



In It Together

A Health Literacy Guide for
Health Professionals Serving People
Living with and at Risk for HIV



In It Together

IMPROVING HEALTH LITERACY FOR ALL



Good health starts with understanding

The capacity to obtain, process, and understand basic health information and services is known as health literacy. Each person's health literacy is shaped by a broad mix of cultural, economic, geographic, linguistic, physical, and social factors. Common feelings clients experience in a health care setting, such as pain, fear, and mistrust, may also impact their health literacy.

As a health professional, you play an essential role in helping all people, but particularly people living with HIV, to understand information related to their health. Clear communication with your clients is essential to helping them make informed decisions about their HIV care and treatment.

Provide materials, services, and space that make it easier for your clients to navigate, understand, and use information and health care services to improve their health outcomes.

Each client that comes to you for HIV care brings a unique cultural identity and life experience to their visit that affect their health-related behaviors.



Research shows that people with low health literacy had lower HIV-related knowledge and medication adherence. Low health literacy has also been associated with higher health care costs.^{2, 3, 4}

This guide provides information and approaches to help you provide clear HIV care and treatment information to your clients while engaging them in discussions about their desired health outcomes.

¹ Wawrzyniak A.J., Ownby R.L., McCoy K, and Waldrop-Valverde D. (2013) Health Literacy: Impact on the Health of HIV-Infected Individuals. *Curr HIV/AIDS Rep.* 10(4): 295-304.

² Huan J.N., Patel N.R., French D.D., Campbell R.R., Bradham D.D., & Lapcevic W.A. (2015) Association between health literacy and medical care costs in an integrated healthcare system: A regional population based study. *BMC Health Services Research*, 15(249).

³ Clark B. Using law to fight a silent epidemic: The role of health literacy in health care access, quality, and cost. (2011). *Annals of Health Law*, 11.

⁴ Hardie N.A., Kyanko K, Busch S, LoSasso A.T., & Levin R.A. (2011). Health literacy and health care spending and utilization in a consumer-driven health plan. *Journal of Health Communication*, 16, 308-321.



CASE STUDY

Michael's Experience

Michael is a 24-year-old Black gay man who was recently diagnosed with HIV but has not connected to care. He is seeing a new doctor at a community health center because he's had swollen glands.

ENTERING THE OFFICE

The front desk staff offers him a warm welcome before asking him to complete the intake forms. Once he's taken to the exam room, the nurse notices Michael has left several sections of the intake form blank, including his HIV status.

She says to Michael, "Let's confirm some of the information on your intake forms together. You're 5'11, 24 years old, African American, have a family history of heart disease, have no previous surgeries, and you're not currently taking any medications. Do you happen to know your HIV status?" He says he has been tested, but does not disclose his status.

MEETING DR. JOHNSON

When Dr. Johnson enters the room, he observes that Michael avoids eye contact and seems nervous. He begins to establish a rapport with Michael, saying, "I see you live off of Park Street. I've heard great things about the neighborhood. How do you like living there?" He then asks him when he last saw a doctor. He also reviews the form and notices Michael's HIV status is unknown.

Dr. Johnson then asks Michael what brought him in. Michael says his throat has been sore.

Dr. Johnson says, "It looks like you have swollen glands. Let's talk about what might be causing this. When was your last HIV test?" Michael now feels more comfortable with Dr. Johnson and confirms that he tested positive for HIV two months ago.

Dr. Johnson says, "I'm glad you're here; this is the first step for us keeping you healthy. Let's talk about what's next. Connecting to HIV care will help you live a long and healthy life. You will learn a lot of new information and terms that will help you understand how to take care of yourself. I'm committed to helping you make important decisions about your care and treatment. Let's start by running your first lab test." Dr. Johnson continues to explain what Michael can expect and what actions he will need to take. He defines the terms, "CD4 count," and "viral load" in easy-to-understand language.

WRAPPING UP THE VISIT


Dr. Johnson says, "We've covered a lot today, and I want to make sure that I've explained things clearly. Let's review what we discussed. What are three things you will do to take care of yourself?"

By the end of the visit, Dr. Johnson senses that Michael is a lot more comfortable. Dr. Johnson tells Michael how glad he is that they are beginning his treatment and walks with him to the front desk to make his next appointment.




Why was Michael uncomfortable at the beginning of the visit?

As a young, Black gay man, Michael feels uncomfortable in health care settings due to real and perceived stigma and discrimination based on his race and sexuality. His lack of knowledge regarding HIV care and treatment and discomfort with health care environments in general adds to his feelings of mistrust, shame, and vulnerability.

 Research to assess the role of stigma has shown that when a patient perceives stigma from a health care provider, they may internalize this stigma, leading to poor medication adherence and treatment outcomes.⁵ For Black men who have sex with men, experiencing stigma from health care providers is associated with longer elapsed time between exams. Medical mistrust among Black adults has also been identified as a barrier to engaging in routine health care.⁶

The Teach-Back Method

Ask the client to repeat in their own words what they need to know or do.

 Research shows that this method helps confirm that the client understands what you have explained to them and can act on this information.^{7,8,9}

What did the clinic staff do to help Michael feel safe and less vulnerable?

Health professionals and health care organizations play an equal role in providing safe, equitable, patient-centered care that provides clients with access to services and information to make informed health decisions.

The front office staff, nurse, and doctor all took steps to build Michael's trust:

- The front office staff **greeted him warmly**.
- The nurse **normalized the review of his intake form** and did not call attention to the fact that he left the question about his HIV status unanswered.
- Dr. Johnson **first connected with Michael on a personal level** and asked open-ended questions to facilitate dialogue.
- The doctor **acknowledged Michael's effort** to connect to care. He also explained HIV terms in easy-to-understand, plain language.
- Dr. Johnson used the **Teach-Back method** to confirm Michael's understanding (see sidebar).

⁵ Mariam D., Olshansky E.F., Lakon, C. (2018) Addressing HIV Stigma in Health Care. *The American Journal of Nursing*, 118(3):11.

⁶ Eaton L.A., Driffin D.D., Kegler C, Smith H, Conway-Washington C, White D, & Cherry C. (2015). The role of stigma and medical mistrust in the routine health care engagement of Black men who have sex with men. *American Journal of Public Health*, 105(2): e75-e82.

⁷ Wu H.W., Nishimi R.Y., Page-Lopez C.M., & Kizer K.W. (2005). Improving patient safety through informed consent for patients with limited health literacy. *National Quality Forum Implementation Report*.

⁸ Wade V. & Frank C. (1997). The effectiveness of patient verbalization on informed consent. *Canadian Journal of Surgery*, 40(2):124-128.

⁹ White C.S., Mason A.C., Feehan M., & Templeton P.A. (1995) Informed consent for percutaneous lung biopsy: Comparison of two consent protocols based on patient recall after the procedure. *American Journal of Roentgenology*, 165(5):1139-1142.



CASE STUDY

Eva's Experience

Eva is a 34-year-old Latina woman who has been living with HIV for seven years. She started ART last year. Today she is meeting with Sandra, her primary care nurse. Sandra asks Eva how she has been feeling. Eva says that she has not been feeling well and does not think that her medication is working.

Sandra starts by asking Eva to explain how she takes her medication. Eva says she takes her pill when she remembers, but she doesn't always take it at the same time and never takes it when she is with other people.

Sandra remembers that there are **three points that Eva needs to be able to understand:**

1. **What is the problem?**
2. **What does she need to do?**
3. **Why is it important to do this?**

Sandra tells Eva, "It's important to take your medication at the same time every day. The medicine keeps the virus from making more of itself, which will make you feel better and keep you healthy."

They talk about Eva's schedule and work together to find the best time for Eva to take her medicine every day. At Sandra's suggestion, Eva decides to set a daily reminder on her phone to help her remember to take her medication.

At the end of the meeting, Sandra and Eva review what they talked about that day. Eva says, "I have to take my pill at the same time every day. I'm going to take my pill when my alarm goes off. If I'm with my friends, I'll just leave for a minute. I have to take my medication to stay healthy."

Why is Eva struggling with medication adherence?

Eva struggles with medication adherence because she does not understand that for the medication to work, and for her to feel better, she needs to take her medication every day at the same time.. Eva has limited health literacy, and finds it difficult to remember when to take her medications.



Studies show people immediately forget 40-80% of the medical

information they receive. Nearly half of the medical information they retain is incorrect.¹⁰

What did Eva's provider do to help her better understand and act on information about her HIV treatment?

- Sandra **framed her conversation** with Eva around the Ask Me 3™ questions (see sidebar).
- Sandra **used plain language** to explain how adherence affects Eva's ability to control the virus.
- Eva and Sandra **worked together** to find a medication schedule that fits into her life.
- Sandra **checked that Eva understood** their discussion and that Eva knew what she has to do when she is at home.

The Ask Me 3™ Technique

Ask Me 3 helps health professionals target their conversations to address three important questions:

1. What is the problem that we are trying to address?
2. What does the client need to do to address this problem?
3. Why is it important to the client that they follow your guidance?

¹⁰ McGuire L.C. (1996). Remembering what the doctor said: Organization and adults' memory for medical information. *Experiential Aging Research*, 22(4), 403-28.



Key Takeaways



Take a Universal Precautions approach.

Assume that any client could have limited health literacy and provide all clients with simple, clear health information and easy-to-read materials.



Look for these indications that your clients may have limited health literacy.

- Do not take medications correctly
- Frequently miss appointments
- Fail to follow through on tests or referrals
- Do not complete intake forms
- Ask few questions
- Have frequent hospitalizations
- Skip important preventive measures



Recognize that perceived stigma affects health.

- A client who experiences stigma from a health care provider may prolong time between visits.
- Mistrust of medical providers is a barrier to routine health care.



Take steps to interact with clients in a health literate way.

AS A HEALTH PROFESSIONAL:

- Use strategies for effective communication with clients (see sidebar).
- Frame your responses using the Ask Me 3™ technique.
- Use the Teach-Back method.
- Assure clients that it is safe for them to talk about anything. No one will judge them or talk about their health without their consent.
- Consider each encounter as an opportunity to strengthen the health partnership between you and your client.

AS AN ORGANIZATION:

- Use health literacy strategies in interpersonal communications and confirm understanding at all points of contact.
- Provide easy access to health information and services and navigation assistance.
- Recognize and respond to a wide range of health literacy skills while avoiding stigmatization.

Effective Communication Strategies

- Ask open-ended questions and avoid questions that begin with “do,” “did,” “can,” or “will” (i.e., “What questions do you have?” instead of “Do you have any questions?”).
- Use plain, non-medical language.
- Limit content to 2-3 main points.
- Repeat key points multiple times.
- Use or create pictures/drawings/illustrations to supplement what you are saying.
- Speak slowly.

Learn more.

Visit targethiv.org/healthliteracy to download additional resources and materials for clients.

Other Resources

HRSA's Health Literacy Resources

hrsa.gov/publichealth/healthliteracy/

HHS National Action Plan to Improve Health Literacy

health.gov/communication/HLActionPlan/

AHRO Health Literacy Universal Precautions Toolkit

ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit

Ask Me 3 – National Patient Safety Foundation

npsf.org/?page=askme3

Institute of Medicine's 10 Attributes of a Health Literate Organization

resources.iom.edu/widgets/Health-Literacy-FLASH/health-literacy.html

Why does health literacy matter?

- **40-80%** of the medical information patients receive is forgotten immediately. Nearly half of the information retained is incorrect.¹¹
- **36%** of American adults have only basic or below basic health literacy skills.¹⁰
- **26%** of patients with limited health literacy did not understand when their next appointment was scheduled.¹⁰
- **42%** of patients with limited health literacy do not understand simple medical instructions.¹⁰
- **Up to 78%** of patient misinterpret warnings on prescription labels.¹¹
- **86%** of patients could not understand rights and responsibilities of a Medicaid application.¹⁰

¹¹ White, S. (2008). Assessing the nation's health literacy: Key concepts and findings of the National Assessment of Adult Literacy. *American Medical Association Foundation*.



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