The HIV Clinic: Providing Quality Care

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Introduction

HIV/AIDS clinical care has improved dramatically over the decades, given the availability of new medications and a better understanding of how best to use antiretrovirals and deliver primary care to persons living with HIV/AIDS. Positive change on such a massive scale, however, brings with it new demands on clinicians.

Along with innovations in HIV drug therapies, HIV/AIDS care has become more complex than ever before due to increasing comorbidities that are attributable to HIV treatment and the aging of the HIV-infected population in the United States. Patient needs also have expanded across a broad spectrum of medical, psychological, behavioral, and social issues. Notably, significant numbers of infected individuals are identified and enter care late in the course of their HIV disease, confronting clinicians with complex and immediate care challenges.

Since the early days of the epidemic, clinicians have received training in HIV/AIDS clinical care through the AIDS Education and Training Centers (AETCs) Program – the clinical training arm of the Ryan White HIV/AIDS Program that is administered by the Health Resources and Services Administration (HRSA) and its HIV/AIDS Bureau (HAB). The AETC network conducts more than 14,000 training events each year with approximately 143,000 health care providers in attendance.

The *Guide for HIV/AIDS Clinical Care* is a pillar of the Ryan White HIV/AIDS Program's mission to continuously improve HIV/AIDS clinical care. The *Guide* was first published in 1993 as a collaborative effort of several regional AETCs. It was subsequently updated and expanded in 2006 and 2011. The version before you incorporates many new insights, but the time-tested format has been retained – easy access to crucial facts for a busy clinician.

The developers of the *Guide* strive to be responsive to how HIV/AIDS clinical care is provided today.

- With more routine HIV testing in medical settings, a large number of individuals are entering care via primary care sites that have relatively limited experience managing HIV/AIDS disease.
- A notable proportion of HIV/AIDS primary care in the United States is provided by advanced practice nurses and physician assistants.
- Shortages in the health care work force are worsening. Experienced staff members are aging and retiring, a limited number of new clinicians are entering primary care and specializing in HIV/AIDS care, and fewer clinicians are available in geographic areas with limited resources.

As a result, front line primary care providers may be less familiar with management of HIV/AIDS disease, as outlined in U.S. Department of Health and Human Services treatment guidelines (available at aidsinfo.nih.gov) and clinical practices presented in this *Guide*.

By presenting best practices in the clinical management of HIV/AIDS disease, the *Guide* can help us continue the remarkable advances in HIV/AIDS care that have made the Ryan White HIV/AIDS Program a model for health care delivery for our Nation and for the world.

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Abbreviations for Dosing Terminology

BID = twice daily

BIW = twice weekly

IM = intramuscular (injection), intramuscularly

IV = intravenous (injection), intravenously

PO = oral, orally

Q2H, Q4H, etc. = every 2 hours, every 4 hours, etc.

QAM = every morning

QH = every hour

QHS = every night at bedtime

QID = four times daily

QOD = every other day

QPM = every evening

TID = three times daily

TIW = three times weekly

Important Notice

The U.S. Department of Health and Human Services (HHS) HIV/AIDS Bureau is committed to providing accurate information on the care of HIV-infected persons. It is important to be aware that management options and protocols change over time. Forthcoming HHS guidance on certain topics may differ from recommendations contained in this *Guide*. Readers are encouraged to check for updates to treatment guidelines at AIDS Info (aidsinfo.nih.gov) and for updates to drug information at Drugs@FDA (www.accessdata.fda.gov/scripts/cder/drugsatfda).

Supporting Patients in Care

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* Based on Sheffield and Casale, see "References."

Background

Patients infected with HIV face a complex array of medical, psychological, and social challenges. A strong provider-patient relationship, the assistance of a multidisciplinary care team, and frequent office visits are key aspects of care. Through both the specific services they provide and their overall approach to patients, clinics can have a substantial impact on the quality of care for HIV-infected persons. For example, a patient-centered clinic environment in which education and supportive interventions are emphasized will greatly enhance patients' knowledge about HIV infection. Improving patients' skills in self-management will increase their participation in making health care decisions and provide a stimulus for more active involvement in their own care.

Special Challenges of Caring for HIV-Infected Patients

Providers need to be mindful of several special issues, including the following:

- Many medical, psychological, and social challenges confront persons living with HIV. The delivery of effective care usually requires a strong provider-patient relationship, a multidisciplinary approach, and frequent office visits.
- The stigma associated with HIV places a major psychosocial burden on patients. Stigma and discrimination must be addressed through strong confidentiality protections, emotional support, and cultural sensitivity. It is important to inform all patients of their rights and responsibilities in a language or manner that is respectful and understandable.
- Underserved racial and ethnic groups are overrepresented among people with HIV. Efforts to understand and acknowledge the beliefs of patients from a variety of cultural backgrounds are necessary to establish trust between providers and patients. Cultural competency is imperative in the field of HIV care.
- Providers play a key role in the public health system's HIV prevention strategy. Disease reporting, partner notification, and risk assessment are important aspects of care. Patients may see this as threatening and may need education and emotional support in order to participate in this process. Patients need to be informed of their rights under the Health Insurance Portability and Accountability Act (HIPAA) and understand the public health implications of HIV.
- Many patients have inaccurate information about HIV infection that can heighten their anxiety, sabotage treatment adherence, and interfere with prevention behaviors. Patients need assurance that HIV is a treatable disease and that, with successful treatment, they can experience a normal life expectancy. They also need to hear explicitly that HIV may be transmitted through sexual contact, injection drug use and other blood contact, and perinatal exposure, and that they can take specific measures to prevent transmission to others.
- Many patients need the support that only a peer can provide. Peer educators should be available to help patients navigate difficult health care systems, medication regimens, and lifestyle changes.

- HIV-infected patients need to have an active voice in their health care. Patient advisory groups can provide valuable program evaluation, which can be used to promote the patient-centered focus of the health care system.

These issues are discussed further in the sections that follow.

Components of HIV Care and Ways to Enhance Care

Important Components of HIV Care

A first step in ensuring that patients are "engaged in care" is the establishment of systems that include mechanisms for coordination and communication of care.

- Clinics must offer a nonjudgmental and supportive environment, because of the sensitive nature of issues that must be discussed.
- A multidisciplinary approach, utilizing the special skills of nurses, pharmacists, nutritionists, social workers, case managers, patient navigators, and others is highly desirable to help address patient needs regarding housing, medical insurance, emotional support, financial benefits, mental health and substance abuse counseling, and legal issues.
- Providers and other clinic staff members should be prepared to conduct appropriate interventions and make timely referrals to community resources and institutions.
- The primary provider should coordinate the various aspects of health care, with close communication among providers across disciplines.
- Individual office visits should be long enough to allow time for thorough evaluation.
- Providers must be able to see patients as frequently as their medical and psychosocial needs require, and clinic scheduling should be flexible so that patients with acute problems can be seen quickly and new patients can receive and access care in a timely manner.
- A range of medical resources, including providers with subspecialty and laboratory expertise, needs to be established. Co-locating services within testing and counseling sites or within HIV clinics is an excellent way to enhance patient compliance (see chapter *Clinic Management*).
- Patient education is a vital aspect of care that begins during the initial evaluation and continues throughout the course of care (see chapter *Patient Education*).

Taking Steps to Enhance Care

Providing comprehensive care for HIV-infected patients requires a patient-centered focus, a multidisciplinary team, and a willingness to spend time on building relationships with patients. Providers should do the following:

- With the help of case management agencies, counseling and testing centers, and patient-care navigators, provide quick and easy access to care to those newly diagnosed and entering into treatment.
- Front-end staff members need to be knowledgeable, compassionate and efficient with the initial patient contact in order to establish a warm and welcoming environment of care for the new patient.
- Make available self-management education to help patients identify problems, teach decision making techniques, and support patients to take appropriate actions to make necessary changes in their lives.
- Offer care in a patient-centered environment that allows the patient to actively participate in care decisions and provides patient-specific education.
- Encourage patients to learn all they can about their condition.
- Give accurate information regarding prognosis and antiretroviral therapy.

- Foster an atmosphere of nonjudgment, trust, and openness.
- Anticipate that significant time will be required for patient education.
- Outline the range of clinic operations and state the expectations for provider-patient communication. Outline how appointments are scheduled and how prescription refill requests are managed.
- Arrange to see patients with acute problems quickly. Establish a triage system to provide efficient service delivery.
- Ensure that there are open lines of communication with all patients to receive and answer questions, assess treatment effectiveness, and manage side effects.
- Provide safe and secure access for patients to communicate with staff. Patient portals can provide quick and direct access to nonemergent information and can provide accurate answers to questions that arise between visits.

Helping Patients Cope with Emotional Issues

Patients coming to terms with HIV infection often experience a range of emotions, including anger, fear, shock, disbelief, sadness, and depression. Loss is a major issue for patients with HIV because health, employment, income, relationships with friends, lovers, and family, and hope all may be threatened. Many patients feel overwhelmed, and even patients who seem to be adjusting reasonably well can find it difficult to keep all of the many appointments that may be scheduled as they initiate care. Providers need to recognize that patients' emotional states affect their ability to solve problems and attend to important medical or social issues. Providers can do the following:

- Assess each patient's emotional state and the availability of friends and family for emotional support. Some patients will need counseling to help them decide whether to disclose their diagnosis to friends, family, or employers as well as support in dealing with HIV infection. Patients often feel hesitant about seeking emotional and practical support.
- Deliver important information in easily understood terms and in small amounts. Reassess patient understanding of crucial information at subsequent visits, and repeat important information as necessary. Realize that many visits may be required before patients are comfortable with their care and the navigation of the health care system.
- Screen for anxiety, depression (including suicidal ideation), and substance use.
- Refer patients to community resources for crisis counseling, support groups, and, if appropriate, psychiatric treatment to help them achieve emotional stability.
- Assist patients in finding a case manager or patient navigator who can help them learn to navigate the health care system and reduce anxiety about keeping their lives in order.
- Assist patients in linking to social work services to assist with enrollment into medical insurance and to meet other social service needs, such as housing, food, child care, and substance abuse treatment.

Helping Patients Develop Self-Management Skills

Self-management support is defined by the Institute of Medicine as the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and setbacks, goal setting, and problem solving.

It can be viewed as a portfolio of techniques and tools to help patients choose healthy behaviors, and as a fundamental shift of the provider-patient relationship toward a collaborative partnership.

After patients have come to terms with their HIV infection, they are ready to embark upon the lifelong process of caring for themselves. Patient self-management involves adopting new health behaviors and requires changes that will occur as a progression of motivational skills. Motivation is defined as the "probability" that a person will enter into, continue, and adhere to a specific change strategy. Patients will feel empowered as they gain the skills and confidence to be active participants in their care.

The following practices should be adopted to foster patient self-management:

- Train staff at all levels on patient self-management concepts and how to incorporate them into care.
- Create an atmosphere conducive to learning these self-management skills, including but not limited to the following areas:
  - Problem solving
  - Medication issues
  - Working with the health care team
  - Planning for the future
  - Goal setting
  - Dealing with difficult emotions
  - Healthy eating
  - Advance directives
  - Sex, intimacy, and disclosure
- Adopt a team approach to health care with the patient as the central team player (patient-centered care).
- Incorporate problem-solving skills into all education efforts.
- Allow the patient time to set small obtainable goals as "first steps" in self-management.
- Realize that many appointments with multiple members of the health care team may be necessary before a patient has all the necessary skills.

Helping Patients Make Positive Changes in Health Care Behaviors

Regardless of whether a patient is new to care or has been in care for many years, the burden of a chronic disease is wearing. Positive change in behavior needs to be an ongoing focus of patient-centered care. After patients have self-management skills, they still need help setting action plans for their health care. The provider needs to help patients adopt realistic action plans by:

- Realizing that new health behaviors require motivation and occur as a progression of learned skills
- Bolstering patients' self-confidence by adopting action plans that:
  - Are realistic
  - Are something that patients find of value (i.e., something they want to do)
  - Are reasonable (it is better to underestimate and exceed the goal than to overestimate and fail)
  - Are action-specific, with small, obtainable goals

Peer Educators and Patient Advisory Groups

Patients need to be active participants in making decisions regarding their health care. Peer educators and patient advisory groups can help patients become more involved in their care.

In order to best support patients, it is helpful to have peer educators available for them during initial and subsequent visits. This helps to decrease patient anxiety and promotes a patient-centered atmosphere. Providers need to realize that peer educators are HIV-infected individuals who:

- Provide a unique approach to client-centered care
- May attend clinical sessions with patients and provide them with referrals for one-on-one counseling and support

- Are "seasoned clients" who have a desire to help patients in their care
- Work under the same confidentiality guidelines as all other staff members

Another valuable tool for patient-centered care is the use of a patient advisory group (PAG). The PAG is the voice of the people that the clinic serves. The HIV program will listen to this group's suggestions and use them to improve patient satisfaction and clinic functionality. The PAG's role could involve identifying clinic problems, recommending changes in the care delivery system, and discussing new treatment approaches. A successful PAG does the following:

- Provides comprehensive, individualized client-based education to all active patients
- Encourages clients to actively participate in treatment decisions and to involve family members and others who comprise their support system
- Designates members who facilitate meetings, promote upcoming meetings, coordinate speakers, and provide feedback to clinic staff and management
- Allows members to serve as cofacilitators, choose topics of discussion, set meeting guidelines, and invite new members
- Fulfills requirements of grants and other funding streams to have enhanced patient involvement

Stigma and Discrimination

Stigma is founded on fear and misinformation. Theodore de Bruyn observed that stigma is associated with HIV because, "It is a life-threatening disease; people are afraid of contracting HIV; it is associated with behaviors that are considered deviant; a belief that HIV has been contracted due to unacceptable lifestyle choices; and, some believe it is the result of a moral fault which deserves punishment."

Stigma can adversely affect how patients are perceived by others and how they view themselves. The stigma associated with HIV/AIDS is such that individuals known to be or suspected of being infected with HIV may be excluded from community activities and suffer isolation or abandonment. Some patients may feel ambivalent about seeking medical care if, by doing so, they risk disclosing their condition. Others may have learned from experience to expect rejection and therefore may not trust care providers. It is essential for providers to be supportive of patients who are dealing with the burden of stigma.

Stigma of Fear of Contagion

Unfortunately, patients and their families are often unaware that routine household contact with a person with HIV poses no risk of contagion. They should be educated about that, and also taught what to do in situations that do pose risk, such as when bleeding occurs. Clinic staff members must model behavior in this area. For example, gloves should be worn only as appropriate during physical examinations and as consistent with universal precautions. There should not be separate facilities or special procedures for HIV-infected patients.

Stigma Associated with Being Gay, Lesbian, Bisexual, or Transgender

Demonstrating respect and providing excellent care to patients with various cultural backgrounds, beliefs, and sexual orientations are central to medical professionalism. Providers should approach patients in an open and nonjudgmental fashion and be familiar with medical management issues unique to these populations, such as appropriate screening for sexually transmitted diseases for men who have sex with men (MSM) and hormonal treatment for transgender patients. Clinic staff members also must be respectful and supportive; having a staff that is familiar with lesbian, gay, bisexual, and transgender (LGBT) cultures is a natural way to create a welcoming environment. Providers and social workers should be aware of community

agencies with resources available to people who are lesbian, gay, or transgender. In addition, providers and clinic staff members should be aware of special legal issues that affect these populations. For example, designating a durable power of attorney for medical decision making can be particularly important in states that do not recognize same-sex partners or spouses as legal next of kin.

Other Special Cultural Issues

African-Americans, Hispanics, and some immigrant groups are disproportionately affected by HIV, and many people of color with HIV infection have major socioeconomic problems such as poverty, homelessness, lack of medical insurance, lack of acculturation, and undocumented immigration status. Many young people with HIV face similar issues. All these obstacles can make accessing health care difficult and attending to health problems less of a priority for the individual. A patient's cultural background influences health-related beliefs and behaviors, and personal or historical adverse experiences may make some patients distrustful of medical care. In addition, some patients' distrust of medical research can impede their willingness to access new drug therapies. Culturally competent communication between provider and patient may substantially affect adherence with therapies. For all these reasons, providers should do the following:

- Carefully explore what each patient believes about his or her health, what would be appropriate treatment, and who should be involved in medical decision making.
- Use professional interpreters to help overcome language barriers.
- Use case managers and peer educators to help bridge social barriers. The team of peer educators should be culturally diverse in order to be effective with all minority groups.

Confidentiality and Disclosure

Confidentiality of medical information is always mandatory, but the stakes are particularly high for patients infected with HIV, who risk losing medical insurance, employment, and the support of friends or family if their diagnosis is disclosed inappropriately. Although people with HIV infection are protected against discrimination under provisions of the Americans with Disabilities Act, discrimination can be difficult to prove, and there are strict time limits after which charges of discrimination can no longer be made.

Protecting Patient Confidentiality

Adherence to the HIPAA regulations is an important aspect of protecting patient confidentiality. Personnel policies should reinforce measures such as requirements that papers and computer screens containing patient-identifying information not be left unattended and should include provisions for documenting whether phone messages can be left for the patient, and if so, with whom.

Helping Patients Disclose Their HIV Status

Patients who have a support network function better than those who are isolated. However, patients' fears of disclosure are often well founded, and providers must find a balance between accepting patients' unwillingness to disclose their HIV status and the need to develop support networks. Patients may find support groups or individual psychotherapy sessions beneficial in deciding when to disclose, and to whom.

The sex and needle-sharing partners of people with HIV need to be informed about their possible exposure to HIV. Local health departments can either assist patients in making these disclosures or provide anonymous partner notification for them.

A patient-centered clinic staff can help patients with disclosure. For example, staff members

could encourage patients to bring their partners to one of their clinic or counselor appointments in order to disclose their HIV serostatus in the context of the clinic visit. This could allow the health care professional to answer the partners' questions and would provide a neutral environment for the disclosure discussion. Risk of intimate-partner violence should be assessed.

Public Health Role of Providers in the HIV Epidemic

Primary care providers must consider their public health role in curbing the spread of HIV. The incidence of HIV remains unacceptably high, and may be increasing in some populations, especially in communities with relaxed adherence to safer sex recommendations.

All AIDS diagnoses and, in some states, all positive HIV test results must be reported to the state health department. State laws vary in reporting requirements and subsequent notification of potentially exposed individuals (see the National HIV/AIDS Clinicians' Consultation Center *Compendium of State HIV Testing Laws* at www.nccc.ucsf.edu), but the name of the source contact is never divulged to the person being notified. Providers should become familiar with the laws of their jurisdiction by contacting their health department. (The Association of State and Territorial Health Officers provides links to all state health departments at www.astho.org.) Providers are required to do the following:

- Inform patients that their AIDS diagnosis or positive HIV status (depending on individual state requirements) must be reported to the state health department, tell them whether partner notification is required, and explain what they should expect regarding efforts that must be made by the patient, provider, or health department to notify sex partners or individuals who may have been exposed to HIV through their needle sharing. Assure them that their names are always kept confidential and are never given to potentially exposed individuals by the health department.
- Carefully assess patients' risk-taking behaviors, educate them regarding HIV transmission, and perform screening for sexually transmitted diseases. (See chapters *Preventing HIV Transmission/Prevention with Positives*, *Initial History*, *Initial Physical Examination*, and *Initial and Interim Laboratory and Other Tests*.)
- Provide counseling to encourage safer sexual practices and make referrals to drug rehabilitation or needle exchange centers as indicated. (See chapter *Preventing HIV Transmission/Prevention with Positives*.)
- Provide information about the role of antiretroviral therapy in reducing the risk of HIV transmission.

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Clinic Management

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Background

HIV outpatient care is unique in that it combines two very different approaches to patient care: long-term health care for individuals with a chronic condition, and the vital public health service of reducing transmission of an infectious disease. Thus, chronic treatment and retention in care are important both for individual patients and for public health.

HIV services often are provided to persons who have challenges in regard to participation in their own health because of discrimination, poverty, active substance use, or mental health disorders. The context of HIV care still is one of persistent stigma regarding HIV infection itself and discrimination against racial, ethnic, and sexual minorities who constitute the groups with the highest HIV prevalence and incidence. At the same time, funding streams from federal, state, and local governments have created opportunities for treatment of uninsured and underinsured individuals and provide resources for creating innovative, effective programs. The Affordable Care Act creates new opportunities to provide care for previously uninsured persons through two insurance mechanisms and other benefits described below. Treatment guidelines, operations research data, and technical support are available to assist in designing, operating, and improving service programs.

Patient Recruitment into Clinic

The persons who were easy to recruit and retain in care are already enrolled; the more challenging patients await recruitment. The U.S. Centers for Disease Control and Prevention (CDC) estimates that up to 25% of HIV-infected persons in the United States are not aware of their HIV infection (Branson, 2006), so there is still much work to be done to diagnose those individuals and link them to care. For newly diagnosed patients, studies show that there often is a substantial delay in attendance at an initial HIV care visit, with only 20-40% of them accessing care within 6 months of diagnosis (Mugavero, 2008). However, for the clinics, the number of newly diagnosed patients who present for care is substantial. A recent survey of 15 HIV programs across the country (median of 1,300 active patients each year) showed that a median of 250 (range 60-730) new patients were enrolled in each clinic each year (Yehia, 2008).

To facilitate linkage to care, every HIV clinic should 1) be linked to agencies that provide HIV testing and services for persons with HIV, and 2) make clinic access easy and comfortable for the clients of those outside services. Many HIV clinics establish referral linkages with community HIV counseling and testing services (CTS), AIDS service organizations (ASOs), sexually transmitted disease (STD) treatment facilities, family planning agencies, drug treatment facilities, local health departments, regional HIV hotlines, and local hospitals and emergency rooms. Many clinics also offer free confidential or anonymous CTS using state or federal funding.

Clinic personnel should build personal relationships with agencies that may provide referrals, invite staff of community agencies to visit the clinic, or hold open houses. Providers from ASOs, such as case managers, can be invited to accompany patients on clinic visits. Referring agencies must know what services the clinic provides and which patients it serves, as well as those it cannot serve.

Various approaches may help facilitate the patient's entry into care. A randomized study showed that using case managers to increase linkage of newly diagnosed persons to care can be effective: 78% of patients who had "strength-based" case management that promoted patient empowerment and self-efficacy kept an appointment within 6 months, whereas only 60% of patients without case management kept an appointment in the time frame (Mugavero, 2008).

Frequently, there is a delay of several weeks for a new appointment with an HIV clinician. Model programs have been established nationwide to improve linkage to HIV care. For example, the HIV clinic at the University of Alabama at Birmingham offers new patients an orientation visit in the HIV program within 5 days of their request for a new patient appointment. In this clinic, an HIV program staff member initiates a welcoming interaction during the patient's first phone call requesting an appointment and invites the patient to an orientation visit. During that visit, a psychosocial assessment is performed, specimens are taken for baseline laboratory tests, any immediate health issues are addressed, and referrals for mental health or substance use disorder care are initiated, if indicated. The orientation visit is used to give patients information on how to use the clinic effectively, provide other on-site nonmedical services, and start processes to access health insurance or AIDS Drug Assistance Program (ADAP) services as needed. The full initial medical visit is scheduled for a later date. In a nonrandomized comparison, the no-show rate at that clinic dropped from 31% to 19% with that approach (Mugavero, 2008).

Success in linking newly diagnosed persons to care may be enhanced through the participation of HIV-infected consumers as peer advocates and peer navigators (see chapter *Supporting Patients in Care*). Either volunteer or paid peer advocates can meet newly diagnosed patients who have been referred to the clinic, help familiarize them with the clinic services and staff, and help them adjust to both the fact of their HIV infection and their role as a chronic care patient. Groups for newly diagnosed persons co-led by a peer advocate and a professional as well as one-on-one interactions with patients within or outside the clinic (e.g., through a buddy system) can help newly diagnosed persons succeed in the clinic. In clinics that use peers, particular attention must be paid to confidentiality issues. The peers must be trained and supervised (see below), and the patients must agree to participate with peers, either individually or in groups.

Clinics differ in terms of the characteristics of people living in their catchment area and in regard to the levels of expertise of clinic staff members. Some successful clinics target a narrow but underserved population and concentrate on meeting the needs of that population. The environment and services offered by the clinic may be tailored to the patient population. For example, a youth-friendly clinic may differ in these respects from one targeting the working poor.

Retaining Patients in Care

Retaining patients in care is an ongoing challenge (see chapter *Supporting Patients in Care*). Among the 15 surveyed HIV clinics mentioned above, the median no-show rate for appointments was 28% (range 8-40%). For new patients, the range was 5-54% and for returning patients it was 2-40%. Across all the clinics there was a median annual loss-to-follow-up rate of 15% (range 5-25%) (Yehia, 2008). A number of approaches may help patients maintain continuous care in the clinic. An AIDS Education and Training Centers (AETC) working group is creating a toolkit for clinics to assist them in applying evidence-based methods to retention in care; this is available from the National Resource Center (NRC) of the AETC (see resources below).

Respect and cultural competence:

Respecting patients and providing them with effective care builds trust and keeps them coming back. New clinic attendees may have strong feelings related to HIV infection (e.g., fear of death) or how they acquired it (e.g., issues of shame or of secrecy). They may lack trust in medical care (from prior personal experiences or from historic events such as the Tuskegee syphilis experiments) or in current treatments (e.g., "Everyone I knew who took AZT died ..."). Some patients believe that HIV was created in government laboratories to target African-Americans and may or may not believe that the clinic staff is part of the conspiracy. It is important that all staff members be trained to anticipate, recognize, and work with issues such as these.

Patients may experience obstacles to care when there are cultural differences or language barriers between themselves and the staff members. Diversity among health care staff can further improve the experience of racial, ethnic, and sexual minority patients.

Welcoming staff attitude:

Providers must know the target population and build a system that will make patients feel welcome. Patients always should be made to feel that they came to the right place (even in cases in which they must be referred on to another provider or clinic). Patients should receive understanding and support, even if they arrive at the clinic without the required managed care referral form (at least for the first few visits).

Welcoming environment:

Physically comfortable waiting and examination areas, with linguistically and culturally appropriate decoration and reading material, are important for patient retention. A clinic that serves parents or children should make available toys or children's books.

Orientation to clinic systems and rules:

New patients need a brief description of clinic staff and services, routine and emergency procedures, prescription refill procedures, and after-hours follow-up. They must understand requirements for referrals from managed care providers, and new patients may need help with fulfilling such requirements. Patients also must be oriented to what is expected of them (e.g., arriving on time, calling to cancel or reschedule appointments) and the consequences of not fulfilling their responsibilities (e.g., clinic rules regarding late arrivals). A handout or pamphlet with this information can be very helpful. Patients need to know how to determine the insurance coverage and other benefits for which they may qualify, and how to find out their options if their insurance coverage changes.

Peer support:

Many programs have HIV-infected staff members who provide specific peer-support services. Patients who have had unpleasant experiences seeking medical care in the past, or those who are not used to engaging in medical care, may get better support from another consumer than from a nonpeer staff member. Youth especially may trust information from peers more so than from adult professional staff members.

Peer advocates or peer navigators may work in this role part time or full time, as either volunteers or paid staff. Often they work specifically to make new or recently returned patients comfortable in the clinic. Some programs designate consumers as peer navigators, emphasizing their role in helping new patients, or patients returning after being lost to care, in finding their way through the health care system and support systems. Peer advocates also can help patients ask questions or make their needs known to the clinic staff. Advocates or peer-support persons can be instrumental in helping patients build self-

esteem and acquire new habits that will enable them to use health care services in a proactive manner. Peers are especially helpful when they model good health behaviors, including adherence with appointments and medications and with avoiding unsafe sex or other HIV transmission activities. In some cases, peers have been the basis of a successful program, but in other cases peers model poor health behaviors and themselves become ill. Peers need to adhere to confidentiality rules and good work habits and need to provide accurate information to other clinic staff. Effective selection, training, and supervision of peers are extremely important.

Systems to support attendance:

Clinics should provide feedback and encouragement to patients about the importance of attending scheduled visits. This can be done through written materials such as posters and pamphlets, as well as through comments made by providers during clinic visits. These very inexpensive interventions have been shown to improve clinic attendance (Gardner, 2012).

Patients should receive appointment reminders about 48 hours before each appointment. Reminders typically are given by phone or mail, although text messaging or other forms of electronic communication may be more useful in some settings. It also may be effective to have a staff member contact patients who have missed appointments to find out what prevented them from attending, offer to reschedule, and try to eliminate barriers to clinic attendance.

Factors such as child care needs, work schedules, and transportation problems can be substantial barriers to attending clinic appointments. Addressing these and other challenges may require coordinated efforts by the clinic staff, case manager, and others. In some instances, AIDS service organizations and other community organizations may have funding available to assist with these efforts.

Some programs have a policy detailing their interventions following one or more missed visits: usually one or more phone calls comes first, then a letter to the last known address, and as a last measure, some programs will dispatch personnel to visit the last known address in an attempt to reconnect with a patient who is lost to follow-up. These efforts are more successful when patients are asked for current telephone, address, and other contact information at every clinic visit. Staff members must know to whom a patient has disclosed his or her status; in verbal and written correspondence, staff members must avoid unintended disclosure of the patient's HIV infection.

It is important to document movement of patients to other locations (including correctional facilities) or other care providers whenever the information is known so that these patients are considered transferred rather than lost. Some states provide public lists of incarcerated persons; larger programs may use those lists to find patients who have been missing for some time.

HIV programs can be aggressive in trying to connect with patients who are missing, but also must respect explicit decisions by competent persons to change providers or to forgo medical care.

Outreach encounters to promote participation in care:

A study of seven sites across the United States, funded by the Health Resources and Services Administration (HRSA), found that outreach by health care professionals increased clinic attendance and that frequent outreach by any program staff member increased adherence with antiretroviral therapy (see "References," below). Outreach by medical professionals included efforts by physicians, nurses, or physician assistants to meet patients outside the HIV clinic setting, often in another part of a medical facility such as an inpatient unit. These encounters were the most expensive type of outreach, but the most effective in engaging new patients in care. Encounters with medical professionals did not increase adherence with medications, however. Other types of outreach, either face-to-face or otherwise (by phone, email, or postal service), by professional, nonprofessional, or paraprofessional staff members, increased adherence with medications, but not with clinic attendance. More frequent encounters of this type were associated with greater improvements in adherence. The results of the study suggest that initial face-to-face contact with medical providers is important for establishing trust that enables new patients to engage in care, and that frequent encounters with other staff members is important for maintaining patients on medications.

Special Population: Women of Color

A 2008 report commissioned by HRSA collected data from the published literature, key informant interviews, and a consultation meeting with Ryan White Care Act (RWCA)-funded providers to provide information on barriers and effective interventions to assist women of color in succeeding with HIV care. Three central themes were extracted from these varied inputs:

1. Development of a responsive care environment that incorporates respect, cultural competency, and flexibility to meet women's needs;
2. Incorporation of peers into the care system as trained and paid participants in the care teams; and
3. Addressing women's needs through care coordination, flexibility, health system navigation, and better coordination and communication between medical and social service providers.

HRSA funded a number of clinical sites to test different methodologies applying these principles through the Special Programs of National Significance mechanism; these projects are ongoing and results are not yet available.

Models of Care

Chronic Care Model

Popular in recent years, the chronic care model refers to a mechanism for providing patient-centered care using a variety of staff personnel and interventions to maximize desired health outcomes. This approach has been most highly developed for diabetes care, but it can apply equally well to a wide range of chronic illnesses. In this model, patient training in self-care is key. In contrast to the tradition of teaching patients the pathophysiology of their health condition in lay terms, with this model, training involves focused skills building so that patients can better monitor their health status, use their discretionary medications, and know when and how to contact the professionals for assistance. Frequent contact

between patient and clinical staff, both face-to-face and through other means, both in clinics and in the community, usually are involved. Care is directed toward panels of patients, not just individual patients. Program-wide monitoring of process and outcome variables, such as frequency and results of CD4 cell counts and plasma HIV RNA levels, informs the practice as a whole as well as the quality of care for individuals. These interventions have been shown to improve outcomes, but do not necessarily reduce costs because the staff time required can be substantial.

Patient-Centered Medical Home

The chronic care model concept has been merged with the concept of a home to coordinate care and medical records for children to create the current model of the Patient-Centered Medical Home or PCMH. This concept usually is applied to primary care providers and practices; however, it potentially applies to a specialist who cares for the most prominent or demanding of a patient's health problems as well as other primary care issues. The chronic care model is limited to treatment of one health condition whereas the medical home model supplements such targeted care (e.g., HIV-specific care) with coordination of the other health services the patient may need. HIV programs often act as the primary care provider, especially for patients who do not have insurance and therefore have limited access to other providers, whether the practice is otherwise a primary care or specialty clinic. Many HIV clinics have the capacity to organize and implement a chronic care approach and to coordinate services across other specialties and providers in order to be a true medical home. Several national organizations provide certification of PCMH status to clinicians and practices. One organization is the National Center for Quality Assurance or NCQA (see details on its PCMH certification process on its website (www.ncqa.org). NCQA will certify individual providers and practices even when they are located within larger institutions. Another organization is the Joint Commission (www.jointcommission.org), which usually certifies PCMH status within an organization that has Joint Commission accreditation for other purposes. General information about the concept and other agencies that provide certification is available online at the National Center for Medical Home Implementation (www.medicalhomeinfo.org). In some states or localities, insurers such as Blue Cross and Aetna have their own certification process. Some health plans provide additional payment to primary care clinicians and practices that are certified as medical home providers, to support the health informatics infrastructure, care coordination, teaching and skill building, and follow-up outside of office visits that are required to manage panels of patients in a proactive manner. The PCMH approach also will provide financial opportunities for practices that become involved in Accountable Care Organizations (ACO), as pay-for-performance models of reimbursement are implemented across the United States. HRSA provides technical assistance to Ryan White grantees interested in being certified as a medical home, and to those interested in learning the lessons of this process even if not seeking certification. Additional information regarding training, resources, and webinars is available on the HRSA Target Center website (careacttarget.org).

PCMH Neighbor

This is a concept for specialty practices who do not wish to or are not able to take up full care coordination for a patient, or who may not be eligible as specialists to become certified as a PCMH (see "References," below). With this concept, a specialist participates in timely and thorough sharing of information and care coordination with a patient's primary care medical home, so that the full array of PCMH services is available without duplication but

with the added expertise of the specialty practice. At this time, there is no additional reimbursement for this status. However, implementing this enhanced level of care coordination with the patient centeredness, proactive approach, and skill building that characterize a PCMH, is expected to improve outcomes and may create opportunities for enhanced reimbursement in the future. This coordination also will be useful for specialist participation in ACOs.

Clinical Services Needed for HIV Care

Optimal array of services provided by an HIV clinic

At a minimum, HIV medical care providers need to offer confirmation of HIV infection, education, recommendations, and management regarding antiretroviral therapy; prevention, diagnosis, and management of HIV-related opportunistic diseases and treatment-related complications; screening and referral for common comorbidities, and linkages to other general health services. Most patients will need additional primary care and specialty health care and support services; it is often more effective and more convenient when these are available on-site rather than by referral. For health interventions to be successful, many patients will need assistance with health behavior change.

The services ideally provided by the HIV clinic include those on the list that follows. Detailed information on most of these topics is available in other chapters in this manual. These standards are derived from the primary care guidelines of the HIV Medicine Association of the Infectious Diseases Society of America (HIVMA/IDSA), the HHS *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*, the HHS *Guidelines for the Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents*, the CDC guidelines on prevention services in HIV care programs, as well as U.S. Public Health Service Prevention Task Force and American Cancer Society recommendations (see "References," below).

- Age-appropriate immunizations including HIV-specific indications for some, including pneumococcal vaccine, influenza vaccine, hepatitis A and B vaccines, quadrivalent human papillomavirus vaccine in appropriate age groups (see chapter *Immunizations for HIV-Infected Adults and Adolescents*).
- Screening for STDs (syphilis, gonorrhea, chlamydia, trichomonas in women, hepatitis B and C) at enrollment and periodically. After the initial screening, new standards promote periodic screening for acquisition of hepatitis C in persons at risk.
- Assessment of ongoing sexual or drug-use behaviors associated with HIV transmission, and counseling or other interventions to reduce transmission behaviors. Interventions regarding sexual transmission behaviors should be linked with family planning.
- General health screening for hypertension, diabetes, dyslipidemia, and cardiovascular risks, and cervical, breast, and colon cancer. The role of anal cytology in screening for anal cancer remains uncertain because of limited data on effective management of anal dysplasia.
- Care of common general medical illnesses including hypertension, dyslipidemia, uncomplicated diabetes, obesity, asthma, and chronic obstructive pulmonary disease. Care of a wider range of disorders, such as congestive heart failure and chronic kidney disease, will vary by practice.
- Evaluation and care of common comorbidities including hepatitis B and C infection and latent and active tuberculosis (TB). Treatment of active TB, including

directly observed therapy, often is provided by public health agencies; treatment of hepatitis may require referral to a specialist (though increasingly HIV providers are likely to manage treatment of HCV in coinfected patients as additional direct-acting antivirals for hepatitis C become licensed, with their improved efficacy and lower side-effect profile).

- Provision or linkage to oral health care, nutritional services, and other medical specialties including ophthalmology, dermatology, and oncology.
- Provision or linkage to HIV care for pregnant women, adolescents, and infected or perinatally exposed infants.
- Behavior change for general health issues including smoking cessation and other unhealthy substance use, diet for weight control, and exercise.
- Behavioral health services for adaptation to the illness, mental health disorders, and substance-use disorders including unhealthy alcohol use.
- Provision or linkage to social support services, including community-based case management.
- Additionally, clinics should have a system in place to protect the safety of their employees in regard to occupational HIV exposure (see chapter *Occupational Postexposure Prophylaxis*).

Resources required in providing comprehensive HIV care

Patient access is maximized in clinics that can accept Medicare, Medicaid (including Medicaid managed care), and county insurance programs. Clinics with access to Ryan White Treatment Extension Act funding must accept patients regardless of health insurance status or ability to pay. Federally qualified health centers also can accept uninsured patients and have an important role in expanding access to care. Every state receives Ryan White Part B funds for an ADAP to pay for antiretroviral agents and often other drugs for the uninsured or other eligible persons with HIV. Details vary by state and are available at each state's HIV hotline (for phone numbers, see hab.hrsa.gov/gethelp/statehotlines.htm). Clinics should assist appropriate patients to enroll in the ADAP, and to access the drug coverage or other clinical services that vary by state.

Within designated metropolitan areas, Ryan White HIV/AIDS Program Part A funding may be available. Clinics planning to serve a moderate-to-high volume of HIV patients can apply for a Ryan White Part C planning grant. Clinics serving women, pregnant women, youth, and families are eligible to apply for Ryan White Part D funding. Clinics may collaborate with other agencies in seeking Ryan White funding. Smaller programs may become satellites of larger Ryan White-funded programs. Other individual providers or small clinics may be eligible for Part B reimbursement for medical care of uninsured persons, by working with local case management agencies.

The ACA created online insurance marketplaces or exchanges, at which persons and families with incomes between 100% and 400% of the Federal Poverty Level (FPL) can purchase affordable insurance using tax rebates (for 250-400% of FPL) and other subsidies (for 100-250% of FPL). In addition,

many states are expanding Medicaid eligibility, for example to persons and families with annual incomes up to 138% of FPL. Another benefit of the ACA for persons with HIV is the requirement that core health benefits, including evidence-based preventive services, are provided by all health plans. HIV patients will benefit from the fact that preexisting conditions no longer disqualify persons from obtaining individual health insurance at competitive rates, and that more employers are now expected to provide health insurance for employees. Ryan White Part B Drug Assistance Program (DAP) funds may be used to assist patients with the costs of health plans if doing so is less expensive than providing direct benefits to DAP beneficiaries. Details about the plans available on the exchanges, their costs and benefits, the role of DAP, and Medicaid eligibility vary by state. HIV provider organizations will need to contract with some of the new plans available on their state exchanges, and providers will need to educate themselves on details of their plans. Local organizations have been designated as Certified Application Counselors (CACs), which allows trained staff to assist patients with enrollment on the exchanges and to certify that hardcopy documentation provided by patients, if needed in the course of online enrollment, is accurate. Other help may be provided by ACA navigators, who can assist clients with enrollment decisions but are not able to certify clients' documentation. Specific details and mechanisms for this interaction between ACA insurance benefits and Ryan White benefits are still evolving. Updated information on the benefits of the ACA for persons with HIV is available on the HRSA Target Center website (careacttarget.org).

Personnel:

For patients who are self-sufficient or can access community-based services on their own, a lone provider potentially can deliver comprehensive HIV care. In most circumstances, however, patient care needs are met more effectively when multiple team members are available at the clinical site.

Facilities:

In addition to the usual office layout, other facilities are useful. An examination room suitable for gynecologic examinations is important. An apparatus for pulse oximetry is very useful in assessing patients with respiratory symptoms. Easy access to facilities for collecting venous blood, urine, and stool specimens should be available. On-site access to rapid tests that do not require Clinical Laboratory Improvement Amendments (CLIA) certification may be useful, such as urine pregnancy tests, fingerstick blood glucose tests, and perhaps the rapid HIV antibody screening tests. Laboratory certification to perform urine analysis and microscopic examination of vaginal fluid specimens is very useful. Refrigeration to maintain vaccines and material for tuberculin skin testing is necessary. Refrigeration also enables the clinic to provide patients with on-site injection of medications required once a week or less frequently.

Training and technical assistance:

Patients look to nontechnical staff to corroborate information given by physicians and midlevel providers. Further, patients expect the same accepting attitude from all staff members. Thus, all clinic personnel need training in both technical and cultural matters. One important resource is the AETC NRC (www.aidsetc.org) and the local performance sites of the AETCs funded by HRSA to provide training and technical assistance to clinics. The NRC, local AETCs, and the website of the National HIV/AIDS Clinicians' Consultation Center (www.nccc.

ucsf.edu) provide detailed and patient-specific education to assist clinicians in making treatment decisions. Written educational materials for staff, such as national and regional treatment guidelines, may be obtained free of charge via the Internet and are updated regularly. Many regional and national meetings provide training in both clinical care and prevention. Assistance with enhancing and implementing systems of care, including instituting a quality management program, also is available from the AETCs. See chapter *Web-Based Resources* for other resources for training and information. The National HIV/AIDS Clinicians' Consultation Center's Warmline provides expert clinical advice on HIV/AIDS management for health care providers. This telephone consultation service is available Monday through Friday, 9 a.m. to 8 p.m. eastern time, at 800-933-3413.

Implementing interdisciplinary care in the clinic

It is not enough to have staff members from many disciplines on the payroll; rather, systems that allow staff members to function as a team must be created. Training with follow-up by supervisors is essential. Specific tasks for each staff member need to be assigned (see Table 1). Ideally, members of the staff can meet for a few minutes prior to each clinic session to anticipate special needs and allocate personnel resources. Some clinics place a checklist on each chart at each visit to indicate which team members a patient is meant to see that day and to confirm that all intended interactions have occurred.

The team's potential can be best utilized if there is a regular opportunity to meet and discuss patients outside clinic sessions, in multidisciplinary team meetings. When all members participate, the discussions can range from the selection of antiretroviral regimens for a patient to addressing the patient's adherence issues or chronic mental illness. Services for infected and affected family members also can be coordinated at these meetings.

Table 1. Clinic Personnel Responsibilities

Tasks prior to a clinic visit

- Remind every patient of appointments via phone call or mail.
- Review charts to list items to address during the visit.

Tasks during a clinic visit

- Verify patient's current contact information and current insurance status.
- Orient new patients.
- Assist with insurance gaps (e.g., teaching about need for referrals, help with insurance application or ADAP).
- Assess other barriers to care and psychosocial needs.
- Assess medication adherence.
- Teach and provide behavior change counseling about medications and self-care.
- Assess ongoing transmission behaviors.
- Teach and provide behavior change counseling about transmission behaviors.
- Educate about clinical trial opportunities (if applicable).
- Make referrals for psychosocial services.
- Make referrals/appointments for medical, dental, mental health care

Tasks following clinic sessions

- Make follow-up calls regarding new medication regimens or referrals.
- Call or mail correspondence to patients who missed their visits.
- Help patients overcome barriers to clinic attendance.
- Extract patient data and enter it into the information system, or upload data from an electronic medical record into reporting or data management software.

Support Services and Linkages Needed for HIV Care

Case management and support services enhance clinical care

Case managers assist patients in accessing the range of services and entitlements that can help them succeed in treatment. This may include helping patients apply for insurance; access support groups; access supplemental food, housing, homemaker, and other concrete services; and access mental health and substance abuse services. Excellent case managers also help motivate patients.

Traditionally, case managers should perform periodic assessments of clients' needs and update their comprehensive care plans at least every 6 months. Home visits can be very useful as part of the assessment. Some case managers or their agencies will provide certain direct services themselves; these may include short-term counseling, transportation for clinic visits, accompanying patients to clinic visits, and providing financial assistance for specific emergencies.

In many localities, HIV case management has been a service provided by community-based agencies. With the evolution of the PCMH concept, and a stronger need to have health care coordination for patients with multiple complex medical conditions, the approach to HIV case management is evolving. A new, and perhaps more useful, model is one in which community-based case managers provide linkage and follow-up for community-based services such as health insurance, transportation, housing, food security, income, and psychosocial support generally. These case managers often have training in a psychosocial discipline. At the same time, medical case managers, usually nurses, provide coordination of medical care services, with support for appointment and medication adherence, side-effect management, self-care, and clinical monitoring between office visits.

Close coordination between clinic staff and case management is important for avoiding duplication of efforts and services. Periodic case conferences between clinic staff and case managers are ideal. Written communication, for example, when sharing case management care plans, can be useful. Case management agencies and clinical sites need to obtain written consent from patients to share the information that allows coordination.

Creating useful linkages with community-based services

Clinics can develop relationships with community-based case managers or directly with providers of specific services, such as mental health, substance abuse, or housing services. Personal contact between staff members of clinics and outside agencies is important for establishing the relationship, and ongoing contacts are necessary for coordination. Community organizations often are pleased to give in-service education to clinic staff personnel in order to streamline the referral process. Clinics should make their expectations clear to community-based agencies. Clinics can function as advocates to ensure that their patients receive the attention and services for which they were referred. Periodic interdisciplinary meetings of clinic staff with representatives of community-based agencies, including case managers, are very useful.

Consumer involvement in HIV clinical care

Many clinics have created patient (consumer) advisory groups to participate in planning and quality management. The role these groups take depends on the specific clinic; some advisory boards educate themselves about clinic issues and provide expert input to clinic processes. Other boards act more as social event or support groups. See chapter *Supporting Patients in Care* for further information.

Enhancements to increase the HIV clinic's effectiveness: information and support

Clinics can enable patients to better care for themselves by providing them with information about HIV and by helping to build a community among them.

Much information is available for patients, including publications on medications, side effects, and adherence. Many clinics display HIV-related education materials, including information on safer sex practices and birth control; many also provide male and female condoms with instructions about their use. In some clinics, a separate area for educational materials may help clients maintain confidentiality. Free educational materials are available from federal and state HIV websites, and the pharmaceutical industry also produces some appropriate materials.

Many ASOs and clinics host support groups for interested patients. Participation must be voluntary, and only patients who are comfortable with revealing their status to other patients will be willing to participate. Some support groups target specific populations. Groups may be more effective if an experienced counselor or mental health provider leads them.

Some clinics hold classes on HIV and adherence. Other clinics provide periodic symposia to keep patients up to date on treatment advances. Clinics serving pregnant women and parents may include classes on birth preparation and parenting. For clinics that have a community advisory board, the board can be the organizing force for these community updates. Both public grants and funds from the pharmaceutical industry may be used to support these events.

Some youth-oriented clinics arrange social events and outings for their patients. Programs for children or mothers may provide support services for both infected and affected children, ranging from formal psychological care to supportive recreational activities after school or during school breaks.

Medical Information Systems: Tools for Enhancing Care

Medical information systems may include Practice Management Software (PMS), Electronic Health Records (EHRs), and Personal Health Records (PHRs). These three types of software may be available as a suite or as separate products that can be linked, although the linkage of separate products sometimes is challenging. Software products may be designed to run on one desktop computer in a small practice or on a computer server that can be accessed by many users simultaneously, or they may be based on the Internet and managed by the vendor. In all instances, backup of the data and maintenance of confidentiality and compliance with *Health Insurance Portability and Accountability Act* (HIPAA) rules and other laws are necessary.

PMS refers to software used principally for scheduling and billing; it includes information on patient demographics, insurance or payer, attendance with appointments, diagnoses, and sometimes other information. This is very useful in tracking clinic productivity and patient adherence with visits, and in developing an overview of a patient population and understanding the finances of a practice. PMS software can provide data regarding some quality measures, because services such as vaccinations and procedures performed within the practice can be tracked easily.

EHR refers to software used for clinical care, as a substitute for or supplement to a paper medical record. Providers enter their notes into these systems, and clinic staff document procedures and interventions performed in the office. With many systems, prescriptions may be written within the system and sent to pharmacies electronically or by fax,

diagnostic tests may be ordered, and test results may be sent electronically into the EHR for clinician review and action. Paper documents often can be scanned into the system so that hard copies of outside reports can be included in the medical record. EHRs that substitute for paper records can reduce issues of storage, retrieval, and access to paper charts once the transition is complete.

EHR refers to software that the patients can access to see part or all of their medical record. These systems are designed to empower patients as members of their health care team, to provide detailed information to them, and to promote interaction between the consumer and provider.

Potential advantages of EHRs

In an era of transformation of the U.S. health care system, much is said about the potential of these software products to increase efficiency and reduce errors. While this potential is real, substantial effort and investment is required to deploy and maintain systems that are useful to clinicians, administrators, and payers. An EHR for a small office or one that is deployed only in an HIV program can be managed fairly easily, and some products developed specifically for HIV care are available. An EHR for a large organization, such as a multispecialty group, is more complex and requires much more planning, training, maintenance, and sometimes customization to meet the needs of all the users.

Success in EHR implementation is greater when the users are involved in the selection and implementation of the system. Commercially available systems run on servers for large organizations may provide options for customization; however, customization greatly increases the cost and complexity of installing the software updates that are likely to be required.

EHRs may be text based (such as the system used by the Veterans Health Administration) or data based. Text-based systems are often quicker to learn; however data-based systems may provide more information for quality and program management and reporting needs and may be more useful for billing functions. Some EHR software packages are available at no cost (such as the Veterans Health Administration system and other open-source software) whereas others are available commercially and are maintained by vendors.

Once fully implemented, EHRs are expected to improve quality by improving communication and coordination among clinicians, reminding clinicians about standards of care and the timing of health maintenance or monitoring, avoiding errors associated with handwritten notes or prescriptions, documenting prescriptions, and providing warnings on potential drug interactions or hazards associated with specific diagnoses. EHRs are expected to lower costs by reducing the expense of maintaining paper records and by reducing duplication by sharing prescriptions, test orders, and test results among all users. EHRs can provide both process and outcome data for monitoring and for quality improvement activities (see chapter *Quality Improvement*), and data for Ryan White grantee reports. They also may make it easier for practices to fulfill and document adherence with the standards of payers.

Medicare and other payers are currently offering incentives for specific uses of EHRs, for example when at least 75% of prescriptions are sent electronically (because this is thought to reduce prescription errors) and for other types of "meaningful use" that are thought to improve the organization of care and adherence with clinical care standards.

Cautions

These software packages are complex entities that require substantial staff time and effort, hardware purchase and maintenance, training, and modifications in workflow. EHRs are not simply replacements for paper records; effective use involves changes in the work habits of clinicians. Successful implementation of an EHR system requires working with the end users as the system is developed so that reasonable compromises and accommodations can be made. Choices must be made regarding both the software and the hardware to be used (e.g., a laptop computer used by a single clinician in multiple examination rooms versus a fixed desktop computer in each room). An EHR system that must share data with another system such as a hospital EHR or a laboratory reporting system can be very complex and require substantial investment of time and money, even when the different software systems use compatible data standards. Effective implementation often occurs over the course of years. Implementation of EHR systems is not a panacea and will not solve all health care system problems, but use of EHRs is likely to be a necessity for functioning in the evolving systems of health care finance and reimbursement, as well as an essential tool for monitoring and assuring quality of care for the individual patient and at a population level.

Ensuring that patients receive necessary services at clinics without EHRs

At clinics in which paper charts are in use, forms, checklists, and flow sheets can be designed to remind providers of care standards, simplify data collection, and serve other purposes as well. Sample forms for initial and follow-up visits are posted on the HRSA HIV/AIDS Bureau (HAB) website (www.hab.hrsa.gov). They include reminders regarding clinical standards, reminders of services required for billing levels, checklists built around definitions used by Ryan White HIV/AIDS Program grantees for reporting to HRSA, and other data for quality management. These instruments often can be used to generate reports to individual providers. Staff members may find it challenging to adjust to using new forms; however, using checklists often saves time by listing required elements of the visit and by reducing the amount of writing. Including representatives from clinical, data, and quality management staffs in the process of designing forms increases the acceptability of new forms or procedures.

Effective Management of HIV Programs

Managing a program with all the components described in this chapter is challenging. For enhancing communication and advancing the clinic's objectives, staff meetings are important. Smaller organizations may include the entire staff at monthly meetings, whereas larger organizations may have staff meetings less often, such as on a quarterly basis. Some larger organizations find it useful to have a monthly interdisciplinary meeting of program leadership, with representation of the different disciplines or program components, such as nursing or clinical care, psychosocial support, data and quality management, behavioral health, research, finance, administration, satellite services, and consumers. These coordinating meetings provide an opportunity for personnel from each discipline to update others on current activities, challenges, successes, and initiatives. They also provide a regular forum for updates on fulfilling grant-related work plan tasks and reviews of financial reports. Minutes of the meetings, which include decisions taken and assignments made, should be prepared and circulated to participants; minutes should be reviewed at the subsequent meeting and reports on assigned tasks should be delivered.

These larger organizations also may have monthly meetings by discipline, for example, comprising the nursing or clinical staff, to transmit information from the larger meeting and to coordinate the discipline-specific activities. In smaller programs, quality management may be part of monthly staff meetings whereas in larger programs it is more practical to have a separate quality management committee (see chapter *Quality Improvement*).

HIV programs often are contained within larger health organizations, and may be outliers with regard to the patients they serve and other features. It is important for program leadership to build and maintain support within the host institution. Where applicable, this may involve reminding the host institution of the grant or other funding the program generates. HIV programs often are on the forefront of innovative health care delivery, for example, in adopting quality management approaches and using other data to assist program management, incorporating EMR and PHR systems, implementing interdisciplinary care that integrates medical care with behavioral health, using a chronic care model or providing a medical home for patients, and linking with community-based programs. An important task for HIV program leadership is making the host institution feel proud and supportive of the HIV program itself.

Suggested Resources

- National Resource Center of the AIDS Education and Training Centers *(www.aidsetc.org)*
- National HIV/AIDS Clinicians' Consultation Center *(www.nccc.ucsf.edu)* (free and confidential advice from a multidisciplinary team):
  - **National HIV/AIDS Telephone Consultation Service (Warmline):** 800-933-3413 *(Monday-Friday, 9 a.m. to 8 p.m. eastern time)*
  - **National Clinicians' Post-Exposure Prophylaxis Hotline (PEPline):** 888-448-4911 *(9 a.m. to 2 a.m. eastern time/7 days a week)*
  - **National Perinatal HIV Consultation and Referral Service (Perinatal Hotline):** 888-448-8765 *(24 hours a day/7 days a week)*
- New York State AIDS Institute guidelines *(www.hivguidelines.org)*
- HRSA Target Center website *(careacttarget.org)*

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Quality Improvement

Bruce D. Agins, MD, MPH

Improving Systems of Care:

"Every system is perfectly designed to achieve exactly the results that it achieves."

Quality improvement (QI) is an important strategy to improve systems and reduce variation in delivery of care and services so that patients receive the right care every time they visit clinic, increasing the likelihood of their achieving the expected benefits and outcomes of care. As we move forward to end AIDS in the United States and meet the goals of the National HIV/AIDS Strategy, QI becomes an even more important methodology to implement in local systems through evidence-based interventions that can improve care, linkage, and retention.

> "Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."
>
> *(Institute of Medicine, 1990)*
>
> "All health care organizations, professional groups, and private and public purchasers should pursue six major aims; specifically, health care should be safe, effective, patient-centered, timely, efficient, and equitable."
>
> *(Institute of Medicine, 2001)*
>
> "Health care interventions that are known to work and save lives are not being implemented for every patient every time."
>
> *(Salzburg Seminar Statement, 2013)*

Quality improvement has become a fundamental component of the HIV service delivery system whether care is provided in dedicated or integrated delivery models. Clinical quality management is a legislative requirement for Ryan White-funded programs. Many clinicians have learned the basics of quality management, which are reinforced through Maintenance of Certification programs directed through medical and specialty boards. Many clinicians not only are participating actively in QI activities, but also are leading improvement efforts in their clinics. Moving beyond the basics, however, remains a challenge for clinicians who have limited time to participate in activities not related to direct patient care. Yet, focusing on quality can reveal important phenomena in the operational processes and delivery systems of the clinic of which the leadership is unaware and may reveal factors that explain why intended outcomes are not always being realized. Additionally, the participation of clinicians in clinic-wide QI improvement activities is often a critical ingredient for their success.

Increasingly, QI work in the HIV field is directed toward achieving important health outcomes such as HIV viral load suppression, retention in care, and reductions in readmissions and emergency department utilization. Simple subanalyses of basic performance data also may reveal disparities in how care is being provided to different patient groups in the clinic, for example, according to age, gender, or race/ethnicity. Careful assessment of the social determinants of health also may show which patients need to be targeted in improvement activities. At the same time, advances in health information technology have made it easier to generate data for performance measurement and to produce simple reports that can be used for improvement activities.

This chapter will review the basics of QI; an appendix at the end of the chapter illustrates concepts with examples of more advanced improvement work. The *Health Resources and Services*

Administration HIV/AIDS Bureau Performance Measures chapter in this manual presents a national quality initiative developed by the U.S. Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) for Ryan White HIV/AIDS Program-funded clinics; HRSA's Performance Measures can be incorporated into the quality improvement programs of local clinics.

The fundamental concepts of QI have evolved over the past century to include the following:

- QI provides an opportunity to solve problems that are part of the system and do not depend on one individual.
- Reducing variation in performance will allow consistent delivery of the best possible care.
- Improving processes within the health care delivery system will lead to improvements in outcomes.
- Data are the key to identifying problems and measuring change.
- Focusing on performance measurement and improvement usually stimulates employees to maximize their performance.
- Team-based problem-solving techniques lead to better care and promote a positive working environment.
- Testing changes will identify solutions that work and eliminate putting ineffective solutions into practice.
- Consumers play a pivotal role in providing the "end-user" perception of the quality of the services delivered; their active participation in the quality management program strengthens improvement work and leads to better results.

In addition, documentation of QI activities helps to demonstrate institution-wide compliance with accreditation responsibilities and funding requirements. Data generated from the clinic's QI program showing improvements over time demonstrate to constituents that the program is successful and help to justify its funding. These data also build the evidence base for determining which interventions are successful and can be disseminated to achieve large scale change.

Finally, quality management systems that are dependent on single individuals will not last when these key players leave the clinic or are absent for long periods, whereas a fully functioning QI program that involves staff working in teams with a clearly defined infrastructure will keep going when even the most dynamic individuals depart.

This chapter will articulate the core principles of QI and describe activities that can be easily adapted into the HIV ambulatory care setting to implement a sustainable quality management program.

Introduction to Quality Improvement

QI includes regular measurement of processes and outcomes to analyze the performance of the system of care with the ultimate goal of reducing variation in care delivery. It involves the implementation of solutions to improve care and the monitoring of their effectiveness in achieving optimal health outcomes for patients. Ongoing cycles of change and remeasurement are implemented to test and try different ideas to determine which practices result in improved care. QI activities in clinics can range from a single team focusing on improving one aspect of care to a

comprehensive QI program with many teams working on a wide variety of improvement projects, with a well-established plan and an oversight committee.

The methods of QI are based on core principles that are readily translated into a practical approach and integrated into the clinical care delivery system (see Table 1). Successful implementation of QI involves actions at two levels: the QI activities and the HIV program processes that provide the structural backbone for them.

Table 1. Core Principles of Quality Improvement

- **Emphasis on systems of care:** improve processes that link to desired outcomes
- **Focus on the customer:** understanding patients' experience in the clinic will identify areas that are important for improving care
- **Measurement:** collect and use data to improve care
- **Involvement of participants:** encourage direct participation in teams by those individuals who implement the processes being evaluated

Measurement and Management Are Not Sufficient

Although it is the bedrock for improving care, measurement alone is not sufficient to improve quality. A common pitfall in implementing QI programs is to rely solely upon performance data, the medical or program director's interpretation of it, and one person's decisions about how to make changes. Successful improvements occur most often when staff members from the systems being assessed work together in teams. When they are engaged in the process, staff members are more likely to generate ideas for improvement and to accept changes. Staff review of improvement charts (e.g., see Figure 1, below) generates pride and a sense of accomplishment based on members' participation in the QI work. These charts may be posted on bulletin boards in common areas of clinics so that everyone can view them.

QI Personnel

The size of the clinic will determine who participates in quality-of-care activities. In small HIV clinics with a primary care provider, case manager, nurse, and support staff, most of the staff members are involved in all aspects of QI work. Larger institutions usually establish an HIV Quality Committee that includes senior management of the HIV clinic, designated QI staff members if there are any, and other key players who work in the clinic. A member of this committee represents the group in the agency-wide QI committee. The Quality Committee identifies the priorities for improvement or agrees to pursue the priorities identified by staff members or patients in the clinic. The Quality Committee also charters improvement teams and identifies potential members who are key stakeholders in the process under investigation. In a small clinic that has only a handful of staff members, all clinic personnel may participate in the quality management program and in QI activities, although perhaps in a less formal way than in larger clinics.

Team Membership and Responsibilities

Teams are formed to address the specific care processes or systems that are targeted for improvement. Team members should be selected to represent the different functions involved in these processes or to represent the components of the system under focus. The size of a team varies according to the size of the clinic and the process under study. In small clinics, the few dedicated HIV program staff members may constitute the project teams, with added representation from different departments as needed (such as from the laboratory, or from other medical disciplines). In larger clinics, teams often include 6-10 members. Membership should include representatives from the different groups in the clinic who are involved in the care process. In

addition to the clinical and case management staff, scheduling clerks and medical records personnel are often important participants, especially when follow-up appointments and documentation are components of the care process or have been identified as areas that need to be improved.

Teams sometimes struggle with engaging physicians in their QI activities. Increasingly, physicians have overcome their reluctance to join process improvement teams, especially since more sophisticated data systems and comparative reports have become available to focus interest on improving care that does not meet standards or falls below mean performance rates. Moreover, physicians are now required to directly engage in practice-based learning and improvement to satisfy requirements for maintenance of professional certification. Studies of physician performance have demonstrated that participation in QI activities enhances job satisfaction and reduces work-life stress.

Involving consumers in QI project teams enhances the work of the team. Consumers who are involved in the clinic's community advisory board often are natural leaders and have a good grasp of clinic processes. Their feedback on the experience of care delivery can reveal areas that need improvement. They know the bottlenecks and can inform the staff how long a clinic visit lasts, whether assessments truly occurred, and whether behavioral interventions are effective. Their ideas about what improves care often diverge significantly from those generated by providers and may not even be recognized unless consumers participate directly in discussions about the system.

Teams are expected to analyze clinical processes, identify areas of change, implement tests of the changes, review data assessing the change, and ultimately make recommendations about which improvements should be adopted in the clinic.

Data Collection

Selecting Measures

Evaluating measurable aspects of care can help in determining the extent to which a facility provides a certain element of care. Quality measures should be based on standards or guidelines, meet the primary goals of QI, and reflect priorities specific to the community and the clinic. In addition, they should represent processes where changes are feasible. For example, in HIV clinics where the population consists of a large number of women, indicators may include rates of routine cervical cancer screening, rates of preconception counseling, or other aspects of care specific to women. In clinics that care for a high volume of patients who have been treated with antiretroviral therapy (ART) for a long time, measures may focus on rates of virologic suppression, screening for adverse effects of antiretroviral medications, and resistance testing. As we focus on our strategies to maximize community viral suppression, measures of linkage to care, engagement, and retention in care become priorities.

Some measures should be selected by soliciting input from patients who attend the clinic (see Table 2). Staff members also often know what aspects of care would benefit from being measured and improved, and they should be consulted to determine priorities. If routine data collection systems already exist in the clinic, data should be reviewed to determine which components of care would be prime candidates for improvement.

Table 2. Methods for Obtaining Input from Patients

- Suggestion box
- Surveys
- Exit interviews
- Focus groups
- Consumer advisory board
- Participation on QI teams
- Membership on the QI Committee

On a national level, the HRSA HIV/AIDS Bureau (HAB) has developed HIV/AIDS Performance Measures for monitoring the quality of care provided in Ryan White HIV/AIDS Program-funded clinics. These measures emphasize important areas of HIV care that are linked to the goals of the National HIV/AIDS Strategy and that are also endorsed by the National Quality Forum, which confers eligibility for inclusion in Meaningful Use criteria and other provisions of the Accountable Care Act that are important for both measuring care and are linked to enhanced reimbursement programs. They form a core package of priority indicators that can be enhanced by those that are identified through analysis of local data, or identified by local stakeholders. See chapter *Health Resources and Services Administration HIV/AIDS Bureau Performance Measures* for these.

Ideally, a balanced set of measures should be selected. Different ways to categorize measures might include the following:

- Structure/process/outcome
- Treatment/care (non-ART)/prevention/nonclinical service
- Provider/consumer/funder driven
- Aspects representing overutilization, underutilization, or misutilization of services

Developing and Quantifying Quality Measures

Three major activities constitute the process of developing performance measures:

- Defining the measurement population
- Defining the measures
- Developing the data collection plan

The measurement population is defined by determining factors such as the location of care being studied, whether both men and women are eligible, the applicability of the measure to various age groups, whether any clinical conditions are necessary to determine the applicability of the measure, the number of clinic visits by the patient, and amount of time the patient has been in care.

After the population is defined, the measure needs to be defined. The measure should be objective and should address specific aspects of quality care. It also should have a straightforward, dichotomous answer. For each measure, specific criteria must be developed to define the "yes" response and the "no" response (see Table 3). This often involves deciding the time period during which an activity has been performed. For example, a measure that evaluates viral load monitoring must include the frequency with which that test should be performed. One simple way to construct this measure would be to ask, "Was viral load measured within the past 6 months?"

Table 3. Examples of Specific Measures with Definitions of Responses

Measure	Definition of Measure	Yes/No Response
HIV Viral Load Monitoring	Was HIV viral load measured in the past 6 months?	**Yes:** Viral load testing was performed **No:** Viral load testing was not performed (or the test was done but results were not documented)
HIV Viral Load Suppression	Was the HIV viral load <200 copies/mL at the most recent test during the past year?	**Yes:** Viral load was <200 copies/mL **No:** Viral load was >200 copies/mL

Several elements of care should be measured simultaneously, whether abstracted from medical records or analyzed through administrative databases. Measures reflecting aspects of patient management should be selected, as should those involving different populations. Measures also should be selected to evaluate various components of the health care system, such as the components of the chronic disease model.

Clinical measures should include those that affect a large proportion of the patient population, such as whether comprehensive mental health screening has been performed.

The data collection plan includes determining the source of information (e.g., whether medical records or an electronic database will be used), how the data will be recorded, who will record the data, and how a data sample will be selected. A representative sample will allow inferences to be made about the overall clinic population based on observations of the smaller sample. Some form of random sampling should be used, either by using a random numbers table or by selecting every *n*th record from the list of eligible patients.

If electronic health records (EHRs) are used, sampling will not be necessary. Careful planning is required, however, to ensure that the measures are included in the electronic system, and that the EHR database is constructed to contain the elements required in the reports generated by the quality evaluation queries.

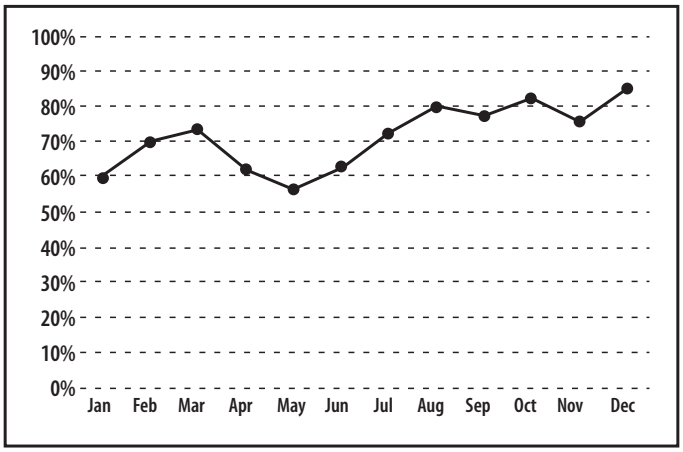
A common pitfall at this point is to think of the measurement sample as a research project. For the purposes of QI, a sample needs only to be current, representative, and readily obtained (i.e., sample size calculations and the achievement of statistically significant results are not necessary).

Analyzing and Displaying Data

Data should be reviewed and distributed to all members of the team and others involved in the care process under evaluation. When possible, data should be displayed in graphic format. After data from multiple time periods have been collected (e.g., percentage of patients with HIV suppression), a simple line graph (run chart) can be constructed with each point representing a performance rate (percentage) for a given period of time. This usually is the simplest and most effective way to show performance data (see Figure 1).

Identifying Targets and Implementing Improvements

Figure 1. Percentage of Patients with HIV Viral Load Suppression, by Month



Adapted from *Measuring Clinical Performance: A Guide for HIV Health Care Providers.* New York: New York State Department of Health AIDS Institute. April 2002.

After the project team has reviewed the data, it must decide where opportunities for improvement exist. The first step in this process is to investigate the care process in greater detail. Several techniques are used to accomplish this goal. The simplest is brainstorming, in which key stakeholders offer their suggestions as to which processes are the best candidates for change. Another easy method is flowcharting, in which the group breaks down the process into its components to identify how it is coordinated and how its parts fit together. A fishbone diagram, or cause-and-effect diagram, may aid in exploring and displaying the causes of a particular problem (Figures 2 and 3). It often helps for staff members to consider factors potentially influencing a process that are not obvious, and to help sort out those factors that are external to the clinic and those that are internal. A *driver diagram* is a visual tool to help understand and prioritize factors that drive desired outcomes, which are called the "primary outcome." *Primary drivers* are the factors that drive the primary outcome. *Secondary drivers* are subsets of factors that influence the primary drivers.

Figure 2. Sample Fishbone Diagram

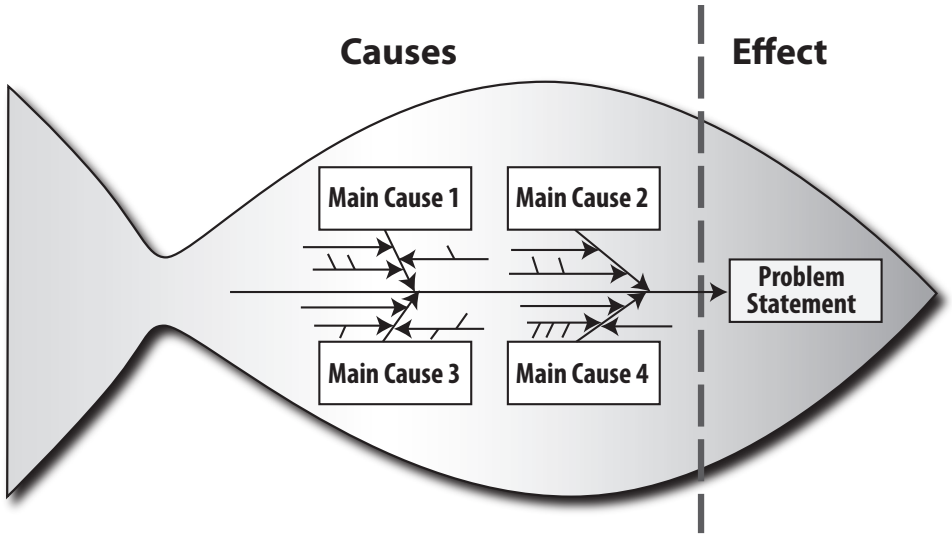
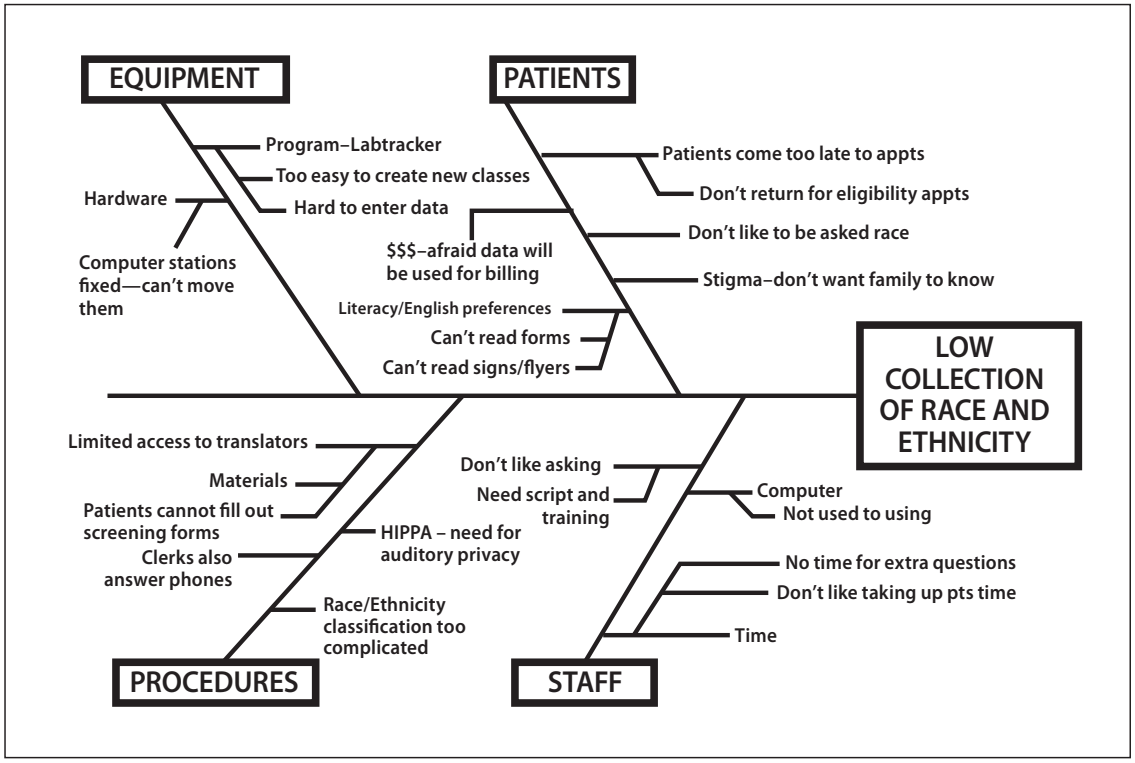


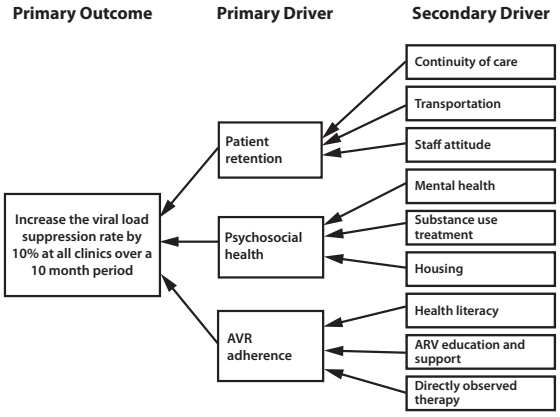
Figure 3. Fishbone Diagram: Low Collection Rates of Race and Ethnicity Patient Data



Used with permission from Kathleen A. Clanon, MD; Low-Income Health Program of Alameda County.

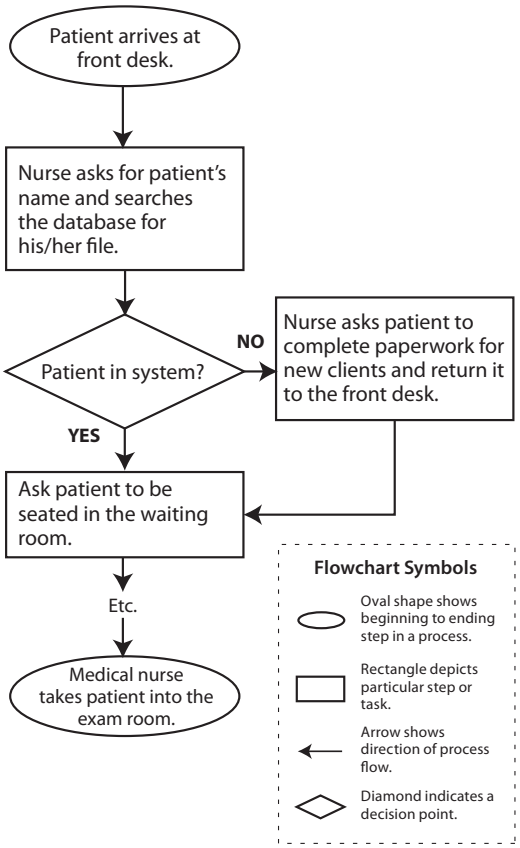
The driver diagram, which can be generated through discussion with stakeholders, is a particularly effective strategy to identify processes that may be key areas to target for improvement goals that will affect the ultimate outcome. For example, if retention in care is the desired outcome, housing status may be a primary driver that, in turn, is affected by access to factors such as entitlements, mental illness, substance use, or health literacy, which then are secondary drivers that, when addressed through QI activities, will affect the primary driver and ultimate outcome. Framing this larger picture of the system that is being improved may be extremely useful for participants at different levels who may be involved in only one aspect of the QI initiative, as well as for those only involved at the macro level who do not recognize the role of the processes being prioritized for ground-level work. An example of a driver diagram focusing on viral load suppression is shown in Figure 4.

Figure 4. Driver Diagram: Viral Load Suppression



Then, the areas that would be most likely to benefit from improvement are selected for change (see Figure 5) and tested in the Plan-Do-Study-Act (PDSA) cycle (see Figure 6). See "Appendix," below, for examples of QI projects conducted in HIV clinics.

Figure 5. Sample Flow Chart



Source: U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. *A Guide to Primary Care of People with HIV/AIDS.* Bartlett JG, Cheever LW, Johnson MP, Paauw DS, eds. Rockville, MD: U.S. Department of Health and Human Services; 2004:145.

Figure 6. Plan-Do-Study-Act Cycle

Plan: Plan the change and collect baseline data

Do: Test the change and collect data

Study: Analyze the data

Act: If the change did not improve the process, try another idea. If the change resulted in improvement, adopt the change, monitor the process periodically, and spread the change throughout the clinic

Source: U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. *A Guide to Primary Care of People with HIV/AIDS*. Bartlett JG, Cheever LW, Johnson MP, Paauw DS, eds. Rockville, MD: U.S. Department of Health and Human Services; 2004:145.

Even if evidence-based criteria on how to improve desired outcomes exist, how they are implemented varies according to the local context. Thinking through the "hows" of an intervention – who will do it, when during the care process it will be done, where it will be done – are important questions to ask as the test of the intervention is planned. After a change has been selected, a test of the change can be quickly implemented and evaluated. A limited implementation of the proposed change can be tested – perhaps with just a few subsequent patients, or those attending on the following day, or those seen by a particular clinician. If the small change does not work, another change can be selected and implemented quickly. If the change is feasible and improvement is noted, it can be adopted more widely, before formal remeasurement occurs, and a regular period of remeasurement can be adopted. If the change was not successful, then another one can be chosen and tested. Occasionally, multiple changes may be tested simultaneously or on different days of the week.

Many different approaches to QI exist and can be implemented successfully. However, sometimes just stepping back to refocus on the three basic questions of the model for improvement presented by Langley et al. (see "Suggested Resources," below) can effectively guide QI activities. These are as follows:

- What do we want to accomplish?
- How do we know that a change will result in an improvement – in other words what measure will we use to demonstrate whether our improvements worked?
- What kinds of changes can we test that will result in an improvement?

Establishing Systems to Support QI

The key to sustaining QI in the clinic is development of an infrastructure that supports ongoing QI activities. The central components of this infrastructure include the following:

- A QI plan with goals and a process to prioritize these goals
- A work plan that clearly defines steps, sets timeframes for completion, and identifies responsible parties
- An organizational framework that displays clear lines of accountability for QI in the organization
- Commitment of senior management staff to support the program, allocate resources, and celebrate its successes
- Creation of a culture that supports quality in the program and that values the activities of QI as part of the regular work of the clinic (see Table 4)

Table 4. Tips for Promoting a Culture of Quality Improvement: Integration of Quality into the Regular Work of the Clinic

- Educate staff members about QI and provide them with the skills to participate in QI activities.
- Consistently articulate the values of QI in staff meetings.
- Display QI data and storyboards (simple statements and visual representations that describe a problem, the evaluation process, the proposed changes, and their implementation, and display the results).
- Celebrate successes.
- Provide opportunities for all staff members to participate in QI teams.
- Reward staff members through performance evaluation for their contributions to the QI program.
- Participate in activities with peers to discuss QI activities, share data and learn about successful strategies to improve care.

- Patient participation, to share experiential knowledge and inform QI program development
- Establishment of a formal QI committee to oversee quality activities, monitor the quality plan, and evaluate its effectiveness

The regular, ongoing work of the QI committee, supported by the clinic leadership, constitutes the backbone of the infrastructure that supports ongoing QI activities. The committee oversees the dynamic process of planning, implementation, and evaluation that involves the following:

- Analysis of data from the QI projects
- Solicitation of feedback from participating staff members and from patients
- Decision-making based on the information from its analysis

These contribute to sustaining the QI program and its activities in the clinic.

Sustaining Improvements

Sustainability is probably the biggest challenge that clinics face in the field of QI. All too often, improvements do not last after initial projects are completed, because the structure and culture to support QI are not present or are not supported. The challenge of sustainability therefore is twofold: to maintain the successes of QI work and its clinical outcomes, and to maintain the systems of QI and keep the QI program vital. By asking questions about how care systems can be improved and how QI activities are progressing, clinicians play an important role in both catalyzing and supporting QI activities.

Appendix: Case Examples of Quality Management Initiatives

Using QI to Improve ART Management and Virologic Suppression

In one community health center, nearly 10% of patients on antiretroviral therapy (ART) were not virologically suppressed. The clinic had adopted a strategy of developing a specific ART management plan for each patient being treated. Review of the charts of the 45 patients not suppressed showed that only 40% had a plan in the chart. Only 20% had a plan that was executed. Improvement goals were set for each step, to increase from 40% to 90% for documentation of an ART management plan and from 20% to 75% for execution of the plan. Over the course of a 4-month period, clinicians and support staff were educated about the plan and decision-support tools were created, including an algorithm showing key decision points for plan development and execution with corresponding prompts in the clinic database. Visit forms were revised to incorporate data fields specific to the ART plans. Reminders also were created. All

changes were implemented through small tests of change with formal remeasurement in 6 months; this showed that 100% of patients had a plan in their charts and that 71% of them had it executed. Continued monitoring showed a dip in performance 4 months later to 88% and 60%, respectively, but with gains restored 3 months subsequently to 100% and 65%, respectively. Vigilance and reaffirmation of the main steps have been keys to maintaining performance. The fields are now being added to the new clinic electronic medical record (EMR) system with automatic prompts based on changes in viral load values.

Another clinic focused QI efforts directly on improving rates of virologic suppression. Data on the HIV viral loads of each specific provider were generated to show comparative rates as a stimulus for improved performance on the part of individual providers. ART regimens were reviewed for their appropriateness, and renewed education about antiretroviral drug combinations and resistance monitoring was introduced. The clinicians reviewed their own patient lists each day. Patients who were not virologically controlled were contacted by phone by the clinician or a nurse. Nurses eventually were assigned directly to the primary care team to facilitate communication with patients and ensure that specific issues raised during phone conversations were addressed during clinic visits. Adherence problems were particularly common, and were addressed through these multiple contacts. Reasons for adherence lapses were identified, which allowed for more effective targeting of service interventions with specific patients, including substance use and mental health service referrals, regimen switching, and targeted adherence interventions. The individual providers improved their patients' rates of virologic suppression from 45% to 62%. Review of suppression rates also showed that a subset of patients remained controlled and did not require quarterly monitoring. A decrease in visit frequency was possible for this group, reducing overutilization of services and unnecessary costs.

Another federally qualified health center with multiple sites struggled with its rates of viral load suppression that ranged from 0% at one small clinic to 47% at another. The medical director was new to the clinic and undertook a thorough investigation of the problem with his team. First, they reviewed the results and matched them with their clinical data and knowledge of the patients. Based on that step, they sent specimens to another lab and found that there had been a major error in the processing of specimens. Once this special cause of their findings was corrected, their rates increased to a range of 50-67%. Then, the team undertook a more thorough investigation of their system and implemented a package of changes based on their analysis and discussions with their patients. Among the improvements the team introduced were the development of a group of adherence educators among their staff, case conferencing *together with the patient* to discuss the results and identify particular issues and concerns that could then be addressed (*managed problem-solving*), biweekly team case conferencing, home visits and phone calls as needed in between visits and preparing provider-specific data results to generate additional incentives for providers to intensify their efforts to work with their patients to decrease viral load. Rates have steadily improved up to the 70-80% range in the short run as the clinic team awaits ongoing measurement results to determine whether it can hold its gains and improve further.

Using QI to Eliminate Disparities

The quality committee in another clinic wanted to determine whether the clinic's performance was consistent across all patient groups and arranged to have the clinic's patient data sorted by race, ethnicity, and primary language spoken. This revealed that data about race, ethnicity, and language spoken were not recorded in a high proportion of

patient records. The team invited patients from their community advisory board to attend a staff meeting where a fishbone diagram was developed to identify potential causes of the poor collection rates of these patient data. Potential reasons were identified in all categories: equipment, patients, procedures, and staff (see Figure 3). A flow chart was developed to identify the sequential steps of data collection. A training program for intake staff was developed, resulting in an improvement in collection of these data to 85%.

Subsequent analysis showed that only 54% of African-American patients and 68% of Latino patients had suppressed HIV RNA whereas white patients had a suppression rate of 75%. A focus group with Spanish-speaking patients revealed that these patients were not getting enough information about medication and its side effects. The QI team decided to aim for an improvement in virologic suppression rates to 75%. A number of changes were implemented and tested throughout the clinic including the addition of peer adherence counseling, using teach-back by nonphysician staff to facilitate adherence problem-solving, along with medication reconciliation. With these new interventions, virologic suppression rates improved to 71% for African-Americans, 80% for Latinos, and 81% for whites. With ongoing QI activities, suppression rates have subsequently increased for all groups and the gaps between groups has narrowed. Ongoing changes aim to narrow these gaps even further.

Finally, in another clinic, analysis showed that major differences in viral load suppression were noted among patients who were stably housed and those who were not. To tackle their low rates, this agency intensified its relationship with their local housing agency and began to investigate other resources in their community to provide transitional housing services.

Suggested Resources

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- McGlynn EA, Asch SM. *Developing a clinical performance measure.* Am J Prev Med. 1998 Apr;14(3 Suppl):14-21.
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- Scholtes PR, Joiner BL, Streibel BJ. *The Team Handbook (3rd Edition).* Madison, WI: Oriel; 2003.

Websites

HIV-Specific

- **National Quality Center (NQC)** *(www.nationalqualitycenter.org)* Provides no-cost, state-of-the-art technical assistance to all Ryan White Program-funded grantees to improve the quality of HIV care nationwide. Website includes training and technical assistance materials
- **The HRSA HIV/AIDS Program:** Quality of Care *(hab.hrsa.gov/deliverhivaidscare/qualitycare.html)*
- **HIV Clinical Resources** (*HIVGuidelines.org*) Quality of Care Section (NY AIDS Institute) *(www.hivguidelines.org/quality-of-care)*
- **Health Care Improvement Project:** HIV/AIDS (USAID) *(www.hciproject.org/improvement_topics/HIVAIDS)*

General QI Websites

- **Institute for Healthcare Improvement** *(www.ihi.org/Pages/default.aspx)*
- **International Society for Quality in Health Care** *(www.isqua.org)*
- **American Society for Quality (ASQ)** *(asq.org/index.aspx)*
- **My Tapestry!** *(www.mytapestry.com/qlinks.html)* (See the "Quality Links" page for extensive resource listing)
- **Agency for Healthcare Research and Quality** *(www.ahrq.gov)*
- **National Association for Healthcare Quality** *(www.nahq.org)*
- **Medical University of South Carolina** *(academicdepartments.musc.edu/fm_ruralclerkship/curriculum/cqi.htm)*
- **Health Quality Ontario** *(www.hqontario.ca/quality-improvement)*
- **The Health Foundation:** Quality Improvement Made Simple *(www.health.org.uk/publications/quality-improvement-made-simple)*
- **USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project** *(www.usaidassist.org)*
- **1000 Lives Plus QI Guide** *(www.1000livesplus.wales.nhs.uk/qi-guide)*
- **NHS Scotland Quality Improvement Hub** *(www.qihub.scot.nhs.uk/knowledge-centre.aspx)*

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Health Resources and Services Administration HIV/AIDS Bureau Performance Measures

Overview

The HIV/AIDS Bureau has revised its performance measure portfolio. The updated portfolio is more focused on critical areas of HIV care and treatment, and, as of November 6, 2013, it contains fewer performance measures. The revisions include:

- Identifying core performance measures that are most critical to the care and treatment of people living with HIV
- Combining measures to address people of all ages living with HIV
- Aligning measures with U.S. Department of Health and Human Services (HHS) priorities, guidelines, and initiatives
- Promoting relevant performance measures used in other federal programs
- Archiving performance measures

Unlike the previous version wherein the portfolio included three groups of core measures intended for various levels of programs' ability to implement, the updated portfolio features a set of *Core Clinical Performance Measures* and consolidates several of the previous clinical measures into four categories: *All-Age Clinical Performance Measures*, *Adult and Adolescent Clinical Performance Measures*, *HIV-Exposed Children*, and *HIV-Infected Children*. The Core performance measures emphasize the essential aspects of HIV care and treatment and align with the milestones along the HIV care continuum (hab.hrsa.gov/data/reports/continuumofcare/index.html).

The *Medical Case Management Performance Measures* target all clients, and focus on two key issues: care plans and medical visits. Medical case management programs are encouraged to utilize the Core clinical performance measures as appropriate.

The *Oral Health Performance Measures* target all clients. The measures are intended for use by programs providing direct oral health services.

The A*IDS Drug Assistance Program (ADAP) Measures* are intended for use by the ADAP. Four measures are included and target all clients, regardless of age.

The *Systems-Level Performance Measures* address aspects of access and entry to care and may be utilized by any system or network.

Two sets of measures not reproduced here *(HIV-Exposed Children* and *HIV-Infected Children)* address a range of clinical, social, and system issues for programs that serve pediatric clients. In addition, the archived performance measures are available for reference on the HRSA HAB website at hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html.

The HIV/AIDS Bureau encourages all organizations providing HIV services to use the Bureau's revised performance measures, including the Core performance measures, and select the appropriate measures for their own portfolio. Measure selection is based on the services that are provided, prominent clinical issues, and patient demographics. The HIV/AIDS Bureau does not promote using every performance measure available because the activities needed to implement performance measurement (e.g., collecting, analyzing, and

reviewing data) can be costly. Individual programs are recommended to consider having some measures that are collected and analyzed more frequently (e.g., every 2 months or quarterly) and others that are collected and reviewed less frequently (e.g., every 6 months or annually). Grantees are not required to use all performance measures. Given the emphasis on using performance measures to improve patient health, grantees may trend performance measures over time and analyze performance measures for disparities in care.

Core Clinical Performance Measures

Measure	Definition
HIV Viral Load Suppression	Percentage of patients, regardless of age, with a diagnosis of HIV with an HIV viral load of <200 copies/mL at last HIV viral load test during the measurement year
Prescription of HIV Antiretroviral Therapy	Percentage of patients, regardless of age, with a diagnosis of HIV who were prescribed antiretroviral therapy for the treatment of HIV infection during the measurement year
HIV Medical Visit Frequency	Percentage of patients, regardless of age, with a diagnosis of HIV who had at least one medical visit in each 6-month period of the 24-month measurement period with a minimum of 60 days between medical visits
Gap in HIV Medical Visits	Percentage of patients, regardless of age, with a diagnosis of HIV who did not have a medical visit in the last 6 months of the measurement year
***Pneumocystis jiroveci* Pneumonia (PCP) Prophylaxis**	Percentage of patients, aged 6 weeks or older with a diagnosis of HIV/AIDS, who were prescribed *Pneumocystis jiroveci* pneumonia (PCP) prophylaxis

All-Age Clinical Performance Measures

Measure	Definition
CD4 Cell Count	Percentage of patients, aged 6 months and older with a diagnosis of HIV/AIDS, with at least two CD4 cell counts or percentages performed during the measurement year at least 3 months apart
HIV Drug Resistance Testing Before Initiation of Therapy	Percentage of patients, regardless of age, with a diagnosis of HIV who had an HIV drug resistance test performed before initiation of HIV antiretroviral therapy if therapy started during the measurement year
Influenza Immunization	Percentage of patients, aged 6 months and older seen for a visit between October 1 and March 31, who received an influenza immunization OR who reported previous receipt of an influenza immunization
Lipid Screening	Percentage of patients, regardless of age, with a diagnosis of HIV who were prescribed HIV antiretroviral therapy and who had a fasting lipid panel during the measurement year
Tuberculosis Screening	Percentage of patients aged 3 months and older with a diagnosis of HIV/AIDS, for whom there was documentation that a tuberculosis screening test was performed and results interpreted (for tuberculin skin tests) at least once since the diagnosis of HIV infection
Viral Load Monitoring	Percentage of patients, regardless of age, with a diagnosis of HIV with a viral load test performed at least every 6 months during the measurement year

Adult and Adolescent Clinical Performance Measures

Measure	Definition
Cervical Cancer Screening	Percentage of female patients with a diagnosis of HIV who have a Pap screening in the measurement year
Chlamydia Screening	Percentage of patients with a diagnosis of HIV at risk of sexually transmitted infections who had a test for chlamydia within the measurement year
Gonorrhea Screening	Percentage of patients with a diagnosis of HIV at risk of sexually transmitted infections who had a test for gonorrhea within the measurement year
Hepatitis B Screening	Percentage of patients, regardless of age, for whom hepatitis B screening was performed at least once since the diagnosis of HIV/AIDS or for whom there is documented infection or immunity
Hepatitis B Vaccination	Percentage of patients with a diagnosis of HIV who completed the vaccination series for hepatitis B
Hepatitis C Screening	Percentage of patients for whom hepatitis C screening was performed at least once since the diagnosis of HIV
HIV Risk Counseling	Percentage of patients with a diagnosis of HIV who received HIV risk counseling in the measurement year
Oral Exam	Percentage of patients with a diagnosis of HIV who received an oral exam by a dentist at least once during the measurement year
Pneumococcal Vaccination	Percentage of patients with a diagnosis of HIV who ever received pneumococcal vaccine
Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan	Percentage of patients aged 12 years and older screened for clinical depression on the date of the encounter using an age-appropriate standardized depression screening tool AND, if positive, a follow-up plan is documented on the date of the positive screen
Preventive Care and Screening: Tobacco Use – Screening and Cessation Intervention	Percentage of patients aged 18 years and older who were screened for tobacco use one or more times within 24 months AND who received cessation counseling intervention if identified as a tobacco user
Substance Abuse Screening	Percentage of new patients with a diagnosis of HIV who have been screened for substance use (alcohol and drugs) in the measurement year
Syphilis Screening	Percentage of adult patients with a diagnosis of HIV who had a test for syphilis performed within the measurement year

Medical Case Management Performance Measures

Measure	Definition
Care Plan	Percentage of medical case management patients, regardless of age, with a diagnosis of HIV who had a medical case management care plan developed and/or updated two or more times in the measurement year
Gap in HIV Medical Visits	Percentage of medical case management patients, regardless of age, with a diagnosis of HIV who did not have a medical visit in the last 6 months of the measurement year (that is documented in the medical case management record)
HIV Medical Visit Frequency	Percentage of medical case management patients, regardless of age, with a diagnosis of HIV who had at least one medical visit in each 6-month period of the 24-month measurement period with a minimum of 60 days between medical visits

Oral Health Services Performance Measures

Measure	Definition
Dental and Medical History	Percentage of HIV-infected oral health patients who had a dental and medical health history (initial or updated) at least once in the measurement year
Dental Treatment Plan	Percentage of HIV-infected oral health patients who had a dental treatment plan developed and/or updated at least once in the measurement year
Oral Health Education	Percentage of HIV-infected oral health patients who received oral health education at least once in the measurement year
Periodontal Screening or Examination	Percentage of HIV-infected oral health patients who had a periodontal screen or examination at least once in the measurement year
Phase 1 Treatment Plan Completion	Percentage of HIV-infected oral health patients with a Phase 1 treatment plan that is completed within 12 months

AIDS Drug Assistance Program Performance Measures

Measure	Definition
Application Determination	Percent of ADAP applications approved or denied for new ADAP enrollment within 14 days (2 weeks) of ADAP receiving a complete application in the measurement year
Eligibility Recertification	Percentage of ADAP enrollees who are reviewed for continued ADAP eligibility two or more times in the measurement year
Formulary	Percentage of new antiretroviral classes that are included in the ADAP formulary within 90 days of the date of inclusion of new antiretroviral classes in the HHS *Guidelines for the Use of Antiretroviral Agents in HIV-1-infected Adults and Adolescents* during the measurement year
Inappropriate Antiretroviral Regimen Components Resolved by ADAP	Percent of identified inappropriate antiretroviral regimen components prescriptions that are resolved by the ADAP program during the measurement year

Systems-Level Performance Measures

Indicator	Definition
Waiting Time for Initial Access to Outpatient/ Ambulatory Medical Care	Percentage of Ryan White Program-funded outpatient/ambulatory care organizations in the system/network with a waiting time of 15 or fewer business days for a Ryan White Program-eligible patient to receive an appointment to enroll in outpatient/ambulatory medical care
HIV Test Results for PLWHA	Percentage of individuals who test positive for HIV who are given their HIV-antibody test results in the measurement year
HIV Positivity	Percentage of HIV positive tests in the measurement year
Late HIV Diagnosis	Percentage of patients with a diagnosis of Stage 3 HIV (AIDS) within 3 months of diagnosis of HIV
Linkage to HIV Medical Care	Percentage of patients who attended a routine HIV medical care visit within 3 months of HIV diagnosis
Housing Status	Percentage of patients with HIV diagnosis who were homeless or unstably housed in the 12-month measurement period

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HIV Care in Correctional Settings

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Background

Caring for HIV-infected patients who are incarcerated is a complex and challenging task. For many of these patients, the prison health service provides their first opportunity for access to consistent health care. This chapter will discuss some of the issues relevant to the HIV-infected population in correctional settings.

Jail vs. Prison Settings

It is important to note the distinction between "jail" and "prison" custodial settings. These terms are often used interchangeably, but doing so can create confusion for health care providers, as the services that an inmate receives while incarcerated may differ greatly according to the type of facility (NYSDOH, 2008).

Jails are locally operated, or managed, institutions that detain individuals who typically are serving short sentences of 1 year or less. They also hold individuals who are awaiting arraignment, trial, or sentencing, or those who have violated terms of their parole (Harrison and Beck, 2006). Because inmates who are detained in jail settings have shorter confinement terms, providers often face time constraints in establishing longer-term treatment plans for chronic conditions such as HIV/AIDS, and for substance use and mental health problems. Opportunities for inmate education also may be more limited. In addition, because jail inmates often are released within days, weeks, or months after initial confinement, establishing continuity of health care may be challenging for providers and administrators (Okie, 2007).

Prisons, in contrast, are operated by state governments or the Federal Bureau of Prisons. Prisons generally detain people who have been convicted of state or federal felonies and are sentenced to terms of longer than 1 year (Harrison and Beck, 2006). The nature of a person's crime, namely a state or federal offense, will dictate the type of prison in which he or she will be detained. The length of sentences for inmates in state or federal custody is longer than those for persons serving time in jail, and prison inmates typically have a firm release date in advance. As a result, HIV-infected inmates released from prison may be more likely to have treatment and discharge plans in place (NYSDOH, 2008).

Note that these characteristics may differ from prison to prison and jail to jail.

Epidemiology

Inmates continue to be disproportionately affected by the epidemic, with the estimated overall rate of AIDS among prison inmates at more than 2.5 times the rate in the United States general population. In 2006, there were 21,980 HIV-infected inmates in federal or state prisons, according to a report from the Bureau of Justice Statistics, and there are many more in jails. With the advent of effective combination antiretroviral therapy (ART), AIDS-related mortality as a percent of total deaths in state prisons decreased significantly between 1995 and 2006, from 34.2% to 4.6% (Maruschak, 2006).

Inmates who have drug- or sex-related illegal behaviors that lead to incarceration often are at high risk of becoming infected with HIV,

hepatitis C virus (HCV), and other pathogens through these behaviors. Their risk factors may include unsafe substance use behaviors, such as sharing syringes and other injection equipment, and high-risk sexual practices, such as having multiple sex partners or unprotected sex. Many inmates also may have conditions that increase the risk of HIV transmission or acquisition, such as untreated sexually transmitted diseases (STDs).

The prevalences of chronic viral hepatitis and tuberculosis are much higher among incarcerated persons than among the general public. Depending on the prison system, 13% to 54% of inmates are infected with HCV (Cassidy, 2003). The incidence is 10 times higher among inmates than among non-inmates and is 33% higher among women than among men (Nerenberg et al., 2002). The Centers for Disease Control and Prevention (CDC) recommends that all incoming inmates be screened for HCV, and those who are infected should be evaluated for liver damage and the need for treatment (Cassidy, 2003). Chronic hepatitis B virus (HBV) infection and tuberculosis also are substantially more common among the incarcerated population than among the general public. The presence of any of these conditions should prompt HIV testing (Nicodemus and Paris, 2002).

Incarcerated Women

Women account for almost 7% of the prison population in the United States (West and Sobol, 2009). The HIV epidemic in the United States increasingly affects women of color, and this trend is reflected in HIV rates among the incarcerated. In terms of total numbers, there are more males than females with HIV/AIDS in state and federal prisons nationally (19,809 and 2,135, respectively). However, the percentage of female inmates with known HIV infection in these settings is higher than that for incarcerated males (2.4% and 1.6 percent, respectively) (Maruschak, 2006).

In many cases, incarcerated women are low-income and have limited education and sporadic employment histories. Compared with men, they are less likely to be incarcerated for a violent crime, and more likely to be incarcerated for a drug or property offense. Women's property crimes often are the result of poverty and substance-use histories (National Institute of Corrections, 2003). Numerous studies have shown that the behaviors that lead to incarceration also put women at increased risk of HIV infection. Risk factors that are present in abundance among female inmates include the following (Hammett and Drachman-Jones, 2006):

- History of childhood sexual abuse and neglect
- History of sex work, with increased frequency of forced, unprotected sex
- High rates of STDs
- High rates of mental illness
- History of injection drug use (IDU) or sex partners with IDU history
- Poverty

Among all women entering a correctional facility, 10% are pregnant (De Groot and Cu Uvin, 2005). These women should be offered HIV testing, and HIV-infected pregnant women should be offered combination ART immediately to prevent perinatal HIV transmission. Many incarcerated women will receive their first gynecologic care in prison. Because the incidence of cervical cancer is higher among women with HIV, referrals for colposcopy should be made for any HIV-infected woman with an abnormal Papanicolaou test result.

Testing and Prevention

The correctional facility is an ideal location for identifying individuals already infected with HIV, HCV, or HBV, and for education

interventions that are geared to prevent infection among those at highest risk of these acquiring diseases. For many adults, the prison or jail setting is a rare potential point of contact with the health care system, making it an important avenue for HIV testing and linkage to care. It also may be an effective setting in which to initiate and maintain individuals on ART.

Inmates commonly are hesitant to be tested for HIV because they fear a positive diagnosis and because of the potential stigma involved. They often lack accurate information about HIV, including awareness of behaviors that may have put them at risk and knowledge of means for protecting themselves from becoming infected. Health care providers in correctional settings are in a key position to evaluate inmates for HIV risk factors, to offer HIV testing, and to educate and counsel this high-risk group about HIV.

HIV testing policies in correctional facilities vary from state to state and among local, state, and federal penal institutions. Depending on the setting, policies may require testing of inmates upon entry, upon release, or both, but as of 2010 more than 50% of state prison systems did not require HIV testing at any point. Some prisons may do HIV testing based on clinical indication or risk exposure during incarceration, and this may be voluntary or mandatory. Most prison systems do provide HIV testing for inmates who request it. See Table 1 for an overview of the circumstances under which inmates in state prisons were tested for HIV in 2006 (Maruschak, 2006).

In high-risk settings such as correctional facilities, routine, voluntary HIV testing has been shown to be cost-effective and clinically advantageous (Paltiel et al., 2005). The CDC supports universal opt-out HIV screening in prisons and jails and has produced the *HIV Testing Implementation Guidance for Correctional Settings* (www.cdc.gov/correctional health/default.htm). This document serves as a guide for individual institutions in determining and establishing the most appropriate testing strategy for their settings, presents the components of such a testing program, and explains obstacles that may be encountered in the implementation process. It also provides information regarding the following:

- Background statistics on HIV in correctional facilities
- Inmate privacy and confidentiality
- Opt-out HIV screening in correctional medical clinics
- HIV testing procedures
- HIV case reporting

Testing inmates for HIV prior to their release is a critical aspect not only of individuals' own health care needs but also of preventing transmission of HIV to others. Knowledge of their HIV status affects people's HIV risk behaviors: Studies have shown that, after learning they are infected with HIV, many persons take measures to reduce the risk of transmitting HIV to others.

Risk-Reduction Education

Given the high HIV seroprevalence among inmates, the reentry of inmates into the community presents a danger of spreading HIV and other infectious diseases, and it is a public health concern. Thus, inmates need adequate HIV prevention counseling before release, both to protect themselves and to decrease the likelihood of infecting others in their communities with HIV (Gaiter and Doll, 1996). The World Health Organization (WHO) has stated: "All inmates and correctional staff and officers should be provided with education concerning transmission, prevention, treatment, and management of HIV infection. For inmates, this information should be provided at intake and updated regularly thereafter."

Risk-reduction counseling addresses specific ways the inmate can reduce the risk of becoming infected with HIV. If an inmate is already HIV infected, the goal of counseling is to reduce the risk of infecting others or becoming infected with a drug-resistant strain of HIV.

Education should include information about the efficacy of ART in decreasing risk of HIV transmission. In addition, it should focus on the use of latex barriers with all sexual activity. Condoms and dental dams are not available in most jails and prisons; nonetheless, the inmate should receive education regarding their proper use. The state prisons systems that provide condoms to inmates are those of Vermont and Mississippi. The larger metropolitan jails in New York City, such as Rikers Island, as well as those in Los Angeles, San Francisco, Philadelphia, and Washington, also provide condoms. Within the systems that allow condoms, inmates' ability to obtain them may be restricted (e.g., limited to one per week or available only via medical prescriptions or dispensing machines) (Sylla, 2007); see chapter *Preventing HIV Transmission/Prevention with Positives*.

No correctional system in the United States provides clean injection needles as a part of a prevention program (Sylla, 2007). However, inmates with a history of IDU should be educated about the risks of sharing needles and injection equipment, specifically the high risk of transmitting or acquiring HIV, HCV, and HBV. Inmates also should be counseled about the risks of sharing needles and other "sharps," such as those used for tattooing or body piercing. Substance abuse treatment should be provided when appropriate. Recovery from addiction often is a chronic process and relapses are common. In addition to substance abuse treatment, risk-reduction strategies should include planning for support after release from the correctional setting. For example, prior to release, inmates should be provided with information about syringe exchange or clean needle access programs in their communities. These programs have proved to be quite effective in decreasing the rate of parenteral HIV transmission (CDC, 1999).

Furthermore, overdose prevention should be discussed with inmates leaving correctional systems. Using heroin after a period of abstinence, such as during incarceration, hospitalization, or drug treatment, is a major risk factor for overdose. Former inmates are at highest risk of overdose within the first 2 weeks after release (NYSDOH, 2008). Overdose risk is heightened when someone has a significant medical condition, such as HIV infection (Catania, 2007). The literature documents an increased number of correctional systems that consider including naloxone (Narcan) prescriptions in prerelease planning for inmates with a history of opiate addiction (Wakeman et al., 2009). Naloxone is a prescription medicine that reverses an overdose by blocking heroin (or other opioids) in the brain for 30-90 minutes (NYSDOH, 2008).

Antiretroviral Therapy in Correctional Facilities

In correctional facilities, as in any setting, a consideration of HIV treatment must begin with educating the patient about the benefits and risks of treatment and the need to fully adhere to the entire regimen, and with an assessment of the patient's motivation to take ART (see chapter *Antiretroviral Therapy*).

Correctional facilities have two main methodologies for dispensing medications to those who are on ART. Each has advantages and disadvantages that can impact treatment adherence. These are directly observed therapy (DOT) and keep-on-person (KOP).

Directly Observed Therapy

DOT is the system in which the inmate goes to the medical unit or pharmacy for all medication doses; dosing is observed by staff members. This system offers the advantage of more frequent interaction between the patient and the health care team, allowing for earlier identification of side effects and other issues. In general, patients have better medication adherence in this system, resulting in better control of HIV. For some inmates, however, the need for frequent visits to the medical unit or pharmacy may be a barrier to receiving proper treatment, particularly if they are housed at a distance from the medical unit. Another disadvantage of DOT is the potential loss of confidentiality, as many inmates feel that the frequency of dosing and the large number of pills they may take will reveal clues that they are HIV infected. In addition, this system puts inmates in a passive role in terms of medication treatment and does not foster self-sufficiency.

Keep-on-Person

KOP is the system that allows inmates to keep their medications in their cells and take them independently. Monthly supplies are obtained at the medical unit or pharmacy. This system offers greater privacy and confidentiality regarding HIV status. It also allows inmates to develop self-sufficiency in managing medications, which may facilitate improved adherence upon release. However, as the KOP system involves less interaction with medical staff, problems with adherence can be more difficult to identify (Ruby, 2000). Problems with refills also can occur. For example, inmates usually must initiate the process for obtaining a refill. They may be told that a refill request was made too early or too late, which can result in delays in dispensing medications, and ultimately, treatment interruptions. In addition, many facilities do not have on-site pharmacies, but rely on local pharmacies, or a regional or central pharmacy in the state; this may further delay refills (NYSDOH, 2008).

In a study comparing DOT in HIV-infected inmates with KOP in nonincarcerated HIV-Infected patients receiving ART as part of a clinical trial, a higher percentage of DOT patients achieved undetectable viral loads compared with the KOP patients (85% vs. 50%) over a 48-week period (Fischl, 2001).

Adherence

Adherence is one of the most important factors in determining the success or failure of ART. For the HIV-infected inmate starting ART, a number of issues can affect medication adherence. These include patient-related factors, factors related to systems of care (including the medication dispensing systems described above), and medication-related factors. The following are suggestions for supporting adherence to ART. (Also see chapter *Adherence*.)

Patient-Related Factors

- Correct misconceptions about HIV and ART that are common among inmates and could affect adherence adversely. Inmates should be educated about the disease process and the role of the medications, along with the benefits and risks of taking ART.
- Use teaching tools that are appropriate in terms of language and reading level. Illiteracy and low-level reading ability are common among inmates. Diagrams and videos may be more effective than reading-intensive material in some cases. Basic HIV education prior to initiation of ART should include the following topics:
  - How the medications work
  - Potential benefits in terms of personal health and reducing transmission risk
  - Consequences of nonadherence

  - Names and dosages of all medications
  - Potential side effects and strategies for managing them
- Encourage participation in peer support groups. These can be effective ways to foster self-esteem, empower inmates to come to terms with a positive diagnosis, allay fears and correct misconceptions about HIV disease, and aid adherence. Upon release, telephone hotlines may be available to provide follow-up support and linkages to community services. To the extent possible, family and friends should be included in the education process.
- Provide alcohol and substance abuse treatment before, or while, initiating ART. Without appropriate treatment during incarceration, linkages to supports, and follow-up treatment upon discharge, inmates are more likely to resume high-risk behaviors that may interfere with adherence to ART. In 2004, nearly one third of inmates in state facilities and one fourth of inmates in the federal system committed their offenses under the influence of drugs (Mumola and Karberg, 2006).
- Use mental health consultation to identify inmates with psychiatric needs. Treatment for underlying mental health disorders should precede or take place concurrently with the initiation of ART to ensure successful adherence. Depression and other psychiatric illnesses are more prevalent among inmates than among the general population (James and Glaze, 2006).

Factors Related to Systems of Care

- Educate the facility's security staff about the importance of timely medication dosing, and communicate with other facilities in advance of a transfer; this can eliminate or reduce the frequency of missed doses.
- Schedule frequent follow-up medical visits in the early weeks after ART is initiated; these can make the difference in whether or not patients "stay the course."
- Consult with an HIV specialist, if possible. If a facility's medical provider lacks experience in treating patients with HIV, the results may be undertreatment of side effects or errors in prescribing medications. Because caring for HIV-infected patients is complicated, HIV specialists can provide assurance that patients are receiving proper care. Of particular concern are patients whose current ART regimens are failing, those who are declining clinically, and those who are coinfected with other diseases such as tuberculosis, HCV, and HBV.

Medication-Related Factors

- Aggressively monitor and treat side effects. The most common barrier to proper adherence to ART is side effects from the medications. Inmates should be educated in advance about potential adverse events and urged to observe and report them. In the first weeks after starting a new ART regimen, patients should be assessed frequently for side effects. For treating gastrointestinal toxicities, antiemetics and antidiarrheals should be available on an as-needed basis. As with all patients on ART, inmates should have appropriate laboratory monitoring.
- Be aware of food requirements. Various food requirements must be considered carefully when administering ART. That can be especially challenging in the correctional environment, particularly in facilities that do not allow inmates to self-administer medications. Make arrangements with prison authorities to provide food when inmates are taking medications that require administration with food.
- Avoid complex regimens and regimens

with large pill burdens, if possible. Simple regimens with fewer pills appear to help improve adherence.

- Avoid drug-drug interactions. Some antiretroviral medications have clinically significant interactions with other drugs (e.g., methadone, oral contraceptives, cardiac medications, antacids). These interactions may cause failure of either the antiretroviral drug or the other medication, or they may cause additional toxicity. Consult an HIV specialist or pharmacist for information on drug interactions.
- Question patients about medication adherence at each appointment.
- ART regimens need to fit into each patient's schedule and lifestyle. This becomes a bigger issue when an inmate is close to release. Education about HIV management, including ART adherence, should begin well before the inmate is discharged back to the community.

Transition to Community Care

It is estimated that 630,000 individuals are released from jails and prisons in the United States each year (Bonczar, 2003; Travis, 2005), and many of these individuals are HIV infected. Many will have difficulty managing even the most basic elements for successful reintegration into their communities. Inmates living with HIV face many challenges when reentering the community, such as finding stable housing, employment, adequate medication supply, follow-up medical care, and psychiatric and substance use treatment services (Hammett et al., 1997).

Ideally, the discharge process at the correctional facility will maximize the likelihood that the person being released will have continuous medical care. At the time of discharge from the correctional facility, all HIV-infected inmates should have a discharge plan that addresses the following:

- Housing
- Health insurance
- 30-day supply of HIV medications
- Follow-up appointments for medical care and, if necessary, psychiatric and substance abuse care

As discussed, inmates in prisons generally serve longer sentences than do those incarcerated in jails, and they have a release date that is known in advance. Thus, HIV-infected inmates in prisons may be more likely than HIV-infected inmates in jails to have treatment and discharge plans in place before their release. However, because the extent of discharge planning resources varies among correctional systems of care, it is important for care providers to discuss the scope of services their clients received while incarcerated to learn of any service gaps upon reentry to the community (NYSDOH, 2008).

The need to find housing often is the greatest challenge for an HIV-infected inmate leaving a correctional facility. In many correctional systems, inmates must document a physical address at which they intend to reside in order to be released. However, problems with housing availability, stability, and location can create significant stressors for an HIV-infected person being released and can compromise the likelihood that he or she will access HIV health care and adhere to an HIV medication regimen (NYSDOH, 2008).

Medication Continuity Issues

HIV-infected individuals leaving correctional settings have a variety of experiences with ARV medication continuity. A short confinement period, for example, can prevent the development of a solid transition plan. Jail inmates may be released without their medications and have no choice but to call or walk into community health centers or clinics for their medications and ongoing

care. Being released from jail after business hours, such as on a Friday night, can result in treatment interruptions over the weekend (NYSDOH, 2008). Depending on the state system, HIV-infected inmates leaving prison are more likely than jail releasees to have a medication supply in hand when they reenter the community. For example, in the New York State Department of Correctional Services, inmates will leave prison with a 30-day supply of HIV medications as well as a prescription for another 30-day supply (NYSDOH, 2008).

For some individuals, interruptions in treatment occur during their time in jail or prison. For example, many inmates choose not to disclose their HIV infection while they are incarcerated. Particularly if the sentence is short, an inmate may feel it better not to mention HIV status and instead plan to resume taking medications upon release. Such treatment interruptions can result in adverse health outcomes (NYSDOH, 2008).

It is important that clinic staff and community-based organizations develop the capacity to work with clients in real time as they present for care in order to help them maintain continuity with their medications.

Strategies for Supporting Inmates upon Release

- A clear way to support clients is to intervene immediately and directly upon their release, such as by meeting them as they step off a bus or exit a facility.
- Engage clients by:
  - Hearing their stories; listening to concerns, wishes, history, perceptions, feelings, and so forth
  - Asking open-ended questions, affirming strengths, listening reflectively, and summarizing discussions and plans
  - Understanding their backgrounds, goals, and motivations (understand "where they are coming from")
  - Avoiding getting caught up in issues about the crimes they committed
  - Identifying perceived needs by asking how services can be beneficial to them
  - Acting honestly by providing a full disclosure of one's role as a provider (e.g., what you can or cannot do)
- Provide material assistance by giving clients something tangible such as a meal ticket, condoms, bleach kit, or hygiene kit.
- Provide information and referrals to short-term and survival services for clients to help improve their immediate situation.
- If possible, accompany clients to support them in obtaining short-term and survival services such as health care, food, shelter, and clothing.
- Respond to emergency situations.
- Support clients in meeting parole or probation requirements to avoid reincarceration. Based on their individual histories, anticipate circumstances that may result in them breaking parole. For example, if a client confides that he or she has anxiety regarding meeting the parole officer, initiate and practice role plays to better prepare the client for this encounter.
- Be culturally competent.
- Link to services (e.g., medical care, mental health, substance use, domestic violence).
- Diversify clinic staffing, and use a multidisciplinary approach, including peer support.
- Think outside the box! (NYSDOH, 2008)

A number of HIV education resources for inmates and correctional health care providers are cited on the Albany Medical College website at www.amc.edu/Patient/services/HIV/index.cfm (go to the section on correctional education).

Table 1. HIV Testing in Prisons: Circumstances Under Which Prison Inmates Were Tested for HIV (by Jurisdiction)

Jurisdiction	All Inmates			Random	High-risk	Inmate request	Court order	Clinical indication	Involvement in incident	Other
	Entering	In Custody	Upon Release							
Federal					X	X	X	X	X	
Northeast										
Connecticut					X	X	X	X	X	
Maine						X	X	X		
Massachusetts						X			X	
New Hampshire	X						X	X		
New Jersey						X	X	X	X	
New York				X	X	X	X	X	X	
Pennsylvania						X	X	X	X	
Rhode Island	X					X	X	X	X	
Vermont						X		X	X	
Midwest										
Illinois					X	X	X	X	X	X
Indiana	X				X	X	X	X	X	
Iowa	X	X				X	X	X	X	
Kansas					X	X	X	X	X	X
Michigan	X					X	X		X	
Minnesota	X					X	X	X	X	
Missouri	X	X	X		X		X	X	X	
Nebraska	X					X	X	X	X	
North Dakota	X	X				X	X	X	X	
Ohio	X					X	X	X	X	
South Dakota						X	X	X	X	X
Wisconsin					X	X	X	X	X	

Jurisdiction	All Inmates			Random	High-risk	Inmate request	Court order	Clinical indication	Involvement in incident	Other
	Entering	In Custody	Upon Release							
South										
Alabama	X		X	X		X	X	X	X	X
Arkansas	X		X	X	X	X	X	X	X	X
Delaware						X	X	X	X	
Florida			X			X	X	X	X	
Georgia	X					X	X		X	
Kentucky					X			X	X	
Louisiana						X	X	X	X	
Maryland					X	X	X	X	X	X
Mississippi	X				X	X	X	X	X	
North Carolina						X	X	X		X
Oklahoma	X					X	X	X	X	X
South Carolina	X					X	X	X	X	X
Tennessee					X	X	X	X	X	
Texas	X		X		X	X	X	X	X	
Virginia						X	X	X	X	X
West Virginia						X				
West										
Alaska					X	X		X	X	
Arizona					X	X	X	X		
California						X	X	X	X	
Colorado	X					X	X	X	X	
Hawaii						X		X	X	
Idaho	X	X			X	X	X	X	X	
Montana						X	X	X	X	
Nevada	X	X	X			X	X	X	X	
New Mexico						X		X		
Oregon						X	X			
Utah	X				X			X	X	
Washington	X				X	X	X	X	X	
Wyoming	X					X		X		

Adapted from Maruschak L. *HIV in Prisons, 2006*. Bureau of Justice Statistics Bulletin. Washington: U.S. Department of Justice, Office of Justice Programs; revised April 2008. Publication NCJ 222179.

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Patient Education

Background

Informed and empowered patients are better able to achieve healthy outcomes as a result of improved communication and development of trust with their care providers. HIV patient education provides patients with knowledge about HIV infection, including prevention, treatment, and other aspects of care, along with tools that enable them to participate more actively in decisions regarding their medical care. Given the complexity and the rapid evolution of HIV information, education and skills-building should be an ongoing activity and a key aspect of the clinical care of HIV patients. This chapter provides a brief review of the areas that should be addressed in patient education and discusses some strategies for integrating patient education into HIV care; additional information on patient education is found in many other chapters, particularly *Supporting Patients in Care*, *Preventing HIV Transmission/Prevention with Positives*, *Smoking Cessation*, and *Adherence*, as well as in the "Patient Education" sections found at the end of most of the clinical chapters.

S: Subjective

A newly diagnosed patient presents to clinic after being referred from a testing center in the community. The patient received the positive HIV test results more than a year ago, but has not been ready to seek care until now. The patient feared hearing that he/she was "going to die." Now, he/she is ready to consider facing this "terminal" illness. The patient received some information about HIV infection at the testing center, but that was months ago.

O: Objective

See chapters *Initial History*, *Initial Physical Examination*, and *Initial and Interim Laboratory and Other Tests* for information on the initial clinic evaluation.

A/P: Assessment and Plan

The patient will need extensive information and education about HIV infection in general, his/her individual health status and prognosis, and the support and care systems that are available. Below are some suggestions about specific areas to review with a new patient.

Topics for Patient Education

Patient education should cover the following topics:

- What is HIV?
- How is HIV transmitted?
- Progression of HIV; prognosis
- Interpretation of laboratory results
- Treatment information
  - General information regarding the benefits of treatment
  - Indications for treatment, goals of treatment
  - General information regarding potential side effects and risks of treatment
  - Access to medication
  - Insurance information
- Treatment options
- Prevention for positives
- Support services and support groups available to the patient

Patient Educators

In most clinics, a number of different personnel may take on the responsibilities of providing health education to patients. They may include primary care providers, nurses, social workers, case managers, and pharmacists. Some clinics have designated health educators whose role is to provide this type of support for patients. Even when a formal health educator is available, a collaborative, multidisciplinary approach to patient education serves both patients and providers optimally. However, it is important to ensure that patient education messages are coordinated and that patients are receiving consistent information.

Patient education must be provided in a language and at a literacy level appropriate for the patient. Patient education should be conducted in the patient's primary language, if possible; otherwise, skilled medical interpreters should be involved.

Conducting Patient Education

Rarely are patients able to absorb all of the necessary information in a single session. Attention and comprehension levels are optimal during the first 15-20 minutes of a visit, after which an individual's ability to absorb and retain information declines. Therefore, clinics should consider strategies to integrate brief patient education messages throughout the course of patient care and to engage patients in this process. Support groups, case managers, and peer educators can be invaluable in this process of engagement.

It is important to keep the medical information specific to the patient. Although there are some areas of education that should be considered for all patients (see above), patients should not be required to have a high level of understanding in each area. Patients should be given the opportunity to learn as much about an area as they would like, and should be encouraged to gain a working knowledge of the information that is necessary to keep them healthy and safe. Patients vary widely in terms of their interest level in mastering the details of their illness. For example, in the area of "What is HIV?" there may be some patients who want to know details about the basic science and immunologic impact of HIV. With this information, these patients might then want to take the lead in making treatment and care decisions for themselves, in consultation with their care providers. Other patients, however, would feel overwhelmed by this volume of information and involvement and may be best engaged in participating in their care by knowing how HIV is transmitted, how to keep themselves healthy, and how to access more information if they want it. Some patients would prefer for their care providers to "just tell them what to do" rather than take the lead in making their own treatment decisions.

There are a number of websites that provide HIV information for patients (see chapter *Web-Based Resources*). Many patients may prefer this form of self-education. Encourage patients to convey any information they discover to their care providers for further discussion. Reminding patients that they can be teachers as well as students can be a useful strategy for engaging patients in this process. In addition, patients may learn of novel tools and information sources that could be useful to others.

The following are some useful suggestions that providers can convey to their patients:

- Define your goals for each visit; please let your provider know your concerns and what you hope to learn in the course of the visit.
- Write down questions and concerns as they arise, and take that list with you to your appointments.
- Meet all the members of your care team and learn their areas of expertise and what they might be able to offer you.
- Ask about support groups and other peer groups that might be able to provide support/education.
- Review brochures and websites that provide additional information.
- Ask supportive friends or family members to accompany you to clinic visits. They may be able to obtain information that is helpful for their role in supporting your health or reminding you of information discussed at visits.