Patient education accessibility

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Abstract

Patient education that overcomes literacy barriers supports quality care. This article provides an overview of health literacy, describes the concepts of readability and accessibility, and discusses how to empathise with the patient’s experience and ask interactive questions. The tips in this article are based on a learner-centred approach and 20 years of publishing X-Plain® patient education tutorials. This information should help health content writers facilitate patient comprehension, improve health outcomes, and achieve care goals set by healthcare providers.

Keywords: Patient education, Patient engagement, Accessibility, Health literacy, Readability

Patient education accessibility involves creating health materials that are designed and presented so that they can be understood by audiences of diverse literacy levels. Certain instructional design principles, along with strategies to enhance readability, help facilitate patient understanding, bridge gaps in health literacy, improve health outcomes, and reduce readmission rates. Successful patient education enables patients and their families to become active members of their healthcare team, empowers them to ask questions, supports communication with healthcare providers, and results in shared decision making.

Health literacy

Health literacy is the ability to understand and process health information in order to make competent choices related to prevention and treatment of health problems. Health literacy is a stronger predictor of health outcomes than age, income, employment status, education level, or race. Low health literacy is associated with poorer health outcomes, including increased rates of hospitalization and mortality. Low health literacy is related to general illiteracy. According to the National Assessment of Adult Literacy, 14% of the United States population struggles to write, read, listen, or speak effectively. The cost of low health literacy for the United States economy is estimated at up to $238 billion U.S. dollars each year. In fact, the mortality rate attributable to low education is comparable to the mortality rate for smoking tobacco, and educational disparities widen with each successive generation.

Medical writers are tasked with simplifying content so that it reaches all patient populations, especially those most at risk for not understanding critical health information. Various educational models and adult learning theories can help medical writers achieve desired behavioural outcomes and support long-term recall of information for health consumers. Common behavioural goals in patient education include making informed decisions, developing skills for self-care at home, committing to medication compliance, and modifying habits for a healthier lifestyle.

Readability and accessible language

Reading level can be calculated with automated formulas that are based on word length, punctuation use, and number of syllables. However, automated readability calculations can be misleading. For instance, you might write ‘See a healthcare provider for treatment without ado.’ According to an online readability calculator, this sentence is written at a fifth grade reading level, even though the word ‘ado’ is not widely used. Saying ‘See a healthcare provider for treatment without delay’ is easier to understand, but the formula generated by a computer gives this sentence a higher readability level because the word ‘delay’ is longer than ‘ado.’ This sentence could still be made clearer: ‘See a healthcare provider for treatment right away.’ The reading level for this sentence is second grade. Writers should therefore use tools that calculate readability in conjunction with their own judgment.

Using such formulas is not the only way to improve readability. Content should be simplified, presented impartially, and organized in a logical order. Content structured so that it gradually
builds understanding from the simple to the complex helps consumers understand the main points and supporting details. The structure and organization of the lesson should be apparent to the patient in advance so that he or she knows what to expect from the program. An ‘advance organizer’ provides clear orientation for users to process the information they are about to take in. Such a map is critical for individuals with learning disabilities or low literacy levels.  

Writers should break down complex medical concepts into short words and sentences. Speaking directly to the patient, using active voice, and avoiding clichés and idioms increases accessibility and reduces confusion.  

Punctuation and numerical values should be chosen based on what is most understandable to the audience. Symbols should be used cautiously. For example, not all patients may recognize the ampersand symbol (&). Conversely, the per cent symbol (%) is more understandable and recognizable than the word ‘per cent.’  

Writers should explain technical or uncommon words with definitions and examples. Information that may be new or unfamiliar to a reader can be phrased strategically so the reader can gather clues from the context to increase comprehension. Using the same word consistently instead of synonyms can also help prevent confusion.  

Using concrete or practical examples to illustrate a point can help further a patient’s understanding and influence their behaviour. For example, ‘Your healthcare provider may recommend that you increase the amount of vitamin A in your diet. Foods that are high in vitamin A are dark green, leafy vegetables and deep orange vegetables. Examples include spinach, carrots and squash.’  

**Keeping the patient’s experience in mind**  

Learning that you have a disease or disorder or that you need a procedure can be frightening and can impact your identity. Stress, such as that caused by an illness or injury, can detrimentally affect a person’s health literacy abilities. Medical writers should be conscious of the patient’s potential experience, while being careful not to sacrifice educational effectiveness. Keeping the patient and their potential sensitivities in mind while developing content can help increase the patient’s satisfaction with the care they have received. Increased understanding and satisfaction empowers patients to ask questions and become active members of their healthcare team. It also facilitates communication between healthcare providers and patients, which saves providers time, enhances the quality of care, and improves health outcomes.  

The tone of patient education should be factual and empathetic. A judgmental or patronizing tone can impede the learning process and negatively affect the patient. Unless writers are aware that their audience has a background in healthcare, it is better to assume they do not have medical field experience or an understanding of biological concepts. Evaluation studies on X-Plain® (the patient education materials published by the Patient Education Institute) show that users who have more experience or who are highly health literate are not offended by simplified content.  

Viewing the patient as a person, rather than a condition, and writing with person-first language are of primary importance. ‘Disabilities are not persons and they do not define persons,’ so medical professionals should refer to affected patients as people with a medical condition or disability, rather than as disabled people. For example, writing ‘people with diabetes’ is more sensitive than ‘diabetics.’ Similarly, ‘to have’ may imply possession and ‘to be’ may imply identity; using ‘have’ rather than ‘be’ is considered less stigmatizing. For example, it is better to say ‘a person with hearing loss’ rather than ‘a person who is hearing impaired.’ Table 1 lists further examples.  

**Table 1: Examples of terms that could be offensive to lay readers and empathetic alternatives**  

<table>
<thead>
<tr>
<th>Term that could be offensive</th>
<th>Empathetic alternative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amputee</td>
<td>A person with an amputated limb</td>
</tr>
<tr>
<td>Bipolar man</td>
<td>A man with bipolar disorder</td>
</tr>
<tr>
<td>Cancer patient</td>
<td>A patient with cancer</td>
</tr>
<tr>
<td>Autistic child</td>
<td>A child with autism or a child who is on the autism spectrum</td>
</tr>
<tr>
<td>Wheelchair-bound woman</td>
<td>A woman who uses a wheelchair</td>
</tr>
</tbody>
</table>

Sensitivity to norms within a community makes patient education empathetic and increases the writer’s credibility. For example, many individuals with hearing loss prefer to use the term ‘Deaf’ to describe their community and culture.  

To ensure that educational programs are accepted and understood by the target audience, involve patients in reviewing the materials during the development process. Patient involvement and review increases accessibility and the likelihood of success as the solution is implemented. Direct online feedback from real patients in clinical settings simplifies
the collection and analysis of patient feedback. An example of an online feedback form is shown in Figure 1.

**Visual instructional design**

Research shows that text paired with simple line drawings engages readers more than text or graphics alone. Line drawings also prevent overstimulation that could impede cognitive processing. Line drawings that clearly represent a concept are more accessible than complex or highly realistic images, such as photographs.

In a study published in *Patient Education and Counselling*, researchers analysed peer-reviewed studies in health education, psychology, education, and marketing journals. They found that:

‘pictures closely linked to written or spoken text can, when compared to text alone, markedly increase attention to and recall of health education information. Pictures can also improve comprehension when they show relationships among ideas or when they show spatial relationships. Pictures can change adherence to health instructions. All patients can benefit, but patients with low literacy skills are especially likely to benefit. Patients with very low literacy skills can be helped by spoken directions plus pictures to take home as reminders or by pictures plus very simply worded captions.'

The design and layout of text and graphics can be used to increase understanding. Text should be presented in a large, simple font. Plenty of blank space should be used to balance the graphics and text on the page. Whenever necessary, bullet point lists can be used to break down or organize information. An example is shown in Figure 2.

**Asking questions**

Interactive questions can be used to facilitate learning while providing corrective and reinforcing feedback. An example of an interactive question and answer set with feedback is shown in Figure 3.

The risks and complications include those related to anesthesia and those related to any type of surgery. Risks of general anesthesia include:

- Cut lips and chipped teeth.
- Headache.
- Nausea or vomiting.
- Problems urinating.
- Sore throat.

The following guidelines for developing questions and answers are based on 20 years of publishing X-Plain® tutorials and enhancing them based on user feedback:

- Questions should be written so that they apply to a wide variety of patients in different healthcare settings.
- Questions should be written about the most important point of the preceding section of the lesson. The most important point could be a concept that will be expanded on in later sections; understanding the concept could be
necessary for the patient to understand what comes later. The most important point could be related to how the patient can practice self-care at home, prevent medication errors, identify a complication, or know when to contact their healthcare provider.

- Ask questions about how the patient can help themselves and improve their health or quality of life. Testing viewers on terminology is not always critical to understanding main concepts. Common misconceptions should be targeted as question topics whenever possible. For instance, during the informed consent process, patients may conclude that the risk of complications for a procedure is high after reading about the many potential complications. It is necessary to emphasize the rarity of complications after listing risks by asking a question confirming the rarity of complications. Confirming that the risk is a possibility, however, helps mitigate liability. An example is shown in Figure 4.

- Clear and simple questions increase the likelihood that the patient will retain correct information later on. Questions should not test the patient on concepts not explained in the lesson. ‘Trick questions’ can undermine patient confidence. Being able to answer a question correctly increases patient satisfaction.

- When a patient answers a question incorrectly, the feedback should explain the correct answer and give the patient a hint.

Conclusion

Medical leaders have identified patient engagement as one of the most critical concerns of health systems during the digital transformation of the healthcare industry. To truly engage patients, health education materials should be designed so that they are accessible to audiences of diverse literacy levels and learning styles. Medical writers should make creative and thoughtful instructional design decisions, and the final product should respect the humanity of patients.

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References


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