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Patient information that promotes health literacy

In this article...
- Why health literacy is important
- How to create effective patient materials
- A checklist of key considerations when compiling materials

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Health literacy is the ability to make informed health decisions in everyday life. For many patients and carers, decision-making is made more difficult by the fact that high-quality information is unavailable to them. The Pulmonary Hypertension Association has created patient materials that promote health literacy to help patients and their families make decisions that are well informed.

Pulmonary hypertension is a complex condition that is managed at nine specialist centres across the UK and Ireland. As the only charity in the UK that is dedicated to supporting people affected by pulmonary hypertension, the Pulmonary Hypertension Association (PHA) UK provides a range of materials to support patients, their caregivers and the health professionals who are treating them. It also aims to ensure that these materials promote health literacy.

What is health literacy?
Many definitions for “health literacy” have been put forward but it is generally accepted to be the ability to make informed health decisions in everyday life (Kickbusch, 2005). For someone to be classed as being health literate they need to:
» Have a basic health knowledge;
» Be able to read, understand and weigh up health information;
» Be able to analyse risks;
» Be able to make calculations and interpretations; and
» Be able to verbally communicate with health professionals.

Who is affected?
A recent European survey found that overall health-literacy levels were poor or could be problematic in around 45% of people, and those most likely to be affected had lower levels of education, were older, had lower social status and lower incomes (European Health Literacy Group, 2012).

However, anyone can be affected by poor health literacy, regardless of age, gender, race or even level of education. An individual’s ability to understand health information can be affected by:
» The use of unfamiliar technical language;
» Stress;
» Anxiety;
» Coping with a new diagnosis;
» Onset of illness; and
» English being a second language.

The importance of health literacy
Without adequate health literacy, patients face serious difficulties accessing, understanding and making effective use of health information. Many studies show that there is a strong, independent link between health literacy and health outcomes, with lower health-literacy levels associated with increased:
» Emergency department use;
» Hospitalisation;
» Self-reported physical health problems;
» Mortality (Office of the Surgeon

Treatment adherence is more likely if patients can access clear information on their condition, which equips them to make informed decisions about their care.
To make informed decisions about their care, patients must be able to understand the information health professionals give them on their condition and the treatment options.

General, Office of Disease Prevention and Health Promotion, 2006; Weiss, 2003).

In the UK, the Department of Health in England (2003), NHS Wales (2010), the Scottish Government (2009) and the National Adult Literacy Agency (2009) in Ireland have acknowledged the negative impact that poor health literacy has on the state of the nation’s health. These organisations are taking this into account in their policies and guidelines.

Applying health literacy principles in practice

Working with colleagues in the NHS, external stakeholders and a medical communications agency, PHA UK developed a range of materials to support patients and caregivers at nearly every stage of the patient journey. Through our experiences, we found that there were essentially five stages to every project:

» Stage 1: Research;
» Stage 2: Content development;
» Stage 3: Layout and design;
» Stage 4: Interactivity, functionality and accessibility;
» Stage 5: Testing.

Stage 1: Research

We found that one of the most important things to do, even before a single word has been written, is to do your research. You need to establish what the need is and at whom the material will be targeted.

Establishing what information is already available to you and your patients will help shape the material you produce. You may even decide, after your research, that there is already something available that meets your needs.

A number of patients with pulmonary hypertension have learning disabilities, primarily due to Down’s syndrome. Colleagues had mentioned that they often had difficulties explaining to these patients the complex diagnostic tests and treatments that are routinely used when treating pulmonary hypertension. An advisory board with colleagues from other specialist centres agreed with this. We researched what was already available and found that, although there was nothing suitable (confirming the need), there were materials from which we could develop ideas, thereby saving time and resources.

The resulting patient workbooks, treatment information sheets and counselling flipchart have been extremely well received and are also being used with patients who have English as a second language.

Once you’ve established that there is a need, you need to research your audience. Knowing exactly who you are producing materials for, what they need and don’t need, how they like information presented to them and the challenges they face on a daily basis enables you to produce something that is not only informative, but also useful. For example, once first-draft artwork had been developed for our learning disabilities material, it was given to a number of people with learning disabilities.

This showed us that some of the drawings were too simplistic and some of the text too difficult to understand. By carrying out research at this stage we were able to modify the materials before they were produced.

Stage 2: Content development

Applying health-literacy principles to content is more than writing in plain English. It also involves tone, context, guidance/signposting and the use of visual materials, such as images, tables and “key points” boxes.

When writing for patients, it is important to remember that they may know very little about their condition, and may be unfamiliar with medical words or jargon. Information should be kept simple, new terms defined and new information put in context. This could be something as simple as showing where an organ is in relation to the rest of the body or explaining complex tests and investigations. We have learnt that everyone appreciates content that is easy to read – including health professionals.

Tone is also very important. PHA UK provides patients and their families with information about organ and tissue donation; this emotive subject requires a tone and language that is sensitive to the information being presented. As an example, phrases such as “in the event of your death” should be avoided and those that are more patient friendly – such as “after you have passed away” – used instead.

Stage 3: Layout and design

By thinking about the needs of the patient, how the patient will use the material and how you want the material to feel, it is possible to design something that is easy to read, understand and apply. This doesn’t have to be expensive; simple things like increasing the amount of white space, using an appropriate font size, using dark text on a light background, making sure the layout is consistent throughout, and using colour to highlight key points can all help improve readability.

To support patients who have pulmonary hypertension, PHA UK has produced a handbook, which aims to provide patients and their families with all the information they may need about their condition. Although extremely useful, the first version of this booklet felt text-heavy and somewhat uninspiring. By breaking up the text, adding more images and a simple design, it was transformed; in 2011, it was highly commended at the British Medical Association’s Patient Information Awards.
Health-literacy principles apply to web and digital materials too. As well as thinking about content, design, layout and interactivity, when it comes to web and digital materials you also need to consider functionality and accessibility.

For the PHA UK website we ensured:
- The text size could be adjusted for those with poor eyesight;
- Navigation made it easy for users to find the information they needed quickly;
- There was a print function for users who preferred to read offline; and
- Videos and animations had easy-to-use controls.

**Stage 5: User testing**

As with doing research before starting a project, carrying out user testing before a final draft is approved can prevent valuable resources from being wasted. Testing your materials on people who will be using it will highlight areas where information is missing, misunderstood or inappropriate, and will allow you to gain valuable feedback on the design and layout. This could save you time, money and resources.

**Conclusion**

Providing information in a clear and easy-to-understand way educates patients and their families, allowing them to make well-informed choices about their healthcare. We have kept health-literacy principles in mind to help us develop appropriate, useful and consistent materials, and used a checklist to help remind us of the important elements (Box 1).

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**References**


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**Box 1. CHECKLIST FOR CREATING PATIENT MATERIALS**

<table>
<thead>
<tr>
<th>Content</th>
<th></th>
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<tbody>
<tr>
<td>Is the content written to appropriate reading age/level?</td>
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<tr>
<td>Is the content based on changing behaviour?</td>
<td></td>
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<tr>
<td>Does the material have a clear purpose?</td>
<td></td>
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<tr>
<td>Is the number of concepts limited to what can be reasonably learnt?</td>
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<tr>
<td>Is the copy written in an active voice?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Layout</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Is the layout consistent throughout?</td>
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<tr>
<td>Does the material include visual elements to guide the reader?</td>
<td></td>
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<tr>
<td>Is there adequate white space?</td>
<td></td>
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<tr>
<td>Does the material use an appropriate font type and size?</td>
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<table>
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<tr>
<th>Interaction</th>
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<tbody>
<tr>
<td>Does the material provide interactive tools, video and audio to facilitate learning?</td>
<td></td>
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<tr>
<td>Does the material provide content that supports the reader through their journey?</td>
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</table>

<table>
<thead>
<tr>
<th>Design</th>
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<tbody>
<tr>
<td>Does the design reflect the purpose of the piece?</td>
<td></td>
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<tr>
<td>Are visuals used to highlight desired behaviours?</td>
<td></td>
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<tr>
<td>Is there appropriate contrast between background and text?</td>
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