

## **What do we know about the format in which people with low levels of health literacy prefer to receive information? A review of the literature**

### **Background**

This review has been commissioned by Jo's Cervical Cancer Trust (JCCT) as part of a work stream which aims to encourage women from Black and Minority Ethnic communities to take part in the NHS Cervical Screening Programme. JCCT is worried by the low numbers of women from those communities who are currently participating in it. Three focus groups were held with BME women with low levels of Health Literacy in June and July 2014. These showed, among other findings, that women from these communities do not want to receive a leaflet about Cervical Cancer or the Screening Programme. Instead, they expressed a wish for the information to be conveyed to them via a DVD.

### **Introduction**

There seems to be a growing consensus that Health Literacy has a significant impact on morbidity and mortality – specifically, low health literacy has been linked to increased risk of hospitalisation, lower uptake of preventative services and screening, poorer self-management and medication adherence <sup>1</sup>.

There also seems to be an increasing awareness that there is a mismatch between the producers and consumers of health information. This seems to be because health information is written at a literacy and numeracy level above the level that can be understood by a significant number of the population. This is illustrated by recent research led by London South Bank University. This shows that 43% of adults (18-65) do not have adequate literacy skills to routinely understand health information and 61% of adults (18-65) do not have adequate numeracy skills to routinely understand health information. This research was carried out exclusively in England <sup>2</sup>

However, there seems to be much less clarity on how health information is received by people with lower levels of Health Literacy, in particular, about what people from BME groups with lower Health Literacy find acceptable – both in terms of the message and the medium. This paper, which uses the World Health Organisation definition of Health Literacy below, will examine what, if any work, has been done in this field.

“Health Literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people’s access to health information, and their capacity to use it effectively, health literacy is critical to empowerment”<sup>3</sup>

### **Overview of Health Literacy Impacts**

There has been a considerable amount of research which examines the impacts of lower levels of Health Literacy on people’s ability to understand health information. Much of this has taken place in the USA and has not generally considered ethnicity as an additional

factor. However, although not focussed exclusively on people with lower Health Literacy levels a Systematic Review, carried out by researchers at Leeds University, also found that:

- Patients value the idea of information that is set in the context of their particular illness and which contains a balance of benefit and harm information;
- Patients do not want written information as a substitute for spoken information;
- Patients expressed great concern about complex language and poor visual presentation of information.<sup>4</sup>

In addition, according to Knapp and Raynor<sup>5</sup>, in the context of explaining risk to patients there are a number of key themes to be aware of when presenting information. These are:

- percentages confuse many people and natural frequencies work better eg 'affects less than 1 in a 100 patients'
- using words like common and rare to describe the likelihood of side effects is confusing
- combining words and frequencies could be advantageous e.g. "rare (affects less than 1 in 100 people)".

It can be argued that many of these concerns and needs are particularly relevant to people with lower levels of Health Literacy. Using the latest national Skills for Life survey <sup>6</sup>, which is carried out every ten years by the Department for Business, Innovation and Skills, Rowlands et al describe how low Language and Numeracy skills (a recognised proxy indicator for lower Health Literacy) can impact on the population's ability to understand written health information.

Rowlands et al demonstrate that, in general, printed health information is written at a level where an adult understands a range of texts of varying complexity and can then accurately and independently follow information of varying length and detail. However, they argue that a 43% of the English working age population have literacy skills below that level – in other words they won't be able to either understand the text or interpret the information. With regard to numeracy, Rowlands et al note that health resources generally present straightforward mathematical information from which an adult can independently select relevant information. However, they note that 61% of the English working age population has numeracy skills below that level which means that cannot select the information that they require.

This research did not specifically explore issues of ethnicity. However, Rowlands et al did note a number of demographic associations with the risk of lower Health Literacy. These included being from a BME community, being born outside of the UK and not having English as a first language. Consequently, it seems likely that BME communities will experience at least the same Health Literacy challenges as the rest of the population in terms of ability to understand health information. In reality this means complex and polysyllabic words such as words with multiple meanings or clinical terms are highly likely to disengage people with lower levels of Health Literacy as is anything other than the most simple statistical or numerical information.

A number of impacts have been noted, mainly in the US, with regard to how lower levels of health literacy seem to affect health behaviour. This seems to be particularly marked when considering self-management of a long term condition or prevention services. With regard to self-management Schillinger et al<sup>7</sup> note that when considering people with Diabetes Mellitus: when compared with people with adequate Health Literacy, people with low Health Literacy were more likely to have less well controlled markers of disease control and more complications e.g. retinopathy, cerebro-vascular disease. With regard to prevention, Garbers and Chiasson<sup>8</sup> note that when compared with people with adequate Health Literacy, people with low Health Literacy were less likely to have undergone cervical screening. Pertinently, this research was undertaken in a BME community – albeit in New York. Garbers and Chiasson argue that “when developing efforts to reach women who have not been screened, programmes and service providers need to be aware that the women most in need of information about screening may be more likely to be unable to read any written materials provided to them, regardless of the language or level of simplicity of the materials. This seems to make a very compelling case for considering providing information in markedly different way i.e. not just a leaflet or poster.

### **Have Information Providers Adopted Different Formats to Communicate with People with Lower Health Literacy?**

As noted above people with lower Health Literacy are likely, among other characteristics, to belong to a BME community. They are also likely to have significant problems understanding written health information and this in turn impacts on their likelihood to take advantage of screening opportunities and to manage a long term medical condition. This section will examine whether health information organisations have used other formats to convey health information to people with lower levels of Health Literacy.

Medication adherence is one area where considerable research has been undertaken to try to ensure that people understand health information. Raynor et al<sup>9</sup> note the existence of a gap between “currently provided leaflets and information that patients (particularly those with lower Health Literacy) would value and find more useful”. They state that the challenge is to “develop methods of provision flexible enough to allow uptake of varying amounts of information on a variety of aspects, depending on needs at different times”. They do not recommend any particular format, adding that testing out such ideas with users would be the optimum approach.

However it can be argued that changes in technology and expectations about consumer involvement in health care are leading to an increase in the access and use of health information from digital sources. For example, a 2010 survey in the United States by PriceWaterhouseCoopers<sup>10</sup> found that people use online tools and resources (54 per cent) second only to consulting a doctor (75 per cent) when gathering information on treatments and conditions.

In its 2014 strategy document on Health Literacy, the Australian Commission on Safety and Quality in Healthcare<sup>11</sup> notes that “today, with changes in technology, people expect a large amount of information to be easily available in a format that they understand. People seek out, or are provided with, health information from a variety of sources and in a variety of formats. The Commission also does not recommend any particular format but, again, notes

that user testing is crucial not only in determining content but also in assessing what format to deliver the content in. It does, however, cite one example of good practice as follows. The Menzies School of Health Research has developed a series of what are described as “talking posters” which address health improvement issues. The posters provide information on “coughing, hygiene and smoking in five different indigenous languages”. The information on the poster, is supplemented by a translation provided in audio form.

The poster can be viewed by clicking on the below link. The viewer is taken to a poster with three different anti-smoking scenarios depicted visually plus a verbal message “clean air grows healthy lungs” plus an option to hear the message in English and a number of indigenous languages. However, it should be noted that although this approach is highlighted as best practice by the Australian Commission on Safety and Quality in Healthcare, it has not been possible to discover whether this approach has been the subject of any evaluation.

[http://www.menzies.edu.au/page/Resources/Smoking\\_is\\_no\\_good\\_clean\\_air\\_grows\\_healthy\\_lungs](http://www.menzies.edu.au/page/Resources/Smoking_is_no_good_clean_air_grows_healthy_lungs)

However, the potential benefits in using a video to provide information instead of relying on either a leaflet or verbal advice was cited in a Systematic Review by Berkman et al<sup>12</sup>. This case showed that a leaflet when accompanied by a “video” plus oral recommendation about the benefits of attending for a mammography improved mammography attendance rates over either a verbal recommendation alone or a leaflet accompanied by an oral recommendation. However, another example cited by Berkman et al confirmed no differences overall in comprehension of information on sleep disorders provided in a leaflet compared to a video. Nevertheless, it is worth noting that the use of a video appears to have been a key factor in enhancing attendance for Breast Screening – increasing the number of BME women attending for Cervical Screening is a key aim of Jo’s Cervical Cancer Trust which recently commissioned a You Gov poll which showed that 53% of women from those communities do not regard the Cervical Cancer Screening Test as a necessary health intervention.

Berkman et al also cited a further example from the field of Public Health where the use of a video seems to have had an impact on the skills and knowledge of individuals. In this RCT participants who received a video presentation and information card answered a higher proportion of questions based on the nutritional information contained on food labels correctly than did their counterparts who only received the information card.

Consequently, it is possible to conclude that health skills, knowledge and understanding can be enhanced by the use of videos to convey health information and that even where this cannot be asserted, there doesn’t appear to be any evidence that the use of a video resulted in less understanding of the health message.

This could be explained by the fact that videos and other non-leaflet based approaches are seen as a highly acceptable method for delivering health advice and information. In a review undertaken by Coulter et al<sup>13</sup>, the researchers found that alternative (to leaflets) resources, such as the internet, audiotapes, videos and virtual health communities could improve health knowledge and result in greater user satisfaction. There were also beneficial effects related

to self-efficacy, involvement in decision-making and confidence in consultations with health practitioners.

However, none of these studies were designed to take into account any factors connected with ethnicity – they were primarily concerned with Health Literacy. However, there is an increasing acknowledgement that ethnicity and cultural appropriateness are also important factors in ensuring that people from BME communities will act upon health messages.

This review also appears to indicate that there has been limited research into what might be the most effective interventions to improve access to primary care and cervical screening for BME people, or on their experience of those services. However, looking specifically at diabetes, Kolb and Duker<sup>14</sup> have found that in assessing a population's education and support needs, different individuals, their families, and communities need different types of education and support. This means understanding the population's characteristics, such as ethnic/cultural background, gender, and age, as well as their levels of formal education, literacy, and numeracy. This may require skills and resources outside the health provider's practice and suggests that the use of non-leaflet resources should be considered.

It also suggests a rationale for involving members of those communities in producing such resources. Work undertaken in the US has demonstrated that this approach can have beneficial outcomes. Poureslami et al<sup>15</sup> cite this type of approach as a method of gaining the insight to develop asthma information that is both culturally and linguistically appropriate. However, it could be argued that that very little work has been carried out to co-produce health information resources with the intended recipients of that information and that none of that limited work has extended beyond the traditional leaflet/printed information arena. Work, as yet unpublished, in Bradford where members of the South Asian community (many of who had lower levels of Health Literacy) were involved in co-producing information with regard to the Diabetic Retinopathy service seems to indicate that this approach is an effective way to both provide information and to encourage people to respond to health messages by changing their behaviour. However, this work did not test out the acceptability of delivering information via a video.

This absence of published insight work, with regard to the acceptability of delivering health information in a video, could be seen as problematic. However, there has been some recent work in the Cancer field, which although unpublished, can offer some clues as to how such a resource might be received. In 2013, the Community Health and Learning Foundation tested a number of resources on behalf of Prostate Cancer UK. This was undertaken in two Focus Groups both of which contained participants from BME communities. Among the resources tested was an on-line short video clip recently developed by Prostate Cancer UK, featuring one of their Specialist Nurses talking about Prostate Cancer risk<sup>16</sup>. Although, there was some concern about the content of the video ("it didn't tell them what to look out for") the format itself was seen as professional and conveyed the seriousness of the subject. They liked seeing a real person talking adding that it kept their attention. These responses were the same regardless of ethnicity. The clip featured one of the Prostate Cancer UK nurses talking about prostate cancer and risk. It lasts about two minutes.

In 2013, the Community Health and Learning Foundation also tested a number of resources, this time, on behalf of Breast Cancer Care. The resources tested were entirely print based

and were tested in eleven Focus Groups in England and Scotland, two of which were composed wholly of people from BME communities. No specific questions were asked with regard to videos as that was not part of the brief. However, <sup>17</sup>a thematic content analysis of the Focus Groups did appear to indicate that participants implicitly indicated that something a little more lifelike would have been welcome to make the information more relevant to them. They expressed this as a wish to see real rather than pictorial images illustrating some of the information. While certainly not a call for the development of a video, it does seem to indicate that participants did not find the paper based resources particularly engaging. As with the work cited above, these responses were the same regardless of ethnicity.

## **Conclusion**

This review has shown that a significant number of working age adults in England do not routinely understand health information i.e. have lower levels of Health Literacy. This is likely to have the same impacts for BME people as for other communities. However, being from a BME community, being born outside of the UK and not having English as a first language are factors strongly associated with low Health Literacy so people from BME communities are likely to be at greater risk.

There is a realisation that some patients have problems understanding health information and that complex written information is not seen as a substitute for the spoken word. However, there is only limited evidence to demonstrate whether using videos is an effective to both communicate information and to have that information acted upon. Nevertheless, where evidence does exist, it can be argued that using video information has certainly not resulted in less understanding. The impacts of using videos to provide information have either been neutral or beneficial in terms of increased knowledge and the skills to act on that knowledge.

One area where the literature is silent is with regard to whether patients and members of the public wish to receive information in different formats. Unpublished work commissioned by two Cancer charities seems to indicate that such formats would be acceptable. However, it would be advisable if such resources were co-produced with the communities for whom they are intended. This would enable the information producers to ensure that as well as meeting their Health Literacy needs, the content would be culturally appropriate. This in turn would increase the likelihood of it being both understood and acted upon. There appears to be no reason why this co-production model should not work with regard to developing a video. In addition, it could be argued that it replicable to other prevention issues and for engaging communities of any ethnicity with lower levels of Health Literacy.

**Jonathan Berry**  
**Community Health & Learning Foundation**

## Bibliography

---

<sup>1</sup> Community Health and Learning Foundation (2014), Health Literacy – the agenda we cannot afford to ignore

<sup>2</sup> Rowlands G, Protheroe J, Winkley J, Seed PT, Richardson M, Rudd R (In progress) Defining and describing the mismatch between population health literacy and numeracy and health system complexity

<sup>3</sup> World Health Organisation (1998), Health Promotion Glossary:

[http://www.healthliteracypromotion.com/upload/hp\\_glossary\\_en.pdf](http://www.healthliteracypromotion.com/upload/hp_glossary_en.pdf)

<sup>4</sup> Raynor DK, Blenkinsopp A, Knapp P et al (2007), Systematic review of research on role & effectiveness of written information to patients about medicines. Health Technology Assessment

<sup>5</sup> Knapp P, Raynor DK et al (2009) *Communicating risk of side effects to patients: an evaluation of UK regulatory recommendations*. Drug Safety

<sup>6</sup> Skills for Life Survey (2011): Headline findings. Department of Business Innovation and Skills BIS Research paper number 57.

<sup>7</sup> Schillinger D, Grumbach K, Piette J, et al (2002). Association of health literacy with diabetes outcomes. JAMA.

<sup>8</sup> Garbers S, Chiasson MA (2004). Inadequate functional health literacy in Spanish as a barrier to cervical cancer screening among immigrant Latinas in New York City. *Prev Chronic Dis*.

<sup>9</sup> Raynor DK, Blenkinsopp A, Knapp P et al (2007), Systematic review of research on role & effectiveness of written information to patients about medicines. Health Technology Assessment

<sup>10</sup> PricewaterhouseCoopers (2010). Top Health Industry Issues of 2011

<sup>11</sup> Australian Commission on Safety and Quality in Healthcare (2014) Health Literacy: Taking Action to Improve Safety and Quality.

<sup>12</sup> Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, et al (2011). *Health Literacy Interventions and Outcomes: an Updated Systematic Review*. Evidence Report/Technology Assessment No. 199.

<sup>13</sup> Coulter A, Ellins J. (2006) Patient-Focused Interventions: a Review of the Evidence. London: The Health Foundation

<sup>14</sup> Kolb LE and Duker PN (2012) National Standards for Diabetes Self-Management Education and Support. The Diabetes Educator

<sup>15</sup> Poureslami I, Nimmon L, Doyle-Waters MMR, FitzGerald JM (2012). Using community-based participatory research (CBPR) with ethno-cultural groups as a tool to develop culturally and linguistically appropriate asthma educational material. Diversity in Health & Care

<sup>16</sup> Berry J (2013) Report on two focus groups held to test the easy read information about prostate cancer. CHLF to Prostate Cancer UK

<sup>17</sup> Berry J (2014) Report on Focus Groups Held to Assess Whether Participants Understood Information Three Items of Easy Read Information Produced by Breast Cancer Care. CHLF to Breast Cancer Care.