

Provider Feedback Forum on HIV Diagnosis and Care

September 11, 2007

Renaissance Chicago O'Hare Suites Hotel

Chicago, Illinois

Department of Veterans Affairs, Veterans Health Administration

Public Health Strategic Health Care Group

October 12, 2007

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Overview and Summary

On September 11, 2007, the Public Health Strategic Health Care Group (PHSHG) convened the Provider Feedback Forum on HIV Diagnosis and Care. The primary purpose of the forum was to obtain feedback from frontline providers about their experiences in diagnosing and providing care to veterans who are living with HIV. PHSHG sought this input in order to help determine priority areas for ongoing and future program and policy efforts.

VA health care providers were invited to submit applications to participate in the forum. In selecting participants, PHSHG sought a representative cross section of frontline providers. Participants represented a wide variety of disciplines including medicine, nursing, pharmacy, laboratory, and mental health. They also represented varying levels of providers, including physicians and physician assistants and nurses and nurse practitioners. Clinicians providing care to patients with HIV represented both primary care (PC) practitioners and infectious disease (ID) specialists. Participants came from sites across the country in both urban and rural settings. This rich mix of participants provided a range of perspectives reflecting the diversity of VA sites.

The forum addressed four major HIV topic areas:

- Models of care and staffing issues;
- Management issues and co-morbidities;

- Prevention and clinical preventive services; and
- Informational and training needs.

For each topic area, participants were asked to identify: 1) what is working well; 2) areas that might require improvement or increased attention; and 3) how the VA Central Office (CO) can better support the provision of HIV-related care.

In the discussion of the four topics, several cross-cutting themes emerged. These included:

- Increasing complexity of HIV-related care;
- Need for greater coordination across services (e.g., mental health, substance abuse treatment, and dental);
- The roles of specialists vs. primary care providers in delivering HIV care;
- Challenges of meeting the needs of a diverse patient population;
- Issues related to co-morbidities and other chronic conditions;
- Support needs of providers (e.g., information and training needs, adequate staffing levels);
- Informational needs of patients; and
- Challenges related to implementing routine HIV testing in VA sites.

It is important to note that while the forum participants focused on the many challenges, barriers, and areas that require improvement, many participants voiced their belief that the care provided to veterans living with HIV is generally very good.

Participants reported having patients leave the system, only to return because the quality of care they received from the VA was superior to their other care options. In addition, participants who had worked in other care settings prior to joining the VA reported there

were often fewer resource-related and administrative challenges in the VA, compared to their previous settings.

It is also important to note that in some instances, participants believed that veterans receiving care through the VA were subjected to a lower standard of care than others who received treatment outside the VA system. This was especially true in terms of implementation of routine HIV testing within health care settings. Existing pre- and post-test counseling and written consent requirements within VA facilities make it difficult to implement the CDC's recommendations related to routine HIV testing in health care settings. Access to dental care, especially preventive dental care, was identified as a significant weakness of the VA system and many participants sought care for their patients through Ryan White-funded programs. It was also mentioned that it can be difficult for veterans receiving care through the VA to take advantage of early access drug programs and to participate in clinical trials.

Regardless of the level of care received, participants believed that care could be improved and thought that policy-related responses were necessary to bring about this improvement. While this was true across patient populations, participants believed that new pressures on the VA from Operation Iraqi Freedom and Operation Enduring Freedom veterans might increase the need for HIV-related services within the system.

The following report discusses the many issues explored during the forum, based on the cross-cutting themes identified above. Many of the topics discussed related to more than one of the themes identified.

1. Increasing Complexity of HIV-Related Care

HIV care is becoming increasingly complex and many treatment options remain incredibly expensive—making the challenge of providing optimal care in a cost-effective manner more difficult than ever. Deciding on an appropriate treatment regimen, monitoring for drug resistance, and identifying appropriate salvage therapy, while monitoring and treating myriad side effects, requires constant attention to ever evolving treatment guidelines. Newly emerging areas of medicine, such as pharmacogenomics, will only add to the complexity, as will the need to treat other chronic conditions in people with HIV (e.g., cardiovascular disease, metabolic syndrome, etc.).

In the face of these increasingly complex treatment challenges, is it appropriate to expect PC clinicians to provide care for people living with HIV? What if ID clinicians or HIV specialists are not available to a patient? What are the best models of care given limited resources? These are the types of questions that confront providers of HIV care as treatment options continue to evolve.

An example of the growing complexity of HIV care is the increasing importance of resistance testing, which can present challenges in terms of interpretation of the results as well as technological challenges in terms of both software (e.g., generating, reporting, and storing results) and hardware (e.g., access to color printers). Some participants had the ability to report results through the Computerized Patient Record System (CPRS) while others needed to wait for the lab to return the results, which could take weeks. Some sites use software that is not compatible with CPRS so results are entered manually, which increases the possibility of entering the wrong results. Given how complex resistance testing has become, participants believed that clinicians will

increasingly need help in this area. Decision-making tools and access to outside expertise will likely be necessary.

Another example of how complex HIV-related care has become is the need to provide anal dysplasia screening to patients with HIV. Research indicates that the risk of anal cancer is elevated for patients with HIV, compared to uninfected individuals; rates are especially high for men who have sex with men. This is an area where there will need to be broad-based education effort on the need to provide the screening. Resources will also be necessary as facilities will need equipment. Providers will also need to be trained on how to carry out the tests and cytologist on how to interpret results. Linkages will also need to be made with oncology and surgery departments.

Many patients prefer to receive their care from the ID clinic and are focused primarily on their HIV-related care needs. They have little awareness of or interest in their PC-related needs. However, some sites do not have sufficient ID clinicians, and HIV-infected patients in this case are seen by PC providers. To support the PC providers, some sites allocate more time for HIV-related care due to the complexity. HIV-related training is also often made available to PC providers.

Pharmacists were identified as a key resource for both ID and PC clinicians. Pharmacists can assist in keeping clinicians current on antiretroviral treatment, guard against drug interactions, and play a role in the provision of primary care (e.g., recommend that patients take aspirin to prevent strokes).

Selected Suggestions from Participants

- Develop standard lab packages for CPRS (e.g. for resistance testing).

- Develop a process for making available newly approved drugs through VA pharmacies, such as sending information on drugs directly to the directors of pharmacies. Sites should contact the VA Central Office if access to newly released drugs continues to be a problem.
- For pilot projects, give smaller amounts of money to more organizations. There is interest in improving care and small grants can be effective in bringing about important changes.

2. Need for Greater Coordination across Services

HIV-infected patients can suffer from many conditions, making coordination of care and communication across providers necessary for optimal care. In addition, as people with HIV live longer, they are developing many of the same chronic conditions, such as diabetes and hypertension, as their non-infected contemporaries. Also, many people living with HIV have mental health issues that may or may not be related to their HIV status.

Often, the treatment of HIV-infected patients is perceived by other providers to be in the realm of the ID clinic. This is true whether the condition is related to the patient's HIV status or not. Regardless of who is caring for the patient, due to the complexity of the condition, it is essential that providers communicate and coordinate care.

While greater coordination across programs can enhance patient services, there are also other benefits. For example, placing pharmacists in ID clinics can result in significant savings by reducing unnecessary refills and preventing drug interactions.

As patients with HIV live longer, access to surgical procedures will become an increasingly important issue. Surgery may be needed for a variety of reasons, and may

be simple or complex, HIV-related or not. For example, as people with HIV live longer, they may need hip replacement surgery. They also may need surgery, such as a liver transplant, related to HIV or a co-morbidity such as hepatitis C. Linkages must be made within Veterans Integrated Services Networks (VISNs) to facilitate these procedures.

Two areas where greater coordination of services is especially important for patients with HIV are mental health and substance abuse treatment services.

Mental Health

Participants reported that some mental health providers seem to be disinterested in addressing HIV. Once a patient is identified as HIV positive, they are referred to the ID clinic and their mental health needs become secondary. Some sites have integrated mental health services within their ID clinic. However, participants thought that for the most part, these services were not well coordinated within facilities and that programs operated as separate silos instead of taking a multidisciplinary approach to care.

Substance Abuse Treatment

A critical part of mental health services for people living with HIV is treatment for drug and alcohol abuse. Participants reported the lack of inpatient treatment as a huge barrier for their patients. While detox may be available, longer term treatment is generally not available. When it is available, often there is no follow up in the community and patients return to the same social networks as before, which often results in relapse. Ongoing support for patients with substance abuse issues is necessary—including harm reduction. Providers must understand that often, multiple attempts are required before abstinence is obtained. Even then, the possibility of relapse always exists and there should be programs to support people after they leave treatment.

Other services that also require better coordination include dermatology, dental care, and for women living with HIV, gynecological services and prenatal care.

Coordination Outside the VA System

While the focus of the discussion was coordination within the system, coordination with other community organizations was also discussed:

Early Access Drug Programs. Delays in obtaining required IRB approval can significantly delay access to early access drug programs for patients in need of salvage therapy. These programs can sometimes be accessed through other organizations in the community.

Clinical Trials. Participation in clinical research can help to attract more providers to the VA. VA should be pro-active in letting pharmaceutical companies know about those sites that are willing to participate in research. Sites should also consider linking with organizations within their communities that are participating in trials.

Selected Suggestions from Participants

- Identify clear cut lines of responsibility and accountability so as to better coordinate care between ID and PC.
- Provide guidance related to facilitating linkages across services (specialty clinics, mental health, and pharmacy).
- Issue directives from VA Central Office describing standards of care necessary for HIV-infected patients (e.g., dental care, treatment for facial lipoatrophy, substance abuse treatment), which can be helpful in removing local barriers.

- Provide guidelines concerning the number of complex patients that can be cared for by a single provider and adequate funding levels to support patient needs.
- My HealtheVet (MHV) can be a useful tool in tracking care and medications.
- At the local level, linkages should be developed across disciplines. It can greatly facilitate referral to specialty services if the ID or PC providers have specific individuals, who they know, to whom they can make referrals. Participants reported that patients are more likely to follow up on referrals when there is this level of “personal” contact.

3. Meeting the Needs of a Diverse Patient Population

Patients living with HIV, across various setting, have both similar and diverse needs. The different needs of patients can result from their location (e.g. urban vs. rural settings); gender; length of time living with HIV; or the presence of other co-morbidities.

Regardless of where they are located, many patients face challenges in accessing services and transportation is an issue for many patients. Urban patients can lack the money necessary to pay for local transportation. Rural patients can face long hours on the road, sometimes in inclement weather, to attend a 20-minute appointment. More flexibility could help to address these challenges. For example, one rural site sends all HIV-infected patients to the nearest ID clinic, which is 3 hours away, for their HIV-related care. Conducting an ID clinic onsite, with one clinician, could significantly reduce the amount of travel required by the 50 patients served by this rural site.

Another issue is the availability of services. Some are offered on a very limited basis, such as once a week or only during regular office hours. This can present a barrier to working patients or patients with small children who require childcare.

Telemedicine can make accessing certain services more convenient for some patients. It is important that telemedicine be presented to patients as an option, not a requirement. For use of telemedicine to be effective, it is necessary to have a well established patient/provider relationship and face-to-face appointments are still necessary. Telemedicine is only appropriate for adherent patients who are doing well on their treatment regimens.

While participants reported serving relatively small numbers of women, they discussed some of the unique needs of female patients living with HIV. Some services for women, such as mammograms and gynecologic care, are often referred to outside providers on a fee basis. Pregnancy is also often handled this way. The unique needs of HIV-infected transgender patients were also mentioned.

No specific suggestions from participants were noted.

4. Co-morbidities and other Chronic Conditions

While there are multiple co-morbidities of HIV infection, participants focused primarily on hepatitis and substance abuse, which are discussed in greater detail below. In discussing these co-morbidities, participants focused on the role of PC providers in providing treatment. Participants opined that many PC providers already face overwhelming workloads and may not have the time to address these issues with their patients. This was considered to be a barrier at the systemic level, requiring a system-level response to ensure that services are as responsive to the needs of patients as possible.

Hepatitis

Participants identified the lack of awareness, both by providers and patients, as a barrier to diagnosis and care. This was true whether it was people with HIV knowing about the risk of hepatitis or people with hepatitis knowing about the risk of HIV. The need for significant educational outreach to both providers and patients about HIV and hepatitis was identified. In addition, it was recommended that HIV programs address hepatitis during the intake of new patients, addressing both screening and vaccination issues. Some programs designate a single provider to conduct intake services, which helps to ensure consistency. The Hepatitis C Resource Centers were identified as good resources for providers.

In terms of providing vaccinations for hepatitis, participants believed that the VA is very effective. However, some additional information on the vaccination needs of HIV-infected patients may be necessary for PC clinicians. It was also recommended that pop-up reminders on the electronic medical record could be a useful tool in terms of promoting vaccination for hepatitis.

Substance Abuse

Continued substance abuse, whether of alcohol or drugs, can greatly reduce the effectiveness of HIV treatment. As mentioned previously, greater coordination across programs is necessary and access to substance abuse treatment must be improved. ID and PC providers also need to understand the recovery process better—multiple attempts may be necessary before long-term sobriety is attained. Providers should also counsel their patients on harm reduction techniques (e.g., sterile injection equipment, reduction in alcohol use) so that if they do continue to use drugs, they and others are at lower risk.

No specific suggestions from participants were noted.

5. Support Needs of Providers

Participants discussed an array of provider-related needs. Addressing these needs will allow the VA to better meet the needs of HIV-infected patients, both now and in the future.

Informational Needs

Providers obtain information from numerous sources, including the Internet, colleagues, conferences, teleconferences, and outside experts. Key sources include:

- Internet – (e.g., CDC, Johns Hopkins, VA’s HIV website, AIDS Treatment Access Program (ATAP), and the New York State AIDS Institute)
- Case Conferences/Roundtables – these allow providers to obtain input into patient care and learn from their colleagues.
- Conferences – not only do they provide information but they offer unique networking opportunities.
- Teleconferences – such as the one on HIV resistance testing, are valuable learning experiences. However, often when provided by EES there is insufficient advance notice to make arrangements to participate. Making these learning opportunities available afterwards, through DVDs or webcasts, is encouraged.
- Outside Experts – this can be critical to providers who lack expertise in HIV, especially those in rural areas and other areas where they may see few HIV-infected patients. The VA should explore ways of making experts from outside the facility more available to providers. This would be especially

valuable if providers could have an ongoing working relationship with a single expert to address patient needs over time.

PC providers treating patients with HIV infection may need an additional level of informational support. This information should include basic information on antiretroviral therapy (e.g., descriptions of available drugs, drug interactions) and resistance testing (e.g., how to interpret results or who to consult to assist with interpretation).

General Training Needs

Participants identified two main issues related to training: 1) enhancing the current training experience, especially for providers who may lack HIV-related experience, such as PC providers; and 2) ensuring that there are adequate numbers of trained providers to serve patients in the future.

As mentioned previously, given the complexity of HIV care, providers will need continual access to information on the latest developments in HIV care. Providers who do not specialize in HIV care will most likely need access to expert consultation.

While there might be strains in the system currently, participants expressed concern about the care of patients living with HIV in the future. According to the participants, when a staff person leaves a position, they are frequently not replaced. Skilled HIV providers are aging and will eventually leave the system. In many smaller facilities, there is only one HIV specialist. If this person should leave, there will be no one to care for HIV-infected patients. In the meantime, as people with HIV infection live longer and additional veterans are diagnosed, the caseload can be expected to increase. To adequately meet these future needs, planning must begin today.

Participants suggested that mentoring opportunities, such as internships for staff nurses with HIV coordinators, be made more available. The HIV training experience for residents must also be made more meaningful, which will not only enhance the training experience for the residents but also improve patient care. Creative approaches should be considered for attracting clinicians to HIV-related care. For example, to attract HIV physicians, the VA might consider developing an International Medical Program for ID fellows.

Staffing

Appropriate staffing is also a concern—there must be a sufficient number of people with the necessary skills to provide required services. Participants asked if there were guidelines related to staffing ratios based on the number of patients served. Participants noted that such guidelines should also include the suggested array of providers. Currently, the VA does not have these types of guidelines.

Participants discussed the roles of HIV and Hepatitis Coordinators. Often, these people fill several other roles within a clinic, which prevents them from focusing on their work as a coordinator. Frequently, they are not replaced if they leave the position. Participants suggested that if sites are required to have these coordinators in place, sufficient resources should be provided to allow for the ongoing staffing of the position.

The need for adequate administrative support was also mentioned, especially as it relates to scheduling of appointments and patient follow up. Relieving clinicians of some of their administrative responsibilities would allow for more time for them to address patient needs.

Selected Suggestions from Participants

- Develop HIV-related materials for providers similar to those developed for hepatitis C by the HCV Resource Centers.
- Develop medication-related materials (e.g., pocket guides).
- Develop HIV-related materials for settings such as the emergency department.
- Develop screening tools for providers (e.g., to identify mental health or substance abuse issues).
- Update the “HIV Prevention Handbook,” which is very popular with providers.
- Present training topics in a general, rather than an HIV-specific manner (e.g., “Sexual Health for Seniors” instead of “Seniors and HIV”).
- Provide guidance on how to streamline the materials approval process at the local level to reduce delays in the dissemination of information.

6. Informational Needs of Patients

Patients have a variety of informational needs. Veterans living with HIV need information on strategies that will help them adopt and maintain safer behaviors. They also need information about their treatment and the importance of adhering to their treatment regimen. Newly diagnosed patients will need information about HIV and how to live with the disease.

Risk Reduction

A major issue as people with HIV live longer is the challenge of maintaining risk reduction practices over time (e.g., consistent condom use). Providers can play an important role in supporting these safer behaviors by regularly conducting risk assessments during appointments (e.g., sexual history, screening for symptoms of STDs

and drug and alcohol use practices). However, these assessments are not always conducted. Some providers simply forget to do it or feel there is not sufficient time. Other providers, especially those that lack experience in working with patients with HIV, may feel uncomfortable raising sensitive issues related to sex and drug use with their patients. Participants noted that it does not necessarily have to be a physician conducting assessments and providing counseling. In many programs, nurses and other members of the care team address patients' prevention needs.

Various strategies were suggested for better addressing the prevention needs of patients. Some of these are focused on the provider. For example, pop-up reminders in the medical record to conduct risk assessments can be used. Providers should be encouraged to include in their notes that risk assessments and counseling have been conducted so that these encounters are documented. There are some tools to help providers initiate the discussion, such as short questionnaires about the patient's recent risk behaviors. More structured discussion can be incorporated into regular annual appointments. Providers could benefit from training in techniques that facilitate these interactions, such as motivational interviewing. Finally, programs should not overlook the value of peer educators (i.e., other veterans living with HIV) and should explore ways to incorporate their services.

Additional issues related to HIV prevention that were discussed include: the importance of counseling patients who request Viagra about safer sex; how to address patients who become diagnosed with an STD, especially if they have a history of repeated infections; and addressing the prevention needs of patients' sexual partners, especially with sero-discordant couples. Participants also discussed the challenge of

maintaining risk reduction practices over many years. Some patients may get to a point where they consider that after 15-20 years with HIV, they need to take a break from practicing safer behaviors.

Treatment Information

Patients also need help understanding their care, which has become much more difficult as HIV care has become more complex. Patients also need ongoing support from providers related to treatment adherence.

Selected Suggestions from Participants

- Develop a series of patient materials on HIV similar to the ones on hepatitis C (e.g., “what is HIV,” tips for the newly diagnosed, risk reduction).
- The website hiv.va.gov is an excellent resource. Adding audio to the site would make the information available to patients with low literacy levels.

7. Implementing Routine HIV Testing in VA Sites

In September of 2006, CDC issued recommendations for HIV testing in health care settings. The *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Healthcare Settings* encourage HIV testing a routine part of medical care.

One recent study showed that of newly detected infections within VA facilities, the majority of the patients have been receiving care from the VA for several years. This indicates that there were many missed opportunities to identify patients with HIV infection and initiate treatment. Health care providers need to know that there are an estimated 40,000 new HIV infections each year in the United States and that nearly 25 percent of currently infected persons are unaware that they are infected with HIV.

Approximately one-third of the forum's participants reported having rapid HIV testing available in their facility but most of the testing was lab-based. Some reported limited availability, such as once a week during clinic or only in certain settings (e.g., emergency department) or circumstances (e.g., needle stick). Currently, according to participants, much of the testing done in facilities is patient driven (i.e., the patient requests to be tested). Participants voiced their opinion that HIV tests are not routinely offered by most providers.

Participants identified the need for increased HIV testing both among patients and the general public. The use of rapid HIV tests was believed to be especially advantageous for some populations, such as homeless individuals or people living in rural areas, since both these populations confront challenges in returning for their test results. There are also emerging populations, such as Operation Iraqi Freedom and Operation Enduring Freedom veterans, who will require access to HIV testing. Greater awareness about the importance of HIV testing on the part of both providers and patients is necessary.

A major barrier to HIV testing is federal law requiring VA providers to document pre- and post-test counseling in the medical record and to obtain separate written informed consent prior to HIV testing. The VA Central Office is working to address these issues at the federal level. Some States currently have laws relating to HIV counseling and consent that could limit implementation of routine HIV testing in that jurisdiction. Participants reported that the contradiction between CDC's recommendations and the VA's current policy makes it very difficult to convince both

the administration and providers within a site about the need for and value of routine HIV testing.

Site-level barriers identified by participants include: lab-related issues pertaining to rapid HIV testing (e.g., CLIA, who will perform the test, training of staff, reporting in CPRS, quality assurance); lack of resources to provide the test; challenges related to linking newly diagnosed patients to care; and resistance to routine HIV testing from some providers outside of ID clinics (e.g., PC, substance abuse treatment).

Selected Suggestions from Participants

- Change the current federal law to permit verbal consent for HIV testing.
- Explore the possibility of including test results in My Health_eVet (e.g., inform patients that they could obtain their results online if they wanted).
- Partner with organizations within the community, such as local health departments, to conduct HIV testing.
- Provide small grants to implement innovative approaches to HIV testing;
- Provide HIV testing to all patients across all VA sites on a single day (1-day HIV testing campaign).
- Use of pop-up reminders in the medical record for clinicians about routinely offering HIV testing.

Attachment: Participant List

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