

Removing barriers to better, safer care

Health literacy and patient safety:  
**Help patients understand**

**Manual for clinicians**

Second edition

Barry D. Weiss, MD

*A continuing medical education opportunity*

*Sponsored in part by AstraZeneca*



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Release date: May 2007  
Expiration date: May 2009

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# Introduction

Communication is essential for the effective delivery of health care, and is one of the most powerful tools in a clinician’s arsenal. Unfortunately, there is often a mismatch between a clinician’s level of communication and a patient’s level of comprehension. In fact, evidence shows that patients often misinterpret or do not understand much of the information given to them by clinicians. This lack of understanding can lead to medication errors, missed appointments, adverse medical outcomes, and even malpractice lawsuits.

There are many reasons why patients do not understand what clinicians tell them, but key among them is inadequate health literacy—i.e., a limited ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment. Clinicians can most readily improve what patients know about their health care by confirming that patients understand what they need to know and by adopting a more patient-friendly communication style that encourages questions.

The need for today’s patients to be “health literate” is greater than ever, because medical care has grown increasingly complex. We treat our patients with an ever-increasing array of medications, and we ask them to undertake more and more complicated self-care regimens. For example, patients with congestive heart failure were prescribed digoxin and diuretics in the past, while today’s patients take loop diuretics, beta blockers, angiotensin converting enzyme inhibitors, spironolactone, and digoxin. They may also receive a biventricular pacemaker that needs monitoring, and they often take medications for hypertension and hyperlipidemia. In the past, these patients were simply instructed to decrease their physical activity, but now they weigh themselves daily, report weight gain to their clinicians, eat low-sodium and often low-fat diets, and participate in structured exercise regimens. Similarly, therapy for patients with asthma was once limited to theophylline pills, but today these patients must learn to use inhalers with spacers

and understand the difference between controller medications and rescue medications. They must also test their peak flow rate, take tapering doses of prednisone, and identify and eliminate allergens from their homes. Patients with diabetes may have the most difficult task of all, as they need to understand factors affecting blood glucose control so they can modify insulin regimens on a meal-to-meal basis in response to finger-stick glucose measurements.

Unfortunately, current data indicate that more than a third of American adults—some 89 million people—lack sufficient health literacy to effectively undertake and execute needed medical treatments and preventive health care. Inadequate health literacy affects all segments of the population, but it is more common in certain demographic groups, such as the elderly, the poor, members of minority groups, and people who did not speak English during early childhood. The economic consequences of limited literacy for the US health care system are considerable, estimated to cost between \$50 billion and \$73 billion per year.

Since publication of the first edition of this manual, a great deal of new information has become available about the effects of literacy on health care and health outcomes. Much of this information has been described in research papers and in a report on health literacy from the Institute of Medicine.

In the pages that follow, this manual reviews the problem of health literacy, its consequences for the health care system, and the likelihood that a clinician's practice includes patients with limited literacy. The manual then provides practical tips for clinicians to use in making their office practices more "user friendly" to patients with limited literacy, and gives suggestions for improving interpersonal communication between clinicians and patients. Finally, the manual concludes with several "case discussions" based on vignettes in the accompanying instructional video.

Health literacy, as defined in a report by the Institute of Medicine, is the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment.<sup>1</sup> Many factors can contribute to an individual's health literacy, the most obvious being the person's general literacy—the ability to read, write, and understand written text and numbers. Other factors include the individual's amount of experience in the health care system, the complexity of the information being presented, cultural factors that may influence decision-making, and how the material is communicated.

## **National Assessment of Adult Literacy**

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Every 10 years, the US Department of Education conducts a national survey to document the state of literacy of the American public. The most recent survey, the National Assessment of Adult Literacy (NAAL) conducted in 2003, provides the most comprehensive view of the general literacy and health literacy skills of American adults. The NAAL tested a stratified representative national random sample of some 19,000 adults who were interviewed in their place of residence. Each participant was asked to provide personal and background information and to complete a comprehensive set of tasks to measure his or her ability to read and understand text, interpret documents, and use and interpret numbers (Table 1).

While the main purpose of the NAAL was to measure the general literacy skills of American adults, specific items were devoted to specifically assessing health literacy. These items focused on the ability of individuals to understand and use text, documents, and numbers pertinent to commonly encountered health care situations. These situations included care of illness, dealing with preventive care, and navigating the health care system.

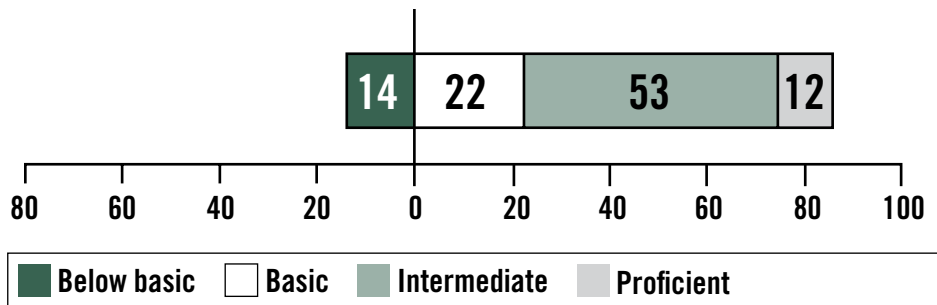
The NAAL results were reported by dividing the health literacy skills of subjects into four levels<sup>2</sup>: “proficient,” “intermediate,” “basic,” and “below basic” (Figure 1). Most doctoral-level clinicians fall into the small percentage of the population that has proficient skills, while 36% of American adults—78 million people—have only basic or below basic skills. Add to this figure the approximately 5% of individuals that could not be tested in the NAAL because they lacked sufficient skills to participate in the survey, and the total number of Americans with limited health literacy totals more than 89 million!

**Table 1. Examples of health literacy tasks on the National Assessment of Adult Literacy**

Level	Sample tasks
<b>Proficient</b>	<ul style="list-style-type: none"> <li>• Calculate an employee’s share of health insurance costs for a year, using a table that shows how the employee’s monthly cost varies.</li> <li>• Find the information required to define a medical term by searching through a complex document.</li> <li>• Evaluate information to determine which legal document is applicable to a specific health care situation.</li> </ul>
<b>Intermediate</b>	<ul style="list-style-type: none"> <li>• Determine a health weight range for a person of specified height, based on a graph that relates height and weight to body mass index.</li> <li>• Find the age range during which children should receive a particular vaccine using a chart that shows all the childhood vaccines and the ages children should receive them.</li> <li>• Determine what time a person can take a prescription medication, based on information on the prescription drug label that relates the timing of medication to eating.</li> <li>• Identify three substances that may interact with an over-the-counter drug to cause side effects, using information on the over-the-counter drug label.</li> </ul>
<b>Basic</b>	<ul style="list-style-type: none"> <li>• Give two reasons why a person with no symptoms of a specific disease should be tested for the disease, based on information in a clearly written pamphlet.</li> <li>• Explain why it is difficult for people to know if they have a specific chronic medical condition, based on information in a two-page article about the medical condition.</li> </ul>
<b>Below basic</b>	<ul style="list-style-type: none"> <li>• Identify how often a person should have a specified medical test, based on information in a clearly written pamphlet.</li> <li>• Identify what is permissible to drink before a medical test, based on a set of short instructions.</li> <li>• Circle the date of a medical appointment on a hospital appointment slip.</li> </ul>

Source: Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America’s Adults: Results from the 2003 National Assessment of Adult Literacy. US Department of Education. National Center for Education Statistics (NCES) Publication No. 2006-483; September 2006.

Figure 1.



Graph illustrates the percentage of participants in the National Assessment of Adult Literacy (NAAL) with health literacy scores in each of the four literacy proficiency categories.

Source: Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. US Department of Education. National Center for Education Statistics (NCES) Publication No. 2006-483; September 2006.

### Proficient skills

At the proficient level, individuals have fully developed health literacy skills and can read and understand virtually all text and numerical information they might encounter in health care settings. These individuals, however, account for only about 13% of the American adult population.

### Intermediate skills

The next highest skill level is termed “intermediate.” Individuals with intermediate health literacy skills constitute about 53% of the population. They can deal with most of the text and numerical information they encounter in health care settings, although they would have difficulty dealing with dense or complicated text and documents. Examples of intermediate skills include checking a reference source to determine which foods contain a particular vitamin or calculating body mass index from information provided on a graph.

### Basic skills

People with basic health literacy skills, who make up 22% of the population, can perform the basic tasks of reading and understanding a short pamphlet that explains the importance of a screening test. They would not be able to reliably perform intermediate-level tasks. Most would have difficulty understanding typical patient education handouts or filling in health insurance applications.

### Below basic skills

About 14% of the American adult population has health literacy skills below even the basic level. These individuals are typically unable to perform the basic tasks needed to achieve full function in today's society, including interactions with the health care system. They can only perform rudimentary literacy tasks like identifying the date of a medical appointment from a hospital appointment slip given to them. They would typically have difficulty with basic-level tasks.

### Population groups at risk for limited health literacy

Persons with basic and below basic health literacy skills are found in all segments of society. In fact, most are white, native-born Americans. Nonetheless, limited health literacy is much more common in certain segments of the population.

Table 2 shows the percentage of certain “high-risk” population groups in which many individuals scored in the basic or below basic levels on the NAAL. These groups include the elderly, persons with limited education, members of ethnic minorities, and people who spoke a language other than English in their childhood home. Unemployed persons, those with limited income, and individuals insured by Medicaid are also more likely to have limited health literacy. Visual difficulties and learning disabilities such as dyslexia account for health literacy deficits in only a very small percentage of NAAL subjects.



**Table 2. Percentage of adult population groups with health literacy skills at NAAL below basic and basic levels**

Group	Below basic	Basic	Total
	%	%	%
<b>Age (years)</b>			
19-24	10	21	31
25-39	10	18	28
40-49	11	21	32
50-64	13	21	24
65 and older	29	30	59
<b>Highest education level completed</b>			
Less than or some high school	49	27	76
High school graduation (no college study)	15	29	44
High school equivalency diploma	14	30	44
<b>Racial/ethnic group</b>			
White	9	19	24
Asian/Pacific Islander	13	18	31
Black	24	34	58
Hispanic (all groups)	41	25	66
<b>Health insurance status</b>			
Employer provided	7	17	24
Privately purchased	13	24	37
Medicare	27	30	57
Medicaid	30	30	60
No insurance	28	25	53

Source: Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. US Department of Education. National Center for Education Statistics (NCES) Publication No. 2006-483; September 2006.

If your patient population includes many individuals in any of the groups mentioned above, it is likely that your practice includes persons with limited health literacy skills. It is important, however, to keep in mind that persons with limited health literacy do not fit into easy stereotypes. Indeed, one study of affluent individuals living in a geriatric retirement community found that 30% scored poorly on a test

of functional literacy in health care situations.<sup>3</sup> And a cover article in *Fortune* magazine told the stories of several billionaire executives who had limited general literacy skills.<sup>4</sup> As with nearly all poor readers, they had developed coping mechanisms that worked in their business and social lives, but might not work well in an urgent health care situation.

## Day-to-day problems associated with limited health literacy

Numerous studies in health care settings demonstrate that persons with limited health literacy skills often have a poor understanding of basic medical vocabulary and health care concepts. For example, one study of patients with limited health literacy found that many did not really understand the meanings of words that clinicians regularly use in discussions with patients—words like “bowel,” “colon,” “screening test,” or “blood in the stool” (Table 3).<sup>5</sup> In another study, one out of four women who said they knew what a mammogram was turned out not to know.<sup>6</sup>

**Table 3. Common medical words that patients with limited literacy may not understand**

- Blood in the stool
- Bowel
- Colon
- Growth
- Lesion
- Polyp
- Rectum
- Screening
- Tumor

Source: Davis TC, Dolan NC, Ferreira MR, Tomori C, Green KW, Sipler AM, Bennett CL. The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Invest.* 2001;19:193-200.

Lack of understanding is not just limited to medical terms. Several studies, conducted in both primary care and specialty practices in different parts of the United States, show that persons with limited health literacy skills also do not understand, or are not aware of, *concepts* basic to common diseases. For example, fewer than half of low literacy patients with diabetes knew the symptoms of hypoglycemia,<sup>7</sup> and the majority of low literacy patients with asthma could not demonstrate proper use of an asthma inhaler.<sup>8</sup> Table 4 shows some other problems experienced by persons with limited health literacy when they interact with the health care system.<sup>9,10,11,12</sup>

**Table 4. Some other health system problems experienced by persons with limited literacy skills**

26%	did not understand when their next appointment was scheduled
42%	did not understand instructions to “take medication on an empty stomach”
(Up to) 78%	misinterpret warnings on prescription labels
86%	could not understand rights and responsibilities section of a Medicaid application

Sources: (a) Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. *JAMA.* 1995; 274:1677-1682; (b) Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. *Arch Family Med.* 1996; 5:329-334; (c) *Fact Sheet: Health literacy and understanding medical information.* Lawrenceville, NJ: Center for Health Care Strategies; 2002; (d) Wolf MS, Davis TC, Tilson HH, Bass PF III, Parker RM. Misunderstanding of prescription drug warning labels among patients with low literacy. *Am J Health Syst Pharm.* 2006; 63:1048-1055.

It is important to emphasize that limited understanding of health concepts and health information is not solely a problem of persons with low literacy skills. Highly literate, well-educated individuals also report difficulty understanding information provided to them by clinicians—usually because clinicians use vocabulary and discuss physiological concepts unfamiliar to those who do not have a medical education. Even patients with average reading levels are often unable to understand consent forms used for research studies on cancer drugs and may not comprehend medication instructions, such as those for what to do about missed oral contraceptive pills.<sup>13,14</sup> And, in a well-known anecdote, a prominent obstetrician reported that he was unable to fully understand the

explanation he received from an orthopedist about his upcoming orthopedic surgery.

### Implications of limited health literacy

The limited ability to read and understand health-related information often translates into poor health outcomes. Most clinicians are surprised to learn that literacy is one of the strongest predictors of health status. In fact, all of the studies that investigated the issue report that literacy is a stronger predictor of an individual's health status than income, employment status, education level, and racial or ethnic group.<sup>15,16,17</sup>

Be aware that education level is a poor surrogate for general literacy skills and for health literacy. Education level only measures the number of years an individual attended school—not how much the individual learned in school. Thus, asking patients how many years of school they completed does not adequately predict their literacy skills. Indeed, fully 39% of NAAL participants with a high school education had only basic reading skills, and 13% had skills below the basic level.<sup>2</sup>

#### Literacy and health knowledge

Patients with limited health literacy have less awareness of preventive health measures and less knowledge of their medical conditions and self-care instructions than their more literate counterparts. This knowledge deficit has been documented for a variety of health conditions, ranging from childhood fever to asthma to hypertension. Persons with limited health literacy skills also exhibit less healthy behaviors (Table 5).<sup>18,19</sup>

#### Literacy and health outcomes

Persons with limited health literacy skills have poorer health status than the rest of the population.<sup>15,16,17,20</sup> Indeed, several studies in diverse settings have shown that, even after controlling for a variety of sociodemographic variables, limited understanding

of health concepts (i.e., poor health literacy) is associated with worse health outcomes. This may be due to the aforementioned deficits in health knowledge, as well as medication errors, poor understanding of medical instructions, and lack of self-empowerment.

### Table 5. Some health knowledge deficits and risky behaviors of persons with limited literacy skills

#### Health knowledge deficits

- Patients with asthma less likely to know how to use an inhaler
- Patient with diabetes less likely to know symptoms of hypoglycemia
- Patients with hypertension less likely to know that weight loss and exercise lower blood pressure
- Mothers less likely to know how to read a thermometer
- Less likely to understand direct-to-consumer television advertising

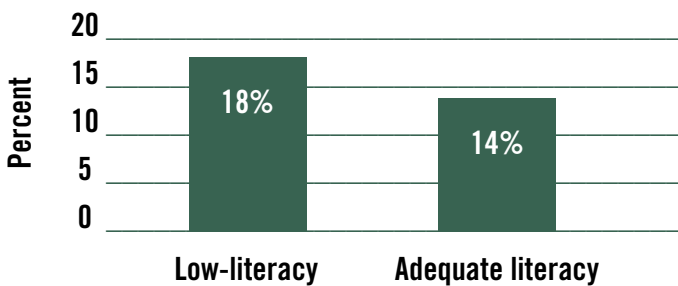
#### Less healthy behaviors

- More smoking, including during pregnancy
- More exposure to violence
- Less breastfeeding
- Less access to routine children's health care

Sources: (a) Davis TC, Arnold C, Berkel HJ, Nandy I, Jackson RH, Glass J. Knowledge and attitude on screening mammography among low-literate, low-income women. *Cancer*. 1996;78:1912-1920; (b) Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension or diabetes. *Arch Intern Med*. 1998;158:166-172; (c) Davis TC, Byrd RS, Arnold CL, Auinger P, Bocchini JA Jr. Low literacy and violence among adolescents in a summer sports program. *J Adolesc Health*. 1999; 24:403-411; (d) Arnold CL, Davis TC, Berkel HJ, Jackson RH, Nandy I, London S. Smoking status, reading level, and knowledge of tobacco effects among low-income pregnant women. *Prev Med*. 2001; 32:313-320; (e) Kaphingst KA, Rudd RE, Dejong W, Daltroy LH. Comprehension of information in three direct-to-consumer television prescription drug advertisements among adults with limited literacy. *J Health Commun*. 2005;10:609-619; (f) Yu SM, Huang ZJ, Schwalberg RH, Nyman RM. Parental English proficiency and children's health services access. *Am J Public Health*. 2006;96:1449-1455.

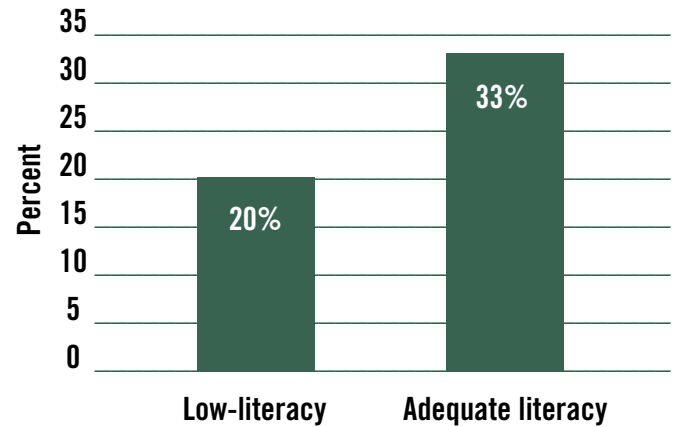
The relationship between limited health literacy and poorer health occurs in all socioeconomic groups and in many disease states. For example, Medicare managed care enrollees (mostly older individuals) are 29% more likely to be hospitalized if they have limited health literacy skills (Figure 2).<sup>21</sup> Medicaid enrollees (mostly individuals with limited income) with diabetes are less likely to have good glycemic control if they have limited health literacy (Figure 3).<sup>22</sup> Indeed, although not all research has come to a similar conclusion, evidence suggests that literacy may be the mediating factor in determining which patients have good diabetes control.<sup>23,24</sup>

**Figure 2. Percentage of Medicare managed-care enrollees requiring hospitalization over a 3-year period**



Source: Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *Am J Public Health*. 2002;92:1278-1283.

**Figure 3. Patients with tight diabetes control**



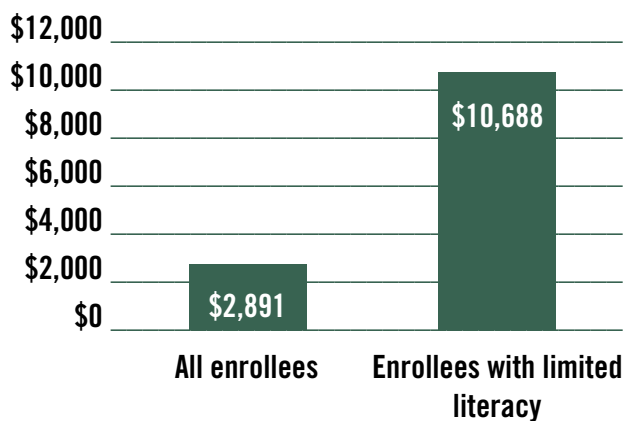
Tight diabetes control defined as a glycated hemoglobin level  $\leq 7.2\%$

Data from: Schillinger D, Grumbach K, Piette J, et al. Association of health literacy with diabetes outcomes. *JAMA*. 2002;288:475-482.

### Literacy and health care costs

The adverse health outcomes of low health literacy translate into increased costs for the health care system. In one small study, the average annual health care costs for all Medicaid enrollees in one state was \$2,891 per enrollee, but the annual cost for enrollees with limited literacy skills averaged \$10,688 (Figure 4).<sup>25</sup> Another study, this one of 3,260 Medicare enrollees in sites around the country, found higher costs for emergency room and inpatient care for people with limited health literacy.<sup>26</sup>

**Figure 4. Annual health-care costs of Medicaid enrollees**



Data from: Weiss BD, Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *J Am Board Family Pract.* 2004;17:44-47

The combination of medication errors, excess hospitalizations, longer hospital stays, more use of emergency departments, and a generally higher level of illness—all attributable to limited health literacy—is estimated to result in excess costs for the US health care system of between \$50 billion and \$73 billion per year.<sup>27</sup> According to the Center for Health Care Strategies, this is equal to the amount Medicare pays for physician services, dental services, home health care, drugs, and nursing home care combined.<sup>28</sup>

### Literacy and the law

The Joint Commission and the National Committee for Quality Assurance have both adopted guidelines specifying the need for patient education information and consent documents to be written in a way that patients can understand.<sup>29,30</sup> Accordingly, failure to provide understandable information to patients may be a negative factor in the accreditation status of a health care organization. The Joint Commission recently published a “white paper” on health literacy.<sup>31</sup>

Our legal system recognizes the patient-physician relationship as a fiduciary relationship, which is the highest standard of duty implied by law. In the case of informed consent, courts consistently state that because of the fiduciary relationship between patients and physicians, physicians have a duty to fully disclose, in good faith and in general terms, the risks and benefits of medical interventions and procedures.

With consistency, courts have described informed consent as a process of educating patients so they understand their diagnosis and treatment. A Virginia court stated that consent is not a piece of paper but rather a process of physicians helping patients understand their condition for the purpose of making informed decisions.<sup>32</sup> The South Carolina Supreme Court declared that a patient must have a true understanding of procedures and their seriousness.<sup>33</sup> Moreover, in Ohio, a court said that the physician’s duty to patients includes fully disclosing information and, as fully as possible, ascertaining that patients understand the information on the documents they are signing.<sup>34</sup>

For patients with limited health literacy skills, clinicians thus need to deliver this information in a clear, plain language format. In fact, clinicians can best serve their patient population by providing *all* patients with easy-to-understand information.

# You can't tell by looking

Given that 89 to 90 million adults in the United States have limited health literacy, you probably see patients every day who have trouble reading and understanding health information. In addition, even persons with adequate skills may have trouble understanding and applying health care information, especially when it is explained in technical, unfamiliar terms. Patients may be verbally articulate and appear well-educated and knowledgeable, yet fail to grasp disease concepts or understand how to carry out medication regimens properly.

Patients with limited health literacy can be difficult to identify. The population groups listed in Table 6 are known to be at higher risk for limited health literacy, but keep in mind that many patients within these groups actually have well-developed skills. Conversely, many patients with limited health literacy do not fall into any of the population groups listed in Table 6.

The important message is that *you can't tell by looking* whether someone has sufficient skills to adequately understand health concepts and carry out health care instructions. Because you can't tell just by looking, clinicians and medical practices can best deliver effective medical care by providing easy-to-understand information to *all* patients. Later in this manual, we will show you how you can do this.

## **Table 6. Key risk factors for limited literacy**

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- Elderly
- Low income
- Unemployed
- Did not finish high school
- Minority ethnic group (Hispanic, African American)
- Recent immigrant to United States who does not speak English
- Born in United States but English is second language

## How can I tell if an individual patient has limited health literacy skills?

### Red flags

While you can't tell by looking, some of your patients may drop clues, or "red flags," indicating they have limited health literacy. If your patients

have ever filled out their registration forms or health questionnaires incompletely or incorrectly, or taken their medications the wrong way, they may have done so because of limited literacy skills or because they were not familiar with the medical terms and concepts in these forms. Other clues to limited literacy are listed in Table 7.

**Table 7. Behaviors and responses that may indicate limited literacy**

### Behaviors

- Patient registration forms that are incomplete or inaccurately completed
- Frequently missed appointments
- Noncompliance with medication regimens
- Lack of follow-through with laboratory tests, imaging tests, or referrals to consultants
- Patients say they are taking their medication, but laboratory tests or physiological parameters do not change in the expected fashion

### Responses to receiving written information

- "I forgot my glasses. I'll read this when I get home."
- "I forgot my glasses. Can you read this to me?"
- "Let me bring this home so I can discuss it with my children."

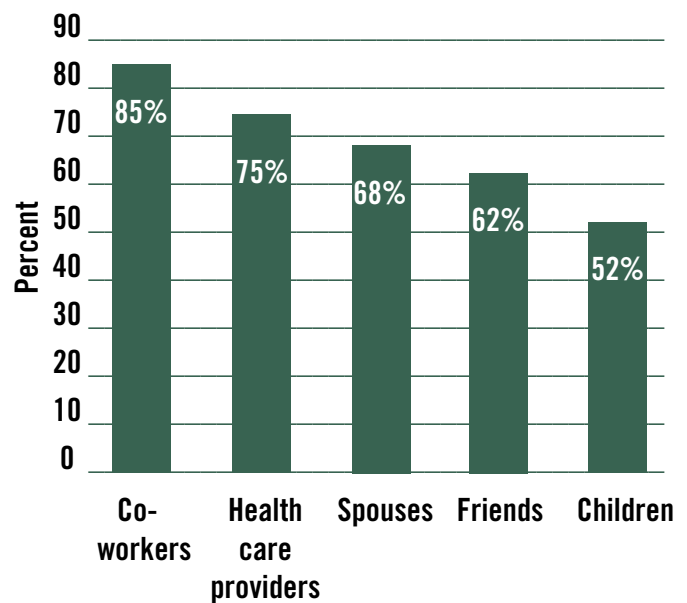
### Responses to questions about medication regimens

- Unable to name medications
- Unable to explain what medications are for
- Unable to explain timing of medication administration

It is important to understand, however, that the absence of such clues *does not* indicate that a patient has adequate health literacy. Most individuals with limited health literacy are undetected by the health care system. In fact, patients with limited general literacy skills go to great lengths to hide this from others, some even going so far as to bring decoy reading materials with them to the clinician's office or handing articles about medications or treatments to their clinician. The majority of patients with limited literacy skills have never told anyone in the health care system, and most have never even told family members (Figure 5).<sup>35</sup> Similarly, patients with well-developed literacy skills who fail to understand health information may also avoid asking questions for fear of appearing "stupid" or annoying to the clinician.

In other words, you can't tell by looking *and* you can't expect your patients to tell you.

**Figure 5. Non-disclosure of limited literacy**



Histogram bars indicate the percentage of persons with limited literacy skills who had never told co-workers, health-care providers, spouses, friends, or their children about their limited literacy.

Data from: Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. *Patient Educ Couns.* 1996; 27:33-39,



### **The social history**

Some physicians have found it helpful to add a question about literacy skills to the social history. After asking about occupation and education, they add “How happy are you with the way you read?” or “What is the best way for you to learn new things?” Use of these and similar questions gives the patient an opportunity to “open up” and discuss the issue if desired.

Recent research in this area has focused on patients’ responses to any one of several specific questions as indicators of limited health literacy skills.<sup>36,37,38</sup> The two questions for which the most validation data are available are “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” and “How confident are you filling out medical forms by yourself?” (Table 8). These questions have been studied in several settings and have sensitivities for detecting limited literacy skills ranging from 54% to 83%.

The discussion that follows can lead the patient and clinician to agree on the importance of understanding health information, and on the need to find alternate ways for patients to learn what they need to know to care for themselves. It is essential that such discussions, and indeed any questions about reading skills, be conducted in a private, safe, and supportive environment, and that all questions are asked in a neutral, nonjudgmental fashion.

### **Medication review**

Another suggested method for identifying patients who have limited health literacy skills is the “brown-bag medication review.” At the time an appointment is made, ask the patient to bring in all medications (prescription and over-the-counter medications, nutritional and herbal supplements, etc). When the patient comes to the office, the clinician or medical assistant can conduct the medication review by asking the patient to name each medication and explain what it is for and how it is taken.

As patients respond to these questions, note whether they identify medications by reading the label or by opening the bottle and looking at or pouring the pills into their hands. Identifying the medication by looking at the pills may be a clue to limited literacy skills. When responding to questions about how to take the medication, the patient may have memorized instructions such as “take one pill three times per day.” However, when probing further with questions such as “When was the last time you took one of these pills?” and “When was the time before that?” the patient’s confusion may become apparent.

### **Measuring health literacy**

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A number of instruments have been developed to assess the health literacy skills of patients (Table 8). For the most part, these tools have been used for research. Some clinicians, however, have used these instruments in their own clinical settings to measure the literacy skills of a sample of their practice’s patients. Doing so permits the entire staff to develop a better sense of the literacy level of their overall patient population, thereby helping ensure that patient education materials and other communication modalities are targeted appropriately to patients’ level of understanding.

While many clinicians and most patient advocacy groups have expressed concern that patients are ashamed and will not want to have their literacy skills assessed when they come to see a physician, a recent study suggests otherwise. The study, which involved nearly 600 patients, randomized 10 private and 10 public practices in Florida into practices that did and did not assess literacy skills of their patients. In the practices that conducted literacy assessments, the assessment was performed by the practice’s nursing staff at the time nurses obtained patients’ vital signs. Fully 99% of patients in the practices that assessed literacy were willing to undergo the assessment, and doing so did not decrease patient satisfaction. In fact, patient satisfaction was slightly higher in the practices that performed literacy assessments, perhaps because the literacy assessment provided an opportunity for more interaction and communication between patients and practice staff.<sup>43</sup>

**Table 8. Some methods for assessing literacy skills**

Methods	Description	Validated in		Length (minutes)
		English	Spanish	
<b>Single question screens<sup>36,37, 38</sup></b>				
	“How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” (positive answers are “sometimes,” “often,” or “always”)	Yes	No	≤1
	“How confident are you filling out medical forms by yourself?” (positive answers are “somewhat,” “a little bit,” or “not at all”)	Yes	No	≤1
<b>Assessment instruments</b>				
Newest Vital Sign <sup>39</sup> ( <a href="http://www.NewestVitalSign.org">www.NewestVitalSign.org</a> )	Screening instrument for use in clinical settings. Patients review a nutrition label and answer 6 questions about the label.	Yes	Yes	3
Rapid Estimate of Adult Literacy in Medicine <sup>40</sup>	Used in both clinical and research settings. Word recognition list. Patients read list of 66 words and are scored on correct pronunciation.	Yes	No	2
Short Assessment of Health Literacy for Spanish-speaking Adults <sup>41</sup>	Patient is presented with 50 words, each with a correct and incorrect meaning, and patient must select correct meaning.	No	Yes	5
Short Test of Functional Health Literacy in Adults <sup>42</sup>	Used mostly in research. Patients questioned about 4 numerical items and 2 prose passages about medical issues from which specific words have been deleted, and patient must select appropriate words from a list of multiple-choice options.	Yes	Yes	8

# Strategies to enhance your patient's health literacy

While there is little that clinicians can do to boost the general literacy skills of their patients, there are strategies you can use to enhance patients' understanding of medical information. In fact, by making your practice more patient-friendly, communicating in easy-to-understand language, creating and using patient-friendly written materials, and verifying patients' understanding of information you provide, you can deliver more effective care to *all* of your patients.

## **Making your practice patient-friendly**

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Imagine that you are one of the nearly 36% of adults in the United States who had basic or below basic general and health literacy skills on the NAAL. You can't read and fully understand an article in a newspaper. You can't fill in a government application for Social Security, Medicare, or Medicaid benefits. You can't follow a bus schedule or a map. You don't really understand what a cancer screening test is, or the meaning of words like "rectum," "tumor," "prostate gland," or "mammogram." Perhaps English is your second language.

Imagine also that you, the patient, are coming to visit *your* practice for the first time today. What will you find there? What paperwork will the staff ask you to produce or complete? What rules and procedures will they ask you to follow? What kinds of paperwork will you receive if you are referred for ancillary tests or consultations with other clinicians, and how will you find your way to those tests and consultations? Will you receive handouts and consent forms? If so, will you be able to understand them (Figure 6)? What do you know about your medical insurance coverage—assuming, of course, you are not one of the more than 40 million Americans without medical insurance?

This section of the manual provides suggestions and tips for making your practice more patient-friendly (summarized in Table 9). While the paragraphs above use the example of a patient with limited general literacy skills, implementing the recommendations in this section will benefit all the patients in your practice.

Figure 6.

---

Your naicisyhp has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.

The text above, which provides basic information about colonoscopy, provides a sense of what it might be like for a person with limited literacy skills to read a handout similar to those you may give to patients in your office. The words are spelled backwards—can you read it?

Individuals with limited literacy skills prefer information with short words and short sentences, and that contains only essential information. Long or

unfamiliar words, written backwards in the example above, are often difficult to decipher. Difficult words slow down reading speed and as a result, decrease understanding. Similar concerns apply to oral communication—simple, plain language is the best way to communicate.

## Communication and medical outcomes

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Studies have shown that effective communication with patients has a beneficial effect on medical outcomes. These benefits include lower rates of anxiety, pain, and psychological distress, and higher rates of compliance and symptom resolution.<sup>49</sup>

In particular, it has long been known that patients' adherence to therapy is heavily influenced by communication style. Specifically, clear and concise instructions delivered to patients by clinicians the patients trust are associated with improved rates of adherence.<sup>50</sup>

## Steps to improving communication with patients

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General consensus exists among health literacy and communication experts that there are six basic methods for improving communication with patients (Table 12).<sup>51,52</sup> Although initially recommended based on expert opinion, research results are providing evidence that these methods work.

## Table 12. Six steps to improving interpersonal communication with patients

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- 1. Slow down.**  
Communication can be improved by speaking slowly, and by spending just a small amount of additional time with each patient. This will help foster a patient-centered approach to the clinician-patient interaction.
  - 2. Use plain, nonmedical language.**  
Explain things to patients like you would explain them to your grandmother.
  - 3. Show or draw pictures.**  
Visual images can improve the patient's recall of ideas.
  - 4. Limit the amount of information provided—and repeat it.**  
Information is best remembered when it is given in small pieces that are pertinent to the tasks at hand. Repetition further enhances recall.
  - 5. Use the “teach-back” technique.**  
Confirm that patients understand by asking them to repeat back your instructions.
  - 6. Create a shame-free environment: Encourage questions.**  
Make patients feel comfortable asking questions. Consider using the Ask-Me-3 program. Enlist the aid of others (patient's family or friends) to promote understanding.
-

## Slow down

Communication is improved—and the risk of malpractice claims decreased—when clinicians spend more time with patients. Only a short amount of time is needed to make a difference. Data from multiple US states indicate that primary care physicians who have been the target of malpractice liability claims spend an average of 15 minutes per patient on routine visits, while physicians who have never had a malpractice claim against them spend an average of 18 minutes. This is a difference of a mere three minutes.<sup>53</sup>

In addition to spending more time, clinicians can optimize the use of this time by creating a “patient-centered visit.” In a patient-centered visit, the clinician focuses on addressing the patient’s concerns. Behaviors such as sitting rather than standing, listening rather than speaking, and speaking slowly can further create an impression that you are focused on the patient, and patients may respond to these behaviors by perceiving that you have spent more time with them than you actually have. These and other useful behaviors are listed in Table 13.

**Table 13. Behaviors that improve communication**

- Use orienting statements: “First I will ask you some questions, and then I will listen to your heart.”
- Ask patients if they have any concerns that have not been addressed.
- Ask patients to explain their understanding of their medical problems or treatments.
- Encourage patients to ask questions.
- Sit rather than stand.
- Listen rather than speak.

Clinicians often express concern that a patient-centered approach results in a substantial increase in the duration of office visits. Research shows otherwise. In one important study, patients who were allowed to talk without interruption for as long as they liked spoke for an average of only one minute and 40 seconds.<sup>54</sup> In another study, patients were permitted to voice their initial concerns at the beginning of an office visit, again for as long as they wished without interruption. The mean spontaneous talking time was only 92 seconds, with a median value of 59 seconds.<sup>55</sup>

While patient-centered visits do not take substantially longer than traditional visits, they create an atmosphere in which patients feel that their needs have been met. This aids in the development of an effective patient-clinician alliance, with potential benefits such as increased patient compliance and decreased risk of malpractice suits.

## Use plain, nonmedical language

You should always seek to use plain, nonmedical language when speaking to patients. Words that clinicians use in their day-to-day conversations with colleagues may be unfamiliar to the majority of nonmedically trained persons.

A good approach is to explain things to patients in language that you might use when talking to your grandmother. This is sometimes called “living room language,” “the language of the family,” or conversational language. Table 14 gives some examples of plain language alternatives to medical words. Conversational language creates opportunities for dialogue between the clinician and patient, rather than limiting communication to a monologue by the physician.

**Table 14. Plain language alternatives to medical terms patients may not understand**

<b>Medical term</b>	<b>Translation into plain language</b>
Analgesic	Pain killer
Anti-inflammatory	Lessens swelling and irritation
Benign	Not cancer
Carcinoma	Cancer
Cardiac problem	Heart problem
Cellulitis	Skin infection
Contraception	Birth control
Enlarge	Get bigger
Heart failure	Heart isn't pumping well
Hypertension	High blood pressure
Infertility	Can't get pregnant
Lateral	Outside
Lipids	Fats in the blood
Menopause	Stopping periods, change of life
Menses	Period
Monitor	Keep track of, keep an eye on
Oral	By mouth
Osteoporosis	Soft, breakable bones
Referral	Send you to another doctor
Terminal	Going to die
Toxic	Poisonous



### **Show or draw pictures to enhance patients' understanding and recall**

The saying that “a picture is worth a thousand words” is particularly true when communicating with patients who may have trouble understanding medical concepts delivered in words. It has long been known that visual images are remembered better than letters and words.<sup>56</sup> That is why we often recall a person's face but not their name, or the picture on a book's cover, but not the name or author of the book.<sup>57</sup>

Research shows that pictures enhance patients' understanding of what they need to do.<sup>58,59</sup> Pictures are not substitutes, however, for written or verbal communication, as understanding is best when pictures are combined with written or verbal explanations.

Furthermore, the most effective pictures are simple ones. For example, if you are trying to explain that an aortic valve needs to be replaced, the illustration should display a heart, an aorta, and an aortic valve. Additional details, such as coronary arteries and other heart valves, and perhaps all the cardiac chambers, should not be included if they are not relevant to the patient's specific health problem. Inclusion of irrelevant details distracts the patient and diminishes the effectiveness of the picture as a teaching tool.

### **Limit the amount of information given at each visit—and repeat it**

Another key to effective communication is to limit the amount of information provided to patients at each visit. This does not mean you should withhold important information. Rather, it means that you should focus your communication on the one or the few most important things a patient needs to know at the time of the visit. The principle behind this approach is that advice is remembered better, and patients are more likely to act on it, when the advice is given in small pieces and is relevant to the patient's current needs or situation.

For example, at a patient's first visit following a diagnosis of type 2 diabetes, the most important message often is that “the sugar level in your blood is high, and you must start taking medicine to lower the sugar level.” Information about physiology of glucose control, while ultimately important for the patient's ability to self-regulate diabetes control, is not important at the first visit and should not be discussed at that time. Information about potential complications of diabetes might be mentioned, but is not the main focus of the visit. The focus of the first visit is the initiation of treatment.

After discussing the key information with a patient, this information should be reviewed and repeated, because repetition is the key to learning and memory. Ideally, the information will be reviewed and repeated by multiple members of the health care team—perhaps by a physician, nurse, pharmacist, dietician, and others.

Repetition can be achieved even after the patient's visit through handouts to reinforce the information provided in person. Consider reading handouts to patients to emphasize the importance of the information. If the handout is too long to read out loud, it may be too complex and consideration should be given to developing and using simpler handouts. Preparation of "patient-friendly" handouts will be discussed in the next section of this manual.

Some experts suggest calling patients several days after delivering important information to further reinforce learning.<sup>60</sup> While not routinely necessary, such phone calls can be helpful for reinforcing particularly important information. When making this call, try to avoid making it seem that you are calling only to repeat the instructions or to check up on the patient. Rather, make it clear that you want to help by stating, "I just wanted to be sure that everything I told you was clear," and "to find out how are you doing with the treatments I recommended...."

### Use the "teach-back" technique

The "teach-back" technique is an effective method for ensuring that patients understand what you have told them (Table 15). It involves asking patients to explain or demonstrate what they have been told. For example, you can say, "I want you to explain to me how you will take your medication, so I can be sure I have explained everything correctly," or "Please show me how you will use the asthma inhaler, so I can be sure I have given you clear instructions," or "When you get home your spouse will ask you what the doctor said—what will you tell your spouse?"

### Table 15. The teach-back technique

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- Do not ask a patient, "Do you understand?"
  - Instead, ask patients to explain or demonstrate how they will undertake a recommended treatment or intervention.
  - If the patient does not explain correctly, assume that *you* have not provided adequate teaching. Re-teach the information using alternate approaches.
- 

In using the teach-back technique, clinicians take responsibility for adequate teaching. If patients cannot explain or demonstrate what they should do, clinicians must assume that they did not provide patients with an adequate explanation or understandable instructions. The result should be new efforts to ensure that patients learn what they need to know. And, of course, it is important not to appear rushed, annoyed, or bored during these efforts—your affect must agree with your words.

Research indicates that the teach-back technique is effective, not just for improving patients' understanding, but also for improving outcomes. For example, patients with diabetes whose physicians assess patient's comprehension and recall with the teach-back technique have significantly better diabetes control than patients whose physicians do not use the technique.<sup>61</sup>

The teach-back technique should replace the more common practice of simply asking a patient, "Do you understand what I have told you?" Experience shows that patients often answer "yes" to such questions, even when they understand nothing.

### **Create a shame-free environment:**

#### **Encourage questions**

To foster effective communication with patients, it is essential to create a shame-free environment in which patients feel comfortable asking questions about what they do not understand. Without such an environment, many patients, even those with well-developed literacy skills, may feign understanding material to avoid seeming “stupid” or annoying to the clinician.

One simple strategy to encourage questions is to let patients know that “many people have difficulty reading and understanding the medical information I give them, so please feel comfortable asking questions if there’s something you don’t understand.” Make certain to follow up on this by answering any questions your patient may have.

Another strategy is to ask patients during the visit if they would like a family member or friend to be with them during discussions about diagnoses and options for treatment. Research shows that patients with limited health literacy often seek the assistance of family or friends after visits with clinicians in interpreting what their clinicians told them.<sup>62</sup> By offering this opportunity in a routine, nonjudgmental way, patients will feel comfortable bringing others into the examination room.

### **Ask-Me-3**

The Ask-Me-3 program is a more formal, but potentially effective approach to encouraging questions.<sup>63</sup> Sponsored by the Partnership for Clear Health Communication, a large consortium of professional organizations that includes the AMA Foundation, Ask-Me-3 encourages patients to ask, and physicians to answer, three basic questions during every medical encounter. The questions are shown in Table 16.

The Ask-Me-3 questions serve as an activation tool that encourages patients to ask questions. Patients are made aware of the program through posters and brochures displayed in the office. Evidence shows that even long after Ask-Me-3 is implemented in a practice, many patients continue to ask the questions and find them a useful framework for engaging in conversation with their clinician.<sup>64</sup>

**Table 16. The Ask-Me-3 questions**

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- What is my main problem?
  - What do I need to do (about the problem)?
  - Why is it important for me to do this?
-

# Creating and using patient-friendly written materials

## Written consent forms and patient education handouts

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The readability of consent forms and patient education handouts has received more attention than perhaps any other health literacy issue. Countless studies in a variety of health care settings have shown that there is a mismatch between patients' reading skills and the reading skills needed to comprehend the consent forms and handouts they are given.<sup>65,66,67,68,69,70</sup> More recent studies reveal that patient education materials on the Internet are also too difficult for the average reader.<sup>71,72,73</sup> Indeed, most written materials intended for patients are written at a difficulty level that exceeds the reading skills of average Americans.

Medical practices should ensure that the reading difficulty level of their patient materials matches the reading skills of the patients. Clinicians can use a variety of approaches to reach this goal. One approach is to develop practice-specific written materials; the principles for doing this are discussed below and shown in Table 17. Alternatively, clinicians can purchase materials that have already been developed on the basis of these principles; such reader-friendly written materials may be found through the list of useful resources at the end of this manual.

Whatever written materials are used, their effectiveness may be increased if the clinician or staff reads them aloud and highlights, underlines, circles, or numbers key points for the patient to remember. Drawing supplemental pictures and writing out steps and directions for individual patients can also be helpful.

## Principles for creating patient-friendly written materials

Written materials that are easy for patients to read and understand are beneficial to all patients. Indeed, evidence indicates that *all patients*—not just those with limited literacy skills—prefer easy-to-read materials to more complex or comprehensive materials.

The basic principles (Table 17) for creating patient-friendly written materials involve attention to (a) the depth and detail of the content, (b) the complexity of the text itself, (c) the format in which the material is prepared, and (d) user testing. The practical application of these principles is reviewed in the following paragraphs. Readers who desire more detailed information on creating easy-to-read written materials for patients can consult standard textbooks<sup>74,75,76</sup> on creating effective patient education information, or attend seminars or workshops offered by experts in the field (see “Useful resources” at the end of this manual).

**Table 17. Formatting checklist for easy-to-read written materials**

---

### General content

- Limit content to one or two key objectives. Don't provide too much information or try to cover everything at once.
- Limit content to what patients really need to know. Avoid information overload.
- Use only words that are well known to individuals without medical training.
- Make certain content is appropriate for age and culture of the target audience.

### Text construction

- Write at or below the 6th-grade level.
- Use one- or two-syllable words.
- Use short paragraphs.
- Use active voice.
- Avoid all but the most simple tables and graphs. Clear explanations (legends) should be placed adjacent to the table or graph, and also in the text.

### Fonts and typestyle

- Use large font (minimum 12 point) with serifs. (Serif text has the little horizontal lines that you see in this text at the bottoms of letters like f, x, n, and others. This text, on the other hand, is non-serif.)
- Don't use more than two or three font styles on a page. Consistency in appearance is important.
- Use upper- and lower-case text. ALL UPPER-CASE TEXT IS HARD TO READ.

### Layout

- Ensure a good amount of empty space on the page. Don't clutter the page with text or pictures.
  - Use headings and subheadings to separate blocks of text.
  - Bulleted lists are preferable to blocks of text in paragraphs.
  - Illustrations are useful if they depict common, easy-to-recognize objects. Images of people, places, and things should be age appropriate and culturally appropriate to the target audience. Avoid complex anatomical diagrams.
-

### Depth and detail of the message

Effective patient education materials focus on instructions for key behaviors that the patient must put into action—not lengthy and unnecessary background information about physiology and pathology. Many patient education brochures are ineffective because they begin with a review of anatomy and physiology or discuss the cause of a disease, rather than beginning with clear statements about what a patient needs to do. Examples of appropriate and inappropriate detail for patient education handouts are shown in Figures 8A and 8B.

Note that the more reader-friendly text in Figure 8B is not an example of “dumbing down” the information. Rather, it is an example of effective application of the principles for creating written patient education materials in a form that *all* patients prefer; i.e., a focus on what the patient needs to know and put into action, while avoiding medical terminology and unnecessary background information.

## Figure 8A. Inappropriate detail and prioritization of information in a patient education handout

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### Streptococcal pharyngitis (strep throat)

Your doctor has diagnosed you as having streptococcal pharyngitis, or “strep throat.” Strep throat is caused by Group A beta hemolytic streptococcus, a common bacteria in the nose and throat that can cause sore throats (pharyngitis) and skin infections. Symptoms of strep throat include pain and redness in the throat, difficulty swallowing, fever, and swollen glands in the neck. Sometimes there is a rash going along with the sore throat, in which case patients are said to have “scarlet fever.” Strep throat occurs most commonly in children.

The symptoms of strep throat go away by themselves, even without treatment. Without treatment, however, a small percentage of patients with strep throat will develop rheumatic fever, a serious disease of the heart and heart valves. When patients get rheumatic fever, heart valves may be damaged, and in the future, the patient may need open heart surgery to replace a heart valve. Although rheumatic fever is uncommon, in recent years there have been more cases reported.

The treatment for strep throat involves taking penicillin, an antibiotic that kills the streptococcus bacteria. The reason for treating strep throat is not to make the sore throat get better quicker. Rather, the reason for treating the strep throat is to prevent the development of rheumatic fever. Treatment with penicillin for 10 days almost always prevents rheumatic fever. It is important that you take the penicillin for the full 10 days, even if you are feeling better before the medicine is used up. That’s because taking the penicillin for less than 10 days may not protect you against rheumatic fever. Patients allergic to penicillin can take one of several other medications.

(274 words; 10th-grade reading level)

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## Figure 8B. More appropriate detail and prioritization of information in a patient education handout

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### Treating strep throat

- Take your pills 2 times each day (once in the morning and once in the evening).
- Take the medicine every day for 10 days—even if you feel better before then.
- Stopping the pills before 10 days can result in serious heart problems.

(43 words; 6th-grade reading level)

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### Complexity of text

Written materials should ideally be created for readability at the 5th- or 6th-grade level, thus ensuring readability by the majority of adults. The reading level should be even lower—ideally at the 3rd- to 5th-grade levels—for practices with a high percentage of patients at risk for limited literacy. The average reading skill of American adults is about the 8th-grade level, while the average reading skill of Medicaid enrollees is at the 5th-grade level.

Text written at the 5th- or 6th-grade level typically is constructed of short words, all or most of which are one or two syllables long. Sentences should be as short as possible, and complex or multi-part sentences should be avoided. Paragraphs should contain no more than two or three sentences. Many health care professionals find it difficult to construct text at such a basic level, but as shown in the example in Figure 8B, it is possible to do so.

Most word processing programs on personal computers contain grammar-checking programs that include a tool for measuring readability. A widely used tool is the Flesch-Kincaid readability score, which is integrated into the grammar checker of Microsoft Word. The Flesch-Kincaid tool measures readability as a grade-equivalent reading level and is a useful guide for measuring complexity of text. However, two caveats must be considered:

First, the Flesch-Kincaid score is based on physical characteristics of the text. Specifically, the score is primarily based on word length (i.e., the number of characters between spaces) and sentence length (i.e., the number of words between periods). Thus, the Flesch-Kincaid tool will compute a reading level even for nonsensical text such as “Xxx xxxxx x xxxxx. Xxx xxxx xxxx xxxxxxxx xxx xxxxxx.” Furthermore, the program counts *anything* before a period as a sentence, thus skewing results if one is not careful. “Dr.” is counted as one short sentence and “i.e.” as two.

Second, the readability score does not consider content or vocabulary. An individual with medical training may easily understand medical text written at a certain grade level, but that same text may be incomprehensible to someone with similar reading skills but no medical training.

To ensure that the content of written materials is understandable, the text must use words that are well known to readers. Authors should avoid technical words or jargon, and define medical words when they are essential. Table 14, which was discussed earlier, presents some common medical terms and jargon, along with suggestions for “plain language” alternatives. Additional examples are shown in Table 18. While most of the suggested alternate wording seems obvious, clinicians regularly use medical terms in conversations with patients.

**Table 18. More examples of common medical terms and jargon and suggestions for alternate wording**

<b>Medical terms or jargon</b>	<b>Alternate wording</b>
Cardiologist	Heart doctor
Catheterize bladder	Put in a tube where your urine comes out
Chemotherapy	Drugs to treat cancer
Echocardiogram	Pictures of your heart
Fractured femur	Broken hip/leg
GI specialist	Stomach doctor
Malignancy	Cancer
Metastatic	Cancer has spread
Noninvasive	Without surgery or needles or cutting skin
Pulmonary embolism	Blood clot in your lung
Radiology department	X-ray department
Tap your knee	Put a needle in your knee and remove fluid

### Format

Format is one of the most critical characteristics of reader-friendly patient education materials. Written material is difficult to read when it contains text that is dense, written in a small print, or presented in long uninterrupted paragraphs. Material is easier to read when text is in larger print and interspersed with blank space. Readability is further enhanced when information is presented or supplemented with bulleted lists and clear illustrations. Table 17 presents a checklist of important formatting options that should be considered when creating written information for patients. The examples in Figures 8A and 8B also give a sense of what constitutes good and bad formatting.

### User testing

After creating written material for patients according to the guidelines in Table 17, it is useful to have the materials reviewed by patients—ideally patients with limited literacy skills—to ensure that what you have prepared can be understood.

The user testing process is more than simply asking patients “Do you like it?” or “Does it make sense?” Rather, it involves asking patients, “From this, can you tell me what you are supposed to do?” and “What does this word/phrase mean to you?” and then revising the text, as needed, to adopt the patient’s language. Modifications should be made in response to reviewer feedback before the written material is put to use.



## Nonwritten patient education materials

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While a great deal of attention focuses on written materials suitable for low literacy audiences, *nonwritten* materials can also be effective patient education tools. These nonwritten materials include graphic illustrations, such as pictures, pictographs, and models, along with audiotapes, videotapes, and various forms of computer-assisted learning applications (Table 19). Increasing research exists to support the effectiveness of these nonwritten modalities, and in many cases they are superior to written materials for patients with limited literacy.

### Graphic illustrations (pictures, pictographs, models)

Research has shown that using pictures, including cartoons or pictographs with verbal explanations and use of models, can greatly increase patient understanding and retention of information.<sup>58</sup> In one study, mean correct recall of information was 85% with pictographs and 14% without.<sup>77</sup> Another study found that patients receiving wound care instructions with cartoons were able to answer questions correctly 46% of the time three days later, compared to only 6% of patients who received only written instructions.<sup>78</sup>

## Table 19. Alternatives to written handouts for patient education handouts

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- Graphic illustrations
    - Pictures
    - Pictographs
    - Models
  - Audiotapes and compact discs
  - Videotapes
  - Information-only computer modalities
    - CD-ROM
    - Downloadable Internet sites
  - Interactive computer modalities
    - Interactive CD-ROM
    - Interactive Internet sites
- 

### Audiotapes and compact discs

Most patients own an audiocassette or a compact disc (CD) player. Providing patients with audiocassettes or CDs is often an easy way to repeat and reinforce health care messages given during office visits. For example, patients who have just been diagnosed with a disease or who are embarking on a new treatment can be given an audiotape/CD that provides a brief summary of their disease or treatment.

When working with any patient, the role of communication is to ensure that the patient provides you with the information you need to formulate a treatment plan, and that the patient has all the information needed to execute this treatment plan. The latter information falls into five main categories, each of which is listed in Table 20. If your patients can answer all these questions when they leave your office, you have done a good job.

As we have discussed in this manual, the patient's limited literacy and the clinician's communication skills are both important factors in health literacy. By being aware of this and applying principles of good communication, clinicians can be a "good doctor" to all their patients. After all, as stated by an adult with limited literacy skills:

*A good doctor is not too busy to help, doesn't use big words, sits down and listens, asks how you are doing today and what your problem is. The doctor asks how you want to be addressed, and doesn't read the chart in front of you (if he does, it shows he hasn't prepared for your visit, which is rude and demeaning). Good doctors tell you things in plain English and break them down into what's really important. If you don't understand what the doctor says, you are comfortable asking him to repeat the explanation. When the doctor repeats and you still don't understand, the doctor goes out of his way to make sure you do.*

**Table 20. Checklist for patient understanding**

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At the end of each office visit, a patient should be able to answer the following questions.

- What is my main problem?
  - What do I need to do (about the problem)?
  - Why is it important for me to do this?
  - Where do I go for tests, medicine, and appointments?
  - How should I take my medicine?
    - When do I take it?
    - What will it do?
    - How do I know if it is working?
    - Whom and when do I call if I have questions?
  - Other instructions
    - What to do?
    - How to do it?
    - When to do it?
  - Next steps
    - When do I need to be seen again?
    - Do I have another appointment? If so, what is the date and time of the appointment?
    - Are there phone numbers to call?
- } The Ask-Me-3 questions
-

# Useful resources

## General reviews about health literacy

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- Committee on Health Literacy, Institute of Medicine, Nielsen-Bohlman LN, Panzer AM, Kindig DA, Eds. *Health Literacy: A Prescription to End Confusion*. Washington, DC: The National Academies Press; 2004.
- Schwartzberg JG, VanGeest, JB, Wang CC, eds. *Understanding Health Literacy: Implications for Medicine and Public Health*. Chicago, IL: American Medical Association Press; 2005.

## Guides to teaching and writing for patients who have limited literacy skills

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- Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*. 2nd ed. Philadelphia: JB Lippincott Company; 1996.
- McGee J. *Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies*. Centers for Medicare & Medicaid Services; 1999. Order from: [www.talkingquality.gov/docs/section3/3\\_5order.htm](http://www.talkingquality.gov/docs/section3/3_5order.htm).
- National Cancer Institute. *Clear and Simple: Developing Effective Print Materials for Low-Literacy Readers*; 2003. [www.cancer.gov/cancerinformation/clearandsimple](http://www.cancer.gov/cancerinformation/clearandsimple).
- National Literacy and Health Program. *Easy Does It. Plain Language and Clear Verbal Communication*. Ottawa: Canadian Public Health Association; 1998.
- Osborne H. *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message*. Sudbury, MA: Jones & Bartlett; 2005.

## Sources for easy-to-read patient education materials

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- LINCS Health & Literacy Special Collection. Boston: World Literacy; 2006. <http://healthliteracy.worlded.org/index.htm>

## Educational programs, workshops, and institutes

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- Cancer, Culture, and Literacy Institute  
H Lee Moffitt Cancer Center, Tampa, Florida  
[www.moffitt.usf.edu/promotions/cclinstitute/index.htm](http://www.moffitt.usf.edu/promotions/cclinstitute/index.htm)
- Health Literacy Institute  
University of New England, Biddeford, Maine  
[www.HealthLiteracyInstitute.net](http://www.HealthLiteracyInstitute.net)
- Clear Language Group  
[www.clearlanguagegroup.com](http://www.clearlanguagegroup.com)

## Organization Web sites

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- AMA Foundation Health Literacy  
[www.amafoundation.org/go/healthliteracy](http://www.amafoundation.org/go/healthliteracy)
- National Institute for Literacy  
[www.nifl.gov](http://www.nifl.gov)
- Partnership for Clear Health Communication: Ask-Me-3  
[www.askme3.org](http://www.askme3.org)
- Pfizer Health Literacy Initiative  
[www.pfizerhealthliteracy.com](http://www.pfizerhealthliteracy.com)
- Reach Out and Read  
[www.reachoutandread.org](http://www.reachoutandread.org)

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The enclosed materials will enable physicians to:

- Define the scope of the health literacy problem.
- Recognize health system barriers faced by patients with low literacy.
- Implement improved methods of verbal and written communication.
- Incorporate practical strategies to create a shame-free environment.

*Sponsored in part by AstraZeneca*

