



In It Together: Improving Health Literacy for All

Goal of *In It Together*



Goal: Improve the capacity of health care organizations to deliver health literate HIV services.

Two curricula



In It Together

IMPROVING HEALTH LITERACY FOR ALL



In It Together

IMPROVING HEALTH LITERACY FOR BLACK MSM

In It Together model

Potential trainers are recruited from communities of focus



Potential trainers participate in a virtual, six-session training of trainers



Trainers provide the Health Literacy Community Training to health care organizations in their community

How *In It Together* benefits health care organizations

**Addressing health literacy
addresses health equity**

Builds the capacity of staff
around health literacy

Inspires use of health literate
practices

Increases patient activation
and engagement

Better health outcomes

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In It Together. Improving Health Literacy for All

Health Literacy Community Training

Training objectives

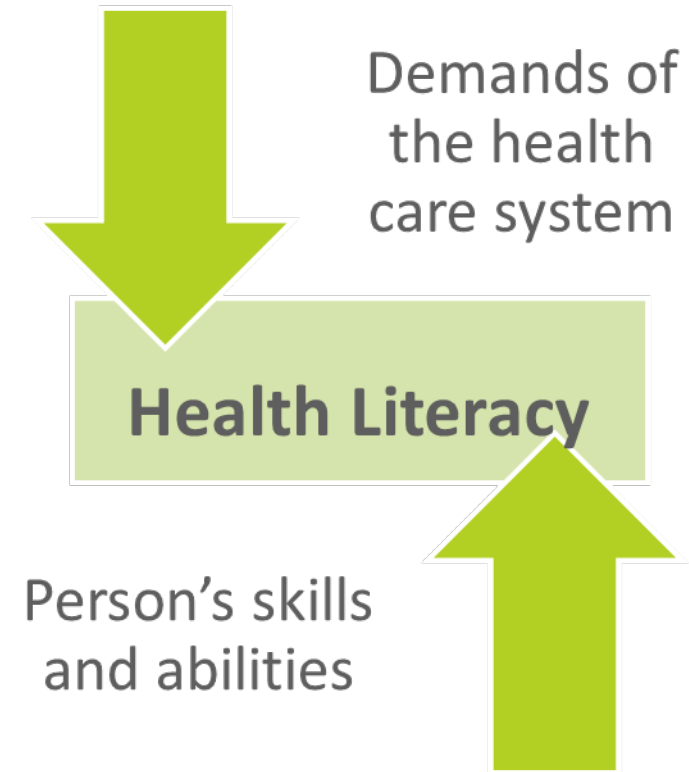
By the end of this training, you will be able to:

- Explain what health literacy means
- Recognize indications that your clients are experiencing limited health literacy
- Apply health literate approaches to improve communication with clients
- Explain the importance of organizational health literacy for your clients
- Identify 3 actions you and your organization can take to promote health literacy and deliver health literate HIV services



Definition of health literacy

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.



Citation: (1) U.S. Department of Health and Human Services. 2000. Healthy People 2010. (2) Committee on Health Literacy, Board of Neuroscience and Behavioral Health, Institute of Medicine. Health Literacy: A Prescription to End Confusion. (Nielsen-Bohlman L, Panzer A, Kindig D, eds.). Washington, D.C.: National Academies Press; 2004.

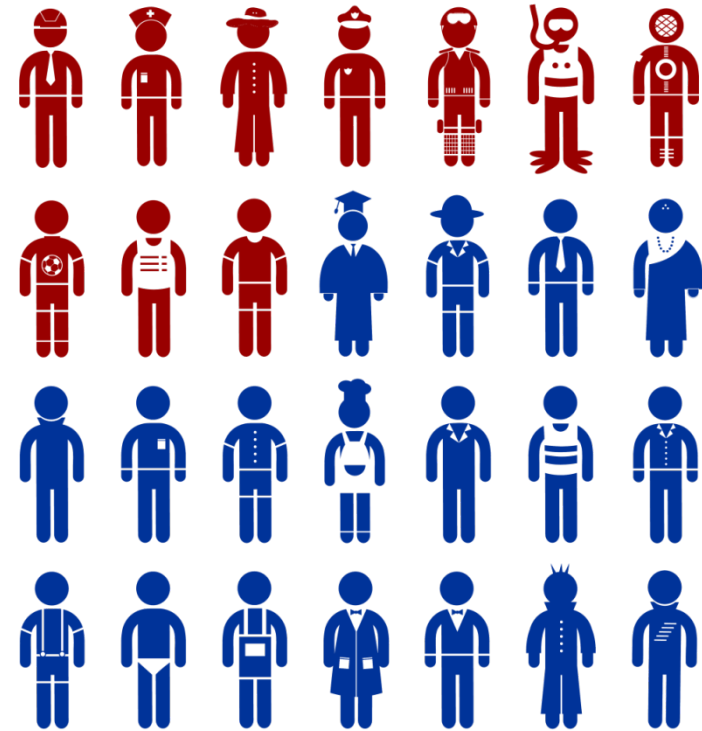
Andrulis and Brach, 2007; Sudore et al., 2009; ODPHP, 2008



Who is at risk?

- Everyone can be affected by limited health literacy
- People most affected by limited health literacy include:
 - Older adults
 - People of low socioeconomic status (SES)
 - People who did not finish high school
 - Communities of color
 - Recent immigrants or other people who speak a language other than English and who have limited English proficiency

89 million adults have limited health literacy.



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How does limited health literacy affect people?

- Limited knowledge of the body
- Limited knowledge of the nature and cause of a disease
- Less awareness of how to prevent illness and stay healthy
- Less knowledge of their own medical conditions and self-care instructions
- Difficulty understanding numeric medical information
- Difficulty understanding when or how to take medication
- Difficulty identifying risks and side effects printed on drug labels



How does limited health literacy affect health outcomes?

People with limited health literacy are:

- More likely to describe their health as “poor”
- Less likely to use preventive services
- Less knowledgeable about medical conditions and treatment
- More likely to use emergency services
- Often ashamed about their health literacy skill level





Indications that a client may have limited health literacy



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General indications

- Does not take medications correctly



General indications

- Does not take medications correctly
- Frequently misses appointments
- Fails to follow through on tests or referrals



General indications

- Does not take medications correctly
- Frequently misses appointments
- Fails to follow through on tests or referrals
- Does not complete intake forms
- Cannot provide a detailed history of their illness or treatments



General indications

- Does not take medications correctly
- Frequently misses appointments
- Fails to follow through on tests or referrals
- Does not complete intake forms
- Cannot provide a detailed history of their illness or treatments
- Asks few questions
- Avoids reading tasks using commonly accepted reasons
- Does not remember information read earlier



Indications among people living with HIV/AIDS

- May not be able to articulate the basics of HIV
- Has a consistently high or unchanged viral load
- Does not take antiretroviral therapies correctly
- Has frequent hospitalizations
- Falls out of care
- Skips important preventive measures
- Has poor health outcomes





Universal precautions approach



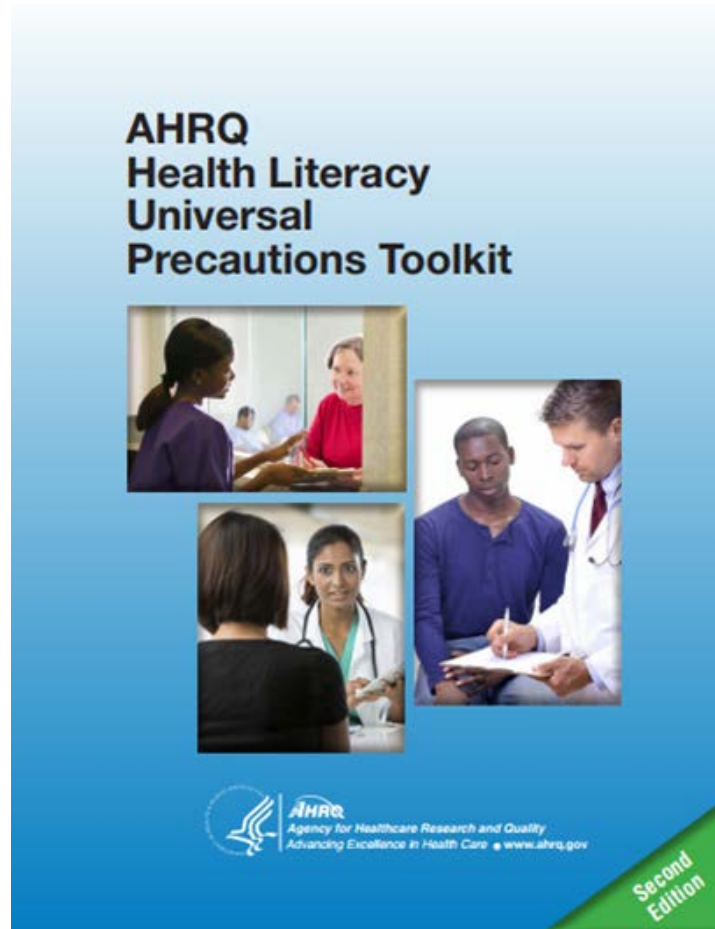
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Premise of the universal precautions approach to health literacy

- Many people struggle with understanding medications, self-care, instructions, and follow-up plans
- Ensure systems are in place to promote better understanding for all clients, not just those you think need extra assistance
- Everyone benefits from simple language



Implementing universal precautions takes an organizational commitment

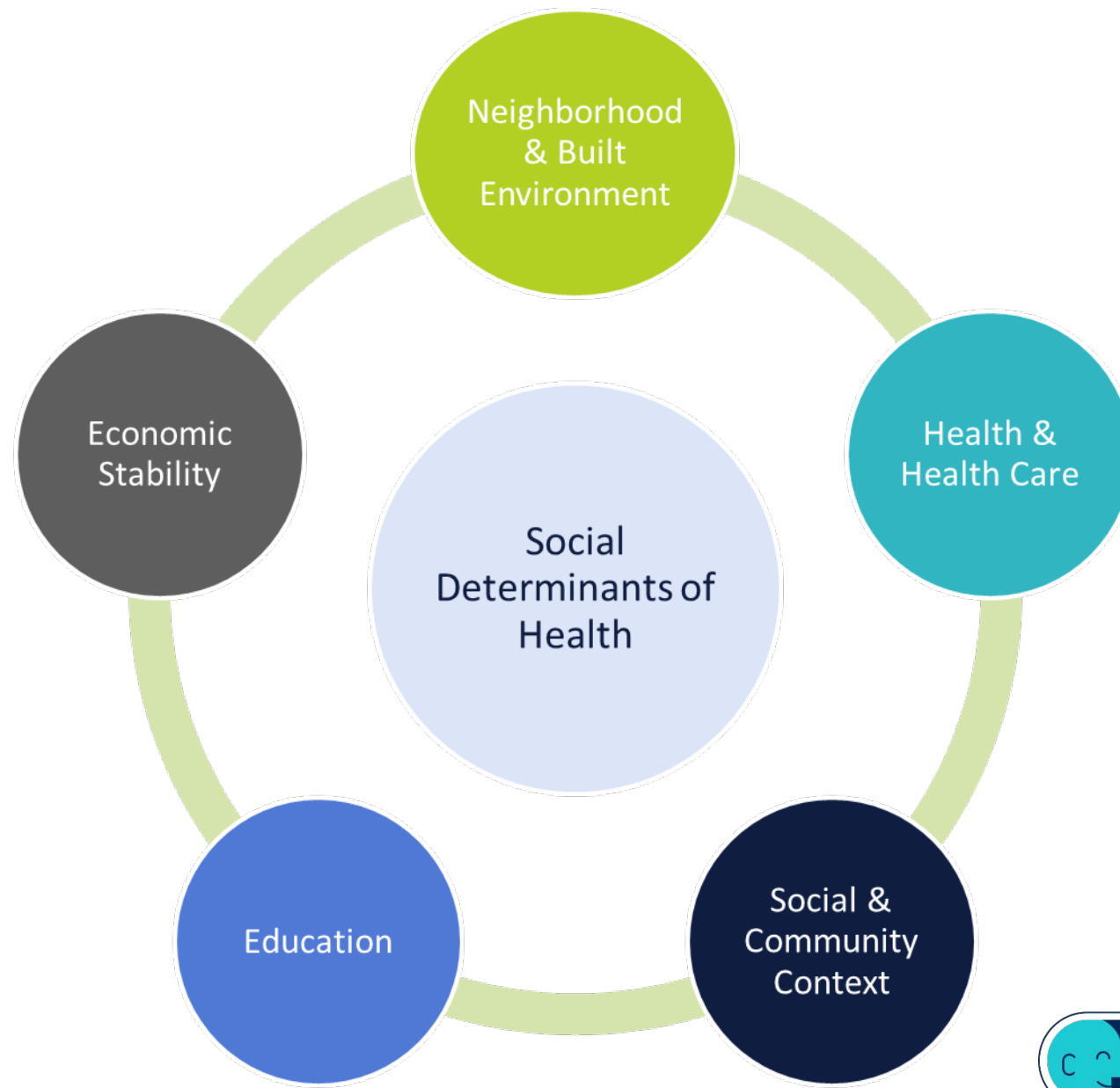


Universal precautions need to be implemented by all staff

Social determinants of health

Health Equity: the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographical areas in health status and health outcomes





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Age

Youth and Young Adults

- May have limited knowledge of the health care system
- May have particular concerns about privacy and confidentiality
- May be affected by their parents'/caregivers' health literacy
- May struggle in the transition between pediatric and adult care

Older Adults

- May have difficulty using print materials
- May have difficulty using documents such as forms or charts
- May have difficulty interpreting numbers and doing calculations
- May be a result of age-related cognitive decline
- May not ask many questions



Housing instability

- Makes it difficult to:
 - Attend medical appointments
 - Establish a relationship with a medical care team
 - Regularly fill prescriptions
- Homelessness can have an impact on the prioritization of medical adherence and options for care.



Incarceration/Justice-involvement

- Incarceration is a risk factor for Tuberculosis, Hepatitis B and C, HIV, and other STIs
- People who are/have been incarcerated have disproportionately high rates of:
 - Depression
 - Serious mental illness
 - Substance use disorders



Gender identity and expression

- **Gender:** A complex concept that includes an individual's sex, sexuality, identities, and social relations
- **Gender identity:** An inner sense of one's self as masculine or feminine, male or female or both or neither
- **Gender expression:** How a person externally communicates their gender identity to others through clothing, preferences, and behavior
- **Transgender:** A broad term that describes anyone whose gender identity, gender expression, and/or behavior do not match their assigned sex at birth. It is not an indicator of sexual orientation



LGBTQ people and health care

Sexual orientation is a socially constructed category that classifies individuals in relation to the gender(s) to which they are sexually and romantically attracted.

- LGBTQ people have unique health needs
- LGBTQ people often expect to be mistreated by health care professionals
- Health professionals should make an effort to help LGBTQ people feel comfortable communicating openly about their health concerns



Country of origin

- People from all countries and cultures of the world live in the U.S.
- People may have been born in the U.S. or have emigrated from elsewhere
- People from the same ethnic or racial group do not necessarily:
 - Speak the same language
 - Use the same dialect
 - Share the same ideas, experiences, and traditions



English language skills

- Just because a person has limited English proficiency does not necessarily mean that they have limited health literacy
- Not all people who speak the same language:
 - speak the same dialect
 - can read or write in that language
- Most health information on the web is written in English

Juckett, G., & Unger, K. (2014). Appropriate use of medical interpreters. *American family physician*, 90(7).
Mogobe, K. D., Shaibu, S., Matshediso, E., Sabone, M., Ntsayagae, E., Nicholas, P. K., ... & Webel, A. (2016). Language and Culture in Health Literacy for People Living with HIV: Perspectives of Health Care Providers and Professional Care Team Members. *AIDS research and treatment*, 2016.



Intersectionality



Intersectionality: The idea that an individual may have multiple identities that intersect to create a whole that is different from the component identities

- A person's intersectional identity makes them unique
- Negative effects can be compounded when a person experiences multiple forms of discrimination at the same time.
- People may respond to instances of marginalization with one identity at the expense of another
- People may feel marginalized by multiple communities



Cultural Diversity

- Cultural groups may share characteristics:
 - Race
 - Ethnicity
 - Language
 - Gender identity/expression
 - Sexual orientation
 - Sexual behavior
 - Country of origin
 - Geographic region
- Every person has a different lived experience

No group is
homogeneous





Attitudes, stigma, and their impact on health- seeking behavior



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Stigma

- **Stigma:** Negative and usually unfair beliefs
- **Discrimination:** Unfair treatment of a person or group of people
- Health care facilities
- Work environments
- Business establishments
- Family gatherings
- Friend groups and social settings
- Institutions of faith
- Institutions of learning
- ...and many other places



Responses to stigma

- Denial
- Shame
- Isolation
- Deceit
- Defensiveness
- Depression
- Guilt
- Withdrawal
- Fear
- Self-harm
- Loss of self-worth



Reluctance to disclose personal information



Clients may be reluctant to share personal information due to concerns about:

- Confidentiality
- Identification as a member of a group
- Fears about stigma/discrimination
- Feelings of shame or denial



Medical mistrust

- Lived personal experiences, or knowledge of historic community mistreatment can prevent individuals from seeking assistance
- This can create barriers to open communication with health care providers
- Take the time to answer questions, and use clear language when talking with clients



Health literacy



Cultural competency



Cultural humility & cultural competency

Cultural Humility

Willingness to increase self-awareness of biases and perceptions and engage in a life-long self-reflection process about how to put these aside and learn from clients (Tervalon, Garcia, 1998)

Cultural Competence

The ability to understand, appreciate, and interact with persons from cultures and/or belief systems other than one's own

Tangney J.P. "Humility: Theoretical perspectives, empirical findings and directions for future research," Journal of Social and Clinical Psychology. Vol 19, pp.70-82, 2000.
McGraw-Hill Concise Dictionary of Modern Medicine. © 2002 by The McGraw-Hill Companies, Inc.



Provider bias

- **Bias:** A preference for one thing, person, or group over another
 - Conscious (Explicit)
 - Unconscious (Implicit)
- Bias can become a prejudice against certain people or groups in ways that are unfair and lead to discrimination



How to reduce implicit provider bias

Some research suggests that implicit bias can be diminished by:

- Increased exposure to counter-stereotypes
- Increased internal motivation
- Increased cognitive empathy
- Increased emotional regulation
- Increased partnership building skills



Face-to-face communication



General strategies to improve spoken communication

- Use plain, non-medical language
- Limit content to 2-3 main points
- Repeat key points multiple times
- Incorporate words/expressions used by client
- Be specific
- Make sure instructions are appropriate for the client's life
- Consider client's cultural context
- Encourage client to ask questions



Important moments in HIV communication

- Explaining what to bring to a medical visit
- Explaining what to expect during a medical visit
- Explaining disease and symptoms
- Communicating medication instructions
- Describing medication side effects
- Explaining what health insurance is and how to use it



Health insurance literacy materials are available at the ACE TA Center <https://targethiv.org/ace>

Stay Covered All Year Long

Now that you've enrolled in health insurance, make sure you keep it.

Health insurance is important because it covers all your health needs, such as HIV medications and care, free preventive care, hospital stays, and substance use and mental health services. This guide covers what you need to do to stay covered throughout the year.

Pay premiums on time2
Report income and household changes4
What to do if you lose coverage6

TIP
Even if you have health insurance, stay in touch with your Ryan White Program case manager. She can help make sure you stay enrolled in ADAP and have access to financial help for insurance and Ryan White Program services like transportation and housing support.

ACE TA Center | Stay Covered All Year Long | Page 1

Making the Most of Your Coverage

Now that you've enrolled in health insurance, use this guide to learn how to start using your benefits.

ACE TA CENTER

Si no tiene seguro de salud, este es un buen momento para conseguirlo.

Tome medidas para una vida sana.

El seguro de salud ayuda a pagar por la atención médica que necesita para mantenerse sano. Con los cambios en las leyes de atención médica, ahora es más fácil conseguir seguro de salud. Más de 16 millones de personas ya se han inscrito, pero hay mucha gente que aún tiene preguntas o inquietudes. ¿Tiene preguntas acerca del seguro de salud? Estas son algunas respuestas:

“¿Para qué necesito seguro de salud? Ya recibo mi atención para el VIH a través del Programa Ryan White.”

“Mi administrador de caso me ayudó a encontrar un plan que cubre lo que necesito para mi salud, incluso los medicamentos para el VIH.”

El seguro de salud ofrece cobertura para todas sus necesidades relacionadas con la salud. Además de la atención y los medicamentos para el VIH, podrá obtener otros servicios de salud que incluyen:

- atención preventiva gratuita, como vacunas contra la gripe y exámenes de detección del cáncer;
- atención y medicamentos para otros problemas de salud como la enfermedad cardíaca o la diabetes;
- hospitalizaciones;
- tratamiento para el uso de sustancias y servicios de salud mental;
- atención para la maternidad.

El seguro de salud protege sus finanzas. Si ocurre algo inesperado, como un accidente de auto, no quedará en bancarrota por pagar sus cuentas hospitalarias.

Centro de Asistencia Técnica de ACE | Obtenga cobertura para una vida sana | Página 1



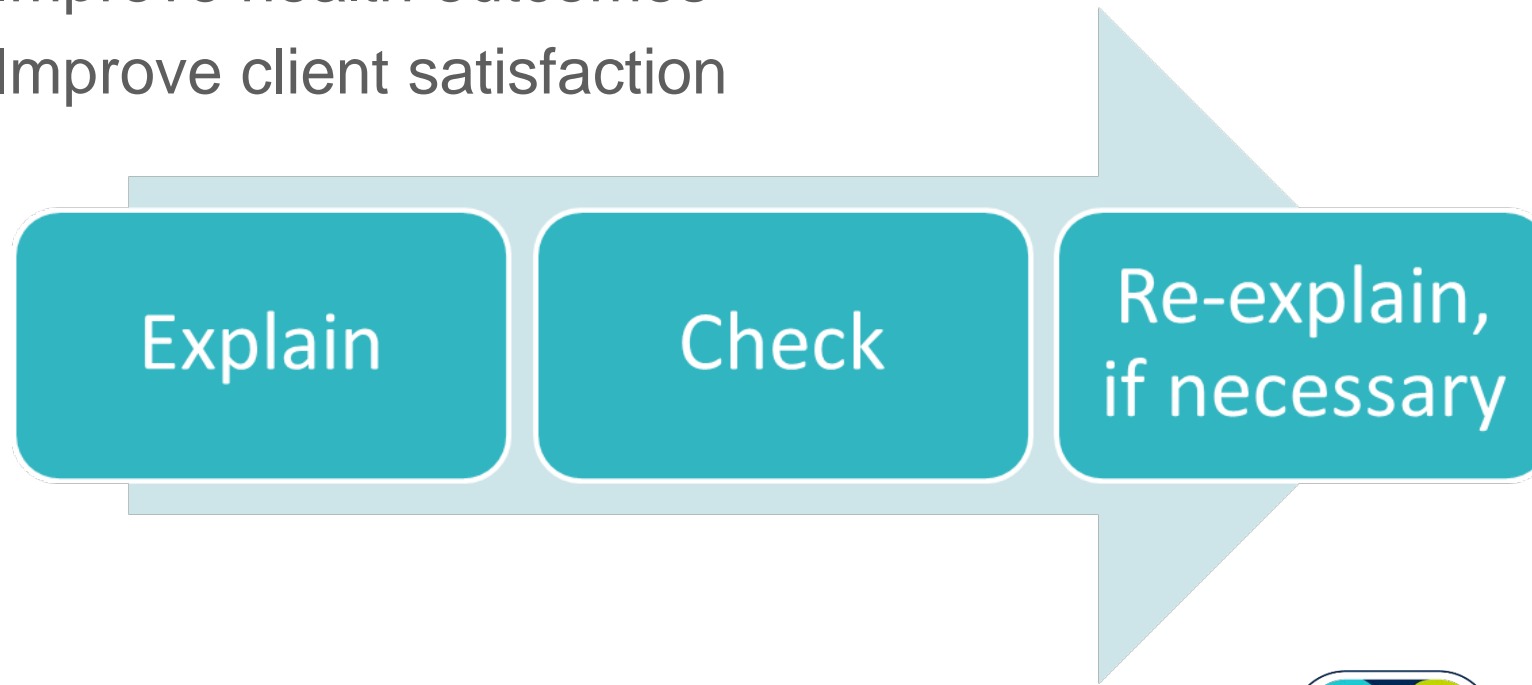
Approaches to address health literacy

- Teach-back
- Ask Me 3
- Show Me



Teach-back Method

- Improve client understanding and adherence
- Decrease call-backs and cancelled appointments
- Improve health outcomes
- Improve client satisfaction



Teach-back prompts



- In your own words, tell me...
- Explain to me...
- How will you explain...
- What will you do if...
- When will you...



The Show-Me approach



Used to confirm that a client understands a skill or how to complete a task action by 'showing' the provider.



Tips for successfully using the Teach-back or Show-Me approaches

- Use open-ended questions
- Self-correct if you begin to use jargon
- Document use of and client's response to teach-back and show-me approaches
- Include family members or caregivers



Try It: Sandra

Your client, Sandra, has been on ART for 6 months and her CD4 count is unchanged. You are going to have her try a new medication, and you want to make sure that she understands her new medication instructions, which are to take 1 pill when she wakes up and 1 pill before she goes to bed, with food.

Using the Teach-Back Method, how would you ensure that you have explained Sandra's medication instructions effectively?



Ask Me 3™ approach

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?



Citation: Miller, M. J., Abrams, M. A., Barbara, M., Cantrell, M. A., Dossett, C. D., McCleary, E. M., ... & Sager, E. R. (2008). Promoting health communication between the community-dwelling well-elderly and pharmacists: The Ask Me 3 program. *Journal of the American Pharmacists Association*, 48(6), 784-792.



Tips for health professionals

- Focus on client
- Pay attention to non-verbal messages
- Listen to seek an overall understanding
- Be empathetic
- Ask questions
- Talk less, listen more



Other tips to communicate clearly



- Be self-aware
- Acknowledge personal limitations
- Sit down with client
- Slow down your speech
- Portray approachable body language
- Make client feel valued
- Ask what they can do to help the client



How health professionals can foster a care partnership

- Respect client's privacy and the privacy of their medical information
- Communicate openly about benefits and risks associated with treatment
- Provide client with information to make informed decisions about their care



Try It: Mateo

Mateo was diagnosed with HIV 2 years ago. With the help of his HIV meds, he's now undetectable. Mateo smiles and says, "That means I'm cured!"

What would you tell Mateo about viral suppression? How would you find out if he understands?



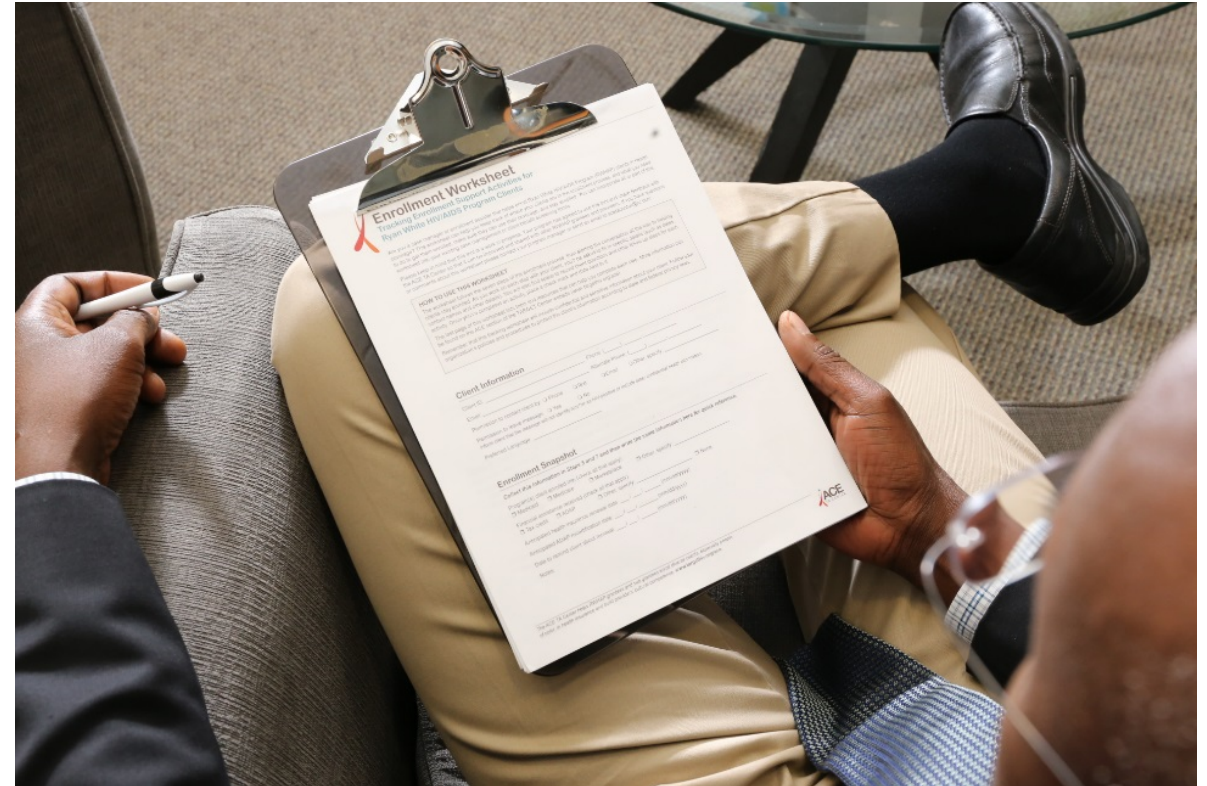
Written communication



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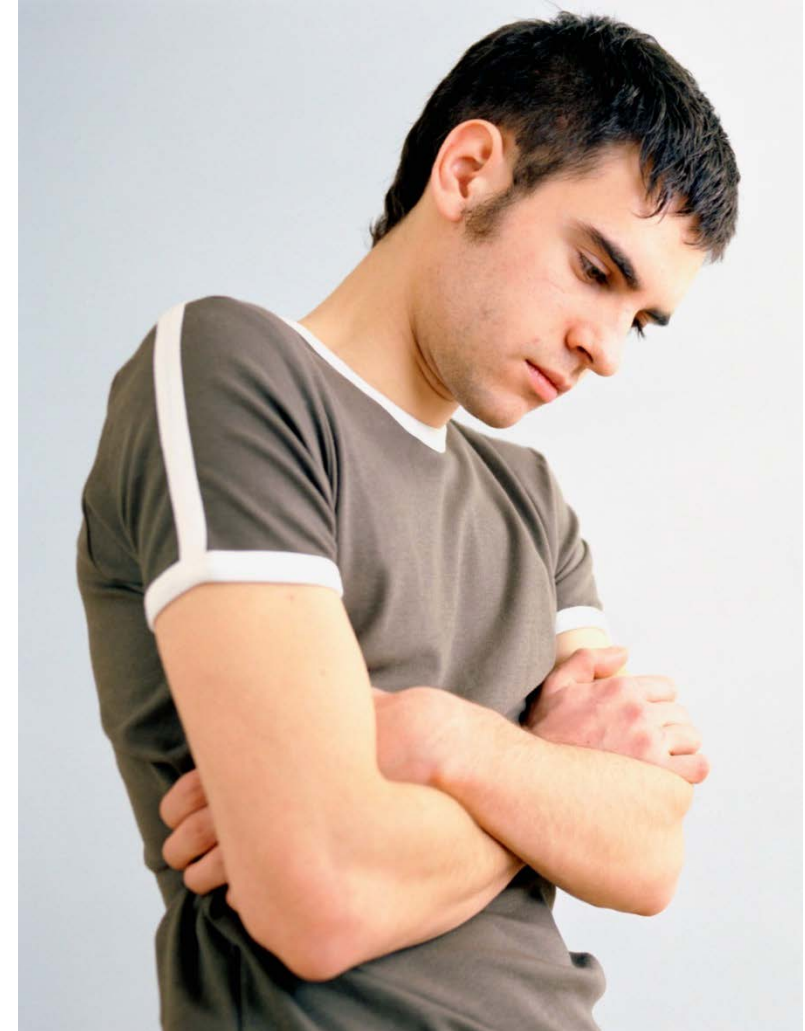
Formatting

- Immediately appealing
- Has a clear and obvious path for the eye to follow
- Uses bolding to emphasize important points
- Uses easy-to-read font in 12 point or larger
 - May be necessary to provide alternative formats for people with visual impairments
- Left-justify text



Avoid

- ALL CAPITAL LETTERS
- *Italicized text*
- Underlined text
- Acronyms and contractions
- Technical words or jargon
- Passive voice
 - Passive voice: The results of your lab work will be sent to you
 - Active voice: We will send you your lab results



Word choice



- Simple words with 1 or 2 syllables
- Short sentences with 10 to 15 words
- Strong, vivid words, including verbs
- Words or phrases familiar to the audience
- At a 6th grade reading level
- Use culturally appropriate words



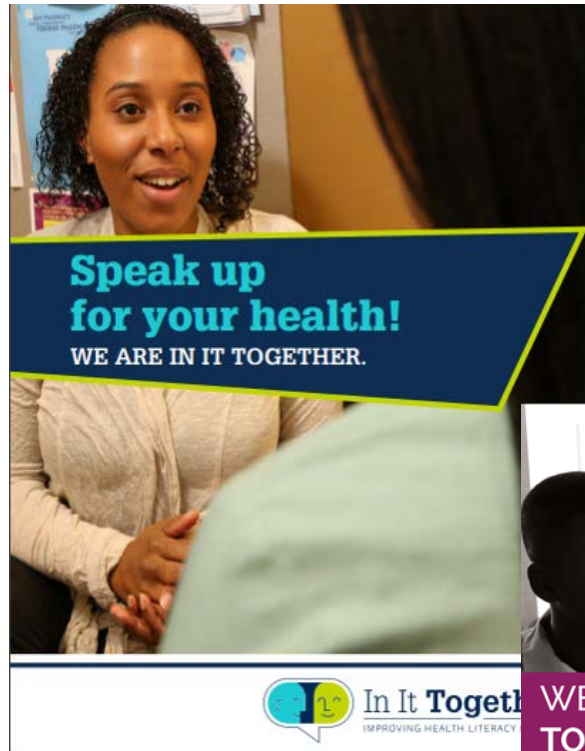
Content

- Focus on the patient's experience of the condition
- Clearly state:
 - What the client needs to do
 - Why the client needs to do it
 - When the client can expect results
 - What warning signs the client needs to watch for
 - What to do if a problem occurs
 - Who to contact with questions



Download posters and brochures

<http://hivhealthliteracy.targethiv.org>



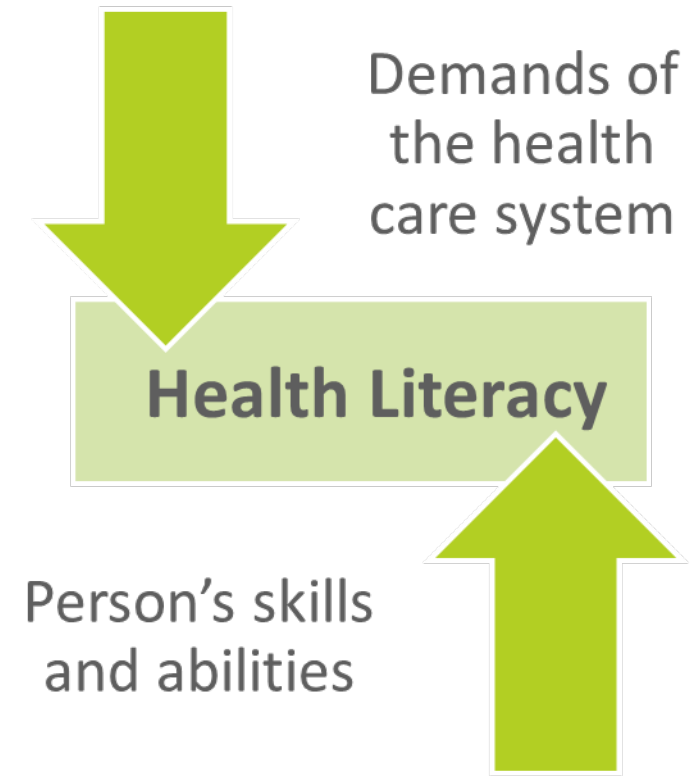
Health literate organizations



Definition of a health literate organization

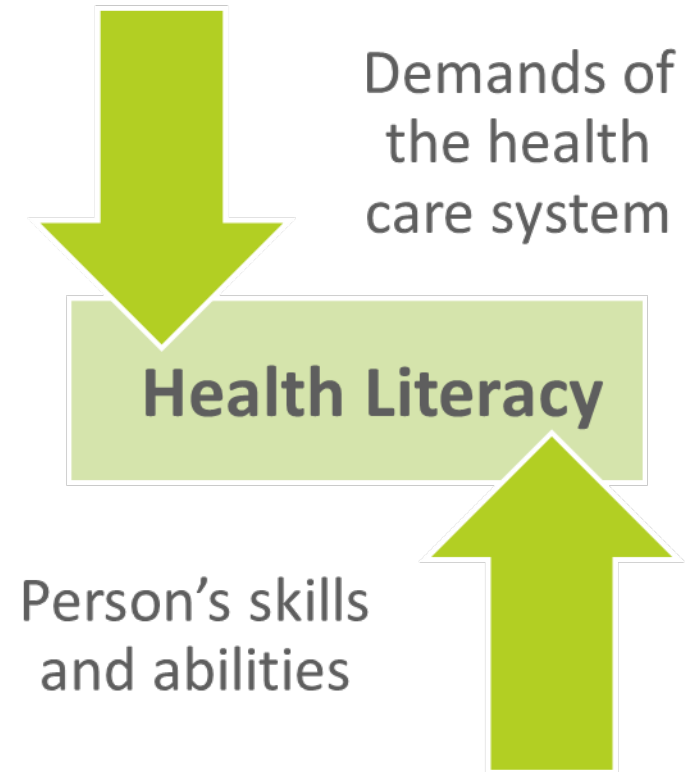
Organizations that:

- Reduce demands placed on the client by the health care system
- Help people find, process, understand, and use health information and services
- Recognize that health literacy, language, and culture are interrelated



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Andrulis and Brach, 2007; Sudore et al., 2009; ODPHP, 2008



10 attributes of health literate organizations



Become a more health literate organization

- Start a discussion of health literacy in the workplace
- Form a health literacy team
- Set health literacy goals
- Create a health literacy improvement plan



The Health Literacy Resource Guide

Health Literacy Resource Guide

Overview

This guide provides a curated overview of health literacy resources, organizational assessments, client assessments, and toolkits that your HIV program can use to begin or enhance efforts to provide services that meet the needs of clients with limited health literacy. The resources in this guide can be adapted to a variety of health care settings.

[Expand](#)

Section 1: Relationship Between Health Literacy and Culture

Resources in this section focus on the relationship between cultural competency and health literacy and provide information that health care organizations can use to improve their cultural competence.

[Expand](#)

Section 2: Organizational Frameworks for Providing Health Literate Services

This section describes overarching care models that health care organizations can use to incorporate health literate practices into all aspects of planning and operations.

[Expand](#)

Section 3: Organizational Assessments and Toolkits

This section contains comprehensive toolkits and assessments designed to look at health care organizations' current communication environments, suggest improvements to organizational practices, and plan for implementation of those improvements.

[Expand](#)

Section 4: Materials Improvement Tools

This section contains tools to help organizations create written materials for print and online media that meet the communication needs of clients of all health literacy levels. These tools focus on how to involve consumers when developing and testing materials, which is an integral step in creating materials for clients.

[Expand](#)

Section 5: Strategies to Improve Communication

This section contains evidence-based verbal communication strategies that health care providers can use in their interactions with clients to ensure that clients are able to obtain, process, and understand the basic health information they need to make appropriate health decisions.



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Start today!

Promote the use of health literate practices

- Universal precautions approach
- Clear communications
- Cultural competence



Request a training

<https://hivhealthliteracy.targethiv.org>



Thank you!

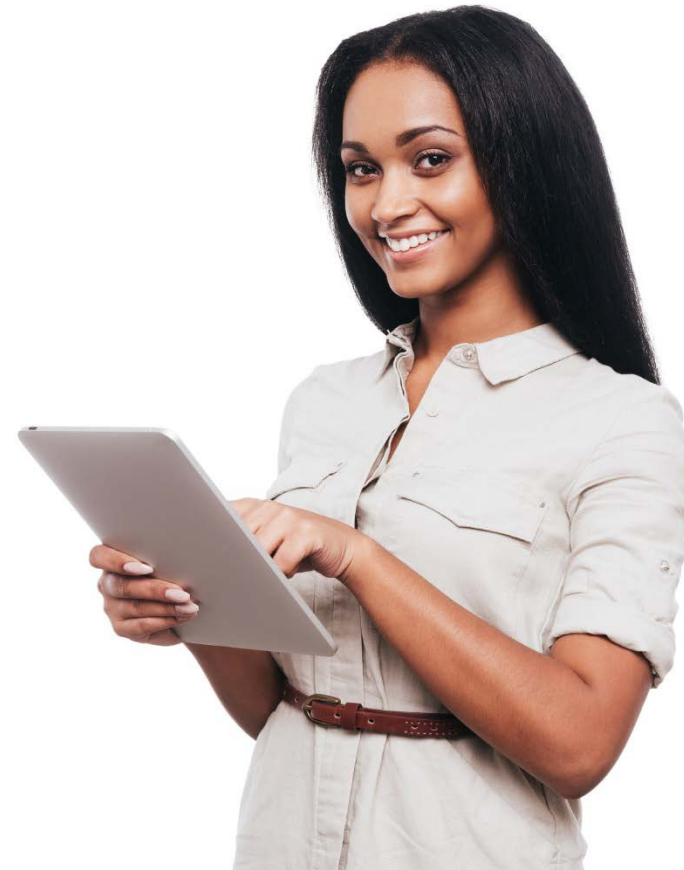
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