In It Together
A Health Literacy Guide for Health Professionals Serving Black MSM Living with HIV
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, 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 his visit. Black/African American gay, bisexual, same gender loving, and other men who have sex with men (MSM) have unique cultural experiences that affect their health-related behaviors.

Research shows that communication, trust, and a supportive patient-provider relationship are important factors in health care utilization and HIV medication adherence among African Americans. Low health literacy has also been associated with higher health care costs.

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.

CASE STUDY

Michael’s Experience

Michael is a 24-year-old, gay Black 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, gay, Black 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 and medical mistrust in the routine health care for Black MSM has shown that experiencing stigma from health care providers is associated with longer elapsed time between exams for both HIV-negative and HIV-positive Black MSM. Medical mistrust among Black adults has also been identified as a barrier to engaging in routine health care. The relationship between perceived stigma and time since last physical is affected by the degree to which one perceives medical mistrust.5

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 Dr. Johnson 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.
- 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).

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**THE TEACH-BACK METHOD**

Ask the client to repeat in his own words what he needs to know or do. This confirms that you have explained to clients what they need to know in a way that they can understand and can act upon.

Research shows that this method helps confirm that the client understands what you have explained to him and can act on this information.5,7,8

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CASE STUDY
Aaron’s Experience

Aaron is a 34-year-old Black man who has been living with HIV for seven years and started ART last year. He is meeting today with Glenn, his primary care nurse. Glenn asks Aaron how he has been feeling. Aaron says that he has not been feeling well and does not think that his medication is working.

Glenn starts by asking Aaron to explain how he takes his medication. Aaron says he takes his pill when he remembers, but he doesn’t always take it at the same time and never takes it when he is with other people.

Glenn remembers that there are three points that Aaron needs to be able to understand:

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

Glenn tells Aaron, “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 Aaron’s schedule and work together to find the best time for Aaron to take his medicine every day. At Glenn’s suggestion, Aaron decides to set a daily reminder on his phone to help him remember to take his medication.

At the end of the meeting, Glenn and Aaron review what they talked about that day. Aaron 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 Aaron struggling with medication adherence?
Aaron struggles with medication adherence because he does not understand how taking his medication can help him to feel better. Aaron has limited health literacy, and finds it difficult to remember how and when to take his medications.

Studies show people immediately forget 40-80% of the medical information they receive. Nearly half of the medical information they retain is incorrect.9

What did Aaron’s provider do to help him better understand and act on information about his HIV treatment?

• Glenn framed his conversation with Aaron around the Ask Me 3™ questions (see sidebar).

• Glenn used plain language to explain how adherence affects Aaron’s ability to control the virus.

• Aaron and Glenn worked together to find a medication schedule that fits into his life.

• Glenn checked that Aaron understood their discussion and that Aaron knew what he has to do when he is at home.

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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
- Cannot provide a detailed history of their illness or treatments
- Avoid reading tasks
- Do not remember information read earlier

**Recognize that 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 and confirm understanding at all points of contact.
- Provide easy access to health information, services, and navigation assistance.
- Recognize and respond to a wide range of health literacy skills.
- Avoid stigmatization.
Effective Communication Strategies

- Ask open-ended questions. 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 hivhealthliteracy.careacttarget.org for additional resources and materials for clients including:
- Health Literacy Resource Guide
- Health Literacy Posters
- Consumer Brochures

Other Resources
HRSA's Health Literacy Resources
hrsa.gov/about/organization/bureaus/ohe/health-literacy/index.html

HHS National Action Plan to Improve Health Literacy
health.gov/communication/HLActionPlan/

AHRQ 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
Why does health literacy matter?

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

\(^\text{10}\) White, S. (2008). Assessing the nation’s health literacy: Key concepts and findings of the National Assessment of Adult Literacy. American Medical Association Foundation.