obtaining, understanding and using health information. These difficulties arise because health information in hospitals is rarely provided in a range of languages,[109] there is a lack of affordable English as a Second Language (ESOL) courses[29] and a lack of social support can mean that there are fewer opportunities to discuss health concerns and share health messages among these groups.[110]

Key literature: Promising initiatives for serving migrant and ethnic minority groups

Community involvement in the design of targeted health literacy initiatives: Empowering people in this way is known to be an effective way of building cultural health literacy. Such involvement helps ensure effective communication of health information to local communities by overcoming language differences, integrating service users' and the public's perspectives and securing commitment to health promotion initiatives.[170 174]

Voluntary and community sector involvement: Initiatives developed and delivered by voluntary and community sector multi-disciplinary teams and inter-organisational partnerships, in or through informal community settings such as libraries,[175] churches[176] or ESOL classrooms,[108] help to build a climate of trust in which to engage underserved, migrant and ethnic minority populations (although these need to be more accessible and affordable to communities). To be successful, health education programmes targeted at migrant communities need to be delivered further to careful inquiry into the social circumstances in which communities live.[177]

Community health workers and link workers: Culturally competent community health workers and link workers, who bring together communities often at risk of limited social support, are particularly effective at increasing the coherence of health communications, improving access to health promotion services, and inspiring greater engagement among migrants and ethnic minority populations.[178] This suggests that using the evidence-based community health champion model,[179] and particularly health champions from a range of ethnic backgrounds, could be an effective asset-based approach to strengthening the health literacy – and thus health

outcomes – of low literacy migrant and ethnic minority people.

Culturally tailored health promotion material and interventions: Interventions such as smoking cessation, physical activity and health eating initiatives that include images of people from different ethnic backgrounds and translated information, or are delivered by a person with a common cultural background,[180] are known to be more acceptable to people who are migrants or from ethnic minority groups, and to increase intervention uptake.[170]

Cross-cultural messages: Cross-cultural communication is about more than using the appropriate language. To make health information truly accessible, it needs to take into consideration idioms, and cultural and social references and visuals. It is a "mistake to assume heterogeneity" across the population in question.[181] Furthermore, if messages do not translate into a target language easily, they should instead be written in plain English.[8]

Information about diet: This could be the hook to better engage migrant and ethnic minority groups with health literacy initiatives. Research has identified a desire among ethnic minority communities for further information related to healthier diet over other healthy lifestyle behaviours.[182] [183] Certain ethnic groups including Bangladeshi, Pakistani and Black African communities have been found to prefer more direct and hard-hitting messages about health that also include a clear rationale for behaviour change.[182]

Interpreting and translating: Health professionals and partners should make appropriate use of interpreters and translators if important health information is to be understood and acted upon within migrant and ethnic minority communities.[170]

Initiative: Refuah Shlema programme, Israel

The Refuah Shlema programme was developed to reduce inequalities and to promote health literacy and the overall health of Ethiopian immigrants in Israel. The overarching aim was to improve communication between primary care workers (physicians, nurses, pharmacists and administrative staff) and immigrants. Three interventions were implemented:

- training and integrating Ethiopian health liaison as cultural mediators in primary-care settings across Israel (capacity-building)
- training clinical staff to increase cultural awareness and sensitivity, and to improve attitudes

[8] Documents written in plain English have been found, in some situations, to be more beneficial than translated material, particularly when languages are difficult to translate effectively.

- community-wide health education activities for Ethiopian immigrants on relevant topics, tailored to each community

Evidence from interview evaluations conducted three years after the interventions were received suggests that the liaisons helped in-depth communications to meet people's health needs. The liaisons also helped to build trust and confidence in the effectiveness of treatment and encouraged patients to make recommended behaviour and lifestyle changes. National quality health indicators for the communities participating in the programme were also monitored and it was found that Refuah Shlema community participants showed average or above average indicators compared with the national or district standards.

Initiative: Action on health literacy in Stoke-on-Trent – Engaging South Asian men with diabetes[184]

As part of a broader strategy to promote health literacy in Stoke-on-Trent, research was commissioned to assess health literacy levels among South Asian men in the local area. STOFHLA-UK scores (Shortened Test of Functional Health Literacy Assessment) suggested that more than half of the South Asian participants could not read, understand or interpret most health texts, particularly older Asian men. In response to this, pilot interventions were designed and implemented as part of the programme which included a peer mentoring scheme for South Asian men. The hypothesis was that engagement with this target group could be improved by involving an interpreter or someone with an insider perspective of their culture. Two peer mentors were recruited to facilitate one-to-one sessions with the target group. They were identified from the original pool of participants and selected based on their high STOFHLA scores.

A learning session, looking at improving communication skills, making sense of health information, navigating through the healthcare systems and improving ability to manage diabetes, aimed to facilitate peer learning and discussion of health literacy-related matters with South Asian men with diabetes to enable them to manage their condition better. Mentoring sessions were facilitated using ABC flash cards, which made use of symbols related to diabetes. Information was presented on A4 sheets, with each covering a specific diabetes issue – for example, A for 'advice', B for 'blood pressure' and so on. Information sheets from Diabetes UK were also translated into different languages.

Qualitative feedback from the participants concerning the peer mentorship programme was generally positive. Everyone either agreed or strongly agreed that the programme helped improve their ability to understand health information, communicate with healthcare professionals and use health services effectively, and

to improve their knowledge of diabetes.

A guide for working with black and minority ethnic communities in Scotland living with long-term conditions is available from Diabetes UK Scotland.[185]

Initiative: A diabetes self-management initiative, US[186]

A diabetes initiative that included a culturally-tailored disease self-management plan delivered via video conference resulted in a significant increase in participants' reported knowledge of diabetes: 92% of participants involved in the intervention achieved 80% or higher on the diabetes knowledge scale, compared with 76% of those in the control group. Participants who received the intervention were also 4.58 times more likely to achieve the desired blood sugar levels at the end of the intervention compared with the control group, and there was a significant positive relationship between participation in the intervention and achieving a healthy body mass index (BMI).

Initiative: The Migrant Friendly Hospitals initiative[110]

The Migrant Friendly Hospitals collaboration between health experts, NGOs and a group of hospitals from 12 European countries, including a number of hospitals in the UK, aims to put "migrant-friendly, culturally competent healthcare and health promotion higher up on the European health policy agenda and to support other hospitals in their quality development towards migrant friendliness by compiling practical knowledge and instruments". Specific interventions include the improvement of interpreting services, more migrant-friendly information, such as use of pictograms, and training for patients and staff training towards cultural competence. This has been translated into improvements such as more accurate transmittance of information and improved understanding among health professionals of cultural diversity issues. The overall patient ratings of interpreting services also improved.

Older people

The World Health Organisation's Active Ageing Initiative advocates that strengthening health literacy is key to promoting active ageing – the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age.[187]

There is growing evidence of the potential for peer support to have a positive impact on individual and community interactive health literacy, and, in turn, critical health literacy.

There are, however, limited studies that highlight programmes that examine health literacy outcomes for older adults. For example, systematic reviews of health literacy interventions for older populations reported difficulties in drawing any firm conclusions as standardised, validated tools to measure health literacy were used in very few evaluations.[188 189] The research suggested that further high quality research is needed to develop evidence-based interactive health literacy programmes targeted specifically at older adults and evaluated using standardised health literacy assessment tools.[188]

Despite consistent evidence that older populations have particularly low e-literacy, recent reviews have found a significant gap in the literature for interventions to help people find health information online. Where such interventions do exist, health outcomes studied are predominantly focused on knowledge or critical health literacy and have been evaluated via self-report methods – findings for which are largely positive.[115 190]

There are a number of practical steps that clinical commissioning groups and local authority departments alike can adopt to help improve and mitigate the effect of limited health literacy in older adults. Promising strategies are outlined in the box below.

Key literature: Promising initiatives for serving older people

Independent, peer advocacy support: Both one-to-one and group interventions, with advocates to help support and speak up for older people, appear to have the potential to help older people to cope better with long-term conditions and their effects, access appropriate services and help, and to empower them to take greater control of their health.

Keeping the same GP: Where possible, clinical commissioning groups and GP practices should try to ensure that older people are consistently given access to the same, trusted GP, as research has found that for older people with limited health literacy, having a good relationship with their doctor helped them to feel more involved in their care.[191]

Group interventions: Interventions involving group-based education sessions, delivered by a health educator, using simplified language and picture-based educational materials and regularly scheduled telephone follow-ups, have been found to reduce the rate of hospitalisations and death. For example, an evaluation of a heart failure self-management programme for older adults found that in the 12 months further to the intervention, 61% of patients in the control group had at least

one hospitalisation or died, compared with 42% of patients in the intervention group.[192]

Written health information: Careful attention to the style and format of written health information can increase impact. Studies have found that for older adults, graphics may be helpful but should only be included if they add clarity to the written content. Older adults benefit from health materials that use larger font (14 point or above). Blue, green and lavender font have been identified as colours older adults find difficult to read and should therefore be avoided.[193] Good practice initiatives have made use of simplified language styles, avoiding technical jargon, and have included diagrams, cartoons and step-by-step detailed instructions to accompany large print to help facilitate understanding.[118]

Internet workshops: Interactive workshops that include instruction (hand-outs of credible health information websites) but that have a greater focus on group collaboration help to improve the interactive health literacy of older adults using the internet. Interactive sessions based in libraries and other community settings, which encourage participants to discuss issues, pose real-life scenarios and problem-solve together, have been evaluated with positive results. For example, one study found that more than 80% of participants could search health databases without assistance post intervention (no baseline comparison) and that the majority of participants (n= not reported), said that they were still using the internet to search for health information six months later.[194]

Tailored strategies: Collaborative health literacy initiatives that also incorporate tailored individual learning strategies are beneficial to older population groups with limited health literacy.[195] Such initiatives benefit from having target population involvement during their development and from being delivered in informal settings such as local libraries or senior citizens centres, and early in the morning, which has found generally to be the optimal and preferred time of learning for older adults.[195] A study that examined the impact of such a tailored approach to an e-health literacy intervention – learning how to access and use a health website – found that overall, participants' knowledge, skills and e-health literacy efficacy improved significantly after the intervention.[195] Targeted strategies for conveying health information to older populations with low health literacy include aiming for face-to-face communication, and repeating information, giving people time to hear and absorb information. Health practitioners should also try to personalise health information and keep information focused.[196]

Initiative: Cancer, older people and advocacy programme

The cancer, older people and advocacy programme across England was started in 2011 and is led by the Older People's Advocacy Alliance (OPAAL). The programme explores the role of independent advocates for older people, to help them better cope with cancer, access services and appropriate help, and have more control over their health and outcomes. Older people who themselves have been touched by cancer are recruited and trained to give other older people a "voice" and additional support when affected by ill health.

Qualitative evidence suggests that independent advocacy is having a positive impact on older people's critical and interactive health literacy, from helping them to understand their illness to voicing concerns, exploring health options and claiming benefits.[197]

Initiative: Age UK booklets for the older population

In 2012, Age UK won the Plain English award for its booklets adapted specially for older populations – including Staying Steady and Healthy Living. The judges said that the information was clearly presented, attractive and informative. They address the reader directly, using an upbeat tone, and the information is easy to understand. They have good contents pages, and the page and section headings are clear. The list of useful organisations at the back of each booklet is arranged in alphabetical order and is an excellent guide to further sources of information.

Initiative: Learning in later life programme, Strathclyde

The learning in later life programme, run by Strathclyde University, Scotland, started in 1987 and is one of the largest programmes of its kind in the world. Classes, aimed at older people, are accessible to all older people regardless of previous educational experience. They are offered during the day and cover an array of topics, including health and computer studies.

There is evidence that adult learning can have indirect health benefits. For example, adult learning can increase social capital and connectedness, including for older people, which in turn, has a positive effect on health.[32 198 199]

Initiative: Reading on a daily basis

Reading on a daily basis has been found to help improve and sustain health literacy levels, regardless of a person's education level. Working age adults who frequently engage in daily reading practices can score up to 38% higher in functional health literacy tests than those who do not read on a daily basis. Older adults (over 65 years) who read on a daily basis can score up to 52% higher than the average for their age.[136]

Disabled people

Owing to limited research on health literacy among disabled people, there is little evidence on what works to strengthen health literacy among this group and the extent to which it improves health outcomes. However, certain health education strategies are known to more effectively increase the ability of disabled people to use and access health literacy-related material, and to strengthen literacy skills more generally.

Key literature: promising initiatives for serving disabled people

Targeted health education strategies for people with intellectual disabilities include using concrete instructions, repetition of what's been done so far and what to expect, and using pictorial instructions and interactive activities.[200]

Specialist communication training is preferable but all health professionals or those involved with the health of disabled people should be mindful of a number of strategies when relaying health messages to people with sensory impairments,[201] including:

- speaking clearly and slowly, making lip patterns clear without over-exaggerating
- keeping the face visible and not smoking, eating or covering the mouth
- using gestures and facial expressions to support communication
- repeating phrases or rephrasing sentences
- writing things down in varied sizes of letters and using different coloured paper and pens

People with physical disabilities and visual impairments are believed to benefit from assistive technology – both hardware and software – such as adaptive keyboards, voice recognition software, eye tracking or head wands, screen magnification software or text-based browsers.[90 202] Additional facilitating factors include: the appropriate communication skills of the GP; doubling appointment time; and nurturing long-term relationships between the GP and/or carer and the person with intellectual disabilities.[203]

Initiative: Books beyond words

Books beyond words are stories for adults told in pictures. They provide information, can help check understanding and can be used as a therapeutic tool for people with intellectual disabilities. They can also be used with people who have low literacy or who have limited understanding of written English.

Books beyond words have been found to enhance understanding and communication, support disclosure and diagnosis, and help with problem solving to enable people with low literacy to have greater control over their health and wellbeing.

Two randomised controlled trials (RCTs) have been conducted.[204] Interventions utilising books beyond words were found to have a significant effect of knowledge and skills both immediately and at six months for both interventions.[204] One RCT of a bereavement intervention found that median scores for irritability, stereotyping, hyperactivity and inappropriate speech reduced post-intervention.[204]

Titles in the series include: Am I going to die? Speaking up for myself, I can get through it, and Sonya's feeling sad.

Books beyond words have won multiple awards, including runner up in the National Learning Disability accessibility category BMA medical book awards, and the Book Trust's Read Easy award.

Box C. Priority actions for local areas

In summary, to promote health literacy and reduce inequalities in health, local areas can take action to:

- adopt an early intervention approach to health literacy – ensuring that promoting health literacy is fully integrated into early years and school curriculums
- consider the integration of health literacy promotion into other local policy and strategy which promote literacy, language, numeracy and ICT skills, for example
- ensure that all health and social care information services are clear and accessible to all, regardless of individual ability
- as part of a broader strategy, improve the economic and social conditions for at-risk groups (the social determinants of health), as these are known to impact on literacy, health literacy, health outcomes and health inequalities
- develop awareness and empower health and social care professionals through training to improve health literacy by strengthening public–professional communications
- invest, develop, evaluate and share good practice in relation to health literacy

initiatives which improve health and reduce health inequalities

- use local knowledge and skills by investing in effective and sustainable community-led approaches, such as ‘health literacy champions’ and using social networks to distribute good health literacy
- develop awareness and empower health and social care professionals (across all tiers of an organisation) to improve health literacy and health inequalities by strengthening public–professional communications. This can be achieved through training, continued education and inter-disciplinary initiatives

6. Areas for further research

Reviews of the health literacy literature have noted that although there have been great advancements in the field of health literacy, many areas for improvement remain.[31 84 139-142]

Importantly, there are large gaps in our understanding of how health literacy – organisational, but particularly individual health literacy – can be improved. Overall, there is a lack of rigorous evaluation studies and theory-based interventions applying quality research design.[66 205] Evaluations are thus not definitive. Studies tend to take place in clinical as opposed to practical settings, are mainly US-based, are based on small populations, and differ in the health literacy measurement tools that they use, how they define health literacy and related concepts, and how they determine and set thresholds for distinguishing between health literacy levels.[66 171] Furthermore, most of the evidence focuses on promoting functional health literacy, but to be health-literate people need to have adequate resources to take greater control over their own, their family's and their community's health – and such resources are most likely to be lacking among at-risk groups.

Another issue is that within the literature, there is variation in how authors use the terms 'literacy' and 'health literacy'. Some authors use the term 'health literacy' explicitly, whereas others simply refer to it as applying general literacy skills to printed materials within a health-related context.[13] The terminology needs to be further clarified.

Overall, there is a particular lack of research concerning disadvantaged or vulnerable groups, and people with low literacy levels are also under-represented in research. Additionally, studies rarely provide adequate detail about the health literacy or associated interventions used, which makes it challenging to unpick and share learning[206] and more regularly report health knowledge and health-related self-efficacy outcomes (as opposed to clinical outcomes).

The limited evidence available on the effectiveness of health literacy initiatives, both in terms of their impact on clinical and other health outcomes, and their cost-effectiveness, and how to improve organisational health literacy and the health literacy of all and targeted groups, therefore makes it difficult to provide definitive recommendations for practical steps that local authorities can take to improve health literacy and overall health, but promising practice is starting to emerge.

More larger-scale, robust and clearly defined health literacy studies are welcomed on how to improve health literacy both in terms of people's abilities and the information and systems they are presented with, and the cost-effectiveness of health literacy interventions. We also need to better understand the economic and health effects of

innovative local approaches to improve the health literacy of low literacy groups. Furthermore, clear definitions and measurement methods of childhood health literacy need to be developed.[207]

The European Health Literacy Survey (HLS-EU) Consortium is the first large-scale study to address comprehensive health literacy. Consideration in England and the UK in undertaking a health literacy population study would significantly aid understanding.

Conclusion

Poor health literacy is associated with poor health behaviours and outcomes. Almost half the population is thought to have limited health literacy.[53] Anyone can have low health literacy. However, low health literacy is central to health inequalities as disadvantaged or vulnerable groups are most at risk − particularly those from disadvantaged socioeconomic backgrounds, disabled people, older people, and migrants and people from ethnic minority groups.

As a person's literacy, language and numeracy skills are not fixed, they can be improved, and health literacy is likewise an amenable determinant of health. Local strategies to improve health literacy therefore have the potential to improve health outcomes more broadly, as well as to reduce health inequalities. To be effective, however, health literacy strategies need to address both individuals' abilities and health and social care responsiveness – the ability to serve people's needs, regardless of individual ability. Strategies that aim at broad populations and which incorporate a particular focus on serving and engaging low health literacy populations are likely to pay the greatest dividends in reducing health inequalities.

This practice resource has identified promising health literacy strategies that local areas can develop, implement and evaluate, including building upon health literacy during the early and school years, developing community-based approaches to health literacy, and ensuring that health and social care services are clear and accessible for all, regardless of ability. This resource has also presented the best available evidence on how to engage underserved populations at increased risk of poor health literacy and poor health outcomes. However, further high-quality research is needed to understand: how to improve health literacy, both in terms of people's abilities and the information and systems we present them with; how health literacy affects health inequalities; and the effectiveness of health literacy initiatives, in terms of their impact on clinical and other health outcomes, and their cost-effectiveness.

A wide range of stakeholders have a role to play in strengthening health literacy. Professionals (across all tiers of organisations) from health and social care services will need to be supported by other sectors, including child and adult education, employers and the third sector, as well as by families and communities themselves, to address health literacy and reduce health inequalities at the local level.

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