



Health Literacy

Report from an RCGP-led health literacy workshop





Royal College of
General Practitioners

Health Literacy

Report from an RCGP-led health literacy workshop

Gill Rowlands MD FRCP FRCGP, Royal College of General Practitioners

Joanne Protheroe MRes PhD FRCGP, Royal College of General Practitioners

Hannah Price BA (Hons), Royal College of General Practitioners

Bob Gann BA (Hons), NHS England

Imran Rafi BSc (Hons) MSc PhD DFMS FRCP MRCGP, Chair of Clinical Innovation and Research, Royal College of General Practitioners

Correspondence

Dr Imran Rafi (irafi@rcgp.org.uk)

The RCGP Clinical Innovation and Research Centre are pleased to have produced this report and facilitated the workshop. We are particularly grateful to Luke O'Shea and his team from NHS England for their support and would like to thank all the workshop participants for their excellent contribution.

The Royal College of General Practitioners was founded in 1952 with this object:

'To encourage, foster and maintain the highest possible standards in general practice and for that purpose to take or join with others in taking steps consistent with the charitable nature of that object which may assist towards the same.'

Among its responsibilities under its Royal Charter the College is entitled to:

'Diffuse information on all matters affecting general practice and issue such publications as may assist the object of the College.'

© Royal College of General Practitioners, 2014
Published by the Royal College of General Practitioners, 2014
30 Euston Square, London NW1 2FB

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior permission of the Royal College of General Practitioners.

Contents

<i>Foreword</i>	iv
<i>Executive summary</i>	v
Introduction.....	1
1. Literature background.....	2
2. Health literacy: an overview	3
3. What challenges does health literacy bring?.....	5
4. The importance of communication	7
5. Low health literacy and health	9
6. The health literacy environment.....	10
7. Good practice.....	11
8. Interactive and critical health literacy.....	13
9. The Information Standard	14
10. Health literacy in practice: case study from the Terrence Higgins Trust	15
11. The NHS England Digital Inclusion Strategy	16
12. Summary of breakout group discussions.....	18
13. Conclusions and call for action	20
<i>References</i>	21
<i>Appendix I: Group members and their affiliations</i>	23
<i>Appendix II: Key texts and other resources</i>	25

Foreword

I would like to congratulate the authors and collaborators of this report, headed by our clinical lead Dr Gill Rowlands, in profiling the important concepts around health literacy. As a working GP I recognise and understand the need to provide meaningful information to my patients in managing their conditions. However, this report highlights the fact that many people engaging both across primary and secondary care may simply not have the assumed levels of healthcare literacy that empowers

them to manage their conditions. Through undergraduate and postgraduate education and training around healthcare literacy we can hope that present and future healthcare professionals will understand the importance and relevance of health literacy. My hope is that this report serves as a catalyst for change.

Dr Maureen Baker
Chair of RCGP Council

Executive summary

Health literacy skills are ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health’.¹ In view of the importance of health literacy to patients and the NHS, NHS England sponsored a meeting, hosted by the Clinical Innovation and Research Centre (CIRC) of the Royal College of General Practitioners (RCGP) in collaboration with the Chair of the Health Literacy specialist group (a Special Interest Group of the Society of Academic Primary Care [SAPC]). The meeting was held in July 2013 and brought together key stakeholders (see Appendix I), which included NHS England, professional and patient advocacy groups. The aim was to facilitate discussion about the important principles around health literacy relevant to primary care.

Central to the discussion was a shared understanding of what is meant by the term ‘health literacy’. Health literacy is needed for patients and the public to understand and act upon health information, to become active and equal partners in co-producing health, and to take control of their health to help to shape health environments and health services for themselves, their families and their communities.

In addition to learning about health literacy and its impact on patients, the public and the NHS, those present brought their perspectives and expertise to the discussions. Several themes emerged as follows.

1. Health literacy is central to ensure fairness and equity in the NHS, with high-quality services being delivered to all.
2. Health literacy is key to more effective use of resources, through increased understanding of how best to access and use health services, through confidence and skills to enable decision-making that is shared between doctors and patients, through to ensuring that patients take a full role in developing services that fit with the needs of local populations.
3. GPs have a central role in this through:
 - a. Improving communication skills, and tailoring information not only to clinical need but also to patient health literacy
 - b. Working with NHS managers to develop health systems and environments accessible to all regardless of health literacy level
 - c. Supporting patients to develop health literacy skills, both in understanding and using health information, and in understanding their rights to clear, accessible information tailored not only to their clinical need but also to their health literacy
 - d. Acting as agents for change through their role as commissioners of health services.
4. NHS commissioners should engage with local community networks and advocates, including the lifelong learning community.
5. Tools to check the effectiveness of communication, and surveys to check patient satisfaction, could be widened to include communication and health literacy.
6. New initiatives must be targeted at those with the greatest need, including those with the lowest health literacy skills. One such initiative, the NHS drive for digital inclusion, may do much to increase access, information

and health literacy skills among those with the greatest need.

7. The Information Standard is an independent certification scheme that is commissioned by NHS England for all organisations producing evidence-based health and care information for the public. Information Standard members can lead the way in developing excellence in health information accessible to all, regardless of health literacy level.
8. The RCGP has a role in highlighting the importance of health literacy among its members, and to work with those who are leading GP undergraduate and postgraduate training to ensure that this takes place.

9. NHS England has a role to highlight the importance of health literacy to commissioners and NHS Trusts.

The meeting ended with calls for action, as follows.

1. That the important discussions and themes arising from the workshop continue to be explored and developed.
2. That the RCGP and NHS England consider working together to develop a five-year plan of action to address the challenges brought through low health literacy, focusing on the themes identified in the workshop.

Introduction

Health literacy skills are ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health’.¹ In view of the importance of health literacy to patients and the NHS, NHS England sponsored a meeting, hosted by CIRC in collaboration with the Chair of the Health Literacy specialist group (a Special Interest Group of the SAPC).

Tim Kelsey, National Director for Patients for NHS England, noted the following points.

- The 1948 health service was set up to deliver a high standard of care for all. Sixty-five years later it is not doing so; there are high variations in health care and health outcomes.
- NHS funding is becoming critical; it is estimated there will be a funding gap of £30 billion by 2020.
- Through giving people more control over their own health, the aim is to find new ways to engage and listen to communities and health services, which is fundamental to controlling the sustainability of the health service.
- At the core of this is health literacy as a way to help and support people to make use of information.

He noted too that:

[t]here is more health information being produced all the time, and we are learning to be [health] literate as a nation; it is important to ensure that no one is left behind. NHS Choices is about to be re-launched as a marketplace for services and tools. The NHS is an engine of social justice and we must make health literacy real in our society. NHS England has found £1 million to take 100,000 people through basic digital training. We will have to move quickly and there is much to do, but this is a good start.

Clare Gerada, the Immediate past Chair of RCGP Council, noted that:

this is very exciting looking forward and in future the NHS will have to try to engage the public in an equal way with regards to their health. It must be questioned how you can have shared decision-making if patients don’t understand the language you are using. GPs come across health inequalities every day. Unless they support the patients to improve their health literacy, how can they further engage patients?

1 Literature background

Health is complex and requires both motivation and skills. There are increasing demands on the public to promote their health and wellbeing, and on patients to be able to understand and manage their health and engage in shaping local health services.² A health literacy skills set is essential. Doctors need good communication skills too in order to share complex information in a clear and manageable way, and to tailor information to patient skills as well as clinical need. This specifically applies to GPs' provision of information, which can include the nature of a diagnosis, the risks and benefits of different treatments, and how to take medications in a safe and effective way. A key role for GPs is to support patients to develop the health literacy knowledge and confidence to improve their own health. Health literacy skills extend beyond consultation, as patients need to know how to access, understand and make use of health services in ways that can promote and maintain good health, to gather, evaluate and use information for health from a range of sources, both within and outside the NHS, and to become meaningfully involved with the development of local NHS services.

Health literacy is an important determinant of health. People can be well educated and even very literate and have low health literacy, but low health literacy is most common in people

with low basic skills. Recent surveys in the UK show that the percentage of adults below the literacy level expected at the end of full-time compulsory education (16 years) is 43%; for numeracy the percentage below the expected level at the end of compulsory education is 78%.³ This is reflected in the levels of health literacy. Forty-three per cent of the English adult working-age population cannot fully understand and use health information containing only text. When numerical information is included in health information, this proportion increases to 61%.⁴

Written health literature and doctors' spoken communication are often not pitched at a level that is inclusive of people with low health literacy. Some of the greatest problems arise from the mismatch between what health institutions demand and expect from patients (by what they produce in print, in oral exchanges, online and in the physical environment) and the skills of the patients and families they are intended to serve. Making services more responsive to patients is a core focus of UK health policy.

Doctors have a responsibility to communicate in a way that takes account of the diverse levels of health literacy of their patients, enabling people to make informed choices about their own health.

2 Health literacy

An overview

Dr Gill Rowlands

Health literacy can be divided into three levels: *functional*, *interactive* and *critical*. GPs are key, as 90% of all encounters in the NHS are in

general practice. GPs have an important role in supporting patients to develop their skills and also have a powerful role in commissioning.

Functional health literacy

These are the basic skills of reading, discussing and understanding text, and being able to do numerical calculations. One way of measuring this is to give people a test (measuring absolute levels of functional health literacy). There are multiple measures, which range in complexity and time. When understanding the relevance of health materials for patients, one important thing to understand is the gap between the complexity of the health information and the skills of those for whom the information is written (relative health literacy). Regarding absolute levels of functional health literacy, results vary as per the measures used. For example, in the US 46% of people operating within the lowest two levels would experience significant problems. With regard to relative levels of functional health literacy, health materials containing only text are too complex for 43% of England's working-age population to be able to understand and use; for materials containing both text (literacy) and numeracy, 61% of England's working-age population find the material too complex.⁴

There is significant regional variation. There is a north/south divide, with London as an island of deprivation in the south of England. However, low health literacy is a problem for everyone; even in the least deprived areas there is still a significant proportion of the population who

cannot understand health materials. Those facing the biggest barriers are older people, black and ethnic minority groups, those with low qualifications, those without English as a first language, those with low job status and those in the poverty trap.⁴

An exploratory analysis of how health literacy skills relate to information communication technology (ICT) skills as measured in the most recent English National Skills Survey (the Skills for Life Survey [SfL] 2011) found a marked overlap.³ For example, for word processing, the study compared people below and above the health literacy threshold. Those who failed the word-processing skills test were significantly more likely to be below the threshold. The same was found when the group tested emailing and spreadsheet skills.⁵

Previous research indicates the impact of low health literacy on patients and the Health Service. Low functional health literacy is linked with more use of hospital services with higher in-patient and Accident and Emergency (A&E) Department use, and with lower rates of screening uptakes including mammography and flu vaccine.⁶ There are also higher levels of mortality in older people.⁶⁻⁸

Interactive health literacy

This is about patients having the skills and confidence to discuss their illness and treatment with doctors or nurses, asking about other

options or questioning why a particular treatment is right for them. This promotes shared decision-making.⁹

Critical health literacy

This is about people trying to take control of the wider determinants of their health, for example having the skills to take action if they identify barriers to health in their environment such as not enough access to fresh fruit and vegetables or not enough open spaces for exercise.⁹ With

critical health literacy, the balance of power transfers to patients and the public.¹⁰ We have to move to this model; it might be uncomfortable for healthcare professionals (HCPs) but it takes patient self-determination and control to a different level.

3 What challenges does health literacy bring?

Health literacy is important. We know it affects health, so it is reasonable to assume it affects wellbeing too. It is a common problem that affects half of the population and is complex and influenced by all areas of life. We have to make sure we develop a range of solutions for individuals and families. We know communities have knowledge about their environments. GPs add to this by providing an environment for people to develop health literacy in a safe

space. Health service managers can ensure information is written in the right way. Health service commissioners are agents for change. The Information Standard (p. 14) is a powerful tool for ensuring that high-quality health information incorporates health literacy.

The issues brought about through low health literacy affect patients, HCPs, managers and commissioners of health services.

Challenges for patients

- Understanding and using the wide range of information relevant to health, which is written at varying literacy and numeracy levels, without being patronised.
- Difficulty assessing accuracy and provenance of health information.
- Understanding medical terms and language.
- Developing the language and skills to challenge and explore doctors' suggestions for treatment.
- Developing the language and skills to manage their own health within the context of their lives, including work, family and community.

Comments from the workshop members

'It is a wonderful idea to improve communication with patients. It is difficult when we look at it from a health inequalities and health information perspective. The gap here is in danger of widening. It is necessary to commission at patient and population level to ensure that those at the bottom don't fall behind.'

'Many people I look after cannot read. If we are moving to a digital platform the people who cannot read or write may be able to come back in.'

Challenges for doctors and other healthcare professionals

- Different styles and levels of communication are needed for people with low health literacy and those with very high health literacy.
- Current healthcare environments do not recognise the needs of people with varied levels of health literacy.
- There is frequently a tension between use of complex medical terminology and more everyday common-sense language.
- There is an absence of acknowledgement and support for people with low health literacy.
- HCPs, including doctors, need to be able to assess, recognise, support and improve the

health literacy of people as an integrated part of clinical practice and prioritise those most in need (for example those with

language barriers or multi-morbidity). HCPs need to measure change by feedback.

Challenges for managers

- Developing streamlined 'health literate' services accessible to all regardless of health literacy level.
- Ensuring 'health literacy awareness' of all staff.
- Ensuring health literacy training for frontline clinical staff and others with face-to-face patient contact.

Challenges for commissioners

- Enabling meaningful engagement of people at all health literacy levels.

The group felt that this is about support from organisations with strong trust relationships in communities. This needs to be resourced and commissioned. Also, the NHS needs to commission personalised services. Research should be used to build or support a compelling narrative.

The group talked about the commissioning environment; there are big challenges but there is sufficient funding to start making a difference. It would be necessary to follow the money. This will not happen overnight, and would most likely entail a five-year programme of work. It is important not to tell commissioners to do this, but to present it as a solution to an existing problem. The NHS needs to understand the value of advocates, and there is evidence that this works. When communicating with patients and the public, short slogans are linked to positive outcomes.

The Year of Care planning model (<http://healthandcare.dh.gov.uk/year-of-care/>) mentions many of these aspects. The Year of Care model from the Chronic Care model is helpful in putting it all together.

The EU Health Literacy Survey

A good study measuring interactive and critical health literacy is the EU Health Literacy Survey.¹¹ This study developed a conceptual framework and then a matrix to measure perceived ability to access, understand, appraise and apply health information across the three domains of health care, disease prevention and health promotion. Eight countries (unfortunately not including the UK) took part in this survey. This replicates the functional health literacy findings in England. People with low literacy skills make more use of hospital services and are less likely to get involved in preventive activity. They are also more likely to die at a younger age. It is interesting that the problem is worse in countries with the most poverty.

4 The importance of communication

Health literacy relates to more than just reading and writing (or 'general literacy'). It also includes the ability to access, understand and act upon health information and services¹² as well as wider issues of motivation¹ and the ability to take control of environmental and social factors influencing health.⁹ Not everybody has had the opportunity to study biology or basic science. Many people have minimal knowledge of health conditions or how their own bodies work. Doctors, having spent many years immersed in the biology of human health and disease, may overestimate the health literacy of their

patients.¹³ Several researchers have found that doctors do not adjust their communication when seeing patients with varying levels of health literacy, and they may fail to realise that they have not made themselves understood.¹⁴

Good diabetes self-care includes patients regularly monitoring their own blood glucose levels to keep them within a narrow range. Yet, patients with diabetes may struggle to make sense of this unless they know that it is part of normal biology for blood to contain some glucose.

Misconceptions and misunderstandings

Patients with limited literacy may feel embarrassed by their lack of understanding or poor reading skills, which can stop them asking for clarification or looking for alternative sources of information.¹⁵ This mismatch in communication is an important factor contributing to poor health.

Doctors may use familiar words in unfamiliar ways. For example, when health practitioners use the term 'chronic' they frequently mean 'persistent', whereas a common alternative understanding of the word is to mean 'severe'.¹⁶ Doctors can unintentionally use words that are unfamiliar to their patients, without realising that the meaning is not clear. Some concepts familiar and obvious to doctors may be alien to patients.

Doctors often supplement brief spoken information during the consultation with leaflets and booklets, assuming they can be understood.

People with poor health literacy will struggle to make use of written health information, which often requires a level of literacy that many patients do not have.⁴ Increasingly, patients are sent copies of clinic letters; they struggle to understand these and this may be a source of frustration and confusion. More and more, the internet is a source of health information. ICT skills are moderately correlated with both literacy and numeracy skills, thus those with low literacy and numeracy skills, and health literacy skills, are also likely to have low ICT skills.^{3,6} Furthermore, those with low health literacy skills will also have the least access to sources of information, including the internet.⁴ New initiatives to increase patient understanding of, and control over, their health and health care, such as access to medical records, may also be less accessible to those with low health literacy skills, arguably one of the groups with the most to gain from such access.

Patients typically retain around half of the information they receive in a consultation, and

only half of what they do retain is generally correct.¹⁷

Treatment errors

Low health literacy can prevent people understanding the diagnosis they have been given. It can also lead to treatment errors. Adults with low levels of literacy have increased rates of misunderstanding medication instructions.¹⁸ All medication in the UK is clearly labelled and a

patient information leaflet is included in the box. Low health literacy prevents many people from being able to interpret this information and this inhibits understanding of medication warnings and precautions.

Shared decision-making

When decisions are made jointly between doctors and patients, this can lead to improved health outcomes, higher levels of patient satisfaction and more effective use of resources.¹² Low health literacy is a barrier to participating

in shared decision-making. This includes the process of informed consent for medical and surgical procedures. Patients must be given enough time and understandable information to fully appreciate the implications of their consent.

5 Low health literacy and health

Poor health literacy has substantial health consequences: people with low health literacy report worse physical and mental health, which is supported by a higher prevalence of a number of serious health conditions, including diabetes and heart failure.⁶ These individuals have less adequate health knowledge, access fewer preventive services and have poorer self-management skills. Repeated studies have shown that those with low health literacy are more likely to access emergency services or to be admitted to hospital, and have a reduced quality of life.⁶ Studies also suggest an increased risk of

dying for older people with low health literacy, compared with their more health-literate peers.^{7,8} This link remains even after other factors, such as poverty, are taken into account.

Personal communication from a physician

One patient with arthritis came in to hospital unable to move due to swollen joints. It turned out that her appointment four months ago had been cancelled but she hadn't known how to get help, and so had simply lived with her deteriorating symptoms.

6 The health literacy environment

Health literacy is an important determinant of access to health care. Doctors instinctively know how to navigate themselves and their families through health services. People with low health literacy may struggle to book or cancel appointments. They may be unsure of how to respond to an adverse reaction to their medication. Many patients with long-term conditions do not know what to do if their health deteriorates between planned consultations. Even working out how to get to the right place in a health facility requires a degree of health literacy.

GPs undertake 90% of face-to-face medical consultations in the NHS and are thus in an excellent position to work with patients and patient advocates to design systems that are more accessible to people with low health literacy. As people who regularly meet patients, they are in a position to identify barriers in the system and work to develop health environments that facilitate better access.

Personal communication from a GP

A patient referred for a chest X-ray didn't have it done because he walked round the hospital and couldn't find the department because the sign read 'Radiology'. He was too embarrassed to ask for directions.

Health service managers can play a key role in developing 'health literate' environments. This can include a health literacy risk assessment of all information and materials given to patients, and clear signage avoiding jargon and using lay terms whenever possible, for example 'heart section' rather than 'cardiology department'. All staff should be made aware of health literacy and the challenges it can bring; all staff with patient contact (clinical and non-clinical) should have regular health literacy training. There are well-developed and tested tools available to help managers develop health-literate services,¹⁹ and managers should be encouraged to use these.

Finally, patient assessment of services is increasing;²⁰ managers should consider adding some simple questions to patient feedback surveys to assess patient views on the clarity, or otherwise, of hospital and GP surgery systems and information. Including patient experts and patient advocates in the design of the systems that are more accessible, including design of buildings and signage in new NHS premises, will help the NHS to provide services accessible to all regardless of their health literacy skills.

7 Good practice

There are several concrete steps that doctors can take to improve communications with all patients, regardless of health literacy level. Speaking slowly, avoiding jargon and repeating points all improve comprehension. Doctors should encourage and expect all patients to ask questions using techniques such as those identified in the 'Ask me 3' patient education programme.²¹

Doctors should first establish what the patient knows and understands before launching into a discussion that begins at a level either too complex or too simple for the patient.

To check understanding and recall of the consultation, doctors should ask for patients to repeat back critical information in their own words. Using this technique, known as 'teach back', will clearly establish whether the patient has understood the consultation.²² When doing this, doctors should emphasise that what they are checking is their own ability to communicate, not the patient's ability to understand. By closing the communication loop in this way, doctors can identify which explanations and communication gaps are most often understood by patients.

This is particularly important when doctors are meeting patients for the first time. Repeating information in this way also reinforces it in patients' minds.

Doctors can also reduce the impact of low health literacy by communicating in ways other than speech and printed material. Some concepts are better conveyed visually. Almost every consulting room has a computer screen, and graphics and multimedia can be used to supplement more conventional illustrations and three-dimensional models.

Doctors should apply a 'universal precautions' approach to communication (that is, communicate clearly and without jargon for all patients) and not only when health literacy is obviously low. It is important to give patients clear opportunities to return with further questions, either written or verbal, at a later date. Patients who are well spoken and educated may also have low health literacy and this may be exacerbated by the stress of being unwell. By consistently practising good communication, doctors can improve care for all their patients.

Comments from the workshop members

- 'Regarding functional literacy, there are huge barriers for someone with learning disabilities. Bringing people to the information may not be realistic. The information may need to change.'
- 'There is much to learn from the learning disabilities field. They have done great work on simplifying information to date (e.g. Books Beyond Words). In the short term we have to simplify the way we do things and need to learn from colleagues. Information should be tailored appropriately for the group that needs to access it. We need to raise the skills of the population at the same time as simplifying information, but one size will not fit all.'
- 'The point [of Books Beyond Words] is to allow people to tell their own story rather than to tell our story. The most important thing is to establish reciprocity and learn from people about their circumstances.'
- 'Whether or not people trust [their GP] influences understanding. We will have to understand health literacy in a more complex way.'
- 'The challenge is how to make the sum of the solutions greater than the individual parts. Any work moving forward should look at bringing the disparate strands together. Having something measurable is very important.'
- 'We need real actions to take forward from today. There is huge momentum and it is our responsibility to ensure it delivers real, hard outcomes.'

'Ask me 3' is a technique for patients to use when dealing with health professionals. By asking these three questions, they can improve communications with their doctor:

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?¹

8 Interactive and critical health literacy

Almost all research to date has focused on literacy and numeracy skills in the health setting, that is, functional health literacy.⁹ However, the expanded definition used in the UK includes wider and higher-level cognitive skills. Interactive health literacy skills are those that enable people to 'actively participate in everyday (health) activities, to extract information and derive meaning from different forms of (health) communication, and apply new information to changing circumstances', while the highest-level skills ('critical' health literacy skills) enable people to 'critically analyse information and use this information to exert greater control over life events and situations'.⁹ These higher-level health literacy skills will be required to enable patients and the public to promote health and wellbeing, protect their health through involvement in illness prevention (for example, involvement in disease screening and understanding of personal and public safety), and manage any illnesses they may develop.

The NHS, like all health services, is having to provide more health care to more people within limited resources;²³ the only sustainable way for this to happen is for increased health promotion and patient self-care.^{24,25} The latest NHS reorganisation is placing an emphasis on patient involvement in shaping local services, with 'no decision about me without me'.² An appropriate and effective way to take these agendas forward is to build interactive and critical health literacy skills in the population. Teaching such skills is complex, but lifelong learning initiatives for individuals and families are showing promising results.^{26,27} The recent movement of public health from the NHS into local authorities²⁸ brings many opportunities for closer working between the NHS, public health, education and social care, including collaborative projects to build patient and public health literacy skills.

9 The Information Standard

The Information Standard is a certification scheme for organisations producing evidence-based health and care information for the public. Any organisation achieving the Information Standard has undergone a rigorous assessment to check that the information it produces is clear, accurate, balanced, evidence-based and up-to-date.²⁹ Information Standard-accredited organisations should be writing at a level that's appropriate for the population. Such approaches

make systems clearer, reduce complexity and improve communications. The Information Standard is thus a powerful driver for change. A recent survey of Information Standard members²⁹ indicated that the majority of members had heard about health literacy but 20% had not. The majority already think they are producing information at the right level; 30% identified one or more barriers to accessing information; and 70% wanted to learn more about health literacy.

10 Health literacy in practice

Case study from the Terrence Higgins Trust

Case study by Dominic Edwardes, Health Improvement and Marketing Director, Terrence Higgins Trust

The key thing about health literacy is that it involves the audience rather than the producer. We need to put the consumer at the centre. The issue with health literacy is people being able to use the information.

The fact that 43–61% of the population have low health literacy skills⁴ is surprising. Information is wasted if it isn't produced in a way that people can understand and find useful. There are three key dimensions to health literacy: reading level, numeracy level and language barriers. We have to understand how people are accessing information. For example, at the Terrence Higgins Trust it is known that gay men like to use iPhones.

Can one size fit all? Yes and no. Using examples from the work of the Terrence Higgins Trust and looking at African audiences we know that stigma is huge in stopping people from accessing information on human immunodeficiency virus (HIV). Most people who have come to the UK think that they have left the problem of HIV behind them. These people also have a strong dislike of sexualised imagery and have lower levels of internet access.

To reach this audience the Terrence Higgins Trust created a healthy-lifestyle magazine, which includes information on HIV. This is proving successful and is in its tenth edition. There are also leaflets about testing, sexually transmitted

diseases (STDs) and HIV. Looking at men who have sex with men, they are familiar with HIV messaging, tend to have higher partner change and love sexualised imagery. They have high levels of internet access and are known to be early adopters of technology. The Terrence Higgins Trust has created a condom campaign online that also encourages STD check-ups.

Messages can look different for different audiences. The Trust has now developed a message that looks broadly the same but that approaches both gay men and the African audience. Both groups are engaged with starting things. The campaign is 'It starts with me' and has slightly different approaches, but the same message for each group. For example, the use of condoms in the campaign resonates with the message of responsibility for the African audience and the message of better sex for men who have sex with men.

The mobile will overtake the desktop and it is important for the Trust to know that creating an app will reach its target audience for men who have sex with men. It is now possible to order a postal HIV test kit via your mobile.

What can GPs do? They can direct HIV sufferers to the Terrence Higgins Trust, they can look for materials produced by the Information Standard and they can promote NHS Choices.

11 The NHS England Digital Inclusion Strategy

Exploiting the power of the digital revolution to transform health care, and delivering interventions that address health inequalities, are leading objectives for NHS England. The NHS England Mandate³⁰ made a commitment to operate at the forefront of new technologies. That Mandate states: '[t]he objective is to achieve a significant increase in the use of technology to help people to manage their own health and care'. At the same time there is a commitment to reducing health inequalities with an NHS 'for everyone regardless of income, location, age, gender, ethnicity or any other characteristic'.³⁰

However, these objectives can be difficult to reconcile. Those who make greatest use of health services, and those experiencing greatest health inequalities, are exactly those least likely to be online,^{17,31} or to have ICT skills.³

- Over 16 million people in the UK lack basic digital literacy skills.
- Over 7 million people in the UK have never used the internet.
- People over the age of 65 account for more than half of all NHS spending. However, 40% of those aged 65 and over do not have access to the internet at home and 5 million of these have never been online.
- People with a disability are three times more likely to have never used the internet. Four million people with a disability have never been online.
- The homeless, offenders, the Gypsy and Traveller community and people in some rural communities experience health inequalities. These people are at an additional disadvantage because of the lack

of internet access or broadband.

Furthermore there is a strong correlation between low levels of digital skills and low levels of health literacy.

- Those working-age (16–65 years) people in England have the least access to sources of health information, including the internet.⁴

The NHS England business plan³² has set out an ambitious programme of digital transformation including:

- giving citizens the knowledge, skills and confidence to manage their own health
- using modern techniques such as social and digital media to supplement other forms of insight, so that we hear views from all sections of society and understand what people are saying about the health services they want to receive
- making best use of digital channels to offer people more convenience, choice and control.

This transformation will not be delivered if the benefits are not available to the 7 million people who have not been online, the 16 million people who lack basic digital literacy skills, or the 21 million people with low health literacy and numeracy.⁴ Extending digital access and boosting digital literacy skills are central to NHS England's approach to equality:

Equality lies at the heart of the NHS, its values, processes and behaviours. People have a right to high quality services, irrespective of who they are, where

they live, or what condition they have. There is clear evidence that people from disadvantaged communities are at greater risk of early death than the average population.³²

People with the lowest health literacy, itself a risk factor for poorer health and higher mortality,^{8,9} also have the least access to sources of health information, including the internet. This finding means that this extension of digital access and digital literacy skills will need to be specifically targeted at groups at higher risk of low health literacy.⁴

Recognising the importance of this challenge, the NHS England business plan³² includes the following commitment: 'Reducing inequalities: 100,000 citizens trained in basic online skills to boost health literacy (by April 2014).'

A programme of work has been designed to deliver:

- the establishment of a network of community hubs in deprived areas to provide training in online skills and assisted digital support in accessing online services
- the development of online training tools
- user testing of digital products and services with less digitally skilled users
- the building of the evidence base on digital literacy's contribution to increased patient empowerment and reduced health inequalities.

The contract to deliver this Widening Digital Participation programme has been let to the leading digital inclusion and skills agency, the Tinder Foundation (www.tinderfoundation.org).

12 Summary of breakout group discussions

In considering issues around health literacy, three breakout groups were set up. These groups considered the role of the GP and professionals, the role of the commissioner and the role of the patients and the public. A framework to consider any future work was defined: issues

around specific outcomes, what will make the biggest difference, what we can expect to change and how this should be measured, when we can expect it to happen, key stakeholders, if extra training is needed, tools needed and a key research question in relation to their area.

GPs and healthcare professionals

In considering the role of GPs and professionals, the discussion was very rich. The group decided that the theme was to centralise the idea that HCPs need to be able to assess, recognise, support and improve the health literacy of people as an integrated part of clinical practice and prioritise those most in need (for example, those with language barriers or multi-morbidity). HCPs also need to measure change by feedback and checking patient understanding of key messages from the consultation, emphasising

to the patient that what is being checked is the doctor's ability to communicate well, rather than the patient's ability to understand. Key stakeholders would include those responsible for under- and postgraduate training. Training will be needed to build in the idea of trust, compassion and reciprocity. Toolkits will be needed and the group talked about using videos and peer review. Research questions could be based around developing an assessment of consultations or be linked to effectiveness.

Health service commissioners

In considering the role of health service commissioners, the key themes that emerged included making information accessible and advocacy, with support leading to better health outcomes. Motivated and activated community

networks were thought to be of importance, which would lead to trust. The challenge for commissioners is to equate the evidence to the benefits.

Patients and the public

In discussing the role of patients and the public, key themes and ideas included the development of test sites, extension of the friends and family test to include health literacy, the right to take an advocate with you, the amount of time allowed in a GP consultation, information

provided before and after a consultation, role models, peers, role of data, and availability of tools to confirm patients' awareness of options. Also of importance was making information accessible before and after the consultation, the value of role models, peers and patient leaders,

and availability of tools to confirm patients' awareness and understanding of their healthcare options. The need for patients to be asked if they understand what is being presented to them was important and this highlights good practice. The idea is to develop a culture change with patients as active partners in care. There are clear research needs around assessing the impact and

accessibility of different forms of information (leaflets, video, etc.), ascertaining whether people accessing lifelong learning to build health literacy skills feel more confident about talking to health professionals, and determining what percentage of people leaving the GP consultation or other settings understand options and information.

13 Conclusions and call for action

Two key themes are described at the beginning of this report: the need for making more effective use of resources and the central role of GPs in accomplishing this by improving their own communication skills, and tailoring information to not only patient health literacy but also clinical need.

Health literacy is a complex, multifaceted concept, but one that has real impact on patients, doctors and the NHS. The problems brought by low health literacy are many, and affect all areas of health and health care. By working together to develop a five-year plan, building on the ideas of the key stakeholders present at the England seminar, the RCGP and NHS England can lead the way in addressing some of the important issues raised by health literacy, resulting in more effective, more patient-centred care in the NHS.

This report calls for action for GPs to play their part in addressing the issues raised by low health literacy in England. A five-year plan should be developed by the RCGP, in partnership with NHS England, to address the following areas.

1. To work with the Health Literacy Group UK to ensure that national health literacy policy recommendations include those arising from the July 2013 workshop and this report.
2. To influence GP training so that all GPs recognise the issues caused by low health

literacy and learn to develop consultation techniques to improve the clarity of their communication with patients with low health literacy and support patients to develop their health literacy skills.

3. To develop recommendations for Clinical Commissioning Groups (CCGs) to consider health literacy approaches by NHS service providers when commissioning services.
4. To develop pilot sites where CCGs can commission health literacy training for patients from adult learning providers, with assessment of the impact of these pilots on patient skills, patient satisfaction with NHS services and their use of NHS services.
5. To ensure that those aspects of the Digital Inclusion Strategy relevant to general practice are highlighted to GPs.
6. NHS England in particular to work with the Information Standard to develop a health literacy guide to be circulated to all NHS Trusts.

We believe that the development and implementation of such a five-year plan could transform the landscape of health literacy in England through development of a health-literate health system accessible to all, and empowered, health-literate patients can work with GPs and NHS England to shape the NHS that England needs.

References

1. Nutbeam D. Health promotion glossary. *Health Promotion International* 1999; **13(4)**: 349–64.
2. Department of Health. *Equity and Excellence: liberating the NHS*. London: TSO, 2010.
3. Department for Business Innovation and Skills. *The 2011 Skills for Life Survey: a survey of literacy, numeracy and ICT levels in England*. BIS research paper number 81. London: DBIS, 2012.
4. Rowlands G, Protheroe J, Richardson M, *et al*. Defining and describing the mismatch between population health literacy and numeracy and health system complexity. Submitted for publication.
5. Rowlands G. The relationship between function health literacy and Information Communication Technology (ICT) skills in England. Presentation to an RCGP seminar. 2013.
6. Berkman ND, Sheridan SL, Donahue KE, *et al*. *Health Literacy Interventions and Outcomes: an updated systematic review*. Rockville, MD: Agency for Healthcare Research and Quality, 2011.
7. Bostock S, Steptoe A. Association between low functional health literacy and mortality in older adults: longitudinal cohort study. *British Medical Journal* 2012; **344**: e1602.
8. Baker DW, Wolf MS, Feinglass J, *et al*. Health literacy and mortality among elderly persons. *Archives of Internal Medicine* 2007; **167(14)**: 1503–9.
9. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International* 2000; **15(3)**: 259–67.
10. Kickbusch I, Wait S, Maag D. *Navigating Health: the role of health literacy*. London: International Longevity Centre, 2005.
11. Doyle G, Cafferkey K, Fullam J. *European Health Literacy Survey (HLS-EU) Executive Summary*. Dublin: University College Dublin, 2012.
12. Nielsen-Bohlman L, Panzer AM, Hamlin B, *et al*. (eds). *Health Literacy: a prescription to end confusion*. Washington, DC: Institute of Medicine, 2004.
13. Baker DW. Presentation to the Royal College of Physicians Working Party on Doctor:Patient Communication.
14. Baker DW, Parker RM, Williams MV, *et al*. The health care experience of patients with low literacy. *Archives of Family Medicine* 1996; **5(6)**: 329–34.
15. Parikh NS, Parker RM, Nurss JR, *et al*. Shame and health literacy: the unspoken connection. *Patient Education and Counseling* 1996; **27(1)**: 33–9.
16. Berry J. Patient misunderstanding of commonly used terms used in a medical context. 2013.
17. Kenny T, Wilson RG, Purves IN, *et al*. A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use. *Family Practice* 1998; **15(5)**: 471–7.
18. Wolf MS, Davis TC, Tilson HH, *et al*. Misunderstanding of prescription drug warning labels among patients with low literacy. *American Journal of Health-System Pharmacists* 2006; **63(11)**: 1048–55.
19. Rudd RE, Anderson JE. *The Health Literacy Environment of Hospitals and Health Centers*. Boston, MA: Harvard School of Public Health, 2006.
20. NHS England. First results from NHS Friends and Family test published. Available from: www.england.nhs.uk/2013/07/30/nhsfft/ [accessed 28 January 2014].

21. National Patient Safety Foundation. Ask me 3. Available from: www.npsf.org/for-healthcare-professionals/programs/ask-me-3/ [accessed 28 January 2014].
22. Schillinger D, Piette J, Grumbach K, *et al.* Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine* 2003; **163(1)**: 83–90.
23. NHS Choices. The NHS in England. Available from: www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx [accessed 28 January 2014].
24. Wanless D. *Securing our Future Health: taking a long-term view*. London: DH, 2002.
25. Cayton H. The flat-pack patient? Creating health together. *Patient Education and Counselling* 2006; **62(3)**: 288–90.
26. *Evaluation of the Second Phase of the Skilled for Health Programme*. London: The Tavistock Institute and Shared Intelligence, 2009.
27. Sykes S. *Healthy Families, Health Literacy Project*. Evaluation report. London: London South Bank University, 2011.
28. Health and Social Care Act 2012. Available from: www.legislation.gov.uk/ukpga/2012/7/contents/enacted [accessed 28 January 2014].
29. Rowlands GP, Roberts S. Health literacy: views from Information Standard members. Royal College of General Practitioners Seminar on Health Literacy, London, 2013.
30. Department of Health. *The Mandate. A mandate from the government to the NHS Commissioning Board: April 2013 to March 2015*. London: DH, 2013.
31. Hennell T. Role of general practitioners in NHS must not be undervalued (letter). *British Medical Journal* 1999; **318(7195)**: 1420.
32. NHS England. *Putting Patients First. The NHS England business plan for 2013/14–2015/16*. NHS England, 2013. Available from: www.england.nhs.uk/pp-1314-1516/ [accessed 28 January 2014].

Appendix I

Group members and their affiliations

John Ballat	Partner, People in Systems	Author of <i>Intelligent Kindness</i>
Roger Banks	Chair	Health Inequalities Forum, Academy of Medical Royal Colleges
Jonathan Berry		CHL Foundation
Alpa Bisarya	Business Manager	Hurley Group
Jabeer Butt	Deputy Chief Executive	Race Equality Foundation
Dominic Edwardes	Health Improvement and Marketing Director	Terrence Higgins Trust
Agatha Ferrao	Health Literacy Lead	Department of Health
Bob Gann	Patients and Information	NHS England
Clare Gerada	Chair of Council	RCGP
Sheena Gibson	Curriculum Development Committee	RCGP
Jo Giles		Generate UK
Chris Gush	Head of Clinical Innovation and Research Centre	RCGP
Adrian Hegenbarth	Research Fellow	RCGP
Helen Jones	Chief Executive	Leeds GATE
Tim Kelsey	National Director Patient Information	NHS England
Graham Kramer	National Clinical Lead for Self-Management and Health Literacy	Scottish Government
Alice Lau	Health Inequalities Standing Group	RCGP
Graham Martin	Health Inequalities Standing Group	RCGP
Samantha Meikle	Programme Director	Improvement Science London
Luke O'Shea	Head of Patient Participation	NHS England
Henry Pares	IT Directorate	NHS England
David Paynton	National Commissioning Lead	RCGP
Joanne Protheroe	GP and Health Literacy Researcher Co-Chair, Health Literacy Group UK	Keele University SAPC/RCGP
Imran Rafi	Chair of Clinical Innovation and Research Centre	RCGP
Laura Robinson	Policy and Communications Adviser	National Voices
Gill Rowlands	Co-Chair of Health Literacy Group UK	SAPC/RCGP
Bernd Sass	Strategic Partnership Manager	Disability Rights UK
Adrian Sieff	Assistant Director	Health Foundation

Mark Thomas	Assistant Director of Policy and Campaigns	RCGP
Harvey Ward	Chair of Patient Partnership Group	RCGP
Tim Warren	Policy Lead on Health	Scottish Government
Charlotte Wheat	Director of Delivery	UK Online Centres
Laura Wigley	Patient Participation	NHS England
Arwen Wilcock	Programme Manager	RCGP
Giles Wilmore	Director of Patient and Public Voice	NHS England

Group 1: What is the role of GPs and professionals in supporting health literacy?

John Ballat	Rebecca Linton
Roger Banks	Graham Martin
Alpa Bisarya	Joanne Protheroe
Sheena Gibson	Imran Rafi
Chris Gush	Mark Thomas
Graham Kramer	Tim Warren
Alice Lau	Arwen Wilcock

Group 2: What is the role of commissioners in supporting health literacy?

Bob Gann	Laura Robinson
Adrian Hegenbarth	Gill Rowlands
Helen Jones	Adrian Sieff
David Paynton	Giles Wilmore

Group 3: What is the role of patients/the public in improving their health literacy (understanding their own health, treatment choices, shared decision-making)?

Jonathan Berry	Luke O'Shea
Jabeer Butt	Henry Pares
Dominic Edwardes	Bernd Sass
Agatha Ferrao	Harvey Ward
Jo Giles	Charlotte Wheat
Samantha Meikle	Laura Wigley

Appendix II

Key texts and other resources

Key texts

Rootman I, Gordon-El-Bihbety D. *A Vision for a Health Literate Canada: report of the Expert Panel on Health Literacy*. Ottawa: Canadian Public Health Association, 2008.

Kickbusch I, Wait S, Maag D. *Navigating Health: the role of health literacy*. London: International Longevity Centre, 2005.

Nutbeam D. The evolving concept of health literacy. *Social Science and Medicine* 2008; **67(12)**: 2072–8.

Baker DW. The meaning and the measure of health literacy. *Journal of General Internal Medicine* 2006; **21(8)**: 878–83.

Zarcadoolas C, Pleasant A, Greer DS. Understanding health literacy: an expanded model. *Health Promotion International* 2005; **20(2)**: 195–203.

Other resources

1. *The Plain English Campaign's Crystal Mark* (www.plainenglish.co.uk/services/crystal-mark.html) is a quality mark used by NHS organisations and the civil service. The Plain English Campaign checks that information is clear, accurate, balanced, evidence-based and up-to-date.
2. *The Tinder Foundation* (www.tinderfoundation.org/) runs UK-wide online learning centres, based mainly in public libraries, to train 100,000 citizens in basic online skills by April 2014.
3. *The Health Literacy Group UK* (www.healthliteracy.org.uk) is a not-for-profit group of health practitioners, adult learning tutors, academics and patient groups committed to raising the profile of health literacy in the UK, with a particular focus on supporting members to build the health literacy evidence base and share best practice.

Published by the

Royal College of General Practitioners
30 Euston Square, London NW1 2FB

Telephone: 020 3188 7400

Fax: 020 3188 7401

Email: admin@rcgp.org.uk

www.rcgp.org.uk

Royal College of General Practitioners is a registered charity
in England & Wales (No. 223106) & Scotland (No. SC040430).



Royal College of
General Practitioners

The Royal College of General Practitioners is a professional membership body with over 48,000 GPs working to improve care for patients. We work to encourage and maintain the highest standards of general medical practice and act as the voice of GPs on education, training, research and clinical standards.