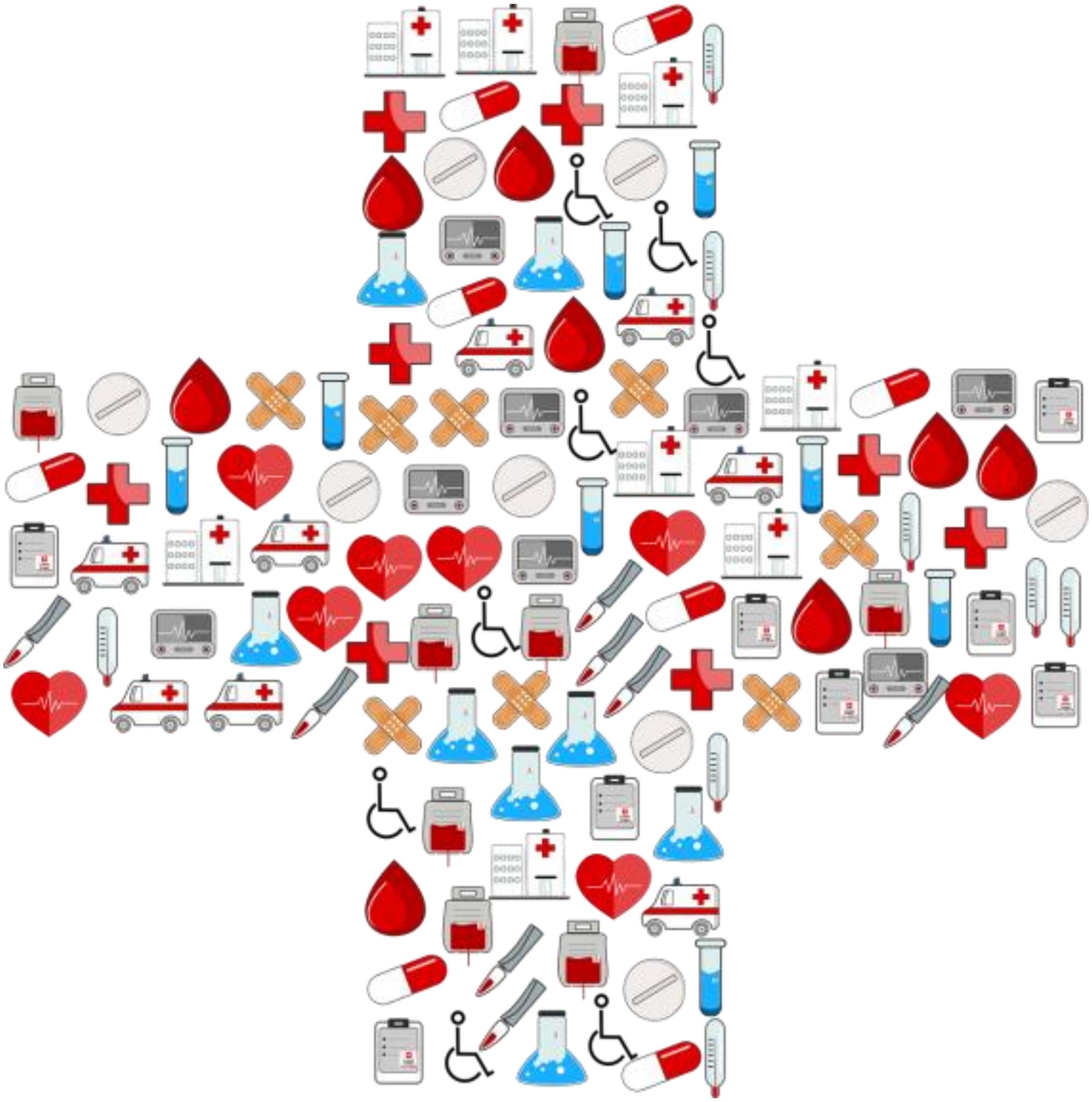
FLEX CEUs

HIV/AIDS



Supporting Patients in Care

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 under-estimate 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

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 selfesteem 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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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.

Initial History

Background

Conducting a thorough initial history and physical examination is important even if previous medical records are available. This is the best opportunity to get a complete picture of the patient's HIV disease status, comorbid conditions, and his or her physical and emotional condition, as well as to establish the basis for an ongoing relationship with the patient. Many of the conditions that put immunocompromised patients at risk of disease can be detected early, by means of a thorough assessment.

The information gathered through the initial history and physical examination will provide a comprehensive standardized database for the assessment and treatment of HIV-related problems, including acute intervention and ongoing prevention services and supportive care.

This chapter includes essential topics to cover during the clinic intake and examples of questions that can be used to elicit important information (the questions should be tailored to the individual patient). This can be completed during the initial visit or divided over the course of two or three early visits. For essential aspects of the physical examination to cover in an initial clinic intake visit, see chapter *Initial Physical Examination*.

HRSA HAB Performance Measures

Percentage of patients 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

(Core measure)

Percentage of patients with a diagnosis of HIV who received **HIV risk counseling** in the measurement year

(Adult and Adolescent measure)

Percentage of new patients with a diagnosis of HIV who have been screened for **substance use** (alcohol and drugs) in the measurement year

(Adult and Adolescent measure)

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

(Adult and Adolescent measure)

S: Subjective

Initial History		
Category / Topics to Cover	**Sample Questions**	
History of Present Illness		
HIV Testing	• What was the date of your first positive HIV test? • Did you have a previous HIV test? If so, when was the last negative result?	
Treatment Status	• Where do you usually receive your health care? • Have you ever received care for HIV? • What was the date of your last HIV care visit? • What is your current CD4 (T-cell) count?	• Do you know what your first CD4 count was? • What was your lowest CD4 count? • What was your highest CD4 count? • Do you know what your first viral load count was? • What is your current viral load count?

Category/Topic to Cover	Sample Questions
History of Present Illness (continued)	
HIV-Related Illnesses	• What opportunistic infection(s) have you had, if any? (PCP, MAC, cryptococcal meningitis, TB, etc.) • What year(s) were you diagnosed with these infections? • Have you had cancer(s)? • What other HIV-related illnesses have you had? Have you had zoster (shingles), oral thrush, pneumonia?
Active TB and TB Testing History	• Have you ever had tuberculosis (TB)? • When was your last TB test? • Was it a TB skin test (TST) or interferon-gamma release assay (IGRA)? • What were the results of this test? • Have you ever had a positive TB result? • What year and what health care setting? • What medications did you take and for how long?

Antiretroviral Therapy (ART) History	• Are you taking HIV medications now?
	• If so, please name them or describe them, and tell me how many times a day you take them.
	• How many doses have you missed in the past 3 days?
	  • The past week?
	  • The past month?
	• What side effects, if any, do you have now? In the past?
	• What HIV medicines have you taken in the past (names or descriptions)?
	• When did you start and stop taking them (dates)?
	• Do you know why you stopped taking these medications?
	• Do you know what your HIV viral load or your CD4 counts were while you were taking your medications?
	• Have you ever had a resistance test?
	• Did you have any side effects to past HIV medications?

Past Medical and Surgical History	
Chronic Diseases	Do you have any chronic conditions, such as the following? • Diabetes • High blood pressure • Heart disease • Cholesterol problems • Asthma or emphysema • Sickle cell disease • Ulcers, acid reflux, or irritable bowel syndrome • Thyroid disorders • Kidney or liver problems • Mental health disorders If so, do you receive medical care for these conditions?
Previous Illnesses	• Have you had any hospitalizations? Where, when, and for what reason? • Have you had any surgeries? When and where? • Have you had any major illnesses, including mental health conditions?
Hepatitis	• Have you ever had hepatitis? What type (A, B, C)? • Do you have chronic hepatitis? • Do you know whether you are immune to hepatitis A or hepatitis B? Have you been vaccinated?

Category/Topic to Cover	Sample Questions
Past Medical and Surgical History (continued)	
Gynecologic and Women's Health	• When was your last cervical Papanicolaou (Pap) test? • What were the results? • Have you ever had an abnormal Pap test? • When was your last menstrual period? • What is the usual length of your cycle? Is it regular or irregular? • Have you noticed changes in your menstrual cycle? • When was your most recent breast examination? • Have you had a mammogram? When? • Have you ever had an abnormal breast examination or mammogram? • Do you get yeast infections? How often? • Do you get urinary infections? • Have you ever had kidney stones?
Obstetric	• How many pregnancies have you had? • How many live births? Ages of children now? • How many miscarriages or therapeutic abortions? • Were you tested for HIV during any pregnancy? What year? • Did you deliver an infant while you were HIV infected? • Was HIV medication given during pregnancy and delivery? • Do you have children? What is their HIV status? • Do you intend to become pregnant?
Anorectal History	• Have you ever had an anal Pap test? • What were the results? • Have you had anal warts? Other abnormalities?
Urologic History	Have you ever had: • Kidney stones • Urinary tract Infections • Prostate infection or enlargement • Have you had a prostate-specific antigen (PSA) test? (What were the results?)
Sexually Transmitted Diseases	Have you ever had any of the following infections? If yes, when was last episode? • Syphilis (If yes, ask about stage, treatment and date of treatment, titer follow-up, and date and result of last titer.) • Vaginitis • Genital herpes • Nongonococcal urethritis (NGU) • Gonorrhea (If yes, ask about sites of infection: oral, anal, urethral, vaginal.) • Chlamydia (If yes, ask about sites of infection: oral, anal, urethral, vaginal.) • Genital warts (HPV) • Proctitis • Pelvic inflammatory disease (PID) • Trichomoniasis

Category/Topic to Cover	Sample Questions
Past Medical and Surgical History (continued)	
Dental/Oral Care	• When was your last oral health examination? • Do you have all your natural teeth? • Do you have partials or dentures?
Eye Care	• When was your last vision examination? • When was your last dilated retinal examination? • Do you wear glasses or corrective lenses?
Medications	• What (non-ARV) medications do you take? • What herbs, vitamins, nutritional supplements, or over-the-counter (OTC) medications, do you take?
Allergies; Medication Intolerance	• Have you had an allergic reaction to any medications? What type of reaction, how severe? • Have you had allergic reactions to other types of exposures? • Have you had severe side effects from any medications?
Immunizations	When was your last vaccination for the following: • Streptococcal pneumonia (Pneumovax; PPV23, PCV13) • Tetanus/Pertussis (Tdap) • Influenza • Hepatitis A • Hepatitis B Did you have chickenpox as a child, or were you vaccinated against chickenpox? What about measles, mumps, and rubella?
Health-Related Behaviors	**Tobacco use:** • Do you smoke? How many cigarettes per day? How long have you smoked? How much have you have smoked in the past? • Besides tobacco, what do you smoke? • Do you chew tobacco? **Alcohol use:** • How often do you have a drink containing alcohol? How many drinks do you have on a typical day? How many per week? • Have you ever had a problem fulfilling work, social, or school obligations because of alcohol use? • Have you ever sought treatment for alcohol-related problems? **Drug use:** • Do you use any recreational or street drugs we haven't covered in earlier questions? Any prescription drugs or medications that were not prescribed to you? • If so, what drugs and how do you use them (inject, smoke, inhale, etc.)? **Drug use (continued):** • How often do you use substances? • Have you shared drug-use equipment with another person? • What pain relievers do you use on a regular basis? • Are you interested in treatment for alcohol or drug use? • Have you ever sought treatment? **Exercise:** • What kind of exercise do you participate in? How frequently? **Diet:** • What do you eat during a typical day? • Do you consume raw (unpasteurized) milk, raw eggs, raw or rare meat, deli meats, soft cheeses, or raw fish? • How much water do you drink during a typical day? • What is your source of water? • How much caffeine do you drink during a typical day?

Category/Topic to Cover	Sample Questions
Sensitive Sexual and Gender History Questions	
Gender Identity	• Do you consider yourself male or female? • Have you had or considered treatment for sex change? • Are you presently taking hormone therapy? • Have you had hormone therapy in the past? • Have you had any gender confirmation (sex reassignment) surgery?
General Sexual	• Do you have sex with men, women, or both? • In the past, have you had sex with men, women, or both? • In the past 2 months, how many sex partners have you had? • In the past 12 months, how many sex partners have you had?
Sexual Practices	• Do you have anal sex? Vaginal? Oral? • How do you protect yourself from sexually transmitted diseases, or HIV reinfection? • For men who have sex with men: • Are you the receptive or insertive partner, or both? • How often do you use alcohol or drugs before or during sex?
HIV Prevention	• Do you know the HIV status of your partner(s)? • Do you take measures to protect your partners from HIV? What measures? • In what situations do you or your partner use condoms or some other barrier? • Are there situations in which you do not use barrier protection?
Sex Trading	• Have you ever exchanged sex for food, shelter, drugs, or money?
Contraception	• What birth control measures do you use, if any? • How often do you use condoms or other latex barriers? • Do you have plans for you or your partner to become pregnant?
Family History	
	Do you have a family history of: • Heart disease? Heart attacks or strokes? • Cholesterol problems? Diabetes? • Cancer? • Mental health conditions (e.g., depression, bipolar disorder, anxiety, phobias)? • Addictions? Which family member(s), and what is their health status currently?
Social History	
Relationship Situation	• What is your relationship status (single, married, partnered, divorced, widowed)? • Do you have children? • Does your partner (and/or children) know about your HIV status?
Living Situation	• Do you live alone or with others? With whom? • How long have you lived in your residence?
Support System	• Who knows about your HIV status? • Which individual has been the most supportive since your HIV diagnosis? • Who has been the least supportive? • Have you used any community services such as support groups?

Category/Topic to Cover	Sample Questions
Social History (continued)	
Employment	• Are you currently employed? • Where do you work? • Describe your job task(s). • What setting do you work in on a daily basis? • Does your employer provide health insurance? • Does your employer know of your HIV status? • If on disability: How long have you been on disability? • What medical condition has made you disabled?
Incarceration History	• Have you ever been incarcerated? When was the last time?
Pets	• What kind of pets do you have, and who cleans up after them?
Travel	• Where have you traveled outside the United States? • When did travel take place?
Mental Health	
Coping	• How do you handle your problems/stresses? • What do you do to relax?
History	• Have ever been diagnosed with depression, anxiety, panic, bipolar disorder, schizophrenia, etc.? • Have you taken or are you taking any medications for these conditions? • Are you seeing a therapist or mental health professional? • Have you had any previous counseling or mental health problems? • Have you ever been hospitalized for a psychiatric condition? • Have you ever thought about hurting yourself? (If yes, probe for previous suicide attempts: Are you feeling that way now?) (See chapter *Suicide Risk* and prepare for immediate referral if necessary.)
Violence	• Have you ever been sexually abused, assaulted, or raped? • Has an intimate partner ever forced you to do something you did not want to do? • Has a partner, family member, or other person ever physically hurt you? • Have you lived in any situation with physical violence or intimidation? • When has this occurred? • Are you afraid for your safety now? • (If yes) Did you seek legal help, therapy, or other type of assistance?
Childhood Trauma	• Was there any alcoholism or drug abuse in your household when you were a child? • Did you experience or observe violence; physical, sexual, or emotional abuse; or neglect?

Review of Systems

For each positive answer, ask about location, characteristics, duration of symptoms, exacerbating and alleviating factors, previous diagnostic workup, and treatments tried.	
General	• Do you ever wake up feeling tired?
Fever	• Do you have fevers? How high, and for how long? How often?
Night Sweats	• Do you ever sweat so much at night that it soaks your sheets and nightclothes?
Anorexia	• How is your appetite?
Weight	• What was your weight 1 year ago? • What is a normal weight for you? • Have you lost or gained weight unintentionally?
Body Changes	• Have you noticed any changes in the shape of your body (describe)? For example, has there been an increase in your waist, collar, or breast size or a decrease in your arm, leg, or buttocks size? • Have you noticed increased visibility of veins in your arms and legs? • Have you noticed thinning of your face, especially around the cheeks?
Head, Ears, Eyes, Nose, and Throat	
Vision	• Have you noticed any changes in your vision, especially blurred vision or vision loss, double vision, new "floaters" or flashes of light? • Have you noticed this problem in one or both eyes? • When did you first notice these changes?
Mouth, Ears, Nose, Throat	• Have you noticed any white spots in your mouth or a white coating on your tongue (thrush, oral hairy leukoplakia)? • Do you ever get sores in your mouth or the back of your throat? Gum problems? • Any nosebleeds? • Do you ever experience hearing loss, ringing in your ears, or ear pain?
Cardiovascular	
Cardiac	• Any chest pain or pressure? Palpitations? • Any shortness of breath during activities or while you are lying down? • How far can you walk or run before you get short of breath? • Any swelling in your feet or legs?
Pulmonary	
Cough	• Do you have a cough? • Can you describe it? Dry or productive, amount, color, odor, presence of blood in sputum? When is it the worst?
Dyspnea	• Do you ever feel short of breath? • Does that happen when you are sitting still, lying down, or moving around? • How severe is your shortness of breath? • What does it prevent you from doing? • Do you ever wheeze??

Gastrointestinal	
Dysphagia	• Do you have any problems with food sticking in your throat or being difficult to swallow? • Do you gag or get nauseated when trying to eat? • Do you notice it is easier to swallow liquids or solids? • Do you have difficulty swallowing pills?
Odynophagia	• Do you have pain in your throat, esophagus, or behind your breastbone when you swallow?
Dyspepsia/Reflux	• Do you ever have heartburn (or a burning feeling rising from the stomach to behind the breastbone)? • When does it happen – after eating, lying down, on an empty stomach? • Do you get the taste of stomach acid in your mouth?
Nausea/Vomiting	• Do you have nausea or vomiting? • When? Are there specific things that cause this?
Diarrhea	• Do you have diarrhea, or more than 3-5 unformed stools a day? • Stool characteristics: bloody, pus, mucus? • Pain or cramping with diarrhea? Tenesmus?
Bowel Habits	• How frequently do you have bowel movements? • Do you have problems with constipation, blood in the stools, or other? • Do you have problems with flatulence or belching after eating?
Genitourinary	
Genital	• Do you have any lesions or sores on your genital area now, or have you in the past? • Have you ever had genital herpes? If yes, how often do you have outbreaks? • When was the most recent outbreak?
Women	• Have you had any lower abdominal pain? • Have you noticed a vaginal discharge or odor? • Do you have any burning or pain on urination? • Frequent urination? • Do you lose control of your urine or have problems getting to the bathroom before you start to urinate?
Men	• Have you noticed any swelling or testicular pain? • Do you have difficulty starting your stream of urine? • Are you getting up at night to urinate? • Have you had burning or pain on urination? • Do you lose control of your urine or have problems getting to the bathroom before you start to urinate? • Do you have any difficulty developing or maintaining an erection? • Any discharge from your penis?

Musculoskeletal	
	• Do you have any muscle aches or pains? Joint pain or swelling? • Back pain? • Have you ever broken any bones? • Do you have chronic pain? • Describe the pain – location, duration, rating (scale of 1-10), alleviating factors.
Skin	
Skin Lesions	• Have you noticed any rash or skin problems? If so, where? • Have you noticed any new moles, bruises, or bumps on your skin? • Do you have any moles that have changed shape, size, or color?
Tinea	• Do you have fungal infections on your skin, especially groin, fingernails, toenails, or feet?
Folliculitis	• Do you have any itchy bumps on your face, back, or chest?
Seborrhea	• Do you have flaking or itching on your skin or scalp?
Neurologic	
Headache	• How often do you get headaches? • Describe the headaches – location, timing, duration, alleviating or aggravating factors. • Do they cause nausea or vomiting? • Does sensitivity to light lead to headaches?
Neuropathy	• Do you have any numbness, tingling, burning, or pain in your hands or feet?
Weakness	• Do you have or have you had any weakness in your arms or legs?
Gait	• Have you noticed any changes in the way you walk?
Memory	• Do you have difficulty with your memory or ability to concentrate? If so, describe.
Seizures	• Have you ever had a seizure or “fit”? • If so, describe the seizure – When? How long did it last? Did you experience loss of consciousness? Did you receive medical care?
Endocrine	
Diabetes	• Have you had any increase in thirst, hunger, or urination?
Thyroid	• Have you noticed changes in your energy level? • Do you have intolerance to heat or cold? • Have you noticed changes in your hair (thinning, coarse texture)?
Sex Steroids	• Have you noticed any changes in your libido? In your energy level, mood?
Hematologic/Lymphatic	
Adenopathy	• Do you have swollen glands? • If so, describe – location, pain, size.
Bruising or Bleeding	• Have you noticed easy bruising or prolonged bleeding after injury? • Nosebleeds or bleeding gums?

Psychiatric	
Mood	• Depression screening: Have you experienced a decrease in your interest or pleasure in your activities? Have you felt depressed, down, or hopeless? • Do you feel more angry, sad, depressed, numb, irritable, or anxious than usual? • Have any major life events have occurred to cause you to feel sad or depressed? • When did these events occur?
Sleep	• How is your sleep? • How many hours do you sleep each night? • What is your sleeping schedule – time to bed and time to rise? • Do you take naps?

HIV Research

Sample Questions	
	• Have you participated in any research protocols? What studies, and when? • Would you be interested in participating in research studies (if available)?

O: Objective

- Conduct a physical examination, focusing on subjective findings elicited in the history. (See chapter *Initial Physical Examination*.) Note: If significant time has elapsed between the review of symptoms (ROS) and the physical examination, perform another ROS.

A/P: Assessment and Plan

- Arrange for baseline/intake laboratory work. (See chapter *Initial and Interim Laboratory and Other Tests*.)
- Compose a problem list. Initiate a medication list (if appropriate).
- Refer the patient to social services, mental health care, local health department partner services, community and other resources, or other clinic services as needed.

During the current visit or a future visit:

- Perform immunizations for pneumonia (Pneumovax), influenza (as appropriate), and other immunizations as indicated. (See chapter *Immunizations for HIV-Infected Adults and Adolescents*.)
- Provide counseling on prevention of HIV transmission (e.g., safer sex and injection practices), as appropriate. See chapter *Preventing HIV Transmission/Prevention with Positives*.

Patient Education

A very important aspect of caring for HIV-infected individuals is educating patients about HIV infection, including goals of care and ways of achieving those goals.

Review the following with each patient:

HIV disease

- Disease course
- Significance of CD4 cell count and HIV viral load
- Possible treatment approaches, including initial discussion about the importance of ART for the patient's own health and for reducing risk of HIV transmission
- Disclosure (e.g., whom the patient may need to tell about HIV status, relevant legal requirements, approaches to disclosure)

HIV transmission prevention and risk reduction for HIV-infected individuals

(see chapter *Preventing HIV Transmission/ Prevention with Positives*)

- Strategies to prevent transmission of HIV to uninfected partners and to prevent acquisition of sexually transmitted diseases, hepatitis, and other infections
- Safer-sex approaches, including the use of condoms or other latex barriers during sexual contacts
- Safer use of recreational drugs

Nutrition

- Maintaining a healthy weight
- Nutritional support resources, if appropriate
- Importance of including a nutritionist in medical care

Mental health

- Stress reduction
- Rest and exercise to enhance a healthy mental state

Adherence

- Importance of keeping medical appointments
- Need for adhering to any medication regimen and the consequences of missed HIV medication doses

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