



**Patient Information Forum**

*For Professionals Working in Consumer Health Information*

**Report**



# Health literacy and health information producers

Report of the findings of a UK wide survey of information producers and providers

**The Patient Information Forum (PiF)**

is the organisation for people working in consumer health information. PiF campaigns to ensure that consumer health information is central to high quality, patient-centred care and helps providers develop high quality information for their patients and the public.

PiF ([www.pifonline.org.uk](http://www.pifonline.org.uk)) is a not-for-profit, independent organisation with members in all healthcare sectors and in every country in the UK.

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- **Professor Theo Raynor**  
Professor of Pharmacy Practice at University of Leeds, UK and Director, Luto Research Ltd
- **Dr Angela Coulter**  
Senior Research Scientist at University of Oxford Department of Public Health and Director of Global Initiatives at the Foundation for Informed Medical Decision Making
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Director at Community Health and Learning Foundation
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Director at Community Health and Learning Foundation

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*'The delivery of high quality and appropriately targeted consumer health information is central to the achievement of health literacy.'*<sup>11</sup>

**Coulter and Ellins, 2006**

Health literacy is broadly about an individual's ability to make sound health decisions in the context of everyday life and as such, it is an important aspect of their capacity to manage their health and care. Although it has a significant impact on health outcomes, it has had a relatively low profile in the UK compared to areas such as shared decision making, behaviour change and health improvement.

Low health literacy compromises people's ability to understand their health needs and to navigate complex healthcare systems, with profound consequences for their health. It is closely associated with significant health inequalities between different groups in the UK. People with low health literacy have poorer health status, are less likely to make healthy living choices, experience higher rates of hospitalisation and emergency admissions and incur substantially higher health service costs.

Low health literacy was once seen as an individual's deficit - their lack of knowledge and skills regarding health issues. It is now recognised that health literacy is a 'systems issue', which reflects the complexity of both health information and the health care system.

It represents a very significant problem and challenge in the UK. For example, around one in five adults cannot read or understand simple instructions or labels such as those found on medicine bottles.

Addressing health literacy issues is a fundamental part of the consumer health information challenge. Understanding and improving health literacy should be a key objective for anyone who works in the field of consumer health information or who communicates with the public in any way about their health.

## **The survey**

347 people took part in a Patient Information Forum online survey which sought to gain insight into health literacy from the information producer perspective; exploring whether information producers know what it means and how important they think it is; what specific strategies they have to address the needs of people with low health literacy and how these strategies are implemented.

Respondents largely reflected the make-up of the health information sector, with the majority of responses coming from NHS and voluntary sector organisations. The survey had a good response from across all UK countries. Most respondents are producing health information in-house. The sample size and nature of respondents reflects the views of the health information sector well.

The vast majority of information producers see health literacy as something that is relevant and important to everyone, rather than to specific groups of people. They believe that all resources should be clear, simple and straightforward in order to meet a wide range of health literacy needs.

Most rate the issue of health literacy as extremely or very important when planning, developing or writing information resources or services. However, fewer than half provide services or resources that address the needs of people with low health literacy and only 10% have a specific policy or strategy.

The main barriers faced when producing information for people with low health literacy include limited funds and resources, limited understanding of needs and limited understanding of how to develop appropriate resources or services.

The findings show that although information producers in the UK have a good understanding of health literacy and its importance, they lack the tools and skills with which to develop appropriate resources and services that meet the needs of people with low health literacy. There is a clear appetite for practical guidance and case studies.

*'It's not that we don't want to produce information in this way; it's how we go about it - the same with learning disabilities, there are no set guidelines to follow when producing information - there are symbols and pictures but no actual written help on how to word patient information.'*

**Survey respondent**



## What is health literacy?

**Health literacy is a broad term that relates to an individual's ability to read, understand and use information to make decisions about their health and care.**

It is sometimes not a helpful term; it means little to patients and the public and a myriad of different things to health professionals, academics and researchers and policy makers. As such, although it is an important aspect of an individual's ability to manage their health and care and make informed decisions, and though it has a significant impact on their health outcomes, it has had a relatively low profile in the UK compared to areas such as shared decision making, behaviour change and health improvement.

Health literacy has been described as: *'the personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health.'*

**Nutbeam, 2000<sup>1</sup>**

There is no universally agreed definition of health literacy. The term has been used in a number of different ways over the last few decades. Some definitions concentrate on 'functional' health literacy - a concept in which health literacy is linked to literacy and numeracy skills and is seen as the ability to read and comprehend written medical information and instructions. Other definitions of health literacy have taken a broader stance; seeing health literacy as an important factor for everyone and emphasising activation, empowerment and citizenship aspects.

Health literacy is: *'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.'*

**US Institute of Medicine<sup>2</sup>**

Health literacy is not just about an individuals' ability to read and make sense of health information. According to the definition adopted by the World Health Organisation, addressing health literacy is an empowerment strategy. Ensuring that people are able to access, understand, appraise and utilise health information effectively is the cornerstone for their active and informed engagement in healthcare and in decisions relating to this.<sup>3</sup>

*'Health literacy seems like the Emperor's new clothes - as an information provider my core concern is making medical information as accessible as possible and increasing the routes for people to access it. It isn't essentially a helpful term.'*

**Survey respondent**

## Why is health literacy important?

**Health literacy describes people's ability to make sound health decisions in the context of everyday life.<sup>4</sup> Low health literacy compromises people's ability to understand their own health needs and to navigate complex healthcare systems, with profound consequences for their health.**

Low health literacy represents a very significant problem and challenge in the UK. Around 7 million adults (20%) cannot read or understand simple instructions or labels such as those found on medicine bottles, while around half the population would be unlikely to understand cancer information brochures routinely used in hospital settings.<sup>5</sup>

As many as 25% of the sample have literacy skills equivalent to a seven year old, numeracy skills reported an even poorer outcome with 53% of respondents below Level 1 (abilities similar to a seven year old).<sup>6</sup>

**National Survey of Adult Basic Skills in Wales, 2004**

More recent research regarding women with breast cancer established that 19% of those in the study would have been unable to understand and consequently act on the written information that they were given.<sup>7</sup> Research published in the BMJ in 2012 found that a third of older adults in England have difficulties reading and understanding basic health related written information. This poorer understanding is associated with higher mortality.<sup>8</sup>

Low health literacy is closely associated with significant health inequalities between different groups in the UK. Health inequalities arise from a combination of socio-economic factors experienced by many people living in areas of deprivation. Consequently, those determinants of health such as education, employment, housing, level of income, environment, ethnicity, not having English as a first language and gender can impact on people's ability to both understand and act on health promotion messages as well as function effectively in clinical settings. Some groups are more likely to be affected by low health literacy, including people from ethnic minority backgrounds, those with a low level of educational attainment and/or who suffer socio-economic deprivation and older people with multiple health conditions.<sup>9</sup>

People with low health literacy:<sup>10</sup>

- have poorer health status
- experience higher rates of hospitalisation and emergency admissions, and have longer stays
- are less likely to adhere to treatments and self-care plans
- have more medication and treatment errors
- make less use of preventative services and more use of unplanned services
- have less knowledge of disease-management
- are less likely to make healthy living choices
- have decreased ability to communicate with health professionals and participate in decision-making
- are less able to make appropriate health decisions
- incur substantially higher health service costs.

## Health literacy and health information

**Successfully addressing health literacy issues is of crucial importance to, and a fundamental part of, the consumer health information challenge - to help turnaround the 'reverse information law' whereby access to appropriate and meaningful information is particularly difficult for those who need it most.<sup>12</sup>**

Whether someone is health literate or not is the result of many complex processes and factors which include education, culture and society as well as health. In order to make an impact on an issue as complex as health literacy improving one area alone, such as consumer health information, is unlikely to be enough to make really significant changes.

Nutbeam (2000) states that improving health literacy involves more than the transmission of health information, it requires more overt alliance between education and health sectors, an understanding of the political aspects of education and a focus on the structural barriers to health.<sup>13</sup> However, Coulter and Ellins (2006) believe that the delivery of high quality and appropriately targeted consumer health information is central to any achievement of health literacy.<sup>14</sup>

Low health literacy was once seen as an individual's deficit - their lack of knowledge and skills regarding health issues. It is now recognised that health literacy is a 'systems issue', which reflects the complexity of both health information and the health care system.<sup>15</sup>

As Graham Kramer, a GP and National Clinical Lead for Self Management and Health Literacy with the Scottish Government says, if we do not begin to see health literacy as our problem, we will consistently deny people the opportunity to access and participate. We would not expect someone in a wheelchair to climb stairs, so we should not expect people to struggle with inappropriate intellectual obstacles.<sup>16</sup>

Understanding and improving health literacy should therefore be a key objective for anyone who works in the field of consumer health information or who communicates with the public in any way about their health.

It is a fundamental goal for us all to improve health literacy. After all, whatever our educational level or social group we all need help to understand our health and take steps to improve it, navigate the health system and to get the right care when we need it. And, as producers there is little point in spending time, effort and money on developing services and resources that can't be read, understood or used.

*'Let's learn... and stop trying to solve low health literacy by locating the problem with the patient. It's for us to make healthcare simpler and more engaging so that it matches people's abilities.'*

**Graham Kramer, a GP and National Clinical Lead Self Management and Health Literacy with the Scottish Government**

## The survey

Although understanding and improving health literacy should be a key objective for anyone who works in the field of consumer health information, health literacy is relatively poorly understood. Few organisations appear to implement specific strategies to address the issue.

The rising importance of health literacy has generated interest among information producers and providers, along with a desire to develop skills and expertise in this area. Whereas in the United States health literacy is embedded widely in policy and practice, in the UK no overarching strategy exists and little is known about what information producers are doing in this area.

The PiF survey aimed to develop an insight into health literacy from the information producer perspective; exploring whether information producers know what health literacy means to their users, how important they think it is, whether they have developed specific strategies to address the needs of people with low health literacy and how these strategies are implemented.

Understanding the existing knowledge base among information producers, and the provision they make for developing resources and services is an important factor in the development of future strategies to begin to address the needs of this group.





By knowing how information producers see health literacy and where the gaps in knowledge are, what resources already exist, and what information producers want and need, we can begin to develop services and tools that will support information producers.

The survey results provide a baseline from which to measure improvement in practice. They also provide evidence of need.



## Method

The survey was initially developed by Sarah Smith, PiF Operations Director and Annie Gilbert, Researcher, from MSD. It was then reviewed and commented on by four expert reviewers and amendments made in accordance with their feedback.

The final survey was opened in January 2013. A wide range of organisations and individuals were contacted by email with an electronic link to the survey. News items were also posted in relevant email newsletters and communications. Details of the survey were posted on LinkedIn, Facebook and Twitter.

Those that received information about the survey included:

- Patient Information Forum members and contacts
- Information Standard members and contacts
- National Voices members and contacts
- Health Literacy UK Group
- Association of Healthcare Communicators and Marketing
- NHS Networks
- NHS Confederation members and contacts
- Patient Experience Network

These organisations were encouraged to send the survey details to their partners and networks. In addition, 20 of the top UK information producers were individually contacted and asked to complete the survey. These included NHS Choices, NHS inform, NHS Direct Wales, Bupa, patient.co.uk, Macmillan Cancer Support, British Heart Foundation and Healthtalkonline.

The survey was open for six weeks. Microsoft Excel and Survey Monkey's beta analysis tools were used to analyse the results and free field responses.

# Headline results

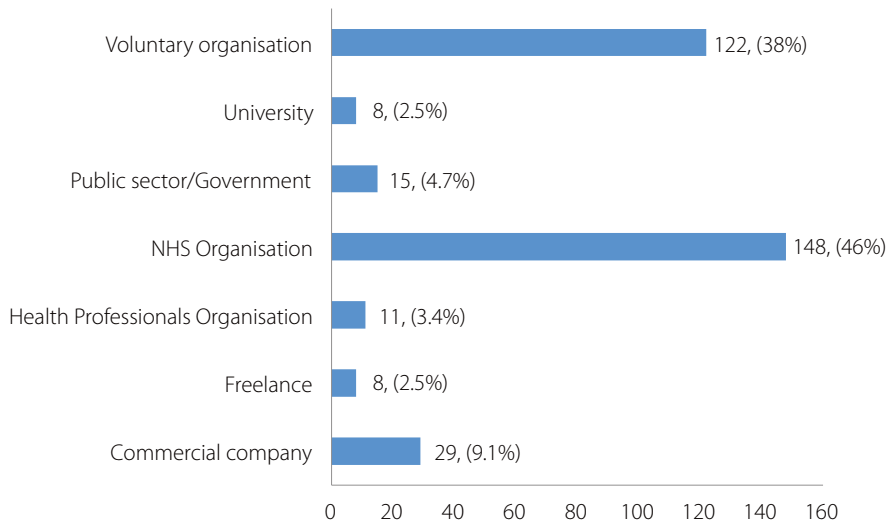
These are the main findings from the survey.

- ➔ The survey respondents are a **good mix of large and small organisations, from all countries in the UK and from all health sectors**. The two largest groups of respondents are from the NHS and voluntary sector. 49% of respondents are Patient Information Forum members and 51% are non-members.
- ➔ Around 80% of respondents produce information **in-house**.
- ➔ Respondents produce information for a **wide range of different groups and audiences**, from people with learning disabilities to those with English as a second language, older people and children. Around 87% chose the option 'general public' to describe their main audience. 35% stated that their organisation produces information specifically for people with low literacy or numeracy skills.
- ➔ Many organisations (71%) had heard of the term 'health literacy'. **Most (91%) see health literacy as something that applies to everyone, and therefore all resources should be clear, simple and straightforward**. Only one in ten think that low health literacy is strongly linked to low literacy and numeracy skills, therefore information should be developed to meet the specific needs of people with poor literacy and numeracy skills.
- ➔ When asked the question 'What does health literacy mean to you?' there were some key phrases that appeared in a high number of responses. For example, 62 (26%) said the **'ability to understand'**. When asked 'How would you describe someone who is health literate?' 55 respondents (23%) said 'able to understand' and 32 (13%) used the phrase **'informed decision'**.
- ➔ There is a **good understanding of how important health literacy is** when producing information - on a rating scale the average was 4.4 out of 5.
- ➔ When asked what their organisation does to address the needs of people with low health literacy, **two thirds (the largest group) undertake engagement or user involvement with health literacy in mind, and half provide telephone based or face to face services**. Only one in 10 has a health literacy policy or strategy.
- ➔ The main barriers faced when producing information for people with low health literacy include **limited funds and resources** (73%), **limited understanding of needs** (68%) and **limited understanding** of how to develop appropriate resources or services (75%).
- ➔ A **practical guide to health literacy is highlighted as a useful tool** for future development (84%), along with good practice examples (80%).

# Full results

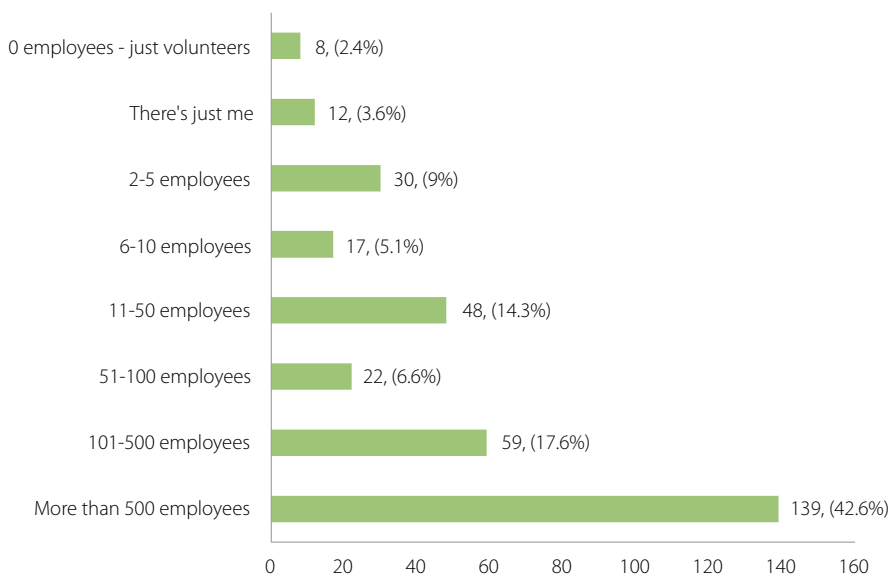
347 respondents of which 338 were analysed once duplicates and blanks were removed. The questions and responses are as follows.

## 1 What is your type of organisation?



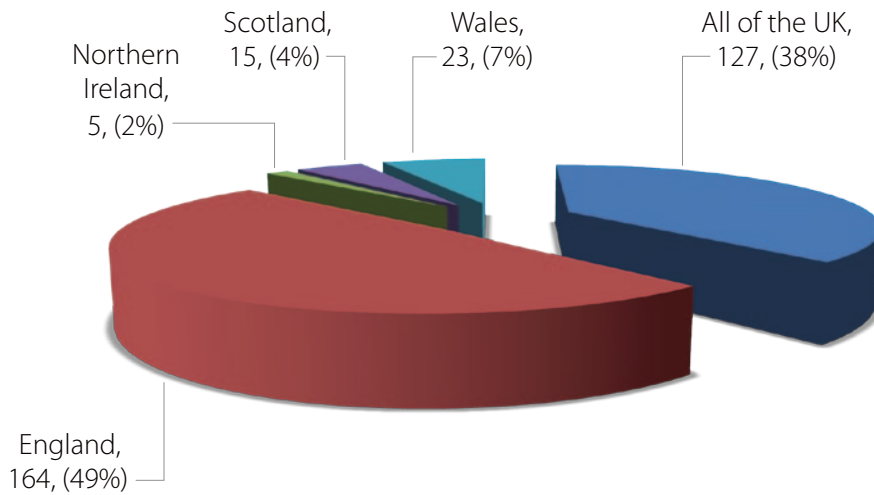
There was a good mix, the largest groups being NHS organisations and voluntary organisations.

## 2 What size is your organisation?



'500 employees or over' was the largest group, followed by those organisations with 101-500 employees (17.6%). This reflects the large number of NHS respondents.

### 3 What is your geographical area?



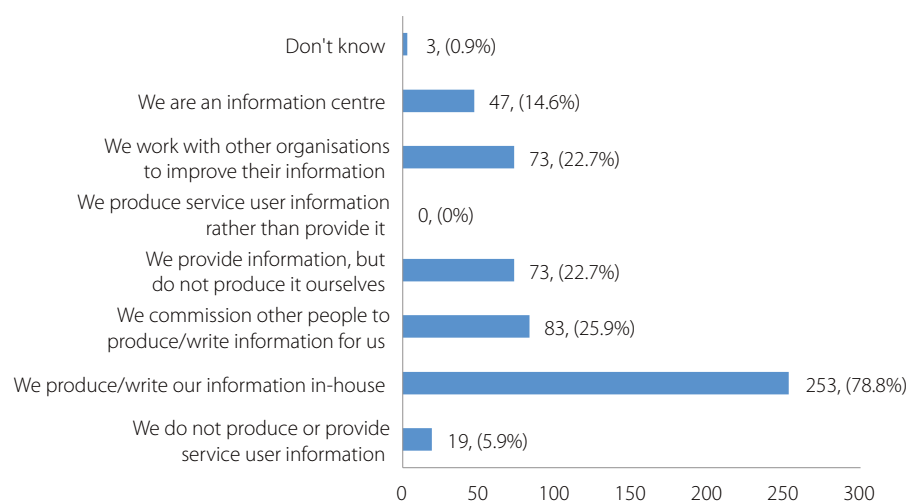
Respondents came from across the UK with the majority based in England (49%).

### 4 How many people in your organisation are directly involved in the production of patient information?



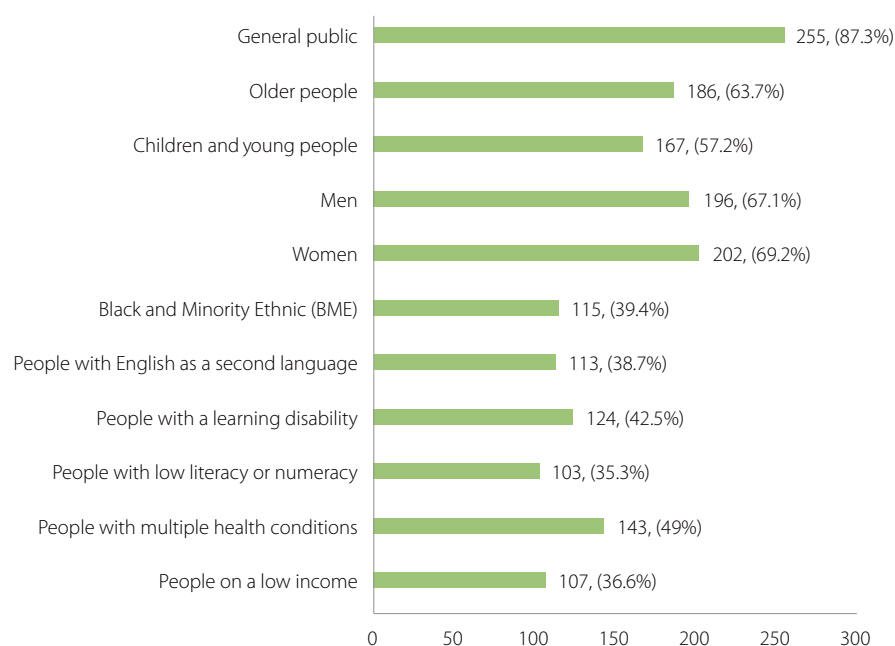
- The two largest groups were those that had between two and five people or between 11 and 50 people involved in producing information.
- The organisations with large numbers of people involved in information production are likely to be in the NHS, where information is produced by individual departments and directorates.

## 5 How does your organisation produce/provide health information for your service users/patients?



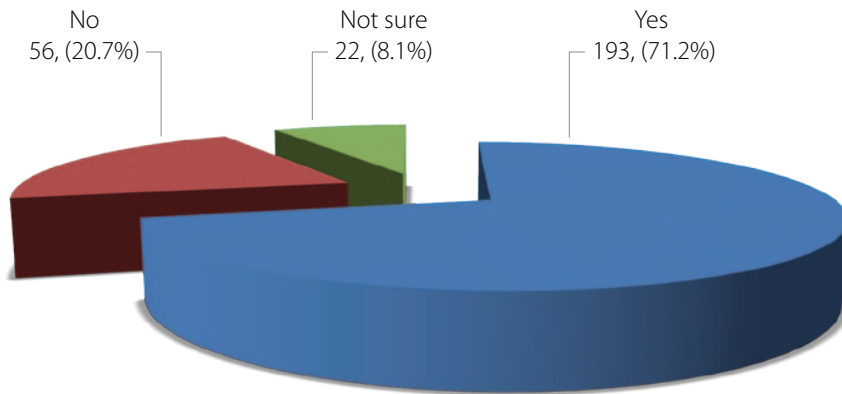
- Most organisations produce their information in-house.
- One quarter commission other organisations or people to produce their information.

## 6 Which groups/audiences does your organisation produce information for?



- As expected, most organisations produce information for the general public.
- Between a third and a half of organisations produce information specifically for groups that are often associated with low health literacy, such as people on a low income and those with English as a second language.

## 7 Have you ever heard of the term health literacy?



There is a good awareness of the term health literacy. Most people had heard the term with only a few saying they had not, or didn't know.

## 8 What does health literacy mean to you?

This was a free field response and 26% of respondents included the phrase 'ability to understand' in their response. The phrase 'Informed decision' was also frequently used (11.4%). These are some direct quotes from respondents which typify the responses.

Health literacy is:

- 'The ability to find, read, understand and use information relating to your health.'***
- 'Being able to make informed decisions about what is best for my health and wellbeing.'***
- 'Knowing how to prevent and (self-)manage health problems; knowing where to find information on conditions; being aware of health services and how/when to use them.'***
- 'Understanding healthcare information and its relevance to you.'***

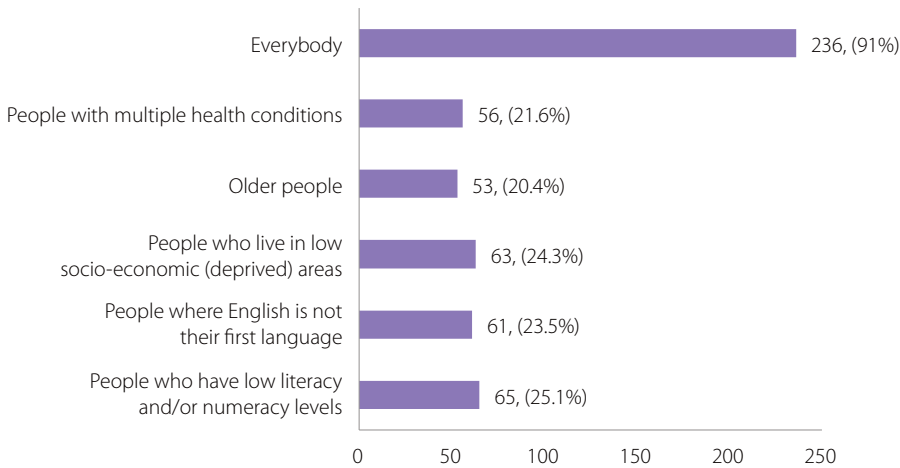
## 9 How would you describe someone who is health literate?

This was a free field response and respondents used phrases such as informed decisions (13.1%), taking control of own healthcare (11.5%) and informed choices (6.6%). These are some direct quotes from respondents which typify the responses.

Someone who is health literate is:

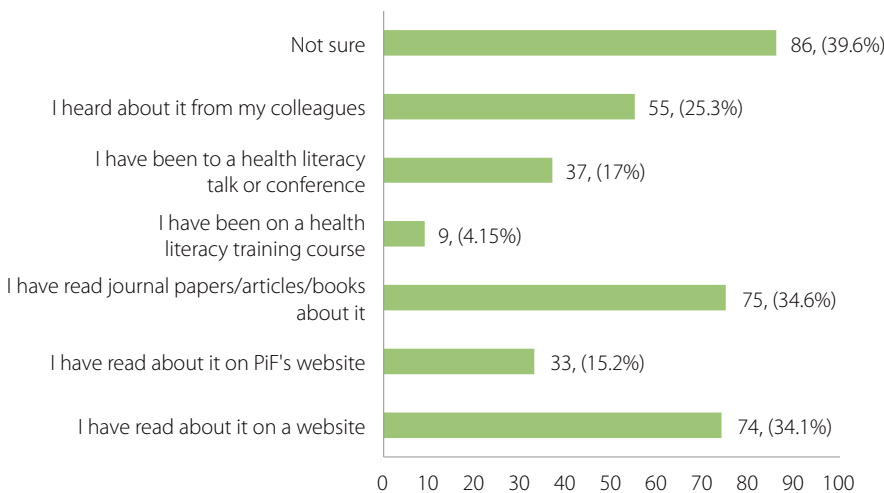
- 'Able/willing to access information and act on it.'***
- 'Someone who knows where to access information in appropriate formats/media in order to make informed decisions about lifestyles, treatment options etc.'***
- '...knows they have options and where to go to find out about them.'***
- '...effectively participates in their own healthcare decisions.'***

**10** When you think of health literacy, which of the following groups do you think it relates to?



- Almost all respondents (91%) felt that health literacy applies to everybody.
- Around a quarter of respondents also identified specific groups, such as people with low literacy and numeracy.

**11** Where did you learn what you know about health literacy?



- Many respondents did not know where they had learned about health literacy.
- Around one third of respondents had read journals or found information online.

**12** Are there any resources, publications, training or events about health literacy that you have found to be particularly useful and informative?

This was a free field response and many respondents used keywords including 'Information Standard', 'NHS' and 'training'. A large number of resources were stated, including websites, seminars and newsletters.

These are some examples:

***'PIF website, NHS Choices and Patient.co.uk'***

***'In-house training on questioning skills and delivering health information.'***

***'The Information Standard seminars are quite broad in their scope and link quite closely to health literacy.'***

***'Health Libraries Group newsletter, CILIP Update, Journal of Information Science.'***

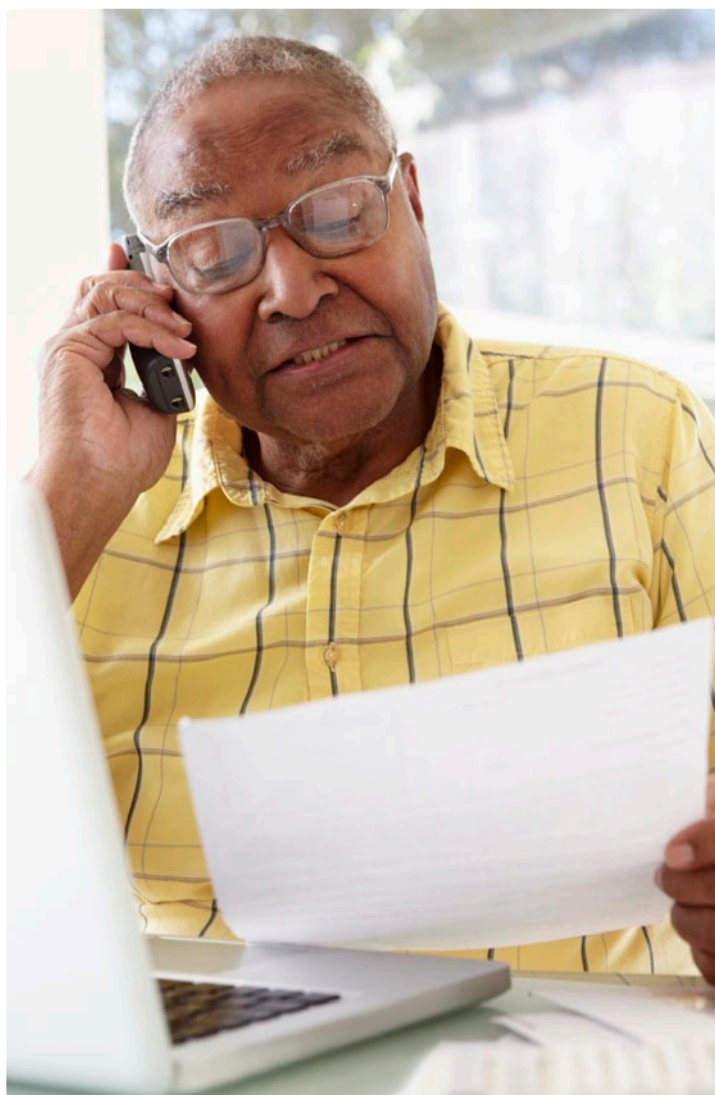
At this point in the survey a definition for Health Literacy was given:

*'The ability to read, understand and act on health information.'*

Some information about health literacy was also given:

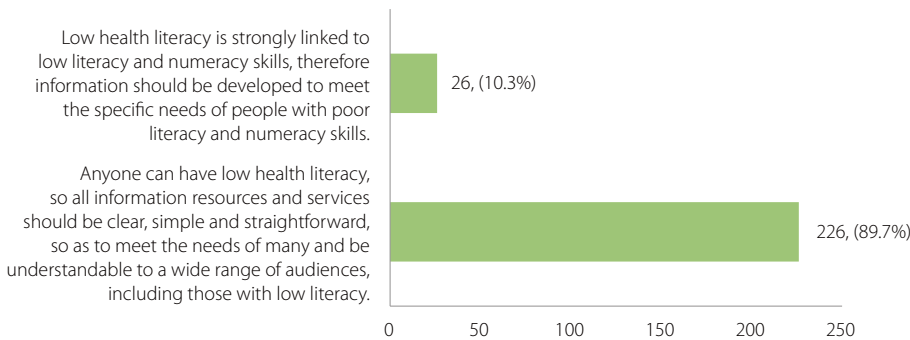
*The American Medical Association (1999) found health literacy to be a stronger predictor of health status than age, income, educational level, race or employment status.*

*Low health literacy levels are likely to be more prevalent among ethnic minorities, older people, lower socioeconomic groups and those with long term health problems and disability.*



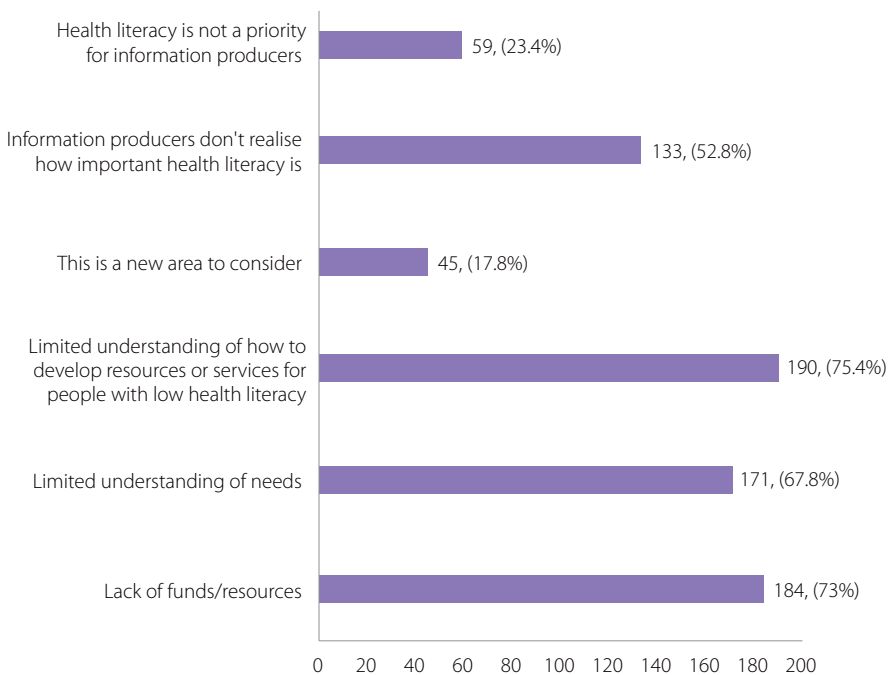


**13** Researchers and policy makers have developed two main approaches to addressing the information needs of people with low health literacy. Please indicate which of these approaches you believe is the most likely to be effective.



Almost all respondents thought that anyone could be affected by low health literacy, and therefore all materials should all be clear, simple and straightforward.

**14** What barriers do you think exist to producing information that addresses low health literacy?



- Three main barriers were identified; limited understanding of how to develop resources or services for people with low health literacy, a lack of funds and resources and a limited understanding of needs.
- Around half of respondents felt that information producers do not realise how important health literacy is.

**15 Please tell us what impact these barriers have on your service users (if any).**

This was a free field response and many respondents used phrases such as 'a lack of control over health', 'adherence to treatments' and 'lack of ability to access relevant information'. Keywords included 'access' and 'understand'. These are some direct quotes from respondents which typify the responses:

***'People not turning up to appointments because they cannot read or tell the time. Not understanding what they are signing for when signing for treatments or operations. Not taking medication properly...'***

***'Lack of consent to treatment. Lack of control over health, lack of opportunities to live healthily, problems with communicating with health professionals.'***

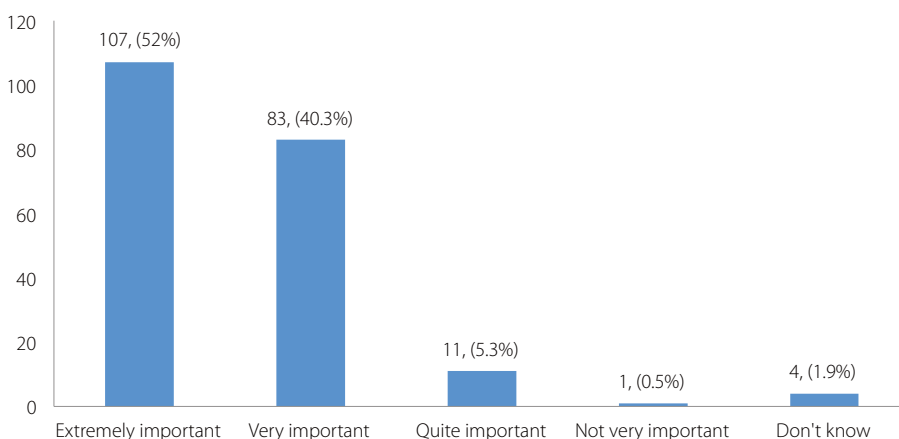
***'Lack of ability to access relevant information and barriers to acting on it.'***

***'People may be embarrassed to admit that they cannot read the literature and so may not then get the information they need.'***

***'If our information is 'beyond' some service users, there is a danger that they will get the message that being in charge of your own health is only for 'brainy' people instead of for everyone.'***

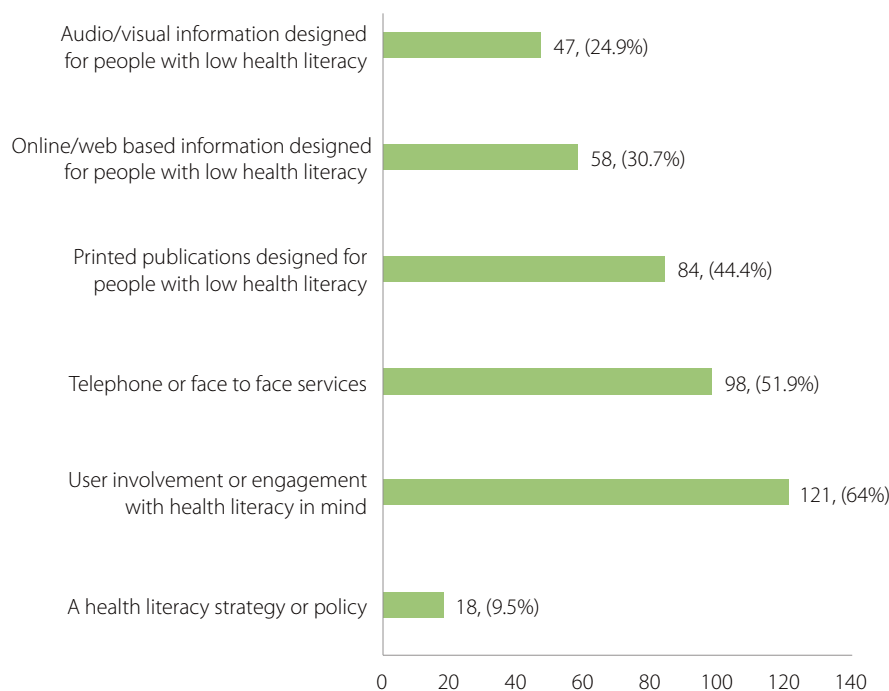
***'We try not to dumb down; and this may be the wrong decision.'***

**16 How important do you think it is to consider health literacy when you are planning, developing or writing information resources or services?**



Most respondents felt that health literacy was either extremely important or very important to consider when developing and writing information resources or services.

**17 Does your organisation have any of the following in place to address the needs of people with low health literacy**



- Two thirds of respondents undertake user involvement with health literacy needs in mind.
- Half provide face to face and telephone information services; these are more likely to meet the needs of people with low health literacy.
- Fewer than 10% of respondents had a health literacy strategy or policy in place.

**18 If you have ticked any of the above, please tell us more about it.**

This was a free field response. There was a good mix of ideas and initiatives, many involving service users, which show a commitment to considering health literacy. Keywords included 'experts' 'face to face' and 'plain English.' These are some direct quotes from respondents which typify the responses:

***'We ask users to review our information and specifically comment on any areas that are hard to understand.'***

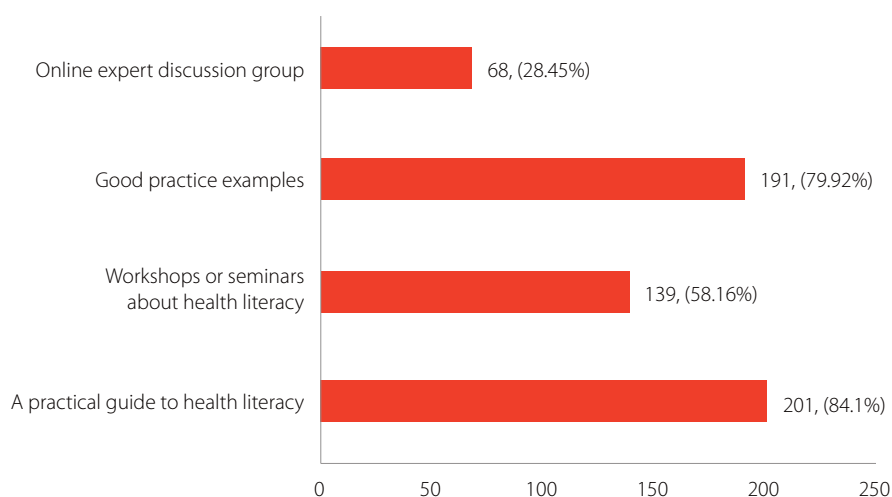
***'We signpost people to relevant information and resources.'***

***'We involve users in the development of all our content - we hold equality assessments to try***

***to reach hard to reach audiences, and we've involved people in decisions about making our content more accessible - we have a telephone helpline with textphone and a translation line available - we don't produce printed info for people with low health literacy but we distribute content developed externally for this audience (and we're hoping to start developing our own content in-house) - we produce a suite of audio materials and have involved users in focus groups to develop these.'***

***'We see patients with a variety of conditions from many cultural backgrounds and with learning and other disabilities. A one size fits all approach does not work.'***

**19** In order for PiF to plan future services or resources around health literacy, we need to know more about how we can help. Please tick any of the below that might be useful for you.



- A practical guide to health literacy, good practice examples and workshops were identified as useful resources.
- E-learning opportunities, evaluation tools and measures and reading lists were other suggestions made.

**20** Do you have anything else to add?

This was a free field response. Respondents were generally supportive of the survey, because it highlights health literacy as an important issue. Keywords included 'resources' 'support' and 'issue'. These are some direct quotes from respondents which typify the responses:

***'Health literacy is two sided: the skills, abilities and understanding of the individual, but also the difficulties that organisations, especially the health and social care system place in people's way. We need to be looking at ways to eliminate those barriers and make it easier for people to navigate their way through the system.'***

***'Lack of health literacy, combined with decreasing knowledge and skills around healthy food and cooking, underpin the growth in obesity in many cases. This stuff starts at school.'***

***'I think that this is a very important issue that you are addressing, which can go a long way to addressing issues around equal access to healthcare.'***

***'It's great that PIF is conducting this survey. Medicine is guided by evidence. The way we produce health information should be guided by evidence too.'***

***'Keep battling away! It is quite alarming how apparently well educated people want to give up responsibility for their treatment choices when they are unwell.'***

# Where next?

The findings from this survey show clearly that among information producers there is both an interest in health literacy and an appetite to learn more about it. Set against this is a lack of understanding about how to produce resources and services that address health literacy, and a general lack of guidance, tools and appropriate training.

Although there is ongoing work in the UK which focuses on research, measurement and policy there is little focus on the end user themselves and in creating services and resources that meet a range of health literacy needs. Clearly, information producers are asking for guidance and practical resources that they can use now. However, it is important to balance this need against the importance of getting these tools right; so that they are evidence based and meaningful and can make a genuine difference, but that they also support national and local policy.

Following the publication of this report PiF will continue to work with other organisations and individuals that are active in the health literacy field, to build collaborative partnerships and to develop appropriate resources for health information producers.

## Acknowledgments

Many thanks go to all of the people and organisations that took part in the survey, for giving so freely of their time and opinion.

## Feedback and updating the report

PiF would welcome any comments on this report, and would ask anyone with any relevant information, or with questions to contact Sarah Smith, Operations Director by sending an email to:

**[operations@pifonline.org.uk](mailto:operations@pifonline.org.uk)**

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