

HEALTH LITERACY AND SELF-ADVOCACY

October 24, 2023



LOS ANGELES COUNTY
COMMISSION ON HIV



LEARNING OBJECTIVES

- Define health literacy and the factors that influence health literacy
- Understand why health literacy is important
- Understand the impact of low health literacy
- Identify the difference between misinformation and disinformation
- Learn how to find reliable health information
- Identify keys to being a good self-advocate

WHAT IS HEALTH LITERACY?

Health literacy is the use of a wide range of skills that improve the ability of people to act on information to live healthier lives (e.g., reading, writing, listening, speaking, numeracy, and critical analysis.)

- **Personal health literacy:**

- How well a person can find and understand health info and services they need
- Use information and services to make good health decisions

- **Organizational health literacy**

- How well organizations help people find health info and services they need
- Help people use that information to make good health decisions.

FACTORS INFLUENCING HEALTH LITERACY

Health literacy is dependent on both individual and systemic factors:

- Communication skills
 - Lack of familiarity with strategies to communicate clearly and confirm comprehension
 - Limited English proficiency combined with lack of qualified interpreter services
- Knowledge of various health topics/issues
 - Limited or inaccurate knowledge about the human body and the causes of disease
 - Use of medical terminology
- Culture
 - Cultural misunderstandings or assumptions among both patients and healthcare providers

FACTORS INFLUENCING HEALTH LITERACY

- The demands of the healthcare and public health systems
 - Pressure on healthcare providers to see patients quickly
 - Complicated bureaucracies for accessing and paying for services
- Demands of the situation/context
 - Anxiety around medical visits and having to make decisions based on limited information
 - Physical or mental limitations
- Digital health literacy skills
 - Unrecognized low literacy among patients

DIGITAL HEALTH LITERACY

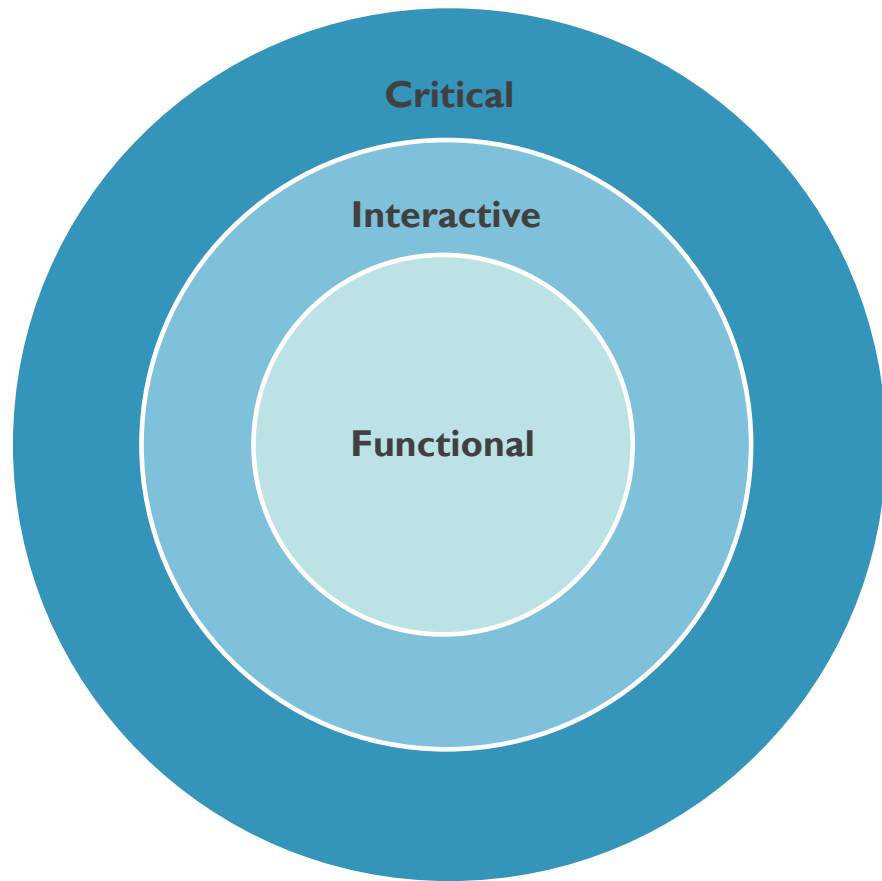
Digital health literacy is the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.

Examples include:

- Accessing your electronic health record
- Communicating electronically with your health care team
- Ability to discern reliable online health information
- Using health and wellness apps



LEVELS OF HEALTH LITERACY



- **Functional** – ability to apply basic literacy and numeracy skills to access and act upon health information
- **Interactive** – ability to obtain relevant information, derive meaning, and apply new information to changing circumstances
- **Critical** – ability to critically analyze information to respond, adapt, and control life events and situations

SCOPE OF THE PROBLEM

- 2003 National Assessment of Adult Literacy (NAAL)
 - 19,000 adults aged 16 and older
 - First nationwide assessment of health literacy
- Tasks used to measure health literacy were organized around three domains:
 - **Clinical** – filling out a patient form
 - **Prevention** – following guidelines for age-appropriate preventive health services
 - **Healthcare system navigation** – understanding what a health insurance plan will pay for

SCOPE OF THE PROBLEM

- **Only 12% of adults have proficient health literacy**
 - 9 out of 10 may lack the skills needed to manage their health and prevent disease
- **14% have below basic health literacy** (can perform no more than the most simple and concrete literacy activities)
 - More likely to report their health as poor
 - More likely to lack health insurance

Limited health literacy is greater among:

- Older adults
- Low socio-economic backgrounds
- People with limited education
- Racial and ethnic minorities
- Persons with limited English proficiency

WHAT CAN LOW HEALTH LITERACY LOOK LIKE?

Adults with low health literacy report feeling a sense of shame and may hide their struggles with reading or health vocabulary. Patients may:

- Frequently miss appointments
- Fail to complete registration forms
- Non-compliance with medication
- Be unable to name medications, explain their purpose or dosing
- Identify pills by looking at them, not reading label
- Be unable to give coherent, sequential medical history
- Ask fewer questions
- Show lack of follow-through on tests or referrals
- Repeatedly use statements such as "I forgot my reading glasses," "I'll read through this when I get home," or "I'm too tired to read," when asked to discuss written material

KEY RESEARCH FINDINGS

- Individuals should not be blamed for not understanding information that has not been made clear
- Everyone, no matter how educated, is at risk for misunderstanding health information if the topic is emotionally charged or complex
- In almost all cases, physicians/health professionals try and believe they are communicating accurate information
- In some cases, patients may believe they have understood directions but may be embarrassed to ask questions



KEY RESEARCH FINDINGS

- Health care organizations have a significant role in ensuring understanding in the health care setting, including systems and procedures
- Perceived “risk” can vary between provider and the patient
- There are challenges in understanding how to select insurance plans and benefits, especially for those who have not previously been insured
- It is increasingly difficult for people to separate evidence-based information from misleading ads and information, especially online



WHY IS HEALTH LITERACY IMPORTANT?

Health Literacy is important for everyone because we all need to be able to find, understand, and use health information and services at some point in our lives.

It can affect people's ability to:

- Navigate the healthcare system, including locating providers/services and filling out forms
- Share health info with providers
- Make good decisions about their health
- Take medicines correctly
- Manage a disease, especially a chronic disease
- Adopt health-promoting behaviors such as exercising
- Act on health-related news and announcements

These also impact:

- Health outcomes
- Healthcare costs
- Quality of care

MISINFORMATION & DISINFORMATION

The terms “misinformation” and “disinformation” are often time used interchangeably when they both hold different meanings and connotations.

Misinformation

- False or inaccurate information shared without the intent to deceive
- When one believes something is accurate, but it is not

VS

Disinformation

- False information deliberately shared with the intent to deceive
- When one knows something to be untrue and shares it anyway with a goal to cause harm

IMPACT OF MISINFORMATION AND DISINFORMATION ON HEALTH

False or misleading information is causing people to make decisions that could have dangerous consequences for their health. Misinformation about diseases, illnesses, potential treatments and cures, vaccines, diets, and cosmetic procedures is especially harmful.

“Health misinformation is a serious threat to public health. It can cause confusion, sow mistrust, harm people’s health, and undermine public health efforts.”

- Dr. Vivek H. Murthy
Surgeon General of the United States

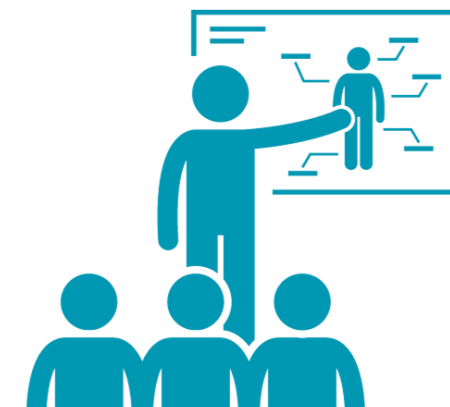
STRATEGIES FOR IMPROVING ORGANIZATIONAL HEALTH LITERACY

Use a Universal Precautions approach – assume everyone has low literacy. Key recommendations include :

- Improve the usability of health information
 - Using **culturally and linguistically appropriate plain** language
 - Using your **audience's preferred communication** channels/format
 - Acknowledge **cultural differences** and practice respect
 - Use a medically **trained interpreter** if needed
 - **Check for understanding** (teach-back method) and ask open-ended questions
 - Make online content **interactive and easy to navigate** and minimize scrolling

STRATEGIES FOR IMPROVING ORGANIZATIONAL HEALTH LITERACY

- Improve the usability of health services
 - Ensure health forms and instructions are **simple and clear**
 - Improve the **physical environment**
 - Use a **patient navigator** program to assist clients
- Build knowledge to improve decision making
 - **Improve access** to accurate and appropriate health information
 - Facilitate health decision making
 - Use formally **trained health educators** to improve health curricula



STRATEGIES FOR IMPROVING ORGANIZATIONAL HEALTH LITERACY

- Advocate for Health Literacy Improvement
 - **Make the case** for improving health literacy
 - Incorporate health literacy in mission and planning
 - **Establish accountability** for health literacy activities



STRATEGIES FOR IMPROVING PERSONAL HEALTH LITERACY

- **Ask your health care provider questions** if there is anything you don't understand or to learn more about your health condition(s).
- **Repeat what your health care provider tells you** in your own words to make sure you understand.
- **Ask for information in the language you understand best.** Health care providers are required to give health information in a language you can understand.
- **Ask for informational printouts or other materials** to help you learn more about your health conditions or treatment options.

STRATEGIES FOR IMPROVING PERSONAL HEALTH LITERACY

- **Bring a trusted friend or loved one to your appointment**, if possible. They can help take notes in case you miss anything, especially if you are sick or stressed.
- **Find reliable sources of health information.** Check your sources to make sure you are getting accurate information or ask your provider where you can find reliable resources.

HOW TO FIND RELIABLE HEALTH INFORMATION

Asking a few questions will help you decide if you can trust a website:

- **Is the source of the information respected and credible?**

- Trustworthy sites provide a way to contact the owners with questions or feedback
- Websites sponsored by government, educational institutions, or credible professional organizations
- Avoid personal websites
- Be cautious of information presented if there are ads on websites or if the site is run by a business
- A trustworthy website has one goal – to give accurate information



HOW TO FIND RELIABLE HEALTH INFORMATION

■ **Is the information up-to-date?**

- Look for the phrase 'last updated' on the webpages to see if the pages are current
- Look for other clues that the website is not up to date such as an outdated events page or outdated news under 'Latest news'
- Check for broken links. If they do not work the website may be outdated

■ **Is the information presented based on facts/evidence?**

- Good health information doesn't promote one treatment over another. It gives you balanced facts based on research.
- Look for links or references to the sources of the information
- Beware of dramatic writing, promises of cures, and claims that sound too good to be true
- Compare the info you find on one credible website with information on other websites to see if it is consistent

SELF ADVOCACY

Self-Advocacy is

- learning how to speak up for yourself
- making your own decisions about your own life (including your health)
- learning how to find information so that you can understand things that affect your health
- knowing your rights and responsibilities

**When you're talking to your provider,
it is important that you advocate for yourself.**

SELF ADVOCACY

Keys to being a good self-advocate:

- Find a doctor that you feel comfortable with and know when it's time to look for a new doctor
- Be prepared and organized
 - List out your questions ahead of time
 - Keep records– symptoms, family histories, discussions with doctor(s)
- Ask questions
 - Be specific and include details
- Work in partnership with your doctor(s). Be an active participant in your own health care.
 - Take responsibility for yourself

SELF ADVOCACY

Keys to being a good self-advocate:

- Learn – about your medical condition(s)
 - Know where to find reliable health information
- Recognize that you might disagree with your doctor
 - Be assertive, but respectful and polite
 - Be able to listen to the opinions of others, even when the opinions differ from yours
- Give feedback
 - Communicate clearly and with confidence
- Know your rights
 - Speak up for yourself and know where to get help

HEALTH LITERACY – ACTIVITY #1

Do you know where to go to seek care?

You fall down the stairs
and sprain your ankle
after dinner

You have a sore throat,
stuffy nose and a
cough

You have a fever over
103 degrees

You need a refill on
your medication

You woke up with
severe ear pain on
Saturday morning

You are having an
allergic reaction, and
your tongue is swelling

HEALTH LITERACY – ACTIVITY #1

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URGENT CARE

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PRIMARY CARE DOCTOR

You have a fever over 103 degrees

EMERGENCY ROOM

You are having an allergic reaction, and your tongue is swelling

EMERGENCY ROOM

You woke up with severe ear pain on Saturday morning

URGENT CARE

You need a refill on your medication

PRIMARY CARE DOCTOR

HEALTH LITERACY – ACTIVITY #2

Writing health information in plain language

Medical Term	Plain language substitute
Carcinogen	
Intravenous	
Pulmonary	
Arthritis	
Hypertension	
Monitor	

HEALTH LITERACY – ACTIVITY #2

Writing health information in plain language

Medical Term	Plain language substitute
Carcinogen	Cancer-causing
Intravenous	Into the vein
Pulmonary	Related to the lungs
Arthritis	Pain in joints
Hypertension	High blood pressure
Monitor	Watch

RESOURCES

- Ask Me 3: Good Questions for Good Health - <https://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>
- Understanding Medical Words Tutorial - <https://medlineplus.gov/medwords/medicalwords.html>
- Questions to Ask Your Doctor - <https://www.ahrq.gov/questions/index.html>
- Health Information in Multiple Languages - <https://medlineplus.gov/languages/languages.html>



We're  Listening
share your concerns with us.

**HIV + STD Services
Customer Support Line**

(800) 260-8787

Why should I call?

The Customer Support Line can assist you with accessing HIV or STD services and addressing concerns about the quality of services you have received.

Will I be denied services for reporting a problem?

No. You will not be denied services. Your name and personal information can be kept confidential.

Can I call anonymously?

Yes.

Can I contact you through other ways?

Yes.

By Email:
dhspsupport@ph.lacounty.gov

On the web:
<http://publichealth.lacounty.gov/dhsp/QuestionServices.htm>



"As a former nurse, trauma surgeon, and public health director [I realized] there was a wall between us and the people we were trying to serve.

Health care professionals do not recognize that patients do not understand the health information we are trying to communicate.

We must close the gap between what health care professionals know and what the rest of America understands."



Dr. Richard Carmona
Former U.S. Surgeon General



Questions?

