

# How informed are your patients?

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# LEARNING OBJECTIVES

- Upon completion of this course, you will be able to:
  - Recall techniques toward improving health literacy through communication, navigation, knowledge-building, and advocacy.
  - Recall factors that affect Health Literacy
  - Recall examples of health literacy best practices.
  - Identify the domains of Health Literacy
  - Create suggestions for addressing health literacy in your organization.

2 CEUs

# Terms to consider

- Literacy may be defined as an individual's ability to read, write, speak, and compute and solve problems at levels necessary to function on the job and in society, achieve one's goals, and develop one's knowledge and potential.
- **Illiteracy** means being unable to read or write; a person who has limited or low literacy is not illiterate .

# What is health literacy?

- **Health literacy.** *Healthy People 2010* (HHS, 2000) cites and applies the following definition of health literacy:
  - The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

# Why is health literacy important?

- Only 12 percent of adults have Proficient health literacy, according to the National Assessment of Adult Literacy. In other words, nearly nine out of ten adults may lack the skills needed to manage their health and prevent disease. Fourteen percent of adults (30 million people) have Below Basic health literacy. These adults were more likely to report their health as poor (42 percent) and are more likely to lack health insurance (28 percent) than adults with Proficient health literacy.
- Low literacy has been linked to poor health outcomes such as higher rates of hospitalization and less frequent use of preventive services. Both of these outcomes are associated with higher healthcare costs.

# Who is at risk?

- Populations most likely to experience low health literacy are older adults, racial and ethnic minorities, people with less than a high school degree or GED certificate, people with low income levels, non-native speakers of English, and people with compromised health status.
- Education, language, culture, access to resources, and age are all factors that affect a person's health literacy skills.

# Factors that affect Health Literacy

- Individual Factors
  - Communication skills of lay persons and professionals
  - Lay and professional knowledge of health topics
- Systemic Factors
  - Culture
  - Demands of the healthcare and public health systems
  - Demands of the situation/context

# Lets talk Statistics

- Only 12% of adults score "proficient" on health literacy, according to the National Assessment of Adult Literacy.
  - In other words, nearly 9 out of 10 adults may lack the skills needed to manage their health and prevent disease.
  - Fourteen percent of adults (30 million people) have "below basic" health literacy.
    - These adults were more likely to report their health as poor (42%) and are more likely to lack health insurance (28%) than adults with proficient health literacy.
  - Low literacy has been linked to poor health outcomes, such as higher rates of hospitalization and less frequent use of preventive services. Both of these outcomes are also associated with higher healthcare costs

# Assessing Health Literacy

3 Domains of health and healthcare information and services were organized to assess health literacy:

1. **Clinical**- encompasses activities associated with the healthcare provider-patient interaction, clinical encounters, diagnosis and treatment of illness, and medication. Tasks from the clinical domain include filling out a patient information form for an office visit, understanding dosing instructions for medication, and following a healthcare provider's recommendation for a diagnostic test
2. **Prevention**- those activities associated with maintaining and improving health, preventing disease, intervening early in emerging health problems, and engaging in self-care and self-management of illness. Examples are: following guidelines for age-appropriate preventive health services, identifying signs and symptoms of health problems that should be addressed with a health professional, and understanding how eating and exercise habits decrease risks for developing serious illness
3. **Navigation**- involves those activities related to understanding how the healthcare system works and individual rights and responsibilities. Examples include understanding what a health insurance plan will and will not pay for, determining eligibility for public insurance or assistance programs, and being able to give informed consent for a healthcare service

## Health Literacy affects an Individual's ability to:

- Navigate the healthcare system, including filling out complex forms and locating providers and services
- Share personal information, such as health history, with providers
- Engage in self-care and chronic-disease management
- Understand mathematical concepts such as probability and risk

# What skills are components of Health Literacy?

- Basic Math skills:
  - calculate cholesterol and blood sugar levels
  - measuring medications
  - understanding nutrition labels all require math skills.
  - Choosing between health plans or comparing prescription drug coverage requires calculating premiums, copays, and deductibles.

# Additional components of Health Literacy

- In addition to basic literacy skills, health literacy requires knowledge of health topics. People with limited health literacy often lack knowledge or have misinformation about the body as well as the nature and causes of disease. Without this knowledge, they may not understand the relationships between lifestyle factors such as diet and exercise and various health outcomes .
- Medical science progresses rapidly and health information can overwhelm even those who have advanced literacy skills and, sometimes, even those with medical training. What people may have learned about health or biology during their school years often becomes outdated or forgotten, or it is incomplete. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained.

# LITERACY AND HEALTH OUTCOMES

- Choosing a healthy lifestyle, knowing how to seek medical care, and taking advantage of preventive measures require that people understand and use health information.
- Given the complexity of the healthcare system, it is not surprising that limited health literacy is associated with poor health.

# Research findings that associate Health Literacy with outcomes

- According to research studies, persons with limited health literacy skills are more likely to skip important preventive measures such as mammograms, Pap smears, and flu shots. When compared to those with adequate health literacy skills, studies have shown that patients with limited health literacy skills enter the healthcare system when they are sicker, are more likely to have chronic conditions, and are less able to manage them effectively. Studies have found that patients with high blood pressure, diabetes, asthma, or HIV/AIDS who have limited health literacy skills have less knowledge of their illness and its management

# Research findings that associate Health Literacy with outcomes

- Those with limited literacy skills have higher rates of hospitalization and use of emergency services and an increase in preventable hospital visits and admissions. They make greater use of services designed to treat complications of disease and less use of services designed to prevent complications. This higher use is associated with higher healthcare costs. Studies demonstrate that persons with limited health literacy skills are significantly more likely than persons with adequate health literacy skills to report their health as poor

# Research findings that associate Health Literacy with outcomes

- Low health literacy may also have negative psychological effects. One study found that those with limited health literacy skills reported a sense of shame about their skill level and may hide reading or vocabulary difficulties to maintain their dignity.
- In one study, 60 patients with low health literacy were interviewed about their experiences in the healthcare environment. Here are some of their responses:
  - I had some papers, but I didn't know they were prescriptions, and I walked around for a week without my medication. I was ashamed to go back to the doctor, but a woman saw the papers I had and told me they were prescriptions. It's bad to not know how to read.
  - All these problems, not knowing how to read, it feels like being blind, ignorant, not able to understand, to explain or ask people. If there are many people around, I feel embarrassed to tell the doctor I cannot understand. I feel really bad, that I am not worth anything, that there is no reason for me to be in this world, that I came into this world only to suffer.
  - What I feel, in my case, if there could be a person that could talk like us, and be kinder, and to ask us if we can read, or offer to fill it out, and with a smile, so we feel the person supports us. But if we see their hard faces, how could we ask for help to fill out the form?

# So, How can we improve our practice?

- As you develop and deliver health information consider the following questions:
  - Is the information easy to use?
  - Are you speaking clearly and listening carefully?
  - Is the information appropriate for the users?
  - The information below is a summary of best practices in health communication that can aid in improving health literacy. Many of these concepts are discussed in depth in the National Cancer Institute's (NCI's) *Making Health Communication Programs Work* and in the Centers for Disease Control and Prevention's tool *CDCynergy*

*Making Health Communication Work* describes the stages of the health communication process. For a communication program to be successful, it must be based on an understanding of the needs and perceptions of the intended audience. The process is divided into four stages:

- Planning and strategy development
- Developing and pretesting concepts, messages, and materials
- Implementing the program
- Assessing effectiveness and making refinements
- The stages constitute a circular process in which the last stage feeds back into the first as you work through a continuous loop of planning, implementation, and improvement (NCI, 2008).
- CDCynergy is an innovative and interactive CD-ROM-based tool that provides practical, step-by-step assistance to public health professionals in designing health communication plans and in developing sound interventions. It allows users to assemble the pieces of a health communication plan systematically by answering questions offered in a specific sequence. The STD Prevention Edition applies the CDCynergy model to STD-specific health problems

# Identify Intended Users

- **Be sure to select materials that are accurate and appropriate for the intended users.**
  - Identify the intended users based on epidemiology, demographics, behavior, culture, and attitude—a process known as **segmentation**. Be sure the materials and messages reflect the age, social and cultural diversity, language, and literacy skills of the intended users. Consider economic contexts, access to services, and life experiences. Beyond demographics, culture, and language, consider the communication capacities of the intended users. Approximately 1 in 6 Americans has a communication disorder or difference resulting in unique challenges; these individuals require communication strategies that are tailored to their needs and abilities

# Evaluate User's Understanding

- Evaluate users' understanding before, during, and after the introduction of information and services. Talk to members of the intended user group before you design your communication to determine what information they need to know and how they will use it. Then, pretest messages and services to get feedback. Test your messages again after they have been introduced to assess effectiveness and refine content when necessary. Use a post-test to evaluate the effectiveness of the information

# Practice Respect

- Ensure that health information is relevant to the intended users' social and cultural contexts. Cultural factors include race, ethnicity, language, nationality, religion, age, gender, sexual orientation, income level, and occupation. Some examples of attitudes and values that are interrelated with culture include:
  - Accepted roles of men and women
  - Value of traditional medicine versus Western medicine
  - Favorite and forbidden foods
  - Manner of dress
  - Body language, particularly whether touching or proximity is permitted in specific situations

# Factors That Can Influence Change

- Some of the multiple barriers to change are noted below:
  - Poverty as well as minority and immigrant status are associated with limited literacy skills. The effects of literacy, income, poverty, and health are related and interdependent.
  - As noted in the section on issues related to measurement, limited proficiency in English and cultural and linguistic differences present important challenges and likely barriers for individuals and populations to receive appropriate health information and services.
  - Practitioners, researchers, or funding agencies in the public health and healthcare fields may be unaware of findings of functional literacy assessments of adults.
  - Reading, writing, and presentation skills are finely tuned in institutions of higher learning but are geared for dialog and discussion among members of highly educated and often specialized audiences. Plain language communication may be considered a new skill.
  - Although public health and medical practitioners work to increase awareness and provide information, neither field has assumed the task of fully educating the public about how the body functions, health research findings, health information, and the environment.
  - Many interventions aimed at low-literacy populations have been developed and implemented; however, little has been done to evaluate the effectiveness of these interventions in terms of meaningful long-term health outcomes.
  - The process of delivering healthcare information, whether oral or written, does not typically include a method to determine whether the information is understood by the recipient.

# Simplify Messages

- Is the information simple and easy to use? As a general guideline, use no more than four main messages. The number of messages will depend on the information needs of the intended users. Give the user specific actions and recommendations, clearly state the actions you want the person to take, and focus on behavior rather than the underlying medical principles
- Use familiar language and an active voice. Choose brief phrases rather than long sentences and group similar information. Many of the same plain-language techniques that make the written word understandable also work with verbal messages; avoid jargon and using everyday examples to explain technical or medical terms the first time they are used

# Spoken Messages

- **SPEAK CLEARLY, LISTEN CAREFULLY**
- To improve communication between healthcare providers and patients, ask open-ended questions using the words "what" or "how" instead of those that can be answered with "yes" or "no." For example, "Tell me about your problem. What may have caused it?" Try asking "What questions do you have?" instead of "Do you have any questions?" (USDHHS, 2008d).
- **USE MEDICALLY TRAINED INTERPRETERS**
- Plain English will not necessarily help individuals who do not speak English as their primary language and who have limited ability to speak or understand English. To better ensure understanding, health information for people with limited English proficiency needs to be communicated plainly in their primary language, using words and examples that make the information relevant to their potentially different cultural norms and values

# Printed Messages

- **ILLUSTRATED**

- Individual learning styles differ and, for many people, visuals are a preferred style—especially for technical information. With printed materials, simple line drawings can help users understand complicated or abstract medical concepts. Make sure to place images in context. For example, when illustrating internal body parts include the outline of the body. Use visuals that educate and help convey your message—don't just "decorate" your document, as this will distract users. Make visuals culturally relevant and use images that are familiar to your audience (USDHHS, 2008d).

- **EASY TO READ**

- When preparing materials for patient use, choose at least a 12-point font and avoid using italics, fancy script, or all capital letters (caps are much harder to read and they make everything look equally important). Keep line length between 40 and 50 characters and use headings and bullets to break up the text. Be sure to leave plenty of white space around the margins and between sections (USDHHS, 2008d).
- Use captions or cues to point out key information. Show the main message on the front of the materials. As an example, here is an easy-to-read flyer developed by the for Disease Control and Prevention (CDC). This flyer was developed in multiple languages

# Strategies for improving Health Literacy

- **Plain Language**

- Plain language is a strategy for making written and oral information easier to understand and is an important tool for improving health literacy.
  - **Plain language** is communication that users can understand the first time they read or hear it. With reasonable time and effort, a plain-language document is one in which people can find what they need, understand what they find, and act appropriately on that understanding.
- Key elements of plain language include:
  - Organizing information so that the most important points come first
  - Breaking complex information into understandable chunks
  - Using simple language and defining technical terms
  - Using the active voice
  - Language that is plain to one set of readers may not be plain to others, so it is critical to know your audience and have them test your materials before, during, and after they are developed. Speaking plainly is just as important as writing plainly. Many plain-language techniques apply to verbal messages, such as avoiding jargon and explaining technical or medical terms.

# Examples of Technical Terms in Plain English

**Do you find it hard to understand engineer jargon? Read these hysterical Technical Terms in plain English:**

1. A NUMBER OF DIFFERENT APPROACHES ARE BEING TRIED—

We are still clueless.

2. EXTENSIVE REPORT IS BEING PREPARED ON A FRESH APPROACH TO THE PROBLEM—

We just hired three kids fresh out of college.

3. CLOSE PROJECT COORDINATION—

We know who to blame.

4. MAJOR TECHNOLOGICAL BREAKTHROUGH—

It works only so so, but looks very hi-tech.

5. CUSTOMER SATISFACTION IS DELIVERED ASSURED—

We are so far behind schedule the customer is happy just to get it delivered.

6. PRELIMINARY OPERATIONAL TESTS WERE INCONCLUSIVE—

The darn thing blew up when we threw the switch.

7. TEST RESULTS WERE EXTREMELY GRATIFYING—

We are so surprised that the stupid thing works.

8. THE ENTIRE CONCEPT WILL HAVE TO BE ABANDONED—

The only person who understood the thing quit.

9. IT IS IN THE PROCESS—

It is so wrapped up in red tape that the situation is about hopeless.

10. WE WILL LOOK INTO IT—

Forget it! We have enough problems for now.

11. PLEASE NOTE AND INITIAL—

Let's spread the responsibility for the mistake.

12. GIVE US THE BENEFIT OF YOUR THINKING—

We'll listen to what you have to say as long as it doesn't interfere with what we've already done.

13. GIVE US YOUR INTERPRETATION—

I can't wait to hear this nonsense!

14. SEE ME OR LET'S DISCUSS—

Come into my office, I'm lonely.

15. ALL NEW—

Parts not interchangeable with the previous design.

16. RUGGED—

Too darn heavy to lift!

17. LIGHTWEIGHT—

Lighter than RUGGED.

18. YEARS OF DEVELOPMENT—

One finally worked.

19. ENERGY SAVING—

Achieved when the power switch is off.

20. LOW MAINTENANCE—

Impossible to fix if broken.

# Check for Understanding

- **Teach-back** is a technique that healthcare providers can use to ensure accurate communication with patients and others. The person receiving the health information is asked to restate it in their own words—not just repeat it—to ensure that the message is understood and remembered. When understanding is not accurate or complete, the sender repeats the process until the receiver is able to restate the information needed. Healthcare professionals can also ask the recipient to act out a medication regimen

# Get Training

- Participate in plain language and cultural competency training and encourage colleagues to do the same. Consider organizing a training session for health professionals and staff in your organization.

Here is a checklist for improving the usability of health information:

- Identify the intended users
- Use pre- and post-tests
- Limit the number of messages
- Use plain language
- Practice respect
- Focus on behavior
- Check for understanding
- Supplement with pictures
- Use a medically trained interpreter or translator

# Health Forms and Instructions

- Healthcare and public health systems rely heavily on printed materials, including:
  - Medical history forms
  - Insurance forms
  - Informed consent forms
  - Patients' rights and responsibilities
  - Test results
  - Directions to the lab or pharmacy
  - Hospital discharge and home care instructions
  - Clinical research protocols and announcements
- These documents, particularly forms that contain blank spaces to be filled in by the user, are often more difficult to understand than regular prose. Consent forms and other legal documents related to patients' rights often contain long sentences and difficult legal terms. It is critical that these forms be translated into plain language. Guidelines prepared by the National Quality Forum encourage healthcare providers to ask each patient to recount what he or she has been told during the informed consent process to check for understanding .
- Tips for improving the usability of health forms and instructions include:
  - Revise forms to ensure clarity and simplicity.
  - Test forms with intended users and revise as needed.
  - Provide plain language forms in multiple languages.
  - Provide clear information about eligibility for public assistance.
  - Train staff to give assistance with completing forms and scheduling follow-up care.
- When seeing voluntary participation in a study, informed consent could be obtained like this :
  - You don't have to be in this research study. You can agree to be in the study now and change your mind later. Your decision will not affect your regular care. Your doctor's attitude toward you will not change.
- When explaining the possibility of new information about risks, you could say:
  - We may learn about new things that may make you want to stop being in the study. If this happens, you will be informed. You can then decide if you want to continue to be in the study.

# Improve Access to Health Information

- Health education materials should be both scientifically accurate and culturally appropriate. Healthcare and public health professionals can develop plain-language health education materials that can be easily shared among practitioners. You can develop partnerships among and across regions, audiences, and fields of interest to increase dissemination of these materials. Health professionals and researchers may want to examine the impact of participatory action research strategies for effective diffusion of health information at the community level
- **Participatory action research** is a process of deeply and systematically analyzing your actions and the effects of your actions within your organization. Researchers examine their work and look for opportunities to improve. The goal of action research is to:
  - Improve practice through continual learning and progressive problem solving;
  - Develop a deep understanding of practice and the development of a well specified theory of action;
  - Create an improvement in the community in which your practice is embedded through participatory research (Center for Collaborative Action Research, 2007).

# PACKAGE INFORMATION WISELY

- Research suggests that providing more information does not necessarily improve decision making and may actually undermine it. People process and use a limited amount of information when making a decision. As the choice becomes more complex, people adopt simplifying strategies that allow them to consider only some of the information. As a result, they may ignore or limit their search for information
- We know that obtaining accurate, appropriate health information is only one element of healthy decision-making. Increased self-efficacy, that is, a person's belief in his or her ability to accomplish a desired task, is a key factor in decision-making. A high self-efficacy for a task may mean that a person is more likely to try it. The way we "package" health information and services can greatly increase self-efficacy
- What you can do:
- Use short documents that present "bottom-line" information, step-by-step instructions, and visual cues that highlight the most important information.
- Align health information and recommendations with access to services, resources, and support.

# PARTNER TO IMPROVE HEALTH EDUCATION

- Adult education includes the instruction of people 16 years of age and older who are not regularly enrolled full-time students. Instruction includes reading, writing, arithmetic, and other skills required to function in society. Health professionals can work with adult educators to identify the specific skills needed to support health literacy. Adult education theory maintains that people want information that is relevant to their lives. According to national surveys, health-related content is likely to engage adult learners.
- Health professionals can partner with adult educators to develop and deliver health lessons, which simultaneously build health knowledge and reaches adults who may not connect with traditional health outreach methods. Construct lessons in which students use health-related texts like prescription labels, consent forms, health history forms, and health content from the Internet
- The U.S. public educational system is a critical point of intervention to improve health literacy. Educators can take advantage of existing skill development and curricula to incorporate health-related tasks, materials, and examples into lesson plans for children and young adults. Many states already have standards for health education that can be enriched to incorporate health literacy skills. Health professionals can support educators by speaking to elementary and secondary students or helping to organize health-related field trips with local schools

# ADVOCATE IN YOUR ORGANIZATION

- As health professionals we must commit to advocating for improved health literacy in our own organizations. We must embed health literacy in our programs, policies, strategic plans, and research activities. To advocate for health literacy in your organization:
  - Make the case for health literacy
  - Incorporate health literacy into mission and planning
  - Establish accountability for health literacy activities
  - Include health literacy in staff training and orientation. Training staff will increase awareness of the need for addressing health literacy and improve their skills for communicating with the public. Make a presentation on health literacy at your next staff meeting. Circulate relevant research and reports on health literacy to colleagues. Post and share resources with others.
- **Identify special programs and projects** affected by health literacy. How can addressing health literacy improve the effectiveness of these programs? What existing or ongoing organizational activities contribute to the improvement of health literacy? How can these activities be recognized and supported?
- **Target key opinion leaders** with health literacy information. Explain how health literacy relates to the organization's mission, goals, and strategic plan and how it can be incorporated into existing programs. Be specific and brief senior staff and key decision-makers on the importance of health literacy
- Use the following **talking points** to make the case for health literacy improvement:
  - Only 12% of adults have proficient health literacy, according to the National Assessment of Adult Literacy. In other words, nearly 9 out of 10 adults may lack the skills needed to manage their health and prevent disease.
  - Fourteen percent of adults (30 million people) have below basic health literacy. These adults were more likely to report their health as poor (42%) and more likely to lack health insurance (28%) than adults with proficient health literacy.
  - There is a mismatch between the reading level of health information and the reading skills of the public.
  - There is a mismatch between the communication skills of lay people and health professionals.

# Improving your Organization

- Adults with limited literacy skills are less likely to manage their chronic diseases and more likely to be hospitalized than people with stronger literacy skills. This leads to poorer health outcomes and higher healthcare costs.
- People's ability to understand health information is related to the clarity of the communication. Health professionals' skills, the burden of medical jargon, and complicated healthcare delivery systems affect health literacy. The benefits of improvement in health literacy include:
  - Improved communication
  - Greater adherence to treatment
  - Greater ability to engage in self-care, improved health status
  - Greater efficiency and cost savings to the health system as a whole.
  - Enhancing health literacy does not always require additional resources. It is a method for improving the effectiveness of the work we are already doing
- **Incorporate health literacy into mission and planning.** Include specific goals and objectives related to improving health literacy in strategic plans, performance plans, programs, and educational initiatives. Goals and objectives may be population-based or specific to the mission of the organization. Convene a work group to develop a health literacy agenda for your organization. Seek input and collaboration from a broad cross-section of employees
- Include health literacy in grants, contracts, and memorandums of understanding. Recommend that all products, including educational materials, forms, and questionnaires, be written in plain language and tested with the intended users. Encourage contractors, grantees, and partners to indicate and evaluate how their activities contribute to improved health literacy
- Incorporate health literacy into Funding Opportunity Announcements (FOAs). These include requests for proposals (RFPs), applications (RFAs), corrections (RFCs), and program announcements (PAs). In addition, provide proposal reviewers with basic health literacy information and training when appropriate
- **Establish accountability** by including health literacy in program evaluation. Incorporate health literacy objectives into evaluation criteria for programs and projects. Include health literacy improvement in budget requests. Designating funding for health literacy activities will hold staff and management accountable and encourage evaluation
- **Implementing health literacy metrics** (measurable objectives) for your organization will help establish accountability for health literacy activities. Below are examples of health literacy metrics. The organization will:
  - Apply user-centered design principles to 75% of new web pages.
  - Ensure that all documents intended for the public are reviewed by a plain-language expert.
  - Provide all new employees with training in cultural competency and health literacy within 6 months of their date of hire.

# Who is responsible for improving health literacy?

- The primary responsibility for improving health literacy lies with public health professionals and the healthcare and public health systems. We must work together to ensure that health information and services can be understood and used by all Americans. We must engage in skill building with healthcare consumers and health professionals. Adult educators can be productive partners in reaching adults with limited literacy skills.

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