



Meeting People Where They Are

Creating a Patient-Centered Care Environment

Ryan White HIV/AIDS Program and Patient-Centered Medical Homes

## PATIENT-CENTERED CARE FOR PEOPLE LIVING WITH HIV

### MEETING PEOPLE WHERE THEY ARE

Engaging with and providing the best possible care for people living with HIV (PLWH) is necessary for helping patients achieve the ultimate goal of viral suppression. Regardless of where on the HIV care continuum a patient is—receiving the initial diagnosis, starting treatment, managing the disease and other health and socioeconomic challenges, or receiving ongoing care—PLWH benefit from a patient-centered care (PCC) approach. PCC places patients—*people*—at the center of their own health care decisions and management and focuses on engagement.

### Patient-Centered Care and the Ryan White HIV/AIDS Program

During the last 27 years, the Health Resources and Services Administration’s (HRSA) Ryan White HIV/AIDS Program has played a critical role in the United States’ public health response to HIV. In 2016, the Ryan White HIV/AIDS Program served more than 550,000 PLWH, providing access to primary HIV medical care, medication, and essential support services to reduce transmission of HIV and to reach and maintain the goal of viral suppression. The PCC approach is implemented by Ryan White HIV/AIDS Program clinics and other provider sites that prioritize the most vulnerable populations—low-income

### ➔ DIRECTOR’S NOTE

This edition of HRSA CAREAction addresses the importance of placing people living with HIV (PLWH) at the center of their own care. This patient-centered care model focuses on shared decision-making, cultural competency, patient engagement, and ongoing communication along the HIV care continuum, to ensure that PLWH receive the care and support they need to achieve viral suppression.

For more than 27 years, the Health Resources and Services Administration’s (HRSA) Ryan White HIV/AIDS Program has been providing a comprehensive system of HIV care and treatment to low-income PLWH who are uninsured and underserved, including minority and ethnic populations, youth, older adults, and women. As leaders in advancing effective models of care, Ryan White HIV/AIDS Program service providers offer comprehensive care and treatment services by creating a supportive, patient-centered environment that empowers PLWH to make informed health care decisions and ensures the highest quality of care.

In addition to describing the elements of patient-centered care, this edition of HRSA CAREAction features “stories from the field”—examples of how Ryan White HIV/AIDS Program recipients implement a patient-centered care approach in their programs and how they continue to improve the quality of care for PLWH.

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PLWH who are uninsured and underserved, including minority and ethnic populations, men who have sex with men (MSM), youth, older adults, and women.

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Ryan White HIV/AIDS Program recipients have been, and continue to be, leaders in advancing the delivery of effective strategies for HIV care. Through a team- and patient-centered approach, Ryan White HIV/AIDS Program providers work with clients along the HIV continuum to address more than just their medical needs. Providers offer primary and specialty care expertise and support services to help patients effectively suppress the HIV virus, address serious treatment side effects, and treat the co-occurring conditions common among many PLWH. A recent study showed that patients who receive care through the Ryan White HIV/AIDS Program have better health outcomes than patients who do not receive Ryan White HIV/AIDS Program assistance. Among uninsured patients receiving care through the Ryan White HIV/AIDS Program, approximately 94.2 percent were prescribed antiretroviral treatment by their health care providers, and approximately 76.7 percent of clients were virally suppressed. By comparison, 52.1 percent, or about half, of patients who were uninsured and not receiving Ryan White HIV/AIDS Program assistance received antiretroviral treatment, and only 39 percent were virally suppressed. Among patients with private insurance, Medicaid, Medicare, or a combination of Medicaid and Medicare, approximately 4 to 7 percent were less likely to be prescribed antiretroviral treatment than those receiving care from the Ryan White HIV/AIDS Program only.<sup>1</sup>

As part of PCC, the Ryan White HIV/AIDS Program providers also address such issues as unstable housing, low income, lack of access to medications or food, discrimination, and other social determinants of health<sup>2</sup>

or factors that greatly affect the health outcomes of PLWH. Providers coordinate behavioral health, case management, and social service needs, including substance use disorder counseling, housing support for those with inadequate housing or homelessness, mental health services, and other core services, such as the following:

- Ryan White HIV/AIDS Program Part B AIDS Drug Assistance Program and the AIDS pharmaceutical assistance programs that allow PLWH to gain access to treatment and U.S. Food and Drug Administration-approved drugs.
- Medical case management services, which greatly help PLWH to manage, follow through, and adhere to their treatment plans.
- Support services, such as access to food banks/pantries, transportation to and from medical appointments, and emergency financial assistance.

## CREATING A PATIENT-CENTERED CARE ENVIRONMENT

Engaging patients and communicating effectively with them are key components in delivering comprehensive health care services within a patient-centered environment. In some cases, HIV can be the least pressing issue for PLWH, who may also be living with other health conditions—such as hepatitis C, cardiovascular disease, diabetes, or mental health issues—and may have such concerns as unstable housing and interpersonal violence affecting their care.

### ➔ HEPATITIS C TREATMENT EXPANSION

The Special Projects of National Significance (SPNS) Hepatitis C Treatment Expansion Initiative supported groups trying to increase access to hepatitis C virus (HCV) treatment for PLWH and ensure that people complete that treatment. About one-quarter of PLWH in the United States also are infected with HCV. HCV affects about 3.5 million people in the United States and is responsible for approximately 19,000 deaths each year. This initiative evaluated the effectiveness of four intervention models to deliver HCV treatment among HIV-positive populations. It also aimed to share best practices and lessons learned with Ryan White HIV/AIDS Program recipients and other HIV medical providers to improve access and quality of Ryan White HIV/AIDS Program services for their clients.

To help ensure that Ryan White HIV/AIDS Program clients are connected to and receive the highest quality of care and services through informed health care decisions, engagement and communication must occur at every point of contact between health care providers and clients. As described in the next sections, engagement and communication incorporate several key elements, such as a supportive environment, shared decision-making, cultural competency, and trained community health workers.

### **Creating a Supportive Environment**

Engaging a patient in care begins with creating an open and supportive environment where he or she has access to treatment, feels cared for, does not feel stigmatized by HIV/AIDS, and—most importantly—is heard and treated with respect. The PCC approach empowers PLWH to become engaged in their own care, alongside the involvement of their family members, caregivers, and the health care team.

### **Shared Decision-Making**

A PCC approach using shared decision-making (SDM) as a model allows patients to guide their own care by focusing the conversation on “what matters to them” as opposed to “what is the matter.” With SDM, Ryan White HIV/AIDS Program providers foster active engagement along the HIV care continuum by sharing and discussing HIV care options with their patients to help them make informed health care decisions. Using this model, health care providers talk about recommended treatment options and adherence strategies, for example, and are encouraged to ask their patients to share what they know about the options and solicit feedback on what might work best for them. SDM has the potential to increase patients’ confidence in their own abilities to make health care decisions, leading to more active involvement in their own health care.<sup>3</sup>

Ongoing engagement and dialogue between health care providers and clients through SDM builds trust and also may improve health outcomes of PLWH. Positive outcomes seen with SDM include retaining patients in care along the HIV continuum, identifying and treating serious health conditions or comorbidities in addition to HIV, improving medical adherence, and lowering health care costs.<sup>4</sup>

### **Embracing Cultural Competency**

Cultural competency—successful engagement with patients from different cultures, including communities vulnerable to HIV, such as ethnic/minority populations, individuals with low literacy rates, those with low

#### **➔ SHARED DECISION-MAKING<sup>5</sup>**

- Improves patients’ knowledge about their care options, including risks and benefits.
- Helps patients make health care decisions.
- Increases the patients’ active role in decision-making.
- Helps ensure that patients’ informed choices are consistent with their values.
- Enhances communication between patients and health care providers.

income, substance users, youth, MSM, and transgender populations—is a priority for the Ryan White HIV/AIDS Program. Health care providers identify the diverse needs of the individual patients, referring them to health and social services specialists who work collaboratively with patients to address their HIV-related needs. To help meet the diverse cultural needs of their patients, many Ryan White HIV/AIDS Program providers hire staff from the same cultural, linguistic, and ethnic backgrounds as their clients, and they educate all staff members on the cultural norms of the patient populations being served. Ongoing cultural awareness training for all staff is critical to maintaining and fostering a culturally competent environment.

Cultural competence is supported across all parts of the Ryan White HIV/AIDS Program.<sup>6</sup> Examples of programs that embrace cultural competence include the following:

- The national and regional AIDS Education and Training Centers (AETCs) of the Ryan White HIV/AIDS Program Part F offer diversity and cultural competency training and resources to grant recipients and providers. The National Multicultural Center AETC produced the seminal BE SAFE training manuals for care of African

Americans; Asians and Pacific Islanders; Latinos; and American Indians, Alaska Natives, and Native Hawaiians.

- The Center for Engaging Black MSM Across the Care Continuum (CEBACC) is an online resource for black MSM and their health care providers to improve the care received by this population. CEBACC offers [His Health](#)—resources to enhance engagement, linkages, and retention in care—and [Well Versed](#), resources and an online conversation forum for health care providers and black MSM about the care issues black MSM face. CEBACC was developed in partnership with the HRSA HIV/AIDS Bureau and the National Alliance of State and Territorial AIDS Directors.
- The “[In It Together](#)” National Health Literacy Project for black MSM was initiated to improve the capacity of health departments and community-based organizations to bolster client engagement and retention in care. Enhanced delivery of materials and services from providers ensures easier access to and navigation of services, thus improving health outcomes.
- The Secretary’s Minority AIDS Initiative Fund provides funding to build the capacity of community-based groups that offer culturally competent services. Minority AIDS Initiative funding (through the RWHAP-supported NMAC’s [formerly known as the National Minority AIDS Council] HIV/AIDS Stigma Program) has helped bring together a diverse cross-section of service providers—health clinics, community organizations, and AIDS service groups—to discuss stigma-related barriers to HIV care within communities of color. The program serves as a conduit for peer-to-peer technical assistance, providing agencies

working on the frontlines of the HIV epidemic with historically marginalized populations an opportunity to share their lessons learned and best practices in retaining these populations in care.

### **Using Community Health Workers and Peer Navigators**

Community health worker (CHW) programs and patient or peer navigators can play an important role within a PCC environment. With strong ties to the community, CHWs and patient/peer navigators are uniquely able to engage with PLWH, help them understand the complex health care system, educate them, and ensure that they receive HIV care. CHWs and patient/peer navigators also act as culturally competent patient advocates and serve as liaisons between the patient and the primary care team. CHWs and patient/peer navigators work closely with the client, case manager, primary care provider, and other team members to ensure that the client’s voice is heard and responded to. Many Ryan White HIV/AIDS Program providers have been building CHW programs to achieve positive health outcomes for their patients. The Ryan White Roper Wellness Center, part of the Roper St. Francis hospital system in rural South Carolina, for example, has added peer navigators as core members of every patient’s care team. One of HRSA’s Ryan White HIV/AIDS Program Part F Special Projects of National Significance (SPNS) Program initiatives that focused on the role of patient navigators with HIV-positive homeless populations (featured below) found that integrating a patient navigator into the HIV team may be an effective strategy for engaging this population in care.<sup>7</sup>

### **Stories From the Field: The Ryan White Roper Wellness Center, Charleston, South Carolina**

The Ryan White Roper Wellness Center, part of the Roper St. Francis hospital system for seven coastal rural counties, is a medical home serving PLWH. The Wellness Center, which receives funding through Ryan White HIV/AIDS Program Part C, employs 20–25 professionals who provide comprehensive HIV care, including social services support and behavioral health counseling and treatment. Every year the clinic serves approximately 800 clients, two-thirds of whom are black/African

American. Most clients served are insured; however, about 10 percent are uninsured.

Taking a patient-centered approach to care is fundamental to the Wellness Center’s comprehensive HIV care services and contributes to the high-quality care and support that clients receive. “We are always thinking of the patient first,” said Kimberly Butler Willis, director of the Wellness Center. “We are not only focused on the quality of the work we provide, but we also make sure our clients are satisfied with what we

do. Sometimes the clients themselves know best what they need.”

A passion for caring for PLWH, fostering open communication between client and provider, practicing shared decision-making, and being culturally aware of the client’s needs are some of the critical elements that form the foundation of the Wellness Center’s successful PCC approach. “Underlying PCC is a sense of mission that clients are to be served and they have particular challenges,” said Dr. Katherine Minnick, medical director. “If we honor that in our own interactions and individual appointments, we are honoring that challenge of being HIV-infected in the South and the particular challenges people find in their families.”

The clinical environment is designed to be welcoming and engaging and to enable all staff to communicate easily with one another and with clients. Patient care teams have multiple opportunities to interact with each other and their clients to address needs and challenges. Every patient is provided a 30-minute health care appointment, with the initial appointment lasting 60 minutes, more time than traditional medical appointments. All staff—primary care providers, peer navigators, nurses, case managers, and social workers—participate in a meeting every Monday morning to review and discuss major concerns and challenges of clients scheduled for the week, as well as those from the previous week. “Mini-teams” also have meetings among themselves throughout the month and with the clients to discuss their progress and any issues or concerns. “Hearing the same information many times emphasizes that communication is flowing through all the meetings and the patient is in the center for all teams at all times so that the message remains clear and it remains the same,” said Ms. Willis.

### **Impact, Success, and Lessons Learned**

Implementing the PCC approach has contributed significantly to the Wellness Center’s success in

helping PLWH manage the disease. Over the years, viral suppression and retention rates have increased, and gaps in care have decreased. Currently, 94 percent of clients are retained in care, and 89 percent have an undetectable viral load. In addition, monthly case manager audits ensure that patient file notes are concise, clear, and organized. Feedback from clients also is critical. Patient satisfaction surveys are conducted regularly to provide insight into a patient’s experience at the Wellness Center and how it can be improved or changed to best meet clients’ needs.

The Wellness Center also is trying to become more integrated into its hospital system by using the hospital services for routine testing. The Wellness Center wants to promote, across the hospital system, the valuable work and services it provides to the clients.

To strengthen patient-centered HIV care programs, the Wellness Center advises other clinics to consider the following:

- Include peer navigators to maintain effective communication between the health care team and clients. Because peer navigators are HIV positive and have to manage their disease and the many challenges associated with it every day, they bring a different passion and energy to the clinic. Peer navigators can make it easier for some patients to talk because patients know they are sharing their challenges with someone who is living the experience and truly understands what they are going through.
- Promote and foster open communication and a spirit of collaboration at all levels. Ms. Willis notes, “Hierarchies can really challenge a team. When all voices are equal, it brings natural connections from your team without being forced.”

## **Stories From the Field: The AIDS Resource Center of Wisconsin**

The AIDS Resource Center of Wisconsin (ARCW) Medical Center funded through Ryan White HIV/AIDS Program Parts C and D grants is home to Wisconsin's largest and fastest-growing HIV health care system. In 2016, ARCW served 3,650 clients; 3,300 of these were supported through the Ryan White HIV/AIDS Program. About 75 percent of clients were male, slightly less than 25 percent were female, and about 2 percent identified as transgender. Half of the clients served were white, 43 percent were black/African American, and the remainder represented Hispanic/Latino clients and clients of other ethnicities. The majority of clients were aged 25–64. Sixty-six percent of the client population lived at or below the federal poverty level.

As an HIV medical home, ARCW puts its clients at the center of its efforts to deliver integrated and comprehensive medical, dental, and mental health care and pharmaceutical and social services. A patient's care team consists of medical providers, case managers and, as needed, specialists—such as psychologists, financial services specialists, attorneys, and dentists—to provide services to meet the unique needs of clients. “It is not simply that a patient comes to one spot to get all his or her services, but that the care team takes on responsibility for the health of the patient that goes beyond what each individual team member would normally provide,” said Dr. Debra Endean, ARCW's vice president and chief operating officer. Clients also are viewed as a core part of the care team. Because patient care plans reflect each patient's personal goals and priorities, patients are empowered to participate actively and responsibly in their own care, increasing the likelihood that they will attend their appointments and adhere to medications.

In 2015, ARCW rolled out a new patient orientation approach. The approach was designed to increase the Center's rates of linkage to care. Each new patient

receives a call prior to the first scheduled appointment introducing him or her to ARCW and providing details on what to expect and whom they will meet at the center. All ARCW staff who interact with clients understand that many clients have experienced multiple traumas in their lifetime. ARCW leadership strongly believes that such awareness and sensitivity are critical to patient engagement and are essential components of an integrated, patient-centered approach to HIV care. Staff at every level need to understand that a traumatized patient who feels ignored or disrespected may be affected more significantly and more negatively than a patient who has not experienced trauma. “Our staff needs to recognize that we must meet people where they are and approach every single client attuned to making them feel welcomed and cared for, and to offer what they need in this environment,” said Dr. Endean. Cultural competence and affirming care is expected from each member of the ARCW team—clients have diverse backgrounds and many identify as members of the LGBT community.

Communication is another key component of ARCW's PCC approach. Staff gather for a “morning huddle” to discuss the clients on that day's schedule and make everyone aware of issues or concerns that the clients might be facing. Care teams also meet regularly to review patient records, discuss updates provided by the case managers, and share information about their clients. Providers can also access such client data as viral suppression, retention rates, and any comorbidities to allow care teams to address any challenges, concerns, or gaps in care with each patient during or between appointments. Care teams normally meet with clients for 30 minutes; appointments can be extended, however, if additional services are needed. Since this initiative began, no-show rates have decreased, and new clients have established relationships with ARCW staff members even before arriving for their first appointment.

## **RYAN WHITE HIV/AIDS PROGRAM AND PATIENT-CENTERED MEDICAL HOMES**

Patient-centered medical homes (PCMHs), a model of care supported by the Centers for Medicare & Medicaid Services, are meant to improve the delivery of primary care. PCMHs build on the PCC approach and focus on a partnership between patients and their primary care team using shared decision-making. With PCMHs, health care providers deliver comprehensive and integrated team-based care that is patient-centered, accessible with shorter waiting times for critical needs, and coordinated across the health care system, connecting patients to medical, behavioral, and social support services. The PCMH also takes a systems-based approach to improving health care quality and safety by collecting and responding to data about their patients' experiences.<sup>8</sup> For people living with HIV, having a "medical home" may streamline and facilitate

navigation of complex care services they need and greatly improve their health.

HRSA supports health centers working toward better care and lower costs for patients through PCMHs. Through HRSA's Accreditation and Patient-Centered Medical Home Recognition Initiative, health care centers are assessed on their approach to achieving PCC, including how they coordinate care and improve quality of care.<sup>9</sup>

HRSA's Ryan White HIV/AIDS Program has supported the development of expert HIV care and treatment programs that have, in effect, become PCMHs for PLWH. Ryan White HIV/AIDS Program recipients are playing an important role in transforming the delivery of primary care by expanding the number of PCMHs with a specific focus on HIV care delivery and improved patient outcomes.



### **MEDICAL HOMES FOR HOMELESS PEOPLE LIVING WITH HIV/AIDS—A RYAN WHITE HIV/AIDS PROGRAM SPECIAL PROJECT OF NATIONAL SIGNIFICANCE (SPNS) INITIATIVE**

People with unstable housing or who are experiencing homelessness are disproportionately affected by HIV; this population is severely underserved and often burdened with mental health conditions, substance use disorders, and lack of access to continuous treatment. These circumstances make this population vulnerable to delayed care and less likely to engage in care and adhere to effective treatment, such as antiretroviral therapy. This SPNS initiative targeted nine community-based clinical organizations and one multisite coordinating center, funding the implementation and evaluation of service delivery to homeless PLWH. The initiative aimed at integrating patient navigators and housing support into a comprehensive HIV medical home to better engage and retain clients experiencing homelessness. The goal was to address the following barriers to care in order to achieve the goal of HIV viral suppression and other positive medical outcomes:

- Lack of engagement and retention in HIV primary and specialty care
- Lack of affordable housing
- Insufficient appropriate mental health and substance use treatment resources
- Inadequate primary care in the medical home model
- Unresolved legal issues
- Interpersonal violence
- Frequent interactions with the criminal justice system
- Lack of transportation
- Lack of legal identification
- Food insecurity

## ➔ THE ROLE OF PATIENT NAVIGATORS IN BUILDING A MEDICAL HOME FOR HOMELESS PEOPLE LIVING WITH HIV/AIDS

The roles and responsibilities of patient navigators within patient-centered medical homes (PCMHs) were explored as part of the Ryan White HIV/AIDS Program Part F SPNS Program initiative’s multisite evaluation by the Medical Home Evaluation Research Team (commonly known as MEDHEART). The evaluators identified key tasks that patient navigators might adopt or modify when establishing effective PCMHs for homeless and unstably housed PLWH who have behavioral health conditions. These key tasks or activities include—

- Providing outreach to link disengaged patients to care
- Working collaboratively with the health care team and patients to develop realistic goals and care plans
- Supporting patient self-management
- Providing emotional support to patients and helping reduce the negative effects of stigma
- Coordinating, connecting to, and informing the patient about services across many systems, including housing and behavioral health services
- Keeping the health team informed about client circumstances

The evaluators concluded that integrating patient navigators into the HIV care team may be an effective strategy to engage homeless PLWH in HIV care and treatment—and ultimately to improve their health outcomes, although additional research is needed.<sup>10</sup>

## ➔ ONLINE RESOURCES

1. Cultural Competency and HIV/AIDS Care  
[hab.hrsa.gov/livinghistory/issues/competency\\_1.htm](http://hab.hrsa.gov/livinghistory/issues/competency_1.htm)
2. Center for Engaging Black MSM Across the Care Continuum  
[careacttarget.org/cebacc](http://careacttarget.org/cebacc)
  - His Health  
[www.hishealth.org](http://www.hishealth.org)
  - Well Versed  
[www.wellversed.org](http://www.wellversed.org)
3. In It Together—National Health Literacy Project for Black MSM  
[www.careacttarget.org/healthliteracy](http://www.careacttarget.org/healthliteracy)
4. Comprehensive, Patient-Centered Program Incorporates Strategies That Help HIV Patients Maintain Their Health, Leading to Enhanced Adherence, Better Outcomes, and Fewer Deaths  
[innovations.ahrq.gov/profiles/comprehensive-patient-centered-program-incorporates-strategies-help-hiv-patients-maintain](http://innovations.ahrq.gov/profiles/comprehensive-patient-centered-program-incorporates-strategies-help-hiv-patients-maintain)



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10. Sarango et al., 2017.

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