You Can’t Tell By Looking!
Assessing a Patient’s Ability to Read & Understand Health Information

The word "testing" can have different meanings and can elicit many different feelings depending on one’s perspective. Archie Willard, an adult learner, who first learned to read when he was 54, gives us a sense of what testing means to those with limited literacy.

“As a dyslexic and an adult learner with reading problems, I speak for many other adult learners. We hate having to take written literacy tests. People with other kinds of handicaps are not continually asked to expose their weaknesses to whatever degree they are handicapped. There is no physical pain in taking a written test, but when we have to take a written test there is a lot of frustration inside each of us. We grew up feeling humiliated because we had poor literacy skills and now we are adults. Written tests are seen as another step backward for us and it turns us away.”

The American Medical Association’s first health literacy videotape was titled Low Health Literacy: You Can’t Tell By Looking, and indeed, this is so true! Knowing that your patient or client has limited health literacy skills is very important if you are going to match the readability level of materials to the reading skills of patients. Also, it is important to know when non-printed teaching materials, such as videotapes, audiotapes, demonstration, models, and other visuals are essential for effective teaching. Keep in mind that how well a person communicates does not indicate a lack of intelligence, but that the skills of reading, writing, and comprehension have not been developed at the same level as good readers. People with low-literacy skills often have the capability to develop these skills; they have not had the opportunity. How do we assess if a person has low literacy skills, especially since these individuals are masterful at hiding the problem? In some cases, persons may not even realize the extent of their inadequacy.

Should health care providers test the literacy of their patients to gauge their level of understanding before they give care?

The trend to test patients’ literacy skills probably began because the Joint Commission on Accreditation of Healthcare Organizations added guidelines to their patient and family education standards that “literacy levels are taken into account when teaching.” The JCAHO standards do NOT require testing, and in fact, they believe it is not desirable.

The development of specific tests for literacy in health care settings may have supported these testing practices. These tests are effective for use in
research purposes when a person gives informed consent, but are not appropriate for use in a general clinical setting. Testing is a sure way to alienate many patients, no matter what their reading ability.

**Reasons why people should NOT be tested for their literacy skills:**

- Even people with very good literacy skills prefer materials that are easy-to-read and many find health care information a challenge to read and understand. They often don’t understand medical vocabulary, and the context and concepts in health and medicine are unfamiliar, such as how the body works or how to navigate the health care system. Stress and anxiety, which impairs the ability to listen, learn, and remember, is high in healthcare settings. Health information and the healthcare system are ever increasingly complex, and therefore more difficult to understand.

- Consider how humiliating a test might be for someone with low literacy skills, especially if they are already anxious and not feeling well. Many of these people have had poor past experiences with schooling and they perceive test taking as a threat.\(^2\)

- Most people with literacy difficulties feel a great deal of shame and are embarrassed by it. In a study of low-literate patients, 67% had never told their spouse, 53% never told their children, and 19% had never told anyone about their reading problem.\(^3\)

- Many times the person himself is not always aware that they have limited literacy skills and they overestimate their abilities. Two-thirds to three-fourths of those reading at the very lowest level report in surveys that they read “well” or “very well,” whereas, 93-97% of persons in the second lowest proficiency level described their reading abilities as such.\(^4\) They often arrange their lives in such a way that they read what they can and they have learned to compensate for their problem with a number of coping strategies.

**What clues help alert you that a person has low literacy skills?**

Most people with limited literacy skills are masters at concealing it, and they are often more articulating in their speech, so it is difficult to surmise a problem exists. Your powers of observation and the types of questions you ask, however, will help alert you to “red flags” that a reading problem exists.

<table>
<thead>
<tr>
<th>Be alert to:</th>
<th>Excuses when asked to read or fill out forms</th>
<th>Characteristics of poor readers</th>
</tr>
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<tbody>
<tr>
<td>• Visual acuity</td>
<td>• “I forgot (lost, broke) my glasses”</td>
<td>• Lift text closer to eyes</td>
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<tr>
<td>• Hearing deficits</td>
<td>• “My eyes are tired” “I have trouble seeing” “The lighting is not good”</td>
<td>• Point to text with finger while reading</td>
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<td>• Elderly</td>
<td>• I’m too tired. I’ll read this when I get home.”</td>
<td>• Eyes wander over page without finding central focus</td>
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<td>• Medications</td>
<td>• “I don’t feel well, will you read it to me?”</td>
<td>• Read slowly</td>
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<td>• Mental / physical disorders that disrupt ability to concentrate</td>
<td>• “I’m not interested now”</td>
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<td>When poor readers read text, they.....</td>
<td>When poor readers interact with health professionals, they.....</td>
<td>Ways poor readers cope with having low literacy skills</td>
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<td>• Struggle with more than one piece of information at a time</td>
<td>• Self-Care Behaviors</td>
<td>• Check “no” to all the questions about illnesses and allergies on a history form to avoid a lot of follow-up questions</td>
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<td>• Skip over hard words</td>
<td>• Frequently miss appointments</td>
<td>• Make excuses for not understanding or reading material given to them</td>
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<td>• Interpret words and visuals literally</td>
<td>• Make frequent errors in medications or self-care instructions; may be considered non-compliant</td>
<td>• Do everything the health provider says without asking questions (“blind trust”)</td>
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<tr>
<td>• Miss meaning of words</td>
<td>• Problem navigating to various locations; lack of follow-through with referrals</td>
<td>• Sign forms without reading the information</td>
</tr>
<tr>
<td>• Miss context of the information</td>
<td>• Give incomplete medical history</td>
<td>• Take instructions literally</td>
</tr>
<tr>
<td>• Get lost in details rather than focus on key points</td>
<td>• Resist changes in routine</td>
<td>• Listen and watch closely to try to memorize information and to do self-care skills exactly as shown</td>
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<tr>
<td>• Can’t make inferences from factual information</td>
<td>• Unable to name medications, explain purposes or how to take them. Identify medications by looking at pills, rather than reading label on bottle</td>
<td>• Look at pills for color, size, shape to identify them rather than reading the label</td>
</tr>
<tr>
<td>• Interpret perceptual information slowly</td>
<td></td>
<td>• Avoid situations where their reading problems may be noticed</td>
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### Communication Behaviors

- Show signs of nervousness or frustration
- Act confused
- Act aloof or indifferent
- React to complex learning by withdrawing or avoiding the situation
- Problem following simple directions
- Fail to ask questions or asks a lot of questions about information covered in the written materials
- Incorrectly answer questions about what was read
- Talk out of context about the topic being read or discussed
- Lack problem-solving skills
- Demonstrate differences between what they hear and what is written
- Check out this table from the Canadian Public Health Association on the differences between skilled and poor readers and learn more about how to get messages across to poor readers. (5)

**Tips from Literacy Experts on How To Get Your Message Across**
What assessment questions help determine if a person has low literacy skills?

Assessing Reading Ability

- Asking a patient how far they went in school is not always a good indicator of reading ability. Most people who can’t read have been through the 10th grade, because they must attend school until they can legally drop out, usually at age 16. Most research shows a 2 to 5 year gap between grade level and reading ability. Often a person’s oral communication is better than their reading, however, these individuals do have a limited vocabulary.

- Some general questions to broach the subject of whether or not there is a reading problem:

  **Q:** Medical terms are complicated and many people find the words difficult to understand. Do you ever get help from others in filling out forms, reading prescription labels, insurance forms, and health education sheets?

  **Q:** “A lot of people have trouble reading and remembering health information because it is difficult. Is this ever a problem for you?”

  **Q:** What do you like to read? (Newspapers are 10th grade reading level and news magazines are at 12th grade)

  **Q:** How often do you read? How much time to you spend reading each day?

  **Q:** When you have to learn something new or unfamiliar to you, what ways do you prefer to learn the information? Do you like to learn by watching TV, listening to the radio, talking with people, trying it yourself, or reading?

  **Q:** How happy are you with the way you read?

  **Q:** Ask patient to read prescription bottle and explain how to take their medicines

- A research study on identifying patients with inadequate health literacy, found the following 3 questions to be an effective screening tool. These questions were not as effective for identifying patients with marginal health literacy.

  1. “How often do you have somebody help you read hospital materials?”
  2. “How confident are you filling out medical forms by yourself?
  3. “How often do you have problems learning about your medical condition because of difficulty understanding written information?”

- **Single Item Literacy Screener (SILS)**

  A research study on identifying patients with inadequate health literacy, found the following question to be an effective screening tool.

  How often do you need to have someone help you when you read instructions, pamphlets, or other written health materials from your doctor or pharmacy?
  **Answer:** Never, Rarely, Sometimes, Often, Always.
  **Threshold:** If they answer ‘Sometimes, Often or Always,’ support is needed.
A study by Fred Miser, MD, MA at The Ohio State University Department of Family Medicine resulted in the use of screening questions to predict limited health literacy among patients with diabetes. The S.O. S. mnemonic is as follows:

**S =** Schooling or educational level attained is below the secondary level.

**O =** Opinion of Self-Rated Reading Ability (SRRA) and Reading Enjoyment (RE)

- For the SRRA ask, “How would you rate your reading ability?” **Answer:** Excellent or Very Good; Good; Okay; Poor; Terrible or Very Poor. **Threshold** is only ‘Okay’ as a reader.

- For the RE ask, “On a scale of 1 to 10, where 1 is ‘not at all’ and 10 is ‘a great deal,’ how much do you like reading?”

**S =** Support or help needed when reading health materials. Ask the SILS question “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy.” **Answer:** Never, Rarely, Sometimes, Often, Always. **Threshold:** If they answer ‘Sometimes, Often or Always,’ support is needed.

What tests are available to measure a person’s ability to read and understand health information?

Screening tests have been developed to help health care providers determine the literacy skills of patients. As mentioned previously, use of these tests is primarily a tool for research, and is not very “user-friendly in the clinical setting. Since people with limited skills feel stigmatized and fear exposure of their inability to read, they may elect to go elsewhere for their medical services if a literacy test becomes part of the routine care. Unless healthcare providers are trained to write and select appropriate teaching materials that are easy to read, knowing a person’s literacy level is a moot point. However, recently there has been some focus on developing screening tools that can be used in the clinical setting. Two such tools (REALM-R and the NVS) are described below.

**Reading Skills Tests:**

The two most popular standardized methods to measure reading skills in health care are the WRAT-R-III and the REALM tests. Reading skills tests measure a person’s ability to decode words. Decoding is an essential step in reading, which requires transforming letters into words and pronouncing the words correctly. Keep in mind that these tests only estimate reading levels because only one indicator of literacy, word recognition and pronunciation, is measured. They do not measure if the patient understands the meaning of the words on the test.

Both these tests call for reading word lists aloud, and are done on an individual rather than group basis. A person’s willingness to read out loud will, in large part, depend on explaining why it’s important to know how well they read and how this information will be used to help us make instructions easy to understand. These tests should be used only to test people whose native language is English.
• **WRAT-R-III (Wide Range Achievement Test-Revised):** (9)

This test has been widely used in school systems throughout the U.S. for over 40 years. The words used are not health related. The patient is asked to read out loud from a card with a list of 42 words, starting with the easiest word and progressing to the more difficult ones. If a word is mispronounced, the tester makes a check mark on a score sheet over the word pronounced incorrectly. The test is stopped after 10 consecutive words are mispronounced. The number of words missed or not tried is subtracted from the list of words on the score sheet to get a raw score. A table of raw scores is used to find the grade rating. The more words a person pronounces correctly, the higher the reading skill.

➢ **To obtain the WRAT-R-III:**

Wide Range Achievement Test (WRAT)
Jastak Associates Inc.
15 Ashley Place, Suite 1A
Wilmington, DE 19804-1314
(800) 221-9728

• **REALM (Rapid Estimate of Adult Literacy in Medicine):** (10, 11)

The REALM has advantages over the WRAT because it measures a person’s ability to read health-related terms and is more likely accepted; it takes less time to give the test; and the scoring is easier. Sixty-six medical and health-related terms are in three columns, starting with the easiest words at the top of the first column and ending with the more difficult words at the end of the third column.

Patients are asked to begin at the top of column 1 and read down the list, pronouncing all the words they can from the 3 lists. Examples of the words listed in the 3 columns include:

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
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</thead>
<tbody>
<tr>
<td>fat</td>
<td>fatigue</td>
<td>allergic</td>
</tr>
<tr>
<td>flu</td>
<td>pelvic</td>
<td>menstrual</td>
</tr>
<tr>
<td>pill</td>
<td>jaundice</td>
<td>testicle</td>
</tr>
<tr>
<td>dose</td>
<td>infection</td>
<td>colitis</td>
</tr>
<tr>
<td>eye</td>
<td>exercise</td>
<td>emergency</td>
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<tr>
<td>stress</td>
<td>behavior</td>
<td>medication</td>
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<tr>
<td>↓</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>incest</td>
<td>directed</td>
<td>impetigo</td>
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</tbody>
</table>

The tester uses a copy of the word list to check the number of words pronounced correctly. If the patient takes more than 5 seconds saying a word, the tester points to the next word. If the patient begins missing most of the words, they are told to look down the lists and pronounce any other words they recognize. Any word not attempted or mispronounced is scored as an error. The number of correct words for each list is counted. The total raw score of the 3 lists is converted into a reading grade range from the REALM scoring chart.

➢ **To obtain the REALM tool and scoring instructions:**

Terry Davis, Ph.D.
LSU Medical Center
1501 Kings Hwy
Box 598
REALM-R

In 2003, Bass, et. al revised the 66 item REALM and to an 8-item version to be used as a rapid-screening instrument. This tool substantially correlated with the WRAT-R and delivery is less than 2 minutes, including the explanation. The words chosen for the REALM-R were: osteoporosis, allergic, jaundice, anemia, fatigue, directed, colitis, and constipation. If the word is pronounced correctly, a correct response is recorded. Additional words could be added relevant to specific content areas, such as words used with diabetes education, and still keep the time for administering to less than 2 minutes. 

In 2008 the Agency for Health Care Research and Quality (AHRQ) 
(http://www.ahrq.gov/populations/sahlsatool.htm) posted two additional REALM tools, based on research conducted for an AHRQ grant:

REALM-S

The Rapid Estimate of Adult Literacy in Medicine—Short Form (REALM-SF) is a 7-item word recognition test to provide clinicians with a valid quick assessment of patient health literacy. The REALM-SF has been validated and field tested in diverse research settings, and has excellent agreement with the 66-item REALM instrument in terms of grade-level assignments. Click here for the REALM-S tool.

SAHLSA-50

The Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50) is a validated health literacy assessment tool containing 50 items designed to assess a Spanish-speaking adult's ability to read and understand common medical terms. The SAHLSA was based on the 66 item REALM. Click here for the REALM-SAHLSA tool.

Reading Comprehension Tests:

To be able to use information to problem solve and make decisions about one’s health care, and to perform the skills necessary for self-care, requires the ability to go beyond decoding words. Comprehending what is read is a step toward making inferences and problem solving. Tools used to test that a person understands what they read are the listening test, TOFHLA and S-TOFHLA, and NVS. These tests are based on specific text passages, and therefore indicate a person’s reading skills for the specific material used.

- Listening Test (13)

This test should take less than 10 minutes to administer, and in addition to testing for what they understand about a passage, it opens discussion about the topic and further questions may be addressed. The following steps should be followed to develop and give this test:

- Select a short passage of not more than one page from currently used material that the person needs to understand and has been tested for readability. The selected text should not take more than 3 minutes to read. Break long passages into segments with a reading and question session for each segment.
- Select the key points in the material, preferably desired healthcare behaviors, and write short questions on the text.
- Prepare the person that questions on the material will be asked.
- Read the passage out loud to the patient at a normal rate, while the patient listens.
- Ask the person the prepared questions about what was read.
  - Determine the percentage of correct answers by dividing the number of right answers by the number of possible right answers.
  - 80% correct is easy material to understand for the person; 70% about right, but the person may need help to fully understand; and less than 70% correct answers means the material is too difficult for effective use.

**Test of Functional Health Literacy in Adults (TOFHLA)**

*Reading Comprehension Test Portion of TOFHLA*

- This reading comprehension test consists of 50 items. Passages are selected from instructions for preparation for an upper GI, the patient rights and responsibilities of a Medicaid application form, and a standard hospital informed consent. The passages are presented with increasing reading difficulty from grades 4.3 to 10.4, and 19.5.

- The health instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear below it. The patient is asked to decide which of those 4 words should go in the blank to make sense of the sentence.

  Example: Your doctor has sent you to have a _______ X-ray.
  - stomach
  - diabetes
  - stitches
  - germs

*Numeracy Comprehension Test Portion of TOFHLA*

- The 17 test items for numerical ability reproduce real-life situations in receiving, following, and paying for medication plans. They are arranged in increasing levels of difficulty. The prompts consist of prescription bottles, an appointment slip, a chart describing eligibility for financial aid, and monitoring results from a medical test.

  Example: Medication Prescription on Bottle:

  GARFIELD IM 16 Apr 93  
  FF941858 Dr. Lubin, Michael  
  PENICILLIN VK  
  250 MG 40/0  
  Take one tablet by mouth  
  four times a day
Patients are asked questions with this prompt:

- If you take your first tablet at 7:00 am, when should you take the next one?
- When should you take the next one after that?
- What about the last one of the day, when should you take that one?

- Both sections take a total of 22 minutes to administer. The TOFHLA comes in large print and in Spanish.

- A short version of the TOFHLA (S-TOFHLA) is available, which takes 12 minutes to administer.¹⁶

- To obtain the TOFHLA tool:

  Peppercorn Books & Press
  PO Box 693
  Snow Camp, NC 27349
  Toll-free phone: (877) 574-1634
  Fax: (336) 272-7009
  [www.peppercornbooks.com](http://www.peppercornbooks.com)
  Email: [post@peppercornbooks.com](mailto:post@peppercornbooks.com)

- The Newest Vital Sign (NVS)

  A quick and accurate bilingual (English and Spanish) screening test for general literacy and numeracy skills applied to health information that can be used in primary care settings was introduced by Dr. B. Weiss and colleagues in the November 2005 issue of Annals of Family Medicine.¹⁷ The Newest Vital Sign is a nutrition label from an ice cream container. Patients are given the label and then asked 6 questions about how they would act on the information they read. They review the label as they are verbally asked and answer the questions, so it takes about 3 minutes to administer.

  The responses are recorded by the provider on a scoring sheet, which has the correct answers. Patients with more than 4 correct responses are unlikely to have low literacy, whereas fewer than 4 correct answers indicate the possibility of limited literacy. The tool was tested on more than 1,000 English and Spanish speaking adults and it was shown to have validity and reliability with the TOFHLA.


References:


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