

CALIBER_{of}CARE

Clinic **A**ctivation to **L**ead and **I**mplement **B**est Practices for **E**nhancing **R**esponse to HIV



Stigma Dialogue Navigator for HIV Clinicians

“Stigma and discrimination associated with HIV and AIDS are among the greatest barriers to preventing further infections, providing adequate care, and alleviating suffering. The stigma surrounding sex, sexuality, and intravenous drug use has prevented millions from receiving information about HIV, how it is transmitted, and how to protect themselves.”

-U.S. National Library of Medicine, National Institutes of Health





To HIV Clinicians and Health Care Providers:

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Amidst the many challenges for clinics providing services to people living with HIV, effective physician-patient communication stands out as a critical component to ensuring that patients receive the care and support they need. Treatment adherence, a crucial part of HIV care, is specifically affected when ineffective dialogue occurs between patients and physicians.

It is with this complex clinic setting in mind, coupled with the need for strengthened patient-physician communication, that the **CALIBER (Clinic Activation to Lead and Implement Best Practices for Enhancing Response to HIV) of Care** program was formed. CALIBER of Care is led by an expert panel of physicians from HIV clinics across the country who have partnered with the International Association of Providers of AIDS Care (IAPAC) to provide physicians with resources to help improve HIV patient care in the clinic setting.

The CALIBER of Care expert panel has identified the need to provide physicians with tools to help them discuss with patients HIV-related stigma, which often inhibits patients from seeking HIV testing and receiving/adhering to treatment and care. The **CALIBER of Care Stigma Dialogue Navigator** is designed to help HIV clinicians and support staff to address the effects of stigma and empower patients to overcome its negative effect. The dialogue navigator is not an algorithm for administering care; instead, it is a professional development and awareness tool that is peer-driven. The goals of the stigma dialogue navigator are to:

- Create real-world guidance for engaging in stigma-free, nurturing, non-judgmental physician/patient communication
- Empower patients to overcome the stigma of living with HIV and stigma as it relates to their treatment and care

Combating HIV-related stigma is an important step toward achieving public health goals, overcoming the HIV epidemic, and improving the general mental and physical well-being of people living with the disease. Therefore, it is important that physicians and HIV care providers communicate to patients in an open and non-judgmental manner.

- According to the World Health Organization (WHO), patient fear of stigma and discrimination are the main reasons why people are reluctant to be tested, disclose their HIV status or take antiretroviral treatments
- Results from a 2010 survey of more than 100 HIV clinics found that 12 percent of respondents stated that stigma is the greatest challenge to providing care to patients with HIV. The survey included program directors and/or clinicians at public health clinics classified as current Part C grantees of the Ryan White HIV/AIDS Treatment Modernization Act

For more information about creating a stigma-free patient care environment in HIV Clinics and patient perspectives on stigma, please visit IAPAC.org.



Fostering Stigma-Free Dialogue with Your HIV Patients

HIV stigma is a complicated issue, and attitudes towards those affected can vary greatly across individuals and groups of people. Religion, gender, sexuality, age and levels of HIV education can all affect how someone feels about HIV.

This dialogue navigator has been developed by the CALIBER of Care Initiative. All topics have been informed and reviewed by a panel of HIV experts practicing in the HIV clinic setting.

What is HIV stigma?

HIV-related stigma refers to prejudice, negative attitudes and abuse aimed at people living with HIV. The consequences of stigma and related discrimination are far-reaching, including being rejected by family, friends and community; decreased quality of treatment in the healthcare setting; an erosion of rights; decreased psychological well-being and decreased success of HIV testing and treatment efforts.

Foundational Steps for Success

- **Put yourself in your patient's shoes, recognizing each patient's individual issues or barriers to care. Set aside your personal beliefs and accept without judgment your patient's past or current lifestyle choices**
- **Understand your community and your patient. Remember:**
 - Stigma affects different groups of people in different ways, based on gender, sexual orientation, gender identity, race, religion and socio-economic status
 - For example, women can be affected differently by HIV-related stigma compared to men. Women may be subjected to pre-conceived notions that HIV was contracted because of sexual promiscuity. Women can face stigma for both their gender as well as their community, with Black and Hispanic/Latina women at increased risk for HIV
 - Gay, bisexual, other men who have sex with men (MSM) and others in the LGBT community and living with HIV can be stigmatized for both their sexuality as well as having HIV. When the HIV epidemic began in the 1980s, a common myth persisted that HIV was a gay man's disease; however, today the face of HIV includes a diverse population, with heterosexuals, Blacks and women representing segments of the patient population
 - Stigma and homophobia can have a major effect on the lives of gay, bisexual and other MSM, particularly their mental and sexual health. Internalized homophobia may affect their ability to make healthy choices, including accessing HIV care
 - Different cultures have different value systems that may conflict with discussions about HIV
 - The Black community is disproportionately affected by HIV, and the stigma associated with HIV and homosexuality may help increase the spread of HIV in these communities. Fear of disclosing risky actions or sexual orientation prevents many from seeking testing, treatment and support. Consequently, many in Black communities lack vital information about preventing HIV infection
- Keep in mind that issues like race, sexual orientation and age may play a role in your patient's ability to address HIV. Keep these factors in mind when having a conversation with your patient:
 - An older patients' risk for HIV may be overlooked simply due to their age, thereby missing opportunities to discuss preventative measures, offer HIV testing or make an early diagnosis that could help patients get proper care. Further, HIV-related stigma may be more severe among older people, causing them to hide their diagnosis from loved ones



- **Treat people living with HIV the same as you would any other disease in order to lessen the stigma. Be sure not to express judgement or discomfort in your body language**
 - Establish eye contact with your patients
 - Avoid closed or judgmental body language, such as crossed arms, hands on hips or narrowing eyes
- **As much as possible, give your patient your undivided and uninterrupted attention. Avoid multitasking during a patient consultation so that you don't appear distracted**
- **Provide a welcoming and nurturing environment that will encourage your patients to talk openly about their experiences. Ask them thoughtful questions about their perspective on the disease and their approach to care. Remind your patients that all discussions with you and your staff are confidential and will not be shared with anyone without their authorized consent**
- **If your patient has not disclosed his or her HIV status to family and/or friends, provide guidance that it is the patient's personal decision about when and with whom he or she choose to share their status. Disclosing HIV status to loved ones can help alleviate some of the stress associated with living with HIV, but the conversation can be difficult**
- **Many communities have support groups for people living with HIV. Provide guidance to your patient regarding groups in your community that can help your patient gain additional support and nurturing**
- **Remember that setting the tone (enabling an open dialogue) will help patients feel comfortable voicing challenges or concerns they have related to their treatment. Discussing treatment challenges, such as side effects and adherence, will ensure patients receive the most appropriate and tolerable treatment options based on their individual needs**

Evaluating Stigma

Use the following checklist to cover key themes related to stigma, and to evaluate the effect of stigma or unfair treatment on treatment success.

- What goals do you have for our appointment today? Are there specific questions or issues you are facing that you would like to talk about?**
- Do family members or friends know about your HIV status? Am I, your physician, the only one who knows your HIV status?**
- How did you feel when initially diagnosed?**
 - Did you feel ashamed or different from others?
 - Did you feel that others blamed you for your HIV status?
- Did you have any fear or concern of being negatively perceived by others following disclosure of your HIV status?**
 - Have you been concerned that your family would reject you or that you would lose friends?
 - Have you feared you would lose your job?
- Have you been concerned that people would avoid you?
- Are you currently facing stigma? If so, how does it affect your daily life?**
- When, where and how do you take your medication daily, and does stigma affect your adherence to those medications?**
 - Have you avoided receiving treatment in the past?
 - Do you hide your medication?
 - Do you pick up your medication at the pharmacy yourself?
 - Do you take your medication at work?
 - Do you ever skip your medication in order to pre-empt side effects in social situations?
- Do you have access to a support network, whether it is personal or professional?**



Opening Up the Lines of Communication

“You have to be honest with your care provider. If you didn’t take the medicine, if you relapsed, or you...had unprotected sex...you got to tell all of that.”

-Tammy, woman living with HIV

Taken from “Everyone Has a Story: A Collection of Women’s Stories and Conversations of Survival and Leadership” (SisterLove)

Treat by Example

It’s important for health care professionals in the clinic setting to be aware of the impact that stigma can have on their patients. If clinicians show signs of discrimination against people living with HIV, patients may feel vulnerable, powerless and even lack confidence in their course of treatment.

Communicate Compassion to Patients – Conversation Starters

Here are some helpful conversation starters that you might try to help convey compassion and empathy for a patient facing stigma:

*“I know experiencing stigma and discrimination can be at times very painful. Many of my patients present similar frustrations...”
(Provide anecdotes to your patients)*

“You are in a safe and confidential environment here. It’s okay to share...”

“What you’re feeling is perfectly normal and common among HIV patients. Try not to bottle up your feelings about these experiences...”



“Sharing what you’re going through with others you trust can be an important part of dealing with your disease...”

“Connecting with others in your situation may help...”



Empower Your HIV Patients to Overcome Stigma

Foundational Steps for Success

- **Knowledge is power. An educated patient will be better equipped to make informed health decisions and to face stigma and discrimination and debunk common misconceptions**
 - For example, a common myth persists that HIV can be transmitted through casual contact, such as shaking hands, hugging or kissing, which adds to the stigma associated with the disease
- **Don't assume all patients have the same literacy level regarding HIV education. Offer regular opportunities to share basic HIV information with your patients and answer their questions**
 - Research has shown that patients with higher health literacy are more likely to adhere to HIV treatment
- **Create patient champions or mentors among clinic staff/patient volunteers to partner with new patients and guide them with strategies for responding to stigma in a positive and forward-looking manner**
 - Provide mentoring skills training to clinic staff/patient volunteers, such as how to act as a positive role model, avoid lecturing or passing judgment, and provide constructive guidance and feedback
 - Encourage mentors to meet with their patients on a regular basis
 - Instruct mentors to keep a log of issues and questions discussed during mentor sessions
 - Encourage mentors to help patients set personal goals for life and wellness with HIV and regularly revisit those goals to evaluate progress
- **Whenever possible, provide access to multilingual and diverse staff members as part of the patient treatment experience at your clinic. Patients will be more likely to share their experiences with staff they can relate to and who understand their cultural background and concerns**
 - Findings from the 2010 Clinic Care survey found that 82 percent of survey respondents stated that providing multilingual or multicultural staff is most valuable to retaining HIV-positive clients in care, indicative of the need for having a diverse clinic staff to address stigma in patients from varying backgrounds



Devastating Impact

“...The stigma associated with HIV and the resulting discrimination can be as devastating as the illness itself: abandonment by spouse and/or family, social ostracism, job and property loss, school expulsion, denial of medical services, lack of care and support, and violence. These consequences, or fear of them, mean that people are less likely to come in for HIV testing, disclose their HIV status to others, adopt HIV preventive behavior or access treatment, care and support. If they do, they could lose everything.”

- UNAIDS, the Joint United Nations Programme on HIV/AIDS



- **Keep a pulse on the community where you practice. It's important to understand the terms your patients and the larger community are using when discussing HIV in order to better relate to them. Be aware of local events and activities that could be supportive platforms for combating HIV stigma**
- **Remind your patients that they are not alone in facing stigma. More than 30 years into the fight against HIV there are large numbers of people successfully living with the disease today, despite the stigma**

Confronting Stigma

Use the following checklist of key areas to enable patients to address HIV stigma in their lives.

- To facilitate a stigma-free environment, deliver comprehensive HIV information in a safe, easily understood manner**
- Provide your patients with the basics of HIV education. Be sure to cover the following:**
 - Methods and risks of HIV transmission as well as protective measures
 - Risky behaviors that may make patients more vulnerable to spreading HIV
 - Treatment options, including the importance of finding an ideal treatment regimen that meets the needs of the individual patient
 - The importance of treatment adherence and methods to encourage medication-taking routines. The role of treatment resistance is also an important discussion
 - Understanding their numbers, including CD4 count and HIV viral load. The more informed patients are, the more in control of their condition they will feel
- Direct patients to services that support the well-being of those living with HIV**
- Emphasize to your patients that HIV can be a chronic, manageable disease. They have done nothing wrong and should not feel ashamed of, or apologetic for, their HIV status**
- Encourage your patients to avoid isolation due to their HIV status and fear of others' responses, as this can result in potentially harmful effects on their well-being**
 - If your patients are unable to discuss their status with family, friends or loved ones, refer them to organized support groups available in the HIV community, many of which offer online support forums
- Remind patients of their rights:**
 - People living with HIV can be selective about who they choose to disclose their status to
 - Health care providers who receive federal funding are not allowed to discriminate or withhold care based on HIV status
 - People living with HIV have the right to enjoy the provision of goods and services regardless of their HIV status, such as finding housing or visiting shops, restaurants and hotels
 - People living with HIV have the right to be informed about treatment options when their current treatment is no longer working or is affecting their daily lives through side effects
- Prominently display, and make otherwise available, information in your clinic about patient rights and resources to turn to if patients feel they have experienced discrimination or if their rights have been violated. Specifically communicate these resources to patients regularly**
 - Provide information about local organizations and AIDS Service Organizations (ASOs) that can provide counseling and legal services
 - People living with HIV can file a complaint through the Americans with Disabilities Act (ADA) if they feel they are being discriminated against by a state or local government or a public organization
- Ensure your staff is knowledgeable about patient rights. Train your employees on patient rights and their role, as health care workers, in empowering patients and on how to direct patients to additional services**



Rising Above

“Regardless [of] the virus, regardless [of] the stigmas, I refuse to allow somebody else to devalue me about something they know nothing about.”

- Elveth, woman living with HIV

Taken from “Everyone Has a Story: A Collection of Women’s Stories and Conversations of Survival and Leadership” (SisterLove)

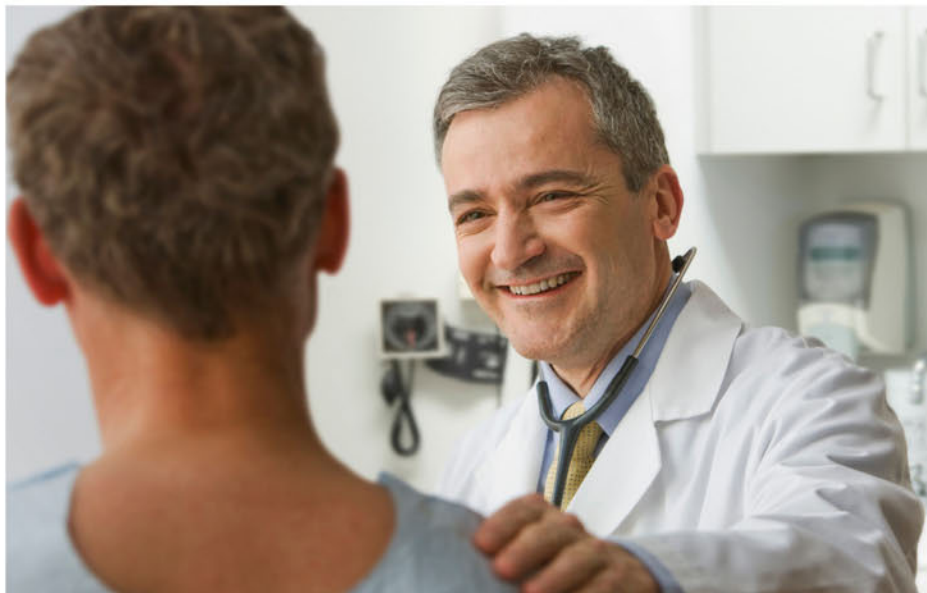
Conversation Starters for Patients

Suggest the following conversation starters to patients addressing their HIV status, and possibly stigma, with trusted family or friends.

“HIV is a chronic, manageable disease that I have been living with for X years...”

“Can you tell me what concerns you about me being HIV-positive? How can we change things so that we feel more comfortable around each other?”

“I would like to help you learn more about HIV so that you can understand how the disease affects me and you, as a part of my family.”



“I’m no different now than I was before my diagnosis. I hope you will support me and treat me the same as you did before I disclosed my status...”

“You mean a lot to me, which is why I’m sharing this news with you...”