

Part 2:

Connecting To Care and Reducing Unmet Need: Survey Of Title I Medical Providers

I. Introduction

The Health Resources and Services Administration/HIV/AIDS Bureau (HRSA/HAB) has placed considerable emphasis on “unmet need” – individuals who know their HIV status but are not “in care” - receiving medical care or HIV medications. Initially, the emphasis was on measuring unmet need and estimating the number or percent of PLWHA who were not in care. The emphasis has now shifted to the next step – bringing those individuals into care or “connecting them to care”. Strategies have been developed across the U.S. to assist in this endeavor.

Although this is an important goal, the Newark EMA HIV Planning Council believes that it is also important to strengthen our existing system of Title I medical care to ensure that PLWHA are not dropping out or not being linked to medical care at available opportunities. Therefore, the Council surveyed existing Title I medical providers to answer the following research questions.

Research Questions:

- 1. How do Title I medical providers follow up on current patients to minimize dropouts from medical care?**
- 2. For those providers currently conducting or planning to conduct HIV Rapid Test, how are patients who receive a “presumptively positive” test result linked to medical care? (Or how will they be linked to care?)**

Outcomes: Question 1 was to yield baseline information about current follow up and gaps. Results could assist the Council and Grantee in developing methods to improve patient follow up so that more patients remain in care. The underlying premise in Question 2 is that implementation of HIV Rapid Test would result in more individuals being tested, with an increase in HIV diagnoses and increased demand for Title I medical care and related services. Responses were to yield initial results on the linkages between HIV Rapid Test and start of HIV-specific medical care, and an indication of the expected [increased] demand for Title I medical care.

II. Methodology

The survey was originally designed to be completed by telephone by Council staff and the Title I medical providers. Following review by the Council's Care and Treatment Committee, this survey was to be distributed to the Title I medical providers for review and development of answers. Council staff were to arrange a telephone appointment to obtain the answers from each provider. It was expected that the call would take approximately 15 minutes. The results would be compiled and a report issued for review by the Council and recommendations where appropriate. The form was to be completed by Council staff.

The final draft survey was reviewed by the Care and Treatment Committee of the Newark EMA HIV Health Services Planning Council at its regularly scheduled meeting of April 14, 2005. Committee members recommended that the survey be e-mailed to providers as well as faxed or otherwise delivered to all Title I medical providers. Providers could then complete the survey at their convenience and return it by e-mail or fax. The survey was revised and finalized accordingly. It is contained in Appendix B.

The Planning Council Executive Director e-mailed the survey plus explanatory cover letter on May 3, 2005 to the 15 HIV medical providers funded to deliver Title I HIV medical care for FY 2005 (March 1, 2005 – February 28, 2006). Surveys were due at the Planning Council on Monday, May 23, 2005. Six surveys were received by that date and numerous follow up phone calls were made during that week. No additional surveys were received and an Interim Report was prepared as of June 6, 2005. Initial findings in the Interim Report were presented to the Care and Treatment Committee at its June 9, 2005 meeting. Council staff conducted additional follow up and surveys were received from eight additional providers – for a total of 14 of the 15 Title I funded medical providers. The Title I medical providers completing the surveys and the provider whose survey is still outstanding are listed in Table 1 below.

The 14 providers completing the survey include three community based providers, three Federally Qualified Health Centers (FQHC), one community health clinic affiliated with a hospital, and seven hospital-based clinics. Ten providers are located in Essex County (Newark); three are located in Union County in Elizabeth, Plainfield and Vauxhall (Union Township); and one is in Morris County (Morristown).

A Final Draft Report was prepared as of June 30, 2005. The report analyzed responses from the 13 providers and set forth conclusions. On July 14, 2005 the Report was presented to the Council's Care and Treatment Committee for review and development of recommendations. Draft recommendations were presented to the Planning Council at its July 20, 2005 meeting, at which time the Council provided comments. Final recommendations have been incorporated into this final report.

**Table 5-1: Title I Medical Providers Surveyed and
Number Responding as of 7/31/05**

Title I Provider	County	6/6	7/31	No
1. ARFC/St. Clare's Social Services	Essex	X	X	
2. Community Health Center at Vauxhall	Union	X	X	
3. CURA – Community United for the Rehabilitation of the Addicted, Inc.	Essex	X	X	
4. East Orange General Hospital	Essex			X
5. Essex Substance Abuse Treatment Center	Essex		X	
6. Morristown Memorial Hospital – Family Health Center	Morris		X	
7. Newark Beth Israel Medical Center	Essex		X	
8. Newark Community Health Centers, Inc.	Essex	X	X	
9. Newark Dept. Health & Human Services/Newark Homeless Health Care Program	Essex		X	
10. Plainfield Health Center	Union		X	
11. St. Michael's Medical Center/Peter Ho Memorial Clinic	Essex	X	X	
12. Trinitas Hospital	Union	X	X	
13. UMDNJ-Div. Adolescent & Young Adult Medicine	Essex		X	
14. UMDNJ – Infectious Disease Practice	Essex		X	
15. UMDNJ – FXB Center (Dept. Pediatrics)	Essex		X	
		6	14	1

III. Question 1: Current Patient Follow Up

Question 1: How do Title I medical providers follow up on current patients to minimize dropouts from medical care?

III.A. Survey Results

Routine medical visit. All 14 providers reported that, when a patient comes in for a routine medical visit, they schedule a follow up visit before the patient leaves the office.

One community provider reported that a follow up appointment is not scheduled if follow up care is not required – estimated at 20% of patients. One hospital based provider (Family Health Center at Morristown Memorial Hospital) has two types of appointments – one with the primary care physician (PCP) and one with the Infectious Disease (ID) specialist. All patients have appointments with the PCP, and approximately 50% see the ID specialist. MMH uses its "EZ-Access" system which allows patients to be responsible and have control over their own medical care. "EZ-Access" reduces the need for action by the Family Health Center. (See section on "Additional Information and Systems" for more detailed description of EZ-Access.)

Reasons for no patient follow up appointment. Two providers (community and FQHC, respectively) reported that a follow up appointment is not given in certain circumstances. First, if follow up care is not required (see above). Second, if a patient is not interested in their care or in another appointment. MMH gives follow up appointments for 50% of patients and the remaining patients manage their own follow up appointments with its “EZ-Access.”

Patient reminders before medical visit. All respondents also reported that they provide reminder notices to patients prior to their next scheduled appointments. Reminders are given by telephone, or in writing by mail if the patient cannot be reached by telephone. One provider – FQHC which treats homeless – reported that reminders can be provided to only 50% of patients because their homeless clientele often do not give correct phone numbers or stable addresses.

Hospital based clinics and FQHCs underscored the benefits of such reminders: they increase patient compliance (more likely to keep appointments) and indicate patient interest in their care.

Percent kept and missed appointments. Providers were asked about the percent of patients who did not keep scheduled appointments initially. The percents varied considerably among providers. It appears that hospital based clinics had a slightly lower percent of missed appointments than community based providers, and hence, higher rates of “kept” appointments and medical compliance. **On average EMA-wide, approximately 25% of medical appointments are initially “missed” and 75% are “kept.”** See Table 5-2 below.

Table 5-2: Estimated Percent of Initial Missed and Kept Appointments for HIV Primary Medical Care among Title I Medical Providers in Newark EMA – As of July 2005

Type of Provider	% Initial Appointments	
	Missed	Kept
Hospital-based Clinics	5%	95%
	10%*	90%*
	20-25%	75%-80%
	23%	77%
	25%	75%
	30-35%	65-70%
Hospital affiliated Clinic	15%	85%
FQHCs	20%	80%
	25%	75%
	50%	50%
Community Based Providers	25%	75%
	47%	53%
	50%	50%

(1 provider did not respond)

* 2 providers

Follow up on missed appointments. All providers follow up with patients who have missed appointments. The type of follow up varies. The most used method was internal appointment or tracking procedures (53 %), followed by standard operating procedures or written protocols (29 %). Other provider-specific methods include (1) telephone call follow up or notice by mail if the patient could not be reached by telephone, (2) home visits scheduled by the staff nurse and staff social worker, and (3) referral to outreach case managers. No one reported using CHAMP for patient follow up. Four providers use more than one method of follow up. Table 5-3.

	#	%
Standard Operating Procedures (SOPs) or written protocols	5	29%
Internal appointment or tracking procedures	9	53%
CHAMP	0	0%
Other*	3	18%
Total	17	100%

* Provider specific: phone calls plus written notes; home visits; outreach case managers.

Reasons for not following up. One community based provider reported following up on missed appointments, but also noted that extensive follow up was not done due to lack of time and lack of resources (staff, etc.). The homeless FQHC reported that follow up could be done for only 50% of clients due to lack of time, lack of resources (staff, etc.), and because they cannot locate clients.

Patients missing appointments who eventually come in for care. Providers gave varying responses as to the percent of patients missing appointments who eventually come in for care. (The question may have been confused with the subsequent question regarding total kept and missed appointments.) Seven providers appeared to answer the question as designed. Of the patients who initially missed their appointments, approximately 50% to 80% of patients came in for care after follow up. Responses ranged from 41%-50% (FQHCs, community-based) to 60%-72%-75%-80% (four hospital based clinics).

Total patients after follow up. In response to the question, “Do you know what happens to those patients who do not come in for their appointments?” it appears that providers gave the overall total of patients who kept their appointments and come in for medical care versus those who never keep their appointments despite follow up efforts. **On average EMA-wide, after patient follow up efforts, only 10%-11% of medical appointments are “missed” and approximately 89%-90% are eventually “kept.”** This increase from 75% to 90% of patients keeping their medical appointments is worth the follow up efforts of the Title I medical providers. Individual providers have varying results. See Table 5-4 and Figure 5-A below.

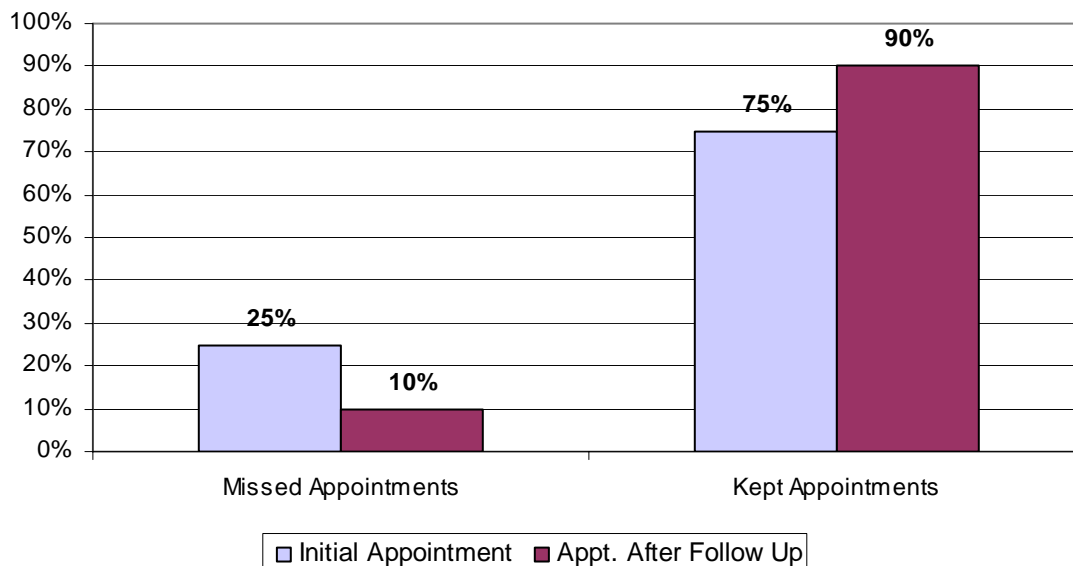
Table 5-4: Estimated Percent of Total Missed and Kept Appointments for HIV Primary Medical Care among Title I Medical Providers After Follow Up Efforts in Newark EMA – As of July 2005

Type of Provider	% Total Appointments	
	Missed	Kept
Hospital-based Clinics ("Patients eventually come in")	1%*	99%*
	10%**	90%**
	20%	80%
	No % given	No % given
Hospital affiliated Clinic	No % given	No % given
FQHC	5%	95%
	10%	90%
	15%	85%
Community Based Provider	30%	70%
	10%*	90%*

* 2 Providers

** 3 Providers

Figure 5-A: Missed and Kept Title I Medical Appointments - Initially and After Follow Up in the Newark EMA, July 2005



Point in time when follow up stops and patients are considered “lost to follow up.”

Provider agency follow up ceases and patients are considered “lost to follow up” in one of two ways: (1) after a certain number of follow up attempts, or (2) after a certain point in time or time interval, or (3) combination of both methods. Twelve providers answered this question. One provider was not certain of the response.

Number of follow up attempts – Three providers use this method and follow up ceases after no response to the following:

- Three contacts
- Three telephone calls plus a letter or postcard
- Two telephone calls or follow up reminders

Certain point in time or time interval – Eight providers stop follow up after the following time periods:

- Six months (two providers)
- Six to nine months
- 90 days of no patient contact, with immediate reinstatement by its electronic medical records system if and when the patient eventually comes in.
- One provider reviews cases four times a year. If patients have not come in during the prior three months, follow up is stopped.
- One year after the last appointment (three providers).

Certain point in time or time interval plus number of contacts – One provider uses this method.

- Three telephone attempts, two letters plus the patient does not come in for one year.

III.B. Conclusions

With respect to the issue of **maintaining PLWHA in Title I medical care as a component of “Connecting to Care”** it appears that all Title I-funded medical providers in the EMA have instituted and are following appropriate procedures to (1) ensure that HIV+ patients are given a scheduled, follow up medical appointment before they leave the office, (2) are reminded of this scheduled appointment close to the appointment date and time, and (3) are followed up by phone and/or mail, as appropriate, if the patients miss the scheduled appointment.

For patients who miss appointments, it appears that agency policies and procedures for follow up activities are appropriate to get people to come into care and for cessation of follow up activities. This is evidenced by the 90% of Title I medical appointments which are “kept” after patient follow up, an increase of 15 percentage points over the 75% of patients initially keeping their medical appointments. The high rate of eventual patient compliance is particularly important given the demographics of the patient population – mostly low income PLWHA who have other priorities of shelter, food, clothing and sustenance which have been well-documented in research literature and needs assessments, and which often take priority over medical care.

III.C. Recommendations

The Planning Council and Grantee may want to further ensure that the above self-reported survey findings reflect actual practice.

- **Patient Follow Up.** The Planning Council may want to review the EMA's standards of primary medical care and determine if the guidelines for patient follow up are adequate to ensure that all reasonable efforts are made to maintain PLWHA in HIV medical care.
- **Monitoring follow up procedures.** As part of its monitoring activities, the Grantee may review provider adherence to their own follow up procedures to verify that the above survey results are actually occurring in each agency. Review of individual case records/patient charts can be of assistance.
- **Educating consumers.** The Council and Grantee may consider educating consumers about the effects of not keeping appointments – “overbooking,” long waiting times, etc. – which are common complaints in the EMA's Needs Assessments. The Council may also encourage peer support or other methods to help patients keep appointments.

IV. Question 2: HIV Rapid Test and Linking to Medical Care

Question 2: For those providers currently conducting or planning to conduct HIV Rapid Test, how are patients who receive a “presumptively positive” test result linked to medical care? (Or how will they be linked to care?)

IV.A. Survey Results

Agencies currently conducting HIV Testing. Of the 15 Title I funded medical providers in the Newark EMA, 14 currently conduct HIV testing. The UMDNJ-Division of Adolescent and Young Adult Medicine (DAYAM) does not conduct HIV testing. See Table 5-5.

Status with respect to HIV Rapid Test. Nine providers are currently performing the HIV Rapid Test – six hospital based clinics and three FQHCs. Two additional providers – one hospital affiliated and one community based provider - plan to conduct the HIV Rapid Test. The three other providers – two community-based and UMDNJ-DAYAM – have no plans to conduct the HIV Rapid Test. (One agency did not respond.) See Table 5-5.

Table 5-5: Status of HIV Testing Among Title I Medical Providers – June 2005

Title I Provider	Conduct HIV Testing?	Conduct HIV Rapid Test?		
		Yes	Plan to Conduct	Do Not Plan to Conduct
1. ARFC/St. Clare's Social Services	X		X	
2. Community Health Center at Vauxhall	X		X	
4. CURA	X			X
4. East Orange General Hospital	X			
5. Essex Substance Abuse Treatment Center	X			X
6. MMH – Family Health Center	X	X		
7. Newark Beth Israel Medical Center	X	X		
8. Newark Community Health Centers, Inc.	X	X		
9. Newark DHHS/NHHCP	X	X		
10. Plainfield Health Center	X	X		
11. St. Michael's Medical Center/Peter Ho	X	X		
12. Trinitas Hospital	X	X		
13. UMDNJ-DAYAM				X
14. UMDNJ – Infectious Disease Practice	X	X		
15. UMDNJ – FXB Pediatric Center	X	X		
Total	14	9	2	3

Note: Because three providers have no plans to conduct the HIV Rapid Test and two providers are currently planning to implement the Rapid Test, the universe of providers for the following questions has been reduced to the nine providers currently conducting the HIV Rapid Test.

Agency departments or sections conducting HIV Rapid Test. The six hospital-based clinics administer the HIV Rapid Test at multiple sites, including the hospitals' emergency departments (ED). Other sites include HIV clinics, counseling and testing (C&T) clinics, and specialty areas of prenatal clinics, labor and delivery and outreach sites. Two FQHCs conduct the test at their HIV clinics only and a third at the agency's Communicable Disease Prevention and Treatment Center ("STD clinic"). See Table 5-6.

Table 5-6: Location of HIV Rapid Test in Medical Provider Agencies

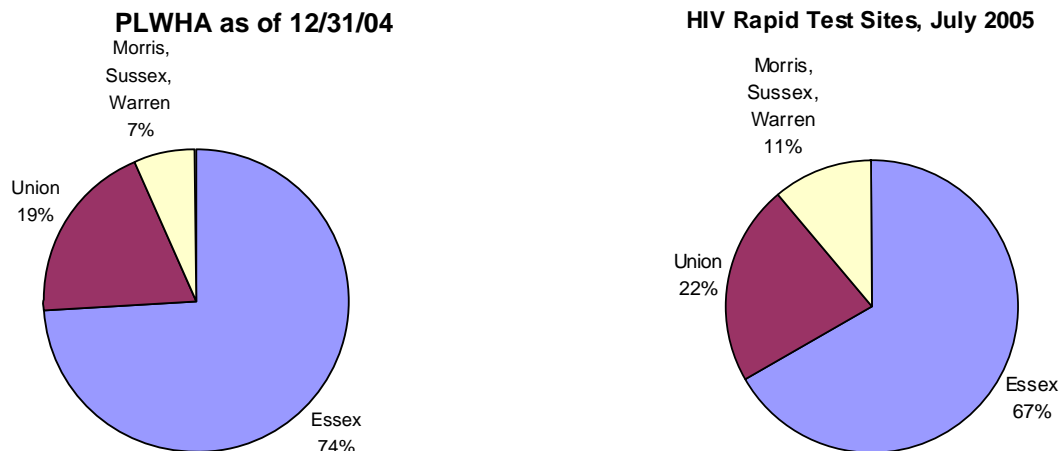
Title I Provider	Emerg Dept.	HIV Clinic	Other	Comments
Hospital-Based Clinics				
6. MMH s– Family Health Center	X	X	X	ED (referrals only), C&T clinic, prenatal clinic, labor & delivery
7. Newark Beth Israel Med. Ctr	X	X	X	Separate HIV C&T suite
11. St. Michael's Med. Center	X		X	C&T Clinic
12. Trinitas Hospital	X	X	X	OraSure at Outreach sites
14. UMDNJ – Infectious Disease Practice	X	X	X	Specific areas of the hospital that request it
15. UMDNJ – FXB	X	X	X	Outpatient Clinics. (Eventually will include inpatient.)
FQHCs				
8. Newark CHC, Inc.		X		
9. Newark DHHS Homeless Health Care HIV Clinic			X	STD Clinic of Newark DHHS.
10. Plainfield Health Center		X		
Total	6	7	7	

C&T = Counseling and Testing

Geographical access to HIV Rapid Test. There is geographical parity in access to HIV Rapid Test in the EMA, as indicated in Figure 5-B below. The Title I medical providers of the Rapid Test are located throughout the EMA in proportion to the geographical distribution of PLWHA in the EMA. Although PLWHA represent those already diagnosed, it is estimated that an additional 25% to 33% of individuals are not diagnosed.¹ This rate appears to be uniform across the United States, without regard to geography. Therefore, it is reasonable to assume that the distribution of PLWHA in the EMA also represents the distribution of undiagnosed PLWHA.

¹ Fleming, P.L., Byers, R.H., Sweeney, PA, Daniels, D., Karon, J.M., and Janssen, RS), (*HIV Prevalence in the United States, 2000*, Ninth Conference on Retroviruses and Opportunistic Infections.

Figure 5-B: Geographical Access to Care - Location of HIV Rapid Test Sites and PLWHA in the Newark EMA



Linkage to medical care following presumptively positive HIV diagnosis from Rapid Test.

Of the nine medical providers who currently conduct HIV Rapid Test, five wait until receiving confirmatory results before linking the patients with HIV medical care (three hospital based clinics and two FQHCs). Once such results are received, medical appointments are scheduled immediately, often on a same day basis. The remaining three hospital based clinics (Newark-based) link patients immediately with medical care following a presumptively positive diagnosis. (One FQHC in Newark did not answer the question.)

Methods to link HIV+ patients to medical care. For patients who are presumptively HIV+, the clinics use a combination of same day appointments, scheduling appointments for the following day or two days, and escort to the HIV Clinic for medical care to ensure that patients keep the appointments. All use Standard Operating Procedures to link HIV+ individuals to medical care. Although some providers wait for confirmatory results, they complete all preliminary steps for medical care at time of the HIV+ Rapid Test result - schedule the medical appointment (to be held as soon as possible after the confirmatory result is received) and complete intake, financial screening and blood work.

Problems in connecting newly-diagnosed patients to medical care. Most (five) providers reported no problems in linking newly diagnosed patients to medical care. Two additional providers (two hospital based clinics + one FQHC) reported some problems. One stated that new patients may be reluctant to get medical care at time of their diagnosis. After several phone calls and reminders, patients are eventually connected to care.² Another underscored that some patients need time to accept diagnosis, and if mental health and substance abuse issues are present, this creates additional difficulties in getting newly diagnosed patients into care. The FQHC serving homeless individuals reported that comorbid factors of homelessness, substance abuse, and depression exist in our newly diagnosed HIV positive patients and these problems must be dealt with in addition to HIV. Also, cultural and social barriers prevent some populations from seeking help.

The three providers also noted that these problems have sometimes resulted in patients not coming into medical care following diagnoses. The patients simply do not make an appointment or miss their scheduled appointment. Ongoing struggles with these problems continuously impact on homeless patients' ability to get into care and stay in medical care.

Increase in HIV+ patients due to Rapid Test. All providers reported that the Rapid Test had resulted in an increase in HIV+ patients in their facilities. One provider estimated an increase of 10-30%. The remaining providers did not quantify the increase. However, many providers added comments regarding the urgency of getting the increased number of patients into medical care. See below.

Comments regarding the impact of HIV Rapid Test on medical care. Providers offered the following comments on the impact of HIV Rapid Test on the need for and responsiveness of medical care. These are indicative of the commitment to ensure that PLWHA access medical care following diagnosis and remain in care.

"Implementation of the HIV Rapid Test has created urgency for the client to seek medical care, having the results of confirmatory HIV test available within 48 hours."

"The closer the referral is made after HIV+ status is learned - the better the changes for patient compliance."

"Quicker response allows us to get patients into care immediately. It avoids patients' becoming lost to contact and ensures more people who need medical care receive it - and sooner."

"The patient can be linked into medical care earlier and is less likely to become lost during the traditional two weeks between the HIV test and Post Test sessions. In the old system, a lot of patients never returned for HIV test results."

² These findings are underscored in results of the *2004 Union County HIV Consortium - Focus Group of Long-Term HIV*. Participants had been living with HIV disease for at least 10 years. While over half (53%) of participants came into medical care right away after being diagnosed with HIV, one third (33%) put off medical care for a long time. The remaining individuals put off medical care for a few weeks.

“Accessibility of services (one stop shopping) to HIV/AIDS care is the key to linking PLWHA to medical care. Colocation of counseling and testing facilities with medical care is essential, as is ready availability of ancillary staff such as Nurse Practitioners who are trained in the medical management of HIV.”

“All providers should make sure that immediate access to care is not a barrier to the patient. [Our agency] continues to improve venues and access for patients entering system for first time or re-entering care.”

“A significant problem in linking patients into medical care is the fact that many patients are able to navigate through the Ryan White system, picking and choosing which services they want to use, without ever stepping foot in a medical clinic.”

IV.B. Conclusions

Some providers who currently conduct HIV Rapid Testing wait until the presumptively positive test results are confirmed before linking patients with HIV medical care. It is not known how long it takes to receive confirmatory test results – days or weeks. Nor is it known whether or how many (percent) of presumptively HIV-positive individuals return to receive their confirmatory results.

The reasons for this delay were not reported in the survey. They could include NJDHSS DHAS policies or recommendations, reimbursement issues, and fear of not receiving funding if the presumptively positive individuals are ultimately HIV negative.

IV.C. Recommendations

All providers have reported the value of the HIV Rapid Test in getting newly diagnosed PLWHA into medical care. Despite some expected barriers among patients – disbelief and denial upon learning of the diagnosis, substance abuse and mental health issues, socioeconomic issues – it appears that all providers are making efforts to address and overcome these barriers on behalf of patients. The Council and Grantee may want to jointly address the Title I medical system to improve linkages between counseling and testing sites and Title I medical providers.

- It is recommended that an initial connection to medical care should be made immediately at time of the HIV test. This linkage can be education of the patient about the availability of care, discussion of clinic hours and the enrollment process, and staff available for treating HIV disease. This connection can be implemented as follows.
 - The Memoranda of Understanding required by the Title I grantee between all Title I providers and counseling and testing sites can be strengthened to ensure same day linkage between counseling and testing sites, including Rapid Test, and Title I medical providers.

- The Planning Council and grantee can advocate for closer linkages between counseling and testing and HIV medical care, through membership on existing committees and participation in ongoing forums, including but not limited to the Statewide Coordinated Statement of Need (SCSN) Committee, NJ HIV Prevention Community Planning Group (NJHPCPG), Governor's Advisory Commission on HIV/AIDS and Other Bloodborne Pathogens, etc.
- The Planning Council may want to discuss the reasons for the delay between a presumptively positive HIV diagnosis and entry into medical care. Issues regarding reimbursement can be explored further.
- The Council may also assess the time it takes to receive confirmatory diagnosis, and explore ways to get a faster turnaround on such testing. (One provider estimated the delay at one week for receipt of confirmatory blood test results.)
- The Grantee may want to explore Title I reimbursement for medical care for those individuals who are given Title I medical care on the basis of a presumptive diagnosis.
- The Council and Grantee should explore how to tighten up the system of Title I medical care to reduce PLWHA using the system between medical providers and thus improving continuity of care.

V. Additional Information and Systems

This section contains more detailed information provided by respondents in the questionnaires, and offers additional insights into the provision of Title I medical care.

St. Michael's Medical Center/Peter Ho Memorial Clinic

Better patient tracking and re-enrollment via Electronic Medical Records System

Implementation of an Electronic Medical Records System by SMMC/Peter Ho has resulted in better patient tracking. "Prior to the implementation of our Electronic Medical Records System in March 2004, we used to keep patients in our data base for at least one calendar year, provided that the patient had at least one clinical visit that year. Now, because of the revision to the policy of patients lost to follow up, we will discharge a patient from care after 90 days. We will admit a patient to service upon their return to care. Patients who have been away from care for six months will be reinstated and required to attend our Mandatory Patient Orientation program.

Newark Department of Health and Human Services – Newark
Homeless Health Care HIV Clinic

Issues related to treating homeless HIV patients

The HIV+ homeless population presents special challenges with respect to connecting them to care for medical treatment. The Newark DHHS/NHHC HIV clinic can provide reminder notices of upcoming medical visits to only 50% of patients because the homeless patients often do not give correct phone numbers or stable addresses. Nonetheless, patients missing scheduled appointments approximate the EMA-wide average (25%), and, with follow up, most (90%) eventually come into care.

Special follow up and outreach efforts are needed via case management and NHHC outreach workers. However, follow up could improve but it is a problem because of lack of time, lack of resources (staff, etc.), and because they cannot locate clients. Many patients are in and out of the correctional system which also impacts on the lost to follow-up status of patients.

Newly diagnosed homeless HIV+ patients experience a disproportionate incidence of substance abuse and mental illness (particularly depression) in addition to their homelessness. All these factors must be addressed in combination with their medical treatment. Patients' struggles with these problems continuously impacts on their abilities to get into care and stay in medical care. The HIV Rapid test has resulted in more patients coming into medical care because they can be linked into medical care earlier and are less likely to become lost during the traditional two week period between initial test and post test counseling sessions. By making services available to address substance abuse, mental health issues and homelessness, more PLWHA would probably be willing to enter and to remain in medical care.

Morristown Memorial Hospital (MMH) Family Health Center

“EZ-Access” patient-self-directed medical appointment scheduling

We have two (2) types of appointment at the Family Health Center for our Ryan White clients. These are:

- (1) Appointment with the Primary Care Physician
- (2) Appointment with the Infectious Disease Specialist.

For Primary Care Physician appointments: We utilize a system process called **“EZ-Access.”** This is a philosophy of allowing patients to be responsible and have control of their medical care. An appointment with a primary care physician is provided on the same day the patient calls for a follow up visit. This allows these appointments to be scheduled at the patient's convenience. On the day of that visit, at discharge the patient is given instructions on the time frame for the subsequent visits, as well as the day of the week when their regular provider is available. Appointments are provided on a “first call, first served” basis. With this system, no show and cancellation rates have decreased significantly, ensuring optimal

utilization of available appointments. Patients who require urgent medical evaluations will always be offered same-day appointments.

For Infectious Disease appointments: Appointments are made through the Nurse Practitioner. Every patient is seen by the Infectious Disease Specialist at least one a year if the patient is stable, or more often if the patient has extensive and complicated medical issues. These appointments are given at least one month in advance in order for the patient to arrange for transportation or request time off from work, since the specialist is available on only two days per week at the FHC. However, the Infectious Disease Specialist is available for consultation by telephone at anytime when she is not scheduled to see patients at the FHC.

Routine follow up appointments: Patients are not given routine follow up appointments with their primary medical provider since our "EZ-Access" program provides as good, if not better, access to our physicians. This program has also given patients more control over the scheduling of their medical care without compromising access. We still ensure same-day access for patients requiring urgent medical evaluation due to the availability of our full-time nurse practitioner.

Reminders via telephone calls are made to patients only with a prior history of failed appointments or those who have to rely on transportation from another agency or family member. Approximately **30%** of patients receive such reminders.

In general, it is not necessary to telephone patients to remind them of their appointments in an EZ-Access system. The patient calls to schedule an appointment on the same day he or she wishes to be seen. Patients who fail to follow up within the time frame recommended at their last appointment are telephoned or sent scheduling reminders. It is estimated that only **5% of patients miss scheduled appointments.**

University of Medicine and Dentistry of New Jersey – Infectious Disease Practice

Improving health outcomes by increasing utilization of Title I medical care

UMDNJ Infectious Disease practice has noted that a significant problem in linking patients into medical care is the fact that many patients are able to navigate through the Ryan White system, picking and choosing which services they want to use, without ever stepping foot in a medical clinic. This reality has resulted in significant comorbid health problems in addition to HIV which exacerbate HIV and complicate medical treatment.

One of the biggest problems we face is the fact that once enrolled in the Ryan White system of care, a patient after the initial visit confirming their HIV+ status has no accountability to participate in their health care. The patient can be in the system, and never see a medical provider. For example, in the existing system:

- HIV+ female patients can continually refuse to have annual Pap exams even though they are 6 times more likely to develop cervical cancer;

- HIV+ patients can refuse to be tested and receive treatment for tuberculosis (TB), a contagious disease;
- HIV+ patients can refuse to be tested and receive treatment for a variety of contagious sexually transmitted infections;
- Patients could still be active drug users, and that problem can and often does go completely unmanaged.

The medical outcomes in these cases can be expected to be a failure.

To help address this issue, some Ryan White sites across the U.S. use a “passport” approach, whereby the patient is issued a passport-type booklet, wherein all providers document the dates and the services provided to the patient. All providers are bound to refuse services until there is an entry from a medical service provider. In order to promote better medical outcomes, we need to have a similar system that includes the following criteria:

- (1) The patient has been given an initial comprehensive medical exam and has been linked to a specific medical provider;
- (2) The patient has seen a medical provider within the past three months;
- (3) Labs have been ordered;
- (4) A TB test was performed and the patient returned in 3 days for a final reading;
- (5) The patient has applied and received medication assistance;
- (6) The patient was offered Hepatitis B vaccine and has been screened for Hepatitis C;
- (7) The patient has been screened for STDs;
- (8) The patient has been offered and given (or refused) pneumovax vaccine during the Fall and Winter months;
- (9) The patient has had a chest x-ray within the past 12 months;
- (10) The patient has been referred for a dental exam;
- (11) The patient has been fully assessed for mental health issues, including depression, and is currently receiving treatment for the problem or has been referred to an appropriate facility;
- (12) The patient has been fully assessed for substance abuse issues and is currently receiving treatment for the problem or has been referred to an appropriate facility;
- (13) Documentation regarding adherence to mental health and substance abuse programs; and
- (14) Documentation from medical staff indicating adherence levels.

The management of HIV is complex with a myriad of variables, and each of them affects medical outcomes. All of these intervening variables are hard to control, but only one variable can without a doubt be controlled and assure improved outcomes – adherence to medical appointments. Patients who are adherent to medical appointments and regimens have better medical outcomes. During their visits with medical providers, patients receive: education regarding the disease, medication management, management of adverse side effects from medications - all of which contribute to increased adherence; nutritional assessments and individualized nutritional regimens which again impact on adherence and efficacy of drug regimens; they are offered vaccines; screened and treated for transmittable diseases; screened

for the appropriateness of being involved in clinical trials; given referrals to a medically appropriate specialty services; mental health and substance abuse issues are identified and dealt with appropriately. All of these medical issues are significant to producing good medical outcomes and reducing the spread of HIV disease. The efficacious management of HIV disease depends on great coordination among the various types of providers.

The Planning Council should examine how to strengthen the relationships demonstrated by many MOAs among NEMA providers to ensure that more PLWHA are receiving medical care in addition to support services; examine the need to strengthen or enforce a minimum standard of four medical visits per year per patient; and review other models that integrate and coordinate medical and non-medical care for PLWHA.