

Newark EMA
HIV Health Services Planning Council



NEEDS ASSESSMENT
UPDATE 2012

July 2012

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT - UPDATE 2012

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LIST OF ABBREVIATIONS

The following abbreviations and acronyms are used in this Needs Assessment.

ACA	Affordable Care Act of 2010 (Patient Protection and Affordable Care Act)
ACS	American Community Survey (of the US Census Bureau)
ADAP	AIDS Drug Assistance Program
ADDP	(New Jersey) AIDS Drug Distribution Program
AETC	AIDS Education and Training Center
ARV	Anti-Retroviral (therapies)
ASI	Addiction Severity Index
CARE Act	Comprehensive AIDS Resources Emergency (CARE) Act
CBO	Community Based Organization
CDC	U.S. Centers for Disease Control and Prevention
CHAMP	Comprehensive HIV/AIDS Management Program (the Newark EMA's Client Level Data Base)
CLD	Client Level Data (system)
CM	Case Management
CM-NM	Case Management – Non-Medical (nonmedical case management)
Cmte	Committee
COC	Continuum of Care Committee of NEMA Planning Council
CQM	Clinical Quality Management
CPC	Comprehensive Planning Committee of NEMA Planning Council
CSAC	Community Service Advisory Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DCFWB	Newark Department of Child and Family Well Being (Formerly, the Newark Department of Health and Human Services – DHHS)
DOT	Direct Observational Therapy
DYFS	Division of Youth and Family Services (New Jersey child welfare agency with in the NJ Department of Children and Families – NJDCF)
DHAS	Division of HIV/AIDS Services. In 2012 this division became the Division of HIV/AIDS, TB and STD Services (DHST)
DHST	Division of HIV/AIDS, TB and STD Services, formerly the Division of HIV/AIDS Services
EIHA	Early Identification of Individuals Living with HIV/AIDS
EIRC	Early Intervention and Retention Collaborative (EIRCs as plural)
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area

ENT	Ears, Nose and Throat (specialist, care)
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration (of the U.S. Department of Health and Human Services)
IDU	Injection Drug User
IP	Implementation Plan
KI	Key Informant [interviews]
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)
MCM	Medical Case Management
MH	Mental Health
MMC	Medicaid Managed Care
MNT	Medical Nutrition Therapy
MOA, MOU	Memorandum of Agreement, Memorandum of Understanding
MSM	Men who have Sex with Men
MSW	Morris, Sussex, Warren counties in the Newark EMA
NEMA	Newark Eligible Metropolitan Area
NHAS	National HIV/AIDS Strategy
NJDOH	N.J. Department of Health (formerly NJDHSS – NJ Department of Health and Senior Services)
NJDS	New Jersey Dental School (at UMDNJ)
NJ-CLAS	New Jersey Culturally and Linguistically Appropriate Standards
PAAD	(New Jersey) Pharmaceutical Assistance to the Aged and Disabled Program
PHS	(U.S.) Public Health Service
PLWHA	People Living With HIV or AIDS
REC	Research and Evaluation Committee of NEMA Planning Council
RW	Ryan White [Program]
RWTEA	Ryan White HIV/AIDS Treatment Extension Act of 2009
RWTMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration (of the U.S. Department of Health and Human Services)
SAMISS	Substance Abuse Mental Illness Screening Survey
SCSN	Statewide Coordinated Statement of Need

TGA	Transitional Grant Area
UBHC	University Behavioral Health Care (of UMDNJ)
UMDNJ	University of Medicine and Dentistry of New Jersey
WICY	Women, Infants, Children and Youth

INTRODUCTION

The information below was extracted from the Ryan White Part A Manual published by HRSA/HAB in 2009 on its website. It reflects requirements of the Ryan White HIV/AIDS Treatment Extension Act (RWTEA) of 2009, Public Law 111-87, October 30, 2009. The citations are referenced to the Public Health Service Act (42 U.S.C. 300ff-11).

Legislative Background

Section 2602(b)(4) requires the planning council to:¹

- A. "determine the size and demographics of the population of individuals with HIV/AIDS, **as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status**";
- B. "determine the needs of such population, with particular attention to:
 - i. individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services;
 - ii. disparities in access and services among affected subpopulations and historically underserved communities; and"
 - iii. **individuals with HIV/AIDS who do not know their HIV status.**"

2602(b)(4)(G) requires planning councils to "establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels."

Section 2602(b)(4)(F) calls for the planning council and grantee to "participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B."

Section 2602(b)(4)(H) requires the planning council to "coordinate with Federal grantees that provide HIV-related services within the eligible area."

Needs assessment data are critical to conducting other planning tasks. Needs assessment results must be reflected in both the planning council's priority setting and resource allocations and in the EMA's/TGA's comprehensive plan. Planning councils are required to:

- Address coordination with programs for HIV prevention and the prevention and treatment of substance abuse
- Include links with outreach and early intervention services

¹ HRSA. HIV/AIDS Bureau. <http://hab.hrsa.gov/tools/parta/parta/ptAsec6chap1.htm#SecVIChap1a>

- Address capacity development needs
- Be closely linked with comprehensive planning and annual implementation plan development, as interconnected parts of an ongoing planning process.

Section 2603(b)(1) specifies that in seeking supplemental funding, the EMA/TGA is expected to include in its application for funding an array of information, including needs assessment data that demonstrate need.

Section 2603(b)(2)(B) specifies that, in making awards for **demonstrated need**, the Secretary may consider any or all of the following factors:

- i. "The unmet need for such services, as determined under section 2602(b)(4) or other community input process as defined under section 2609(d)(1)(A).
- ii. An increasing need for HIV/AIDS-related services, including relative rates of increase in the number of cases of HIV/AIDS.
- iii. The relative rates of increase in the number of cases of HIV/AIDS within new or emerging subpopulations.
- iv. The current prevalence of HIV/AIDS.
- v. Relevant factors related to the cost and complexity of delivering health care to individuals with HIV/AIDS in the eligible area.
- vi. The impact of co-morbid factors, including co-occurring conditions, determined relevant by the Secretary.
- vii. The prevalence of homelessness.
- viii. The prevalence of individuals described under section 2602(b)(2)(M).
- ix. The relevant factors that limit access to health care, including geographic variation, adequacy of health insurance coverage, and language barriers."

HAB/DSS Expectations

Needs assessment is expected to generate information about:

- The size and demographics of the HIV/AIDS population within the service area, including those who are unaware of their HIV status (not tested), and
- The needs of PLWHA, with emphasis on individuals with HIV/AIDS who know their HIV status and are not receiving primary health care, and on disparities in access and services among affected subpopulations and historically underserved communities.

HAB/DSS expects Part A needs assessments to meet all legislative requirements and to provide a sound information base for planning and decision making.

PURPOSE AND METHODOLOGY

The purpose of the Needs Assessment - Update 2012 was to conduct an in depth assessment of important issues raised by the 2011 Needs Assessment, and issues emerging in the Ryan White Program as we transition to national healthcare reform. The Council and its committees were asked to identify the most important issues to be addressed by the Update 2012. A comprehensive list was developed, and the top three issues were retention in care (in follow up to the 2011 Needs Assessment), the changing HIV system, and community viral load and viral load suppression.

The Needs Assessment – Update 2012 was mindful of the National HIV/AIDS Strategy and sought information that would enable the EMA to improve access to and retention in care.

The goal of the Needs Assessment - Update 2012 was to obtain as much input as possible about the community from provider agencies, while utilizing existing sources and work done by the Council. The Council utilized quantitative methods including a review of CHAMP client level data for CY 2011 and FY 2011, and qualitative methods including interviews of key informants to obtain comprehensive and detailed input from providers. In contrast to the 2011 Needs Assessment which used new technology – online Survey Monkey – for survey completion, for 2012 we used a Key Informant questionnaire in Microsoft Word format to allow agencies to enter detailed information, with enough available space, and allow agencies to save the document to their desktop and complete the survey in increments as information was obtained. Upon completion, providers emailed the survey document to the Council. This method was easier for providers due to the length of the survey and need for comprehensive and detailed responses. The Council followed up with individual Key Informant telephone interviews with each provider, to clarify any responses and obtain additional information. Results of the phone interviews were added to the hard copy survey, and all results were tabulated. This method was found by providers to be appropriate for the information requested.

Information was also obtained through public testimony, information discussions and reports, and new analysis of client level data (CLD) from the EMA's Comprehensive HIV/AIDS Management Program (CHAMP) system. The methodologies are discussed in each chapter.

Data on utilization of Part A and MAI (Part F) services was obtained from the Newark EMA Grantee and the Comprehensive HIV/AIDS Management Program (CHAMP) system.

The Needs Assessment - Update 2012 incorporates directions from HRSA/HAB and reflects current policies and information including the National HIV/AIDS Strategy and retention in care.

Part 1: Retention in Care

Follow Up to the 2011 Needs Assessment Study of Ryan White Clients Lost to Service

1.1 Background

The Council and committees were interested in more detailed follow-up information regarding clients “lost to service” in the 2011 Need Assessment. Information is to include demographics, geography, service utilization and similar factors for clients who dropped out and returned to care and those who dropped out and did not return. The purpose is to determine if there are any discernible trends or groupings among subpopulations.

Research Question #1

What are the characteristics of people who were “lost to service” in FY 2009 and were there any differences between those who returned to care in FY 2010 in those who did not? What are the barriers to retention of PLWHA in care and potential solutions?

Specific services include:

- **Data Review and Analysis.** Review the longitudinal file of CHAMP data for FY 2008, FY 2009 and FY 2010 for all Part A/F clients developed for the 2011 Needs Assessment. Using SPSS and other programming, determine subpopulations by those who did and did not return to care in FY 2010. Prepare cross tabulations by relevant demographic and geographic categories as well as other statistical analyses. Consult with the Council and committees to determine any specific tabulations they are interested in and perform tabulations.
- **Report of Data Review.** Prepare initial report of findings including tables and graphs showing clients lost to follow up in FY 2009 by whether or not they returned in FY 2010. Include demographics, geography and services received including subtypes and provider types, as well as the results of provider case reviews in reasons for failure to return/retention in care.
- **Provider Survey/Key Informant (KI) Interviews.** Obtain information from medical providers and other agencies regarding experience with barriers to retention in care. This can be done by provider survey, Key Informant interview, or discussion at Council and committee meetings. Identify follow up issues where needed and consult with providers individually or as a group. Prepare draft report of findings.
- **Obtain information regarding three specific issues.**
 - **Insurance pre-approval and “copays”.** Obtain information from providers and/or medical billers regarding pre-approval for services, imposition and collection of co-pays in general and with respect to manage care, particularly Medicaid managed care for PLWHA.

- **Health Insurance Premium and Cost Sharing.** Obtain information from the Grantee and HRSA HAB regarding the definition and scope of this service category, and feasibility of paying insurance “copays” for medical visits and other services.
- **EIRCs.** Obtain information from the Grantee regarding the status of and, if available, results of initial meetings of the Early Intervention and Retention Collaboratives (EIRCs).
- **Provider review of reports.** Seek review and input from the Council and committees and providers regarding preliminary findings in both reports above. Identify additional information and tabulations needed. Complete the required tabulations and analyses.
- **Final Report.** Consolidate the above information and prepare final report for this assessment update. Include recommendations for improving client follow up, based on responses from providers, Council committees, and for re-engagement in care. Identify areas where Council can allocate resources and/or make directives to grantee to improve retention in care and reduce lost to follow up.

Methodology

The method was to use Ryan White agencies as **Key Informants (KIs)**. A typical KI process includes an interview using an Interview Tool. As the Research and Evaluation Committee (REC) developed the tool and information to be obtained, however, it was apparent that the “tool” would be more of questionnaire. But we agreed that we would need to talk to KIs to get more information and clarification that might not be covered in the questionnaire. It was decided that the KI portion would have two steps: Step 1 – Completion of KI questionnaire, and Step 2 – Follow up KI interview after review of questionnaire responses to get more clarification and fill in information gaps.

For Step 1, the REC developed the questionnaire to capture information regarding retention in care, shown in Appendix A. The questionnaire was sent out to 20 provider agencies – 13 providing Ryan White medical care and seven providing nonmedical services. The rationale for this mix of providers was to capture information from all of the medical providers and to supplement that information from agencies who provided supported the medical care system in the RW continuum of care.

For Step 2, it was agreed that REC members would conduct the follow up interviews. This approach would spread the workload, shorten timeframe for completion, and would enable REC members to participate. This approach fulfilled these goals and also enabled the project to incorporate perspectives of REC members and issues of importance to them.

Responses were received from 16 providers – 11 medical providers and five nonmedical agencies - for a total response rate of 80%. This section incorporates all responses to KI questionnaires and interviews.

1.2 Data Review and Analysis

The 2011 Needs Assessment reported on a sample of 155 clients who had received Ryan White service in FY 2008 but were lost to service in FY 2009 and FY 2010.

The purpose of this section was to review the data in more detail and to determine any similarities or trends that could help agencies target these populations before they dropped out of care. The analysis is done by (1) demographics, (2) services received, (3) CD4 and Viral load.

Reasons for Lost Clients

Agencies identified the reasons for “lost” clients through chart reviews. The chief reason is that the agency did not follow up after the client did not show for appointments, or the client just dropped out despite agency follow up. A number had died but were not recorded on CHAMP. Only a very small percent had non-working phones. **One-third of cases could have been “closed” or completed/discharged and not “lost to service” if agencies had completed follow up and updated CHAMP.**

Table 1: FY2008 Clients Lost and Did Not Return – Reasons (n=155)

Reason for No Return	%
Patient Was Never Lost	11%
Deceased	14%
Relocated Outside NEMA	8%
Transferred to another provider	5%
Discharged	3%
Returned in 2011	2%
Phone not working, mailbox full,	2%
Receiving Service Outside NEMA	2%
Unknown. Never returned.	54%
Total	100%

Progress on Reducing “Lost to Follow Up” in FY 2012

In order to reduce failure to follow up or “lost to service” found in the 2011 Needs Assessment, CHAMP implemented a “9-month reminder” for 2012 which appears at logon for clients with no activity in the preceding 9 months. Agencies are required to take action on the case by reviewing the patient chart and following up with the client if needed and recording current status in CHAMP. The agency can discharge the client, and re-open whenever the client returns. All clients remain in the CHAMP data base even when they are “discharged” so all information can be retrieved just by entering the Client ID.

Progress to date in FY 2012 is very positive. Agencies have taken action on these cases, updated patient circumstances, and have updated discharge status particularly as related to “transferred out”. The number of “Suspended-No Contact” has decreased by 60%. Thanks to the Council’s CHAMP Subcommittee for its work on this recommendation.

Characteristics of FY 2008 “Lost to Follow Up” Clients who had no Further Contact with Agency

The table below shows the characteristics of the “lost to follow up” clients who had no further agency contact – no reason given, based on agency chart review.

Based on these findings, agencies must make efforts to ensure that **“new clients in their first year of Ryan White services”** are engaged in and retained in care, particularly those receiving **medical care**. A

“new client” has never before received Ryan White services per the CHAMP current and historical data base.

Table 2: Characteristics of FY2008 Clients Lost and Did Not Return for No Reason

Characteristic	Lost to Follow Up	EMA/RW General Pop	Comment
Gender	Female = 32% Male = 67% Transgendered = 1%	Female = 40% Male = 60% Transgendered <1%	No significant difference. Maybe slightly higher for males.
Race/Ethnicity	Afr Amer = 59% Hispanic = 26% White = 9%	Afr Amer = 69% Hispanic = 17% White = 13%	No significant difference. Maybe target Hispanic/Latinos.
Age	Age 35-59 = 71%	Age 35-54 = 69%	No significant difference
Geography	Essex = 73% Union = 17% Morris = 10%	Essex = 71% Union = 20% Morris = 6%	No significant difference
5 Cities	5 Cities = 77% Newark = 47%	5 Cities = 74% Newark = 46%	No significant difference.
Poverty Level	<100% FPL = 93%	<100% FPL = 80%	Must target very low income
New Client FY08	Yes = 43%	New = 11%	Must target new clients
Medical Care FY08	Yes = 76% No = 24%	Yes = 63% No = 37%	Must target those in Medical Care
Health Insurance FY08	No Insurance = 66%	No Insurance = 47%	Must target Uninsured

Based on these findings, populations to be targeted for retention in care are:

- Hispanic/Latinos
- Very low income (<100% Federal Poverty Level)
- New clients
- Those in medical care – especially new clients
- Uninsured

New Client Characteristics and Need for Follow Up

Examining the characteristics of FY 2008 new clients who left the Ryan White program in FY 2009 with no further contact shows the reasons for targeting these individuals for retention in care activities. This is a small population so care should be taken in extrapolating to all clients.

- **“Hard to reach”** – 1/3 of new clients were defined by CHAMP as “hard to reach” and received a substance abuse or mental health service during FY2008.
- **CD4** – new clients tested for HIV were categorized as “HIV per CDC”.
- **High viral loads** – of the new clients who had a viral load test, 11% had undetectable VL (<200%), 33% had VL 1,000-49,000, 11% had VL 50,000-99,999, and 44% had VL 100,000+.

Retaining new clients in the Ryan White system is essential for containing the epidemic and will help address all three National HIV/AIDS Strategy goals – (1) reduce incidence by preventing spread of HIV,

(2) increase access to those low income uninsured, and (3) reduce disparities among racial/ethnic minorities.

1.3 Provider Survey/Key Informant Interviews

This section sets forth the responses to the questions in the questionnaire and from interviews of Key Informants.

#1 Retention in Care (patient follow-up) policies and procedures for the first and subsequent missed appointments.

The agencies provided an extensive array of follow-up methods.

#2 Staff positions performing follow-up.

To perform follow up, the majority of agencies used Medical Case Managers (MCMs) - medical providers - or Case Managers (CMs) for nonmedical providers. Additional staff include an Advanced Practice Nurse (APN), outreach navigator or patient navigator, nursing staff including nurse case managers and registered nurses, multidisciplinary medical team, social worker, and registration/front desk staff.

#3A Percent of patients missing regularly scheduled appointments.

The percentages ranged from a low of 10% to a high of 30 to 40% with an average of 20% to 25%. It is safe to say that **one quarter of patients do not keep their regularly scheduled medical appointments.**

#3B Trends over time regarding regularly scheduled appointments that are missed.

The majority of respondents indicated no change but some indicated a decrease and others an increase. Reasons are discussed below.

#3C Reasons for trends regarding regularly scheduled appointments that are missed.

- **Decreases.** Respondents cite consistent application of protocols, diligence by medical case managers in foreseeing individual client barriers to care and providing reminder phone calls before medical visits, frequent follow-up calls by MCMs, and reinforcement by the physician of the reasons why follow-up appointments are needed.
- **Increases or simple failure to keep appointments.** Reasons include:
 - Denial about HIV diagnosis especially for new patients.
 - Substance abuse, mental health issues, substance abuse relapse.
 - Homelessness.
 - Failure to take medications due to side effects.
 - Wait time, lack of waiting room space.
 - Difficulty in obtaining entitlements.
 - Patient phone numbers that are wrong or which have been disconnected since the last appointment.
 - Lack of transportation to medical care.
 - Medical care is not a priority for some patients.

- **First week of the month** – receipt of benefits (welfare and Social Security checks).
Note: this is a new reason but cited by numerous providers.
- Inclement weather.

#4 Differences in retention between newly diagnosed (using medical care within the first 1-2 years following diagnosis) and those in care for a long time.

Respondents noted differences in these two populations.

- **Newly Diagnosed Patients:**

- Have difficulty in accepting a diagnosis and regular medical routine. They are still in denial which interferes with understanding of the need for regular medical care. **The most frequently cited reason for failure to keep appointments is denial of HIV diagnosis.**
- Have more unstable health situations.
- Require more staff time. They need time to develop trust with the providers and MCMs.
- Are overwhelmed with information and can only retain bits and pieces, including knowing their lab values, medication and medical terms.
- Frequently take several initial scheduled appointments before they actually show up.
- Younger newly diagnosed often do not return after intake without several reminders and after the first visit with the physician. Extensive outreach is needed to redirect them back into care.
 - In contrast, some newly diagnosed young MSM are adherent with care and treatment possibly out of shock and fear. Once they see that the medications are tolerated, they feel better, and get on with their lives.
 - However, like most young people, the doctor's appointments "interfere" with their busy lives and they tend to slack off. Contact with them is fairly easy (due to cell phones, smart phones, text messaging, e-mail, etc.), and getting them back on track as possible.
- In some clinics the newly diagnosed patients are more motivated and tend to follow-up with their appointments more consistently than those who have been in care for a long time.
- Are more fearful of their recent diagnosis and are looking for support and counseling which we are able to provide.
- With perinatally infected children, it really depends upon the child's guardian as to whether they keep appointments or not.
- Patients feel good, are not sick so there is no incentive to see the physician. Also, there is lack of education and lack of trust between the newly diagnosed patient and the system of care.

- **Long Term Patients:**

- For the most part, the patients who have been in care for a while have become more compliant with taking medications and not missing appointments.
- Long term patients usually are much more consistent with visits unless they are experiencing personal issues.
- Age is a factor. The older the patient, the better the adherence.

- The older more experienced patients fall into **two separate categories**:
 - Those who are doing well on medications, adhering to treatment, and maintaining their treatment plan.
 - Those who have been struggling with substance abuse, life issues, and mental health issues. They have been living with the disease for many years and even though clinically they are not doing well, in their opinion they are fine and do not need to come to the doctor, have their labs checked, and take medications. **This is the most difficult population to care for.** People who have been positive for over 10 to 15 years and are still living may have adapted to **feeling sick as their norm.** They don't remember what well feels like. The mental frame of reference is skewed so you cannot convince them that they need medical treatment.
- Because of the medications people are living longer and healthier lives but lately some agencies have seen complaints of long-term clients who are experiencing side effects while taking certain medications, which leads to them not keeping follow-up appointments.
- **All Patients regardless of year of diagnosis:**
 - Notwithstanding diligence of MCMs, our goal of having 100% retention has not been reached due to other aspects of clients' lives. We find that unstable housing, untreated mental health, substance abuse or child care, and incarceration affect the client's retention in care.
 - Phone numbers which are wrong or disconnected, making patient contact difficult or impossible. (Despite follow-up and update of phone numbers in the patient chart.)
 - Many patients have **pay-as-you-go phones** which are frequently disconnected.
 - Medical care is not a priority. Getting housing or a job takes precedence over keeping a medical appointment. Patients often turn up when they can or want to.

#5 Do you go out into the field to locate patients who have failed to keep appointments?

There were three categories of responses to this question.

- **Agency policies.** A number of providers including hospital-based clinics and the Veterans Administration have agency or institutional policies which prohibit these fieldwork activities. (However, the NJ VA facility uses community outreach nurses to inform veterans of the availability of care and treatment available at VA New Jersey Health Care System.)
- **Scope of field work.** Some medical and non-medical agencies, including those with non-medical case management, perform field outreach - as a regular practice or only in exceptional circumstances.
 - Some often accompany clients to appointments to ensure connections. In addition home visits or visits to neighborhoods frequented by the client are often done.
 - Some only do in extreme cases, including for pregnant patients, but normally do not do outreach.
 - One medical provider has a comprehensive home visitation program in place.
 - Some medical providers do field outreach but not using Ryan White Part A services.
 - Another medical provider has a "peer navigator" funded by Part A to perform patient follow-up.

- **No funding.** A number of agencies do not have funding for this position or staff to perform these activities. They cite the need for someone who is street smart, a peer, and reliable. Others partner with CBOs and alternate care sites to try to locate patients.

Staff positions for agencies performing outreach or patient follow-up include: Ryan White community/patient Navigator, Medical Case Managers particularly associated with Incarcerated Discharge Planning (IDP) programs, Registered Nurse, and mental health and substance abuse counselors where appropriate in certain situations.

Barriers to Patient Follow up for missed appointments, e.g., in March 2012, include issues mentioned previously.

#6 Barriers to patient follow up for missed appointments.

Some agencies experienced no barriers. For the remaining providers, responses to this question were categorized into two categories - systems issues and patient issues.

No Barriers

- There are no barriers. Follow-up efforts are conducted on a regular basis per the established protocols and practices. (One provider)
- There are no systems issues. (2 providers)
- Agency hours are good - agency is open seven days a week. If blood cannot be drawn at scheduled appointments it will be done by the MCM when patient comes in.
- Patient issues such as telephone and address used to be a problem but their demographic data is verified at every clinic visit.
- There are occasional patient issues. However, thanks to the electronic registration/practice management systems, HIV staff can easily look up patients' numbers (including emergency numbers) and compare them to the numbers provided during the HIV medical case management assessments.
- We have the staffing to provide phone and mail contact to patients provided they keep us informed of current contact information.

#6A Systems Issues, e.g., not enough staff, hours of clinic operation. Systems issues are listed in order of frequency.

- **Limited staff.**
 - Limited staff. (Our MCMs are part-time and have other responsibilities in addition to Ryan White (RW) HIV patients.)
 - Not enough staff including a retention specialist going into the field.
 - Lack of community outreach workers to locate missing clients within the community
 - Would like to add GYN doctor.
- Limited appointment availability.
- **Lack of agency-provided transportation.** (2 responses)
- **Lack of sufficient or extended hours.**
 - No weekend hours.
 - Employed patients need different hours of operation.
 - Would like to add evening hours and another day to clinic.
 - Hours of operation (we are not a full-time clinic).

- **Lack of space**
 - Lack of space. HIV-infected patients and other medical patients now wait in the same space which is insufficient.
- **Health insurance issues**
 - Health insurance or lack of it.
 - Barriers due to Medicaid Managed Care. Patients must go through their Primary Care Provider (PCP) before they can be accepted by our agency.
 - Need for referrals and authorizations before providing medical care.
 - Patients often do not know their PCP who was randomly assigned. Patients often do not see their PCP and they continue to see the HIV specialist for all their medical needs.
- **Problems with specialty care.**
 - Long waiting lists at the specialty providers, who are not available and frequently have long waiting lists.
- **Internal agency issues**
 - Registration does not check and change addresses and phone numbers each time the patient comes in for medical appointments. Pharmacies mail medications to addresses including rehabilitation agencies and the patients are no longer living there.

#6B Patient Issues

- **Transportation**
 - Transportation – lack of or none. Coordination of transportation availability with employment hours. Location.
- **Behavioral health issues**
 - Substance abuse issues and addiction. Active substance abuse. For one agency this is a primary barrier.
 - Active mental health issues. Mental health issues not managed.
- **Stigma**
 - Disclosure issues
 - Stigma
- **Housing**
 - Unstable housing.
 - Homelessness
 - Some of our patients are in shelters or temporary housing and we are unable to contact them by mailing address. Phone numbers change but we are not notified.
 - Homeless patients are often transient between shelters and temporary housing. This makes it hard to contact them to help them adhere to treatment.
- **Incorrect patient information or contact information.**
 - Phone numbers and addresses change. Many times the phone numbers and addresses are incorrect or have changed.
 - Deliberate misinformation due to immigration status/transient population. Difficult time contacting patients for missed appointment when information provided is incorrect.
 - Incorrect demographic information (patients to not give correct information).
 - Wrong or disconnected phone numbers; and when mailing contact letters, some of them come back with incorrect addresses.
 - Wrong phone number (patients are constantly changing their phone numbers or their phones are cut off).

- No voicemail set up.
- Voicemail box full or not accepting calls.
- Phones not accepting calls, unable to pay for phone bill.
- Incorrect addresses, changed phone numbers, or service disconnection. Wrong phone number and addresses (transient population).
 - Sometimes this occurs, but we try to get two separate numbers and an emergency contact at intake.
- Frequently changed cell phone numbers.
- Change of address not communicated to staff.
- **Patient adherence issues**
 - Patient adherence issues, i.e., forgot appointment, other commitments, climate barriers, cancellations, and unknown
 - Patients not responding to phone/mail contact.
 - Failure to return our calls.
- **Other priorities including employment, work, welfare, HOPWA.**
 - Employment issues
 - Other commitments, e.g., work or school schedules.
 - Other more pressing issues, e.g., welfare appointments, HOPWA appointments.
- Hospitalization.
- Difficulty with entitlements.
- 90% of our patients (most of them are homeless) come to our facility with no personal identification documentation or with inadequate ID. Case managers must apply for Social Security and Medicaid documents for new registrants. We create an agency specific ID but some referral clinics and specialists will not accept it, which is a barrier to delivering needed services.
- [Lack of] childcare.
- Self pay patients had been required to pay a \$50 co-pay toward their care. However, this barrier was removed after Medical Director interceded. However, instituting sliding fee scales might present a barrier.

#6C Percentage distribution between systems and patient issues.

Respondents estimated the impact on retention in care in terms of distribution between systems and patient reasons. They provided a range of responses. Listed below is the estimated distribution between systems and patient issues provided by 14 agencies and the average and median percentages.

Approximately 1/4 of problems with retention and keeping appointments are estimated to be systems issues and ¾ are patient issues.

Table 3: Distribution of Systems and Patient Issues Contributing to Retention In Care in Newark EMA

# Agencies	Systems Issues	Patient Issues
1	80%	20%
3	50%	50%
3	25%	75%
2	20%	80%
1	15%	85%
2	0%	100%
2	10%	90%
Total 14		
Average	27%	73%
Median	23%	78%

#7 What other issues adversely impact retention in care? (e.g. mental health, substance abuse, homelessness, copayments, transportation, etc.)

Providers indicated that the **top 4 issues of mental health, substance abuse, homelessness, and transportation** adversely impacted retention in care.

Most providers (93%) indicated that mental health issues adversely impacted retention in care. Additional percentages are shown below. Please note that this table shows causes specifically identified by providers, but that this is not all-inclusive or a ranking.

Table 4: Issues Adversely Impacting Retention in Care

Issue	% Responses
Mental Health problems	93%
Substance Abuse problems	87%
Relapse	7%
Transportation	80%
Homelessness	67%
Housing Issues	7%
Financial Barriers	20%
Copayments	20%
Managed Care	7%
Recently Released/Incarceration	14%
Medical care is unimportant	7%

Agencies gave the following clarifications and additional information:

- Mental health (MH), substance abuse (SA) and homelessness define the great majority of our population. 85%-95% of our residents suffer from mental health and/or substance abuse.
- In addition to MH, SA, homelessness, transportation – clients are not ready to face their diagnosis.
- Transportation – many need bus tickets to come to their medical and lab appointments.
- Clients with CDS (Controlled Dangerous Substance) charges.
- Financial circumstances affect retention.
- Patient instability is a major issue – whether due to above 4 issues and unemployment, no medical coverage, no income, and personal issues.

- All above and managed care. Due to need for referrals from PCP [for Medicaid managed care], pre-authorizations required and multiple co-pays. Clients report that it is more expensive in terms of out-of-pocket costs.
- In addition to SA, MH, it is a problem for newly-diagnosed patients because it takes 30 days to be approved for welfare (GA) and Medicaid “Plan G” including medical transportation access.
- Recently released do not qualify for GA and it is very difficult to get them to come to care.
- Patients often use lack of transportation as an excuse, but they are able to travel locally to meet other needs.
- What brings people into care is food and bus tickets.
- Poor services provided by Medicaid transportation cans (late pick-up, no communication, wrong times, wrong dates).
- Many patients fail to see the importance of keeping medical appointments and following through with care plans.
- Relocation of patients to another state – Florida and North Carolina - is a problem in addition to substance abuse

#7A Quantify or estimate the percent impact of these issues on retention in care.

This question was difficult to answer. But agencies showed two extremes:

Low impact at 15%-20%	3 providers
Moderate impact at 50%	1 provider
High impact at 70%-98%	4 providers

#8 Recommendations for improving retention in care.

Many agencies indicted that there was little they could do – **patients have to be willing to remain in care and adherent to medications.** But they did offer recommendations shown below.

#8A For the Ryan White program, e.g., funding, change in service categories.

Systems Issues (by provider agencies). This includes answers to #8 and #8A)

- Creating more specialized small groups for severely demented/mentally ill residents so they will not feel left out and can benefit from small group counseling.
- Improve collaboration with [off-site] substance abuse treatment agencies. Continued coordination of care with other agencies involved in treatment of common patients.
- Execute Memoranda Of Understanding (MOUs) to solidify collaborations.
- Increase access to Paratransit system or bus passes.
- Determine actual number of clients lost to follow-up within an agency by checking and updating status of suspended/inactive clients in CHAMP.
- Increase resources to minimize barriers to care that are beyond patient control.
 - Make bus tickets available to clients who have doctors’ appointments.
 - More housing opportunities should be available to PLWHA.
 - Have vouchers distributed for shelter to clients that have CDS charges. Invest and create shelters for Megan law offenders that are in non-populated areas, e.g., abandoned factories or warehouses.

- Provide adequate funding for services, such as housing, transportation, respite care, etc.
- Implement treatment adherence program (grant application is in progress)
- Expand home visitation program – visits in a timely manner
- Continue funds for transportation for agency's van and driver. MCM can then focus on medical service and other retention issues.
- Increase funding for support services.
- Consider use of buddy/companion services to provide support.
- Have a complete team such as Program Coordinator, Infectious Disease MD, Registered Nurse, Medical Case Manager, and Retention Specialist that will be working 100% in this issue.
- More communication between the recipients of the grants.
- Improve tracking of Ryan White Services received by patients. Some clients are getting medical care and prescriptions from more than one medical provider, and might be selling their medications. This has to be tracked.
- Provide psychiatric care for clients who are still deeply/abusing substances. There is such a distinct difference between mental health and psychiatric care when dealing with this group. More than likely they have underlying psychiatric disorders that may respond well to medications and psychotherapy combined. This treatment plan may result in them no longer self-medicating with illegal substances, be able to focus clearly and improve their daily functioning. Improved mental health can readily result in improved retention in care.
- Making registration personnel more responsible for checking and updating patient information e.g., address/telephone numbers, etc., prior to appointment date and again at each visit.
- Finding effective ways to educate patients about the importance of medical follow-up. This is a challenge because the concept of HIV/AIDS is somewhat abstract and difficult for our patients to grasp, especially when they feel healthy, regardless of poor medication adherence.
- Increase in patient education about keep their information up to date, importance to compliance with medical regimen. Provide onsite MH/SA counseling. Use using social media or texting as appointment reminders and communication for other issues.
- Expansion of devoted HIV care hours.
- Educating patients.
- Increase transportation.
- Create a sub-category within Primary Medical Care that directly addresses the need for Palliative Care/Pain Management education and protocols.
- Award monetary credit for each Memorandum of Understanding established with an outside provider.
- More money to update our CHAMP computer. It is very slow.
- Increased funding for MCM and Navigation support, Bus Tickets. More funding for person to perform follow up activities.
- More funding for incentives such as transportation and food vouchers. Increase these secondary services to help the population to improve retention.
- Allocate some funding for patient navigators to assist patients through the systems necessary to get them engaged in and retained in care.
- Decrease funding for primary medical care and increase funding for medical case manager services.
- Increase funding for psychosocial/patient education services.

- Some funding dedicated to outreach as this has been proven through an ISIS study we conducted among high risk women in Newark NJ

#8B For clients, how to improve client contact and other ways of reaching and retaining clients in care.

- Stress the importance of bringing families and personal support systems for fully into the care picture.
- Increase the use of volunteer peer navigators, like the old buddy system.
- Aside from phone calls and letters not much else our facility can do.
- Increased enrollments (and slots) in day treatment programs - Day care, Substance abuse, Mental Health, Occupational.
- We continue to provide reminder calls to patients prior to appointment time whenever possible, continued assessment of barriers to care, scheduling flexibility when possible, treatment adherence education, better coordination of care with other providers
- Keep in regular contact and develop genuine collaborations and relationships.
- We need to address each issue by itself. We need to ensure that registration staff updates patient's information on every medical visit. Also, asking patients alternative phone numbers to contact.
- Free cellular phone for medical contact. Educate our patient to use the internet and create email addresses so they may communicate to MCM through email. --"free cellular phone" – limited access, i.e., life line.
- Well, one on one contact is a must - phone calls, letters, texts, emails, etc.
- Perhaps we could develop something along the lines of a centralized Patient Navigator/ Outreach Worker system. These folks could assist in location of clients through outreach and assist in navigating them through the medical, mental health and social systems. Frequently our clients wind up in multiple sites within the NEMA receiving duplication of services or half completed treatment plans. Patient Navigators may decrease this from playing out and assist in stronger engagement into a specific healthcare system.
- Within NEMA having these positions in place to follow-up with patients (centralized contact person). Funded through RW contact.
- This question ties up with the #8 and #8a. With improvement of psychosocial and patient educational services, patients can benefit from more efficient community outreach. Delivering the message in the community and bringing the patient to the clinic could potentially improve their attendance and retention in care. Attending to their psychosocial needs helps them focus on important aspects of their lives like health care.
- Possibly texting clients to remind them of their appointments. Most patients have pay as you go cell phones which often get turned off at the end of the month and on at the beginning.
- We are exploring **electronic messaging and email/text communications**, but this is at the early stages. We have noticed that email is a surefire way to get in contact with our program's service recipients; even the homeless patients respond to their email.

#9 Other comments.

Most agencies did not add additional comments. However three agencies provided insight on issues not otherwise addressed above.

Bilingual and Multilingual Services and Educational Materials.

- An important way to keep clients in care is to have **bilingual doctors** in the clinic. Not only Spanish but Creole and other languages. I have one Greek client who speaks some English and some Spanish and thus can understand more or less in those languages. The client goes to [UMDNJ] where he has problems with language and understanding. Creole should be emphasized due to Haitian clients.
- The only Spanish language-speaking provider in the area is at Newark Health Department. There is no one in Union County. The problem is that when a translator is used sometimes we/they (client) lose information.
- Preprinted materials to hand to patients for reinforcement of care and why a specific treatment is needed in both **English and Spanish**. If we are handing out the same information at all avenues of care we can then all build on the same themes and we can standardize the care no matter where they go.

Addressing/Understanding Poverty Issues

- The majority of our patients are coping with the reality in which they have to deal with the consequences of poverty, mental health, substance abuse and other psychosocial issues. All of these factors obstruct their ability to make health a priority. Addressing their needs is a vital factor in being able to improve health outcomes.

1.4 Health Insurance Premium and Cost Sharing

The purpose of this section of the Needs Assessment is to obtain information from federal sources – HRSA HAB – regarding the scope of this service category and whether it could be used to fill some of the gaps in Medicaid Managed Care and other situations regarding health insurance.

The definitions in the 2011 RSR Manual released in January 2012 is:

“Health insurance premium and cost sharing assistance is the provision of financial assistance for eligible individuals living with HIV to maintain continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.”

The Council asked the Grantee to assist in this portion of the Needs Assessment Update, by obtaining the most current information from HRSA HAB. Federal staff agreed to make a presentation on this service category at a federal site visit to the Newark EMA scheduled for July 2012. Unfortunately, the site visit was never held, was rescheduled to August 2012, and now the date is unknown.

The Council and Grantee will continue to pursue the issue during 2012 to obtain information regarding use of this service category.

1.5 Early Intervention and Retention Collaboratives (EIRCs)

Early Intervention and Retention Collaboratives (EIRCs) were developed for FY 2012 to fulfill the federal requirement regarding strategies for Early Intervention for Individuals with HIV/AIDS (EIIHA). The purpose of the EIRCs is to ensure an integrated approach to prevention and care activities. EIRCs are partnerships that bring together the Part A providers, all other Ryan White Program resources and the HIV Prevention resources (CDC and state-funded) to ensure a comprehensive continuum of service from education, prevention activities, outreach, testing and diagnosis of HIV to medical care, Prevention for Positives, and retention for those who drop out of care. EIRCs enhance the system established by MOUs with a mandatory regional organization and specific goals and objectives to be accomplished. Every Part A provider is required to be a member of an EIRC and attend scheduled meetings. Initially, five EIRCs were proposed – one in Union County, one covering the Morris, Sussex, Warren region, and three covering Essex County. It has been determined that only two EIRCs are needed for Essex County - for a total of four EIRCs in FY 2012.

The EIRCs have begun to meet. In June 2012 there was a EMA-wide EIRC meeting to present an overview of the goals, objectives and expectations of EIRCs - the need to review data on counseling and testing, referral and linkage to medical care among CTR agencies and Part A providers. Regional EIRCs began meeting in August 2012, and are completing the testing, referral, linkage analysis. “Linkage” is complete when the individual has a CD4 or viral load tests completed, or begins anti-retroviral (ARV) medications.² In other words, **linkage occurs at completion of the first HIV medical visit.**

Results of testing, referral, linkage. As of early August 2012, one EIRC had met in Union County. Data showed that all individuals who tested HIV-positive had been referred and linked to medical care except for two individuals. The reasons for failure to link these two individuals were related to incarceration.

- One individual had been tested and had an appointment scheduled within one to two weeks for the initial “linking” HIV medical visit. The individual did not keep the medical visit appointment, because he was in jail.
- The second individual had been tested in the county jail, and, as part of the Part A discharge planning program, had been counseled to have a medical appointment immediately upon release which would be scheduled by the Discharge Planner. The individual had no interest in HIV medical care or other services and stated this explicitly to the Discharge Planner.

Initial regional meetings of the remaining EIRCs will be completed in August 2012. Additional cases of “failure to link” will be identified and the specific circumstances will be reported by the EIRCs to the Grantee and Council. The Grantee will continue to monitor results of subsequent meetings and report results to the Council.

Recommendation. The first EIRC recommended that CHAMP assist in identifying “failure to link” by issuing regular “exception reports” of the client IDs who were not linked to care. This will enable agency

² The HRSA HAB definition for “linkage” under EIIHA is the same as the definition for “met need” in the unmet need analysis.

staff to follow up on client circumstances and reach out to the clients if possible and encourage them to come into HIV Medical Care.

1.6 Conclusions and Recommendations

The following conclusions and recommendations are listed in no specific order but have been suggested by the Key Informant respondents.

- **Agencies must continue to follow up on the CHAMP “9 month reminder”** which indicates clients with no activity in the preceding 9 months. If agencies take action by (1) contacting the client, (2) updating the patient record, and (3) updating CHAMP including suspending the case or discharging the patient (record can be re-opened if patient returns), this will significantly improve the EMA’s performance and reduce the “lost to service” numbers.
- **Agencies must continue to track those who have transferred out to other agencies or are receiving care outside of the EMA.** (E.g., Bergen Regional Medical Center for behavioral care.)
- **Agencies must focus “retention in care” efforts on the following populations:**
 - Hispanic/Latinos
 - Very low income (<100% Federal Poverty Level)
 - New clients – especially those receiving in medical care (due to high viral loads)
 - All clients in medical care
 - Uninsured
- It appears as though approximately 20% to 25% of patients do not keep regularly scheduled medical appointments. Reasons for missed appointments are ¼ systems issues, and ¾ patient issues. **Should the Newark EMA accept “20% to 25% missed appointment rate” as the norm?** And work around this in scheduling, quality management, and patient management? Should we compare this rate with other non-HIV disciplines and providers?
- The EMA must decide whether improvement in retention in care – specifically, ensuring that patients keep medical appointments – is a priority.
 - If so, the next steps are to identify the methods or “best practices” to make such improvements.
 - Agency actions.
 - Patient actions.
 - Once these are implemented, then develop targets for improvement (e.g., percent increase by agency).
- The EMA should research and identify resources to fund these Retention In Care activities. Options include:
 - **Internal agency resources.** Use of better tools or protocols or check lists during patient visits to improve future follow-up. Such as, verifying phone numbers (including on-site phone calls if needed), verifying e-mail addresses, use of e-mail for patient contact with patient permission, etc.

- **Non-Part A/F resources.** Encouraging agencies to seek non-Part A or F funding for retention in care activities. Such as use of unused Part B funding in cooperation with the New Jersey Department of Health (NJDOH).
- **Part A/F resources.** There appears to be a need for additional or redirected Part A or F funding for retention in care/non-medical case management/outreach activities.
 - Need for specific job descriptions, activities and performance benchmarks for patient follow-up.
- Identify resources for peer navigators, patient follow-up in the field, and retention in care specialists. This is particularly important for homeless patients, but also for the vast majority of patients served in the urban areas. Develop a **model for peer navigator, retention in care specialist, and similar positions. List qualifications, skills, and responsibilities.**
- Continued or increased use of support groups to improve retention. Referral to support groups by Part A/F funding agencies who do not hold these groups themselves. Use of EIRCs and resource inventories to identify these groups.
- Recommend that the NEMA (grantee) build capacity so that new patients can be seen by a medical provider on a walk-in basis on the day of diagnosis. (Cross check this with agency EIHA policies and procedures.)
- EIRCs should continue to identify newly diagnosed who “fail to link” with medical care and investigate and report the reasons.
 - To facilitate this investigation, CHAMP should produce appropriate “exception reports” of those referred but not linked to medical care (do not have the initial HIV medical visit).
- It is recommended that the Council’s **Continuum Of Care (COC) Committee** follow-up on these conclusions and recommendations then develop a list of protocols or checklists for patient follow-up and industry-wide “missed appointment rates”.

Part 2: Study of the HIV Care System

2.1 Background

The Council and committee members have identified issues related to the changing patient population and HIV health system and care of PLWHA within the Ryan White program. The Council and Executive Committee suggested that when another survey of the system is done, we might want take a look at what type of HIV system we have, because HIV is a different disease. There are the effects of the medications, the need for the involvement of Infectious Disease specialists/primary care specialists and the issue of the aging HIV population. How do you decide if the medical condition is a result of aging or a result of HIV? The question is how should funding be directed, because there is the idea that everything is taken care of once it involves HIV. An additional issue is the importance of collaboration and interaction among the agencies as the other aspect of identifying the client's needs.

Research Question #2

What are the features of the current HIV care system, how does it serve the current and aging HIV population, and how can the EMA use the strengths of Ryan White system to address PLWHA needs in a changing health care environment?

Specific services include:

- Focus on four specific topics:
 - (1) **Medical Case Management versus Case Management.** What are the differences between the services? Where are the services needed? What gaps does each service fill? How can these services be used to improve client health outcomes?
 - (a) Investigate use of an MCM **acuity screening tool** by one provider agency.
 - (2) **Laboratory testing and the impact on funding.** As the population ages additional testing is needed for age– related conditions. Identify these tests and assess the need, frequency, and impact on cost.
 - (3) **Electronic Medical Records (EMR).** What is the impact of EMR on the role of Medical Case Management? How can an EMR be used to facilitate MCM activities, and how can MCM feed into EMR.
 - (4) **Scan of the funding system.** Ryan White is the payer of last resort. How does this fit in with other funding streams including New Jersey Charity Care, Medicaid Managed Care, Medicare, and private health insurance.
- **Research.** Identify sources to obtain this information, including online research, New Jersey government, meeting minutes of the Planning Council and committees, and interviews of Key Informants.
- **Key informant interviews.** Identify key informants, develop appropriate KI survey tool to capture needed information, conduct KI interviews, write up results.

- **Report.** Prepare report of findings in each of the four areas. Identify recommendations made by participants and key informants. Include recommendations for FY 2013 Ryan White service priorities and resource allocations.

Methodology

The Research and Evaluation Committee (REC) developed a questionnaire to be used as a tool for Key Informant interviews. The tool was reviewed by the REC and Council, approved and finalized. It was determined that KI interviews would be conducted by members of the REC. There would be two phases: (1) Send the tool to the KIs for review and completion, (2) conduct a telephone interview to answer any questions raised in the completed questionnaire and to obtain additional information if needed.

The REC also identified the Grantee as a KI and developed a tool to obtain information about the Ryan White Service Category “Health Insurance and Premium Cost-Sharing Assistance.” As the New Jersey Medicaid program shifts to a managed care model for the elderly and disabled, including those with HIV disease, can this category be used to pay for “copays” or “cost-sharing” required of Medicaid Managed Care (MMC) beneficiaries – specifically for medications and physician visits.

Key Informants included 20 individuals – 13 Part A/F medical providers and seven (7) additional agencies selected by the Council, Grantee, Subgrantee and REC because of their unique services and service delivery models which would provide another perspective on the HIV system.

The Council sent out the questionnaire to the 20 KI’s on April 20, 2012 and received the results. KI interviews were scheduled and conducted from late May through June 15, 2012. Results were compiled and are shown below. A total of 16 agencies returned questionnaires (80% response rate) – 11 medical providers and 5 non-medical providers - but some did not respond to any or all questions.

2.2 Medical Case Management

Definitions in 2011 RSR Manual released in January 2012.

Medical case management services (including treatment adherence) are a range of client-centered services that link clients with health care, psychosocial, and other services provided by trained professionals, including both medically credentialed and other health care staff. The coordination and follow up of medical treatments are a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care through ongoing assessment of the client and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include: (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic reevaluation and adaptation of the plan, at least every six months, as necessary over the life of the client. It includes client-specific advocacy and review of utilization of services. This includes all types of case management, including face-to-face, telephone, and any other forms of communication.

Case management services (non-medical) include advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Non-medical case management does not involve coordination and follow up of medical treatments.

#1 Does your agency utilize the position of medical case manager (MCM)?

All of the 11 medical provider agencies who responded use the position of MCM.

#1A Does the MCM perform all of the functions in the HRSA HAB definition listed above?

Yes, all of the medical providers MCM perform all of the functions in the HRSA HAB definition.

One agency noted that the MCM(s) also perform navigation and follow-up activities in addition to medical-related issues. Another noted that all of their MCM are all certified/licensed Social Workers who performed all required functions. A third agency noted that the MCM is supervised by a Program Coordinator to ensure all functions in the HRSA definition are followed. A fourth agency noted that it works collaboratively with CBOs in the area and MCM(s) make referrals for support services, i.e., emergency assistance, housing, legal advocacy. MCMs co-manage patients with these CBOs so that services are coordinated.

#1B Agency titles for the position of MCM and their qualifications, credentials, etc.

Agencies have a range of titles for the position of MCM depending upon the role of the MCM in the agency. However, most are either nursing/medical assistants or social workers and related titles and experience.

Title	Qualifications/Credentials
<i>Nursing (7 agencies)</i>	
RN/Medical Case Manager	Minimum RN from accredited college or university. Must possess an active license to practice as an RN in NJ. Minimum two (2) years HIV/AIDS experience. Acute/critical care experience preferred.
LPN and RN (BSN)	(No qualifications/credentials provided.) Self-explanatory.
RN, CMA's.	Case Managers are certified.
RN	Our medical case manager is a registered nurse.
RN	Both MCMs are Registered Nurses. One has a Master's Degree in Nursing Case Management.
Medical Case Manager or Patient Navigator	Nursing - RN, Social Worker-BA-MSW with previous experience with HIV.
Certified Medical Assistant	Certified Medical Assistant, HIV Counseling and Testing through the NJDHSS, certification will be completed next year.
<i>Social Services (licensed) (4 agencies)</i>	
Social Services Program Manager (Director of Social Services)	Minimum two (2) years' experience in supervision of HIV Case Managers and a Bachelor's degree in social work or related field.
Case Manager Certified Social Worker	Minimum two (2) years' experience in clinical social work working directly with clients and Bachelor's degree in social work or related field. Social Work certification preferred (two on staff).

Title	Qualifications/Credentials
MSW	MSW required. One LCSW and 1 LSW.
CSW, LCSW, LPC	All are Masters prepared professionals.
General Social Services/Health care (7 agencies)	
Case Manager Admissions Coordinator	Minimum two (2) years' experience in healthcare or social work setting, working directly with clients and Ryan White Case Management certification.
Case Manager Discharge Coordinator	Minimum two (2) years' experience in healthcare or social work setting, working directly with clients and Ryan White Case Management certification.
Case Management Assistant	Minimum Bachelor's degree in business or related field. Experience in administration in healthcare setting and computer data input preferred.
Incarcerated Discharge Planner (IDP). MCM-Treatment Access Counselors.	The position is occupied by 3 staff members: <ul style="list-style-type: none"> • High School Diploma with 10 years' experience as a MCM • Nurse with 2 years' experience as a MCM • Bachelor's Degree with 3 years' experience as a MCM
Medical Case manager	Bachelor's level education with a minimum of one year of professional experience in a healthcare setting.
MCM	Will need to have a Bachelor's degree in any human social services such as Psychology, Social Work, etc.
HIV Medical Case Manager	Minimum of Bachelor's Degree in Social Work, Mental Health, or Medical related Field. Experience with HIV population preferred.

#1C Where does the MCM fit into the care team – what role does the MCM play?

All Medical Case Management staff are equal partners on the interdisciplinary Care Team and fulfill all of the roles detailed in the HRSA HAB MCM definition. More specific comments are listed below.

Veterans Hospital (provides Ryan White funded MCM). Our facility provides medical care to approximately 478 HIV infected veterans, of those, 237 are Ryan white eligible recipients. Our Ryan White funded HIV case managers provide an individualized health care plan for our patients to include his/her spiritual, cultural, dietary and social needs. They provide a range of patient centered services that result in coordinated plan which links patients to ongoing medical care, psychosocial and other services. Our medical case managers ensure that our patients maintain their HIV care appointments three times per year, have updated lab work (HIV viral load and CD4 count) prior to their medical appointments and have a service plan updated at least twice per year. They interact with Ryan White agencies and other non-Ryan White funded agencies, shelters, transitional housing programs, nursing homes, hospice, legal advocacy programs, food programs, alcohol and drug treatment programs, and transportation companies on behalf of the patient.

Agency providing MCM to physician practice. The MCM meets with all clients receiving services at our agency.

- To secure adherence to care and treatment
- To educate each client on their current individual health

- To follow up after each doctor's appointment and reiterate new goals
- When necessary, to remind the clients of their upcoming doctor's appointment
- To conduct referrals to other necessary services including mental health, substance abuse, legal support and housing
- Provide monthly educational medical workshops for the clients
- Our MCM follow up not just with the Smith Clinic but with all medical providers affiliated with our clients

Medical Providers.

- MCM is often the entry point for new clients referred to program. Complete MCM screening, including assessment of mental health, substance abuse, financial status, entitlement, etc. Co-located collaboration with medical physicians. Liaise with care providers and patient when hospitalized. Facilitate discharge planning. Facilitate acquisition of records when clients move into system or leave our program.
- MCM plays a vital role, and is a gatekeeper between the patient and the provider.
- MCM is an integral part of the care team and is consulted for treatment plan development.
- MCM will assist the medical team in patient care. MCM coordinates services and performs all functions in Newark EMA MCM standards of care.
- MCMs are a vital component to assisting and coordinating patient's follow-up and carry out care plan. They act as advocate for clients' needs with physicians, assist the physicians and collaborate with other service providers.
- The MCM coordinates a lot of the care that our patients need – the MCM will schedule appointments with outside specialists or will schedule appointments for tests that the provider requests. The MCM also makes reminder or follow-up calls to check if the patient made these appointments.
- The MCM is a major part of the multidisciplinary health care team that provides services to the patient. They work directly with the patient, RN and Medical provider to design a comprehensive health care plan that will meet the individual needs of the patient. The MCM conducts an initial psychosocial assessment of the patient upon their registering at the clinic and updates it every 6 months. The plan of care is a living document that is changed according to the ever-changing needs of the patient.
- Our MCMs are an integral part of a multidisciplinary team , which meets after each clinic session to discuss the missed appointments and to discuss the care plans of the patients seen in that clinic session.
- Advocate, Navigator, Coordinator.
- The MCM is integrated into the care team, works with physician to see patients during their visit, and is the point of contact for all patients in the program. The MCM also is there when a patient is newly diagnosed and starts them into care immediately.

#1D Does the MCM link the client with non-medical services, such as housing, emergency financial assistance, and other benefits? If No, who performs these functions? If No, does your agency perform these functions?

Most agencies (11) reported that the MCM does link the client with non-medical services and performs services otherwise performed by nonmedical case managers. One agency has a team of social workers who performs this function (the MCM is a nurse) which is part of the integrated team. Another small provider refers clients to another agency which provides support service linkages.

#2 Does your agency utilize the position of Non-Medical Case Manager (CM-NM)? If yes, what functions does the CM-NM perform? Where does the CM-NM fit into the care team – what role does the CM-NM play?

Nearly all agencies funded for medical case management (medical providers) reported they did not use the CM-NM position. However, one agency reported using the nonmedical case manager due to different definitions. That is, the medical case manager is typically a nurse or medical professional. Nonmedical case managers are social workers. Both of these categories are covered under the Ryan White “medical case management” service category definition.

A few medical providers stated that CM-NM funding would assist in field outreach and other services needed to locate patients who had dropped out of care. One agency reported a barrier between MCM and CM-NM in that the patients had to register for the nonmedical case management services and/or CBO services in addition to registration for the MCM services.

One agency reported having three outreach case managers which were funded by Ryan White Part B and New Jersey Division of Youth and Family Services (DYFS). They conduct outreach follow up for missed appointments through home visits/telephone calls, arrange transportation, accompany patients to other medical visits, e.g., GYN. They also accompany patient to welfare offices, social security offices, legal services, court appointments, substance abuse treatment, etc., and also facilitate a women’s support group.

The nonmedical agencies who responded use the position of CM-NM. One agency reported that the CM-NM engages in case management and discharge planning. This agency reported that the case manager ensures that the client is receiving medical care while in jail and links them to medical care after release.

#3 Does your agency receive funding for MCM?

Medical provider agencies received funding for MCM. Non-medical provider agencies did not, with one exception of an agency which is providing MCM for a medical provider.

#4 Does your agency receive funding for CM-NM?

Non-medical provider agencies received CM-NM funding.

#5 If No to either question regarding MCM and CM-NM, would you like to be funded for these positions? What role would both positions play in managing the patient's HIV care?

About half of the MCM agencies reported that they did not need funding for nonmedical case management. The other half however cited some benefits. A nonmedical case manager might be useful resource for administrative and other interagency contact functions, could be used as a treatment adherence counselor, could focus on social aspects of patient care in coordination with MCM and would ensure that any gaps were filled. Clients are more consistent with their HIV care when their other basic needs are taken care of, e.g., housing, food, etc. One agency said they had been very successful with patient navigators that assist in identifying patients' needs and linking them to social services, transportation, and other services.

#6 How well is the MCM and CM-NM system working? Are there any gaps in patient access to services using the MCM and CM-MN?

About half of the agencies said that the MCM and CN-NM systems were working well. They were able to coordinate with case managers from other agencies and able to meet the needs of their patients. They felt there were strong open lines of communication with the multidisciplinary care team as well as CBOs. Both services are fully integrated within an agency. Additional comments were made.

- The amount of documentation required is so time consuming that it takes away from the personalized service. It takes hours to do biopsychosocial assessments as well as detailed care plans.
- There is a need for more Nutritional Counseling.
- An agency can follow-up on Core Services referrals (predominantly internal referrals) but does not always know if client actually received a support service referral. An appointment for a support service referral is not usually made.

#7 Do you have any suggestions or recommendations for the Ryan White program regarding MCM or CM-NM?

Approximately half of the respondents gave no answer and the others had the following suggestions.

- Clearer distinction is needed between MCM and CM-NM and specific responsibilities - where one ends and the other begins.
- More available and consistent training with case management training program.
- Training on the Transgender population, incorporating pre-exposure prophylaxis into our practice, treatment adherence.
- The Case Management Training program appears to have changed leaders and formats quite frequently over the years. This has led to a lack of communication, repeating classes, some people required to take review tests to pass and some not, and no direction regarding yearly requirements to sustain the certificate.
- Funding for CM-NM in addition to MCM so they can work together on the medical and social aspects of clients. CM could spend more time on concrete service needs around housing, food, benefits and could do field visits when necessary.

- Increased MCM funding due to the high level of acuity among some populations, e.g. urban populations.
- Caseload (number of patients per MCM) should be recommended with one-stop shopping organizations taken into consideration.

MCM Acuity Screening Tool

One provider agency reported using a **Medical Case Management Acuity Screening Tool** to “triage” patients on the extent of need for MCM services. The reason is due to high volume of medical patients and insufficient funding to serve all patients with full MCM services. This tool is in Appendix B.

Acuity Tool. The tool is completed by our MCMs and determines the level of need of the patient.

- Once the acuity level is determined then the patient is assigned an MCM and a service plan is developed. The MCM assessment tool and acuity scale are divided into seven categories; 1) Access to health care, 2) Health status, 3) Treatment adherence, 4) HIV knowledge, 5) Behavioral and Psychosocial, 6) Family situation, 7) Environmental Factors. Once the assessment is completed, each area is scored and totaled for acuity to determine the appropriate management level of care needed.
- The acuity grading is from levels 1 to 4. Level 1 is self-management and does not require a MCM and referral(s) are provided as needed. Level 2, basic management requires minimal MCMs, requires a face to face assessment and an annual reassessment with a minimum of contact every 6 months to verify contact information.
- Clients with scores above 2 mean that the client has medical and/or psychosocial needs that are complex and will benefit greatly from the assistance of a medical case manager (MCM) to provide monitoring and follow-up. Level 3 is moderate management which requires a MCMs assistance to access and/or remain in care with minimum contact every 30 days (telephone or face to face). Level 4 is considered intensive management; the patient is medical unstable, needs to be engaged on a concerted and consistent basis.
- Minimal contact should be at least every 2 weeks (telephone or face to face) initial service plan and reevaluation of service plan every 30 days once the acuity score is determined, cases are then referred to the MCM supervisor for assignment to a medical case manager. This step assures that the MCM assignment is both appropriate and timely.

Other agencies use comprehensive intake tools, the SAMHSA Substance Abuse and Mental Illness Symptoms Screener (SAMISS) tool, and client interviews but all patients in these agencies receive MCM services.

2.3 Electronic Medical Records (EMR)

This section assesses the impact of Electronic Medical Records (EMR) on the role of Medical Case Management and discusses how can an EMR be used to facilitate MCM activities, and how can MCM feed into EMR.

#8 Does your agency or health institution/system have or use an electronic medical records system? If not, do you plan to use an EMR system?

Of the 13 medical providers, eight have an operational EMR, and the remaining five are in the process of implementing an EMR or will implement by year-end. The nonmedical providers do not have EMR's and have no plans to acquire them.

#9 Has the EMR led to improved patient care? If yes, describe how. If No, describe how it has not led to improved care.

One agency has had an EMR for several years and reports that it has improved patient care tremendously. Two others who have completed installation also said that it has improved patient care. The remaining agencies have noted that their EMR is fairly new and they are still customizing it and have not been able to use it to its full potential yet. However the goal is that it will improve patient care. Expectations are high that EMR will be a benefit.

Respondents gave numerous reasons on how the EMR has led to improved patient care.

- Faster and more comprehensive access to patient charts for both input of notes and access to interdepartmental information on the patient.
- Decreased medication and treatment errors due to greater legibility of typed notes rather than handwriting.
- Decreased potential for negative medication interactions due to automatic system cross-checks.
- Speedier transmission of medication prescriptions.
- Reduced cost of storing electronic versus paper records.
- So much to list here: Clinical reminders are crucial to improving patient care. Our EMR "reminds" providers to test for HIV, Hepatitis, perform substance abuse screening, vaccinations etc. Access to patient's record if they have received care at another VA facility outside the state. Ability to see radiographs/diagnostic tests without having to sign out into another system. Ability to see other providers' notes and to electronically send your notes to another provider in order to coordinate care.
- All staff members have access to the EMR, which improves communication and updates information to all who are involved with the client. It allows for flags (or e-mails) to be sent through to the system to each user's desktop within the EMR. It has also improved our CQI activities through accurate data collection and reporting mechanisms.
- The EMR allows for all members of the multidisciplinary team to view the patient's encounters and coordinate care between one another. It is easy to use, eliminates storage issues, and increases patient safety, sharing records, saves time, quicker access to records and cost efficient.
- Improved documentation in terms of legibility, more accuracy in ordering labs and medications, checking for interactions, accessing the integrated medical record, including demographics, dental services and case management notes, easing communication between services, lab tracking and reviewing, to name a few.

#10 If you have MCM staff, does the EMR facilitate MCM activities? If yes, please describe how. If no, why not.

Several agencies responded that the EMR does facilitate MCM activities, others said that it was too early in the EMR's infancy to draw conclusions, and one said that at present the EMR adds obstacle because its rollout is in its infancy and everyone is getting used to it which is time-consuming.

One agency noted that the use of templates for many of our notes reduces the time spent documenting and allows us more face time with patients. Another noted that documentation of activities in the in the EMR can be viewed by all members of the healthcare team. A third underscored this feature, noting increased access to medical information including treatment plans, referrals, outstanding or pending labs, received labs, tabulation of labs for trends, etc.

One obstacle noted by one agency is that there are several different EMR systems being used in the larger agency system which presents issues of compatibility, and results in "half paper, half electronic format."

2.4 Laboratory Testing and the Impact on Funding

#11 What HIV tests do you routinely order for your HIV+ clients?

The following tests were listed:

- CD4 (and CD8)
- Viral Load (by PCR – Polymerase Chain Reaction)
- Phenotyping or genotyping testing as appropriate
- Toxoplasmosis (yearly)
- Hepatitis profile (yearly)
- RPR (Rapid Plasma Reagin) (yearly, for syphilis)
- Sexually Transmitted Infection (STI) screenings - Chlamydia (yearly)
- Tuberculosis testing (yearly)
- Lipids
- CBC (Complete Blood Count)
- Cholesterol
- Triglycerides
- GGT (Gamma-Glutamyl Transpeptidase)
- LDH (Lactate Dehydrogenase)

#12 What tests to you order for your HIV+ clients that can be considered "age related", that is, more likely to be ordered for a patient age 45 and older?

#12A What types of tests are these?

#12B How often do you order these tests?

The following age-related tests are ordered as often as needed, yearly, or other recommended intervals, based on patient age (50 and older), patient risk factors, prior results and similar factors as clinically indicated.

- Screening Tests related to:
 - Hypertension,
 - Cardiovascular disease (EKG),
 - Diabetes (HgA1c)
 - Orthopedic/arthritis – related health conditions,
 - Age – related cancers.
- PSA (Prostate Specific Antigen)
- Hemocult
- Cholesterol screening, lipid panel
- Mammogram, breast cancer screening
- Colonoscopy, colon screening
- Hormone levels
- Bone density (DEXA scan – Dual Energy X-ray Absorptiometry), Vitamin D levels
- Urine microalbumin
- TSH (Thyroid Stimulating Hormone)
- Thyroid
- Kidney function
- Pap tests and endoscopies.

#12C What are the estimated costs of these tests?

Costs of tests were difficult to obtain because most are covered by insurance and amounts are not necessarily made available to the medical provider. Some agencies gave lab costs of CD4 and others tests of \$1,800 - \$2,000; HIV RNA and CD4 of \$1,100; with PSA about \$120 (but other tests are more expensive).

#12D What is the trend over time – increasing, decreasing, or no change?

Several agencies said that the trends were increasing over time as the population of PLWHA was aging and living longer. They were ordering more “age-related” tests. Other agencies did not know the trends. However, one agency who noted the increase also stated that the agency has sometimes deferred doing the tests for Ryan White clients due to limited lab funds.

2.5 Scan of the Funding System

Ryan White is the payer of last resort. The concern is how does this fit in with other funding streams including New Jersey Charity Care, Medicaid Managed Care, Medicare, and private health insurance.

#13 Does your agency accept Medicaid Managed Care (MMC) as a payer for HIV care?

Of the 11 medical providers who answered this question, 9 or 82% accept MMC. One additional provider accepts Medicaid (fee for service) for labs and specialty physician visits but not MMC because it is not the patient’s Primary Care Provider (PCP). The other agency is the Veterans’ Administration Hospital in East Orange which does not participate in MMC.

Response from VA is included below to provide information about how the VA system works.

“The Veteran’s Health Administration (VHA) operates the nations’ largest integrated direct health care delivery system and it is committed to provide 100% access to care. Unlike Medicare, which operates as an insurer by reimbursing beneficiaries for the cost of medical care provided by doctors and other providers in private practice as well as by private and public hospitals, VHA provides care directly to veterans. The Dept of Veterans Affairs is a federal agency and therefore cannot bill Medicare, another federal funded agency, but it can bill Medicare supplemental health insurance for medical care, supplies and prescriptions. Veterans can use their Medicare benefits anywhere except in health care facilities run by the VA and the Department of Defense. A small percentage (13%) of our veterans is Medicare/Medicaid eligible. The NJ VA is a federal agency and therefore does not operate under state programs such as Medicaid, which is a state administered program that operates under broad federal rules. Veterans that qualify for Medicaid will not pay any co-pays for VA health care. Our agency cannot become Medicaid certified per federal regulations.”

#13A If yes, what is the approximate number and percent of MMC patients.

The percent of MMC patients ranges from a low of 30% to a high of 90%, with a **median of 40%**.

#14 Do your medical staff members serve as the primary care provider (PCP) for MMC clients?

Of the 12 medical providers answering this question, six (50%) serve as the MMC Primary Care Provider. Two (12.5%) of these six noted they are the PCP for some of their clients or for some of the health plans. The remaining six providers are considered “specialists” and require referrals from the MMC PCP for treatment.

#14A If No, what functions do your medical staff members perform?

The function performed by medical staff members is HIV Specialist or Infectious Disease Specialist.

#14B If No, how is your agency coordinating with the managed care primary care provider and how are your HIV patients getting approvals for referrals?

Providers with in-hospital systems stated that many of the patients’ PCP’s are located within the hospital system, so getting referrals to their Infectious Disease practices is no problem.

For those providers not within hospital systems, getting referrals from PCPs is difficult. Many patients are not aware of who their PCP is and do not want to visit and share their HIV status with a new designated provider. Also, clients must be in contact with the PCP for non-HIV-related issues. Referrals are easy to obtain but they are not always made with the HIV provider the client has known for years. Sometimes, patients are required to switch HIV physicians.

For some agencies, Medical Case Managers (MCMs) are assisting patients in navigating between the PCP and HIV specialist. Several agencies advise/remind patients when they need referrals and, if necessary, the agency (MCMs or others) will obtain the referral for the patients. One agency noted, “Our MCMs

and providers have a good working relationship with the MMC case managers, who assist with referrals. If a patient shows up without a referral, the MCMs are able to directly contact the MMC case managers to get approval for a visit. This allows for the patient to be seen immediately. We often have ‘walk-ins’ and this system works particularly well for those patients who may need immediate care.”

#15 Have you noticed an increase in patients with Medicaid Managed Care (MMC)?

All agencies who answered this question have noticed an increase in MMC patients.

#15A If Yes, how has this affected your practice?

Most agencies reported negative impact on their practice. This impact consisted of extra steps, need for prior authorization, considerable time spent by the provider and staff justifying the treatment with the HMO, and the need for all providers to become credentialed in HMOs serving the HIV population.

From the patient perspective, many patients are dissatisfied with (1) having to go to an outside lab for tests, (2) the referral process, and (3) the requirement to pay co-pays to get needed care. Patients with low incomes and the homeless have no money to pay co-pays. The need for a referral is a problem among several agencies particularly those not credentialed for MMC.

A few providers noted there had been some internal administrative issues regarding MMC which had resulted in a delay in care, but these had been addressed and barriers have been removed for patients.

Another agency noted a reduction in Part A billable units on the CHAMP system due to MMC. This was due to enforcement of federal policy by the grantee that MMC is considered “payment in full” for medical care and that Ryan White is payer of last resort only for services not otherwise covered by health insurance including MMC.

#15B If Yes, have your MMC clients been able to access the full formulary of medications?

Several providers said that their MMC clients have been able to access the full formulary of medications most or all of the time. Others said it depends on the managed care company. One agency said no - that MMC results in numerous denials and delay in patients starting necessary medications they need. Several other providers said there were delays due to prior approvals needed for non-HIV medications, even if patients had been on these non-HIV medications for a long time. Another reported that co-pays were required for medications, but not for HIV medications. Need for prior approval required agencies to spend considerable time - even hours - with managed-care companies to obtain the necessary approval.

Several providers noted that there was a two week waiting period for enrollment to be completed in New Jersey ADDP and patients to start receiving needed medications.

#16 Does MMC present any advantages or benefits for treating HIV patients? E.g., easier access to services, payment for treatments, etc.

The general consensus was that there are some benefits to MMC but more drawbacks. Some providers have not noticed any advantages or benefits so far.

Benefits are:

- MMC ensures a good referral base (larger provider pool to select from) for the clinic.
- Pays for HIV medications.

Drawbacks are:

- Need for prior authorization creates significant time obstacles for staff.
- MMC does not reimburse sufficiently to cover the cost of providing care to patients.
- Decrease in formulary of medications.
- Frequent denials of medications which increase the workload of providers and MCMs to determine which medications in the class the insurance plan will cover.
- Limited number of specialists in the plan for subspecialty care leading to an increase in waiting time for appointments.

#17 Does MMC present any barriers to treating HIV patients? E.g., need for prior approval from primary care provider for HIV care, etc.

Barriers cited by providers included:

- Patients need to obtain referrals for service. Some patients do not understand the concept of having to go to another provider in order to be seen by their HIV provider. This can result in missed appointments. Also it can be difficult to get a timely appointment to obtain a referral prior to their upcoming scheduled HIV appointment. This can result in rescheduling HIV visits.
- Patients have to pay co-payments. Copayments (\$20-\$40) are hard for patients. Patients often refuse procedures because they are unable to pay the copayment.
- Labs are in an outside location. Patients in MMC have to go to LabCorp or Quest to obtain blood work. Often times they delay getting their blood work drawn or just do not follow through. Also it is sometimes labor intensive to get the results of the blood work from the lab in time for the patients scheduled appointment.
- Hospital/organization does not accept some insurance types. Our organization contracts with only two managed Medicaid providers in the state, so individuals who belong to others must either transfer their coverage or go to another provider.
- Preauthorization issues that may delay implementation of appropriate care and receipt of needed medications.
- MCMs reimbursement rates are low.
- The clinic is a PCP for some clients, but HIV specialist for others. If the patient has someone else listed as their PCP (which they often do because if they don't choose a PCP one is assigned to them) it can be difficult to get certain tests done. Certain tests also require authorization.
- Some pediatric patients have a hard time finding a PCP who has open panel slots. A lot of the Pediatric PCP's in the area have closed their panels to new patients due to volume.

- Unable to locate specialists for sub-specialty care.
- Some of our pediatric patients and their families would greatly benefit from DOT (in home - direct observational therapy) to improve treatment adherence. The vast majority of MMC's do not allow DOT services. Sometimes we have to negotiate with DYFS to get approval for them to approve DOT citing medical neglect. This can be distressing for families to have DYFS involvement.
- MMC presents a delay in care barrier by requiring prior/pre authorizations when radiology tests such as x-rays, CT scans, and MRI's are ordered for diagnostic purposes. This process is long and often takes staff hours to complete and then wait either for more requests for information or approval or denial. Most importantly, it is a huge possibility to lose the patient in the meantime.
- One agency noted that NJ Horizon Health allows the agency to be a PCP, but that other insurance companies do not allow it. The need for prior authorization and referrals becomes burdensome for the clinic. Specialty care for HIV patients is limited and appointments are often not available, because most patients are self-pay or charity care. Appointments could take up to one year.

#18 Do you have any recommendations for improving the system between Ryan White and managed care for your HIV patients?

Recommendations included the following:

- Stop Medicaid Managed Care.
- If MMC cannot be stopped, there should at least be an HIV-specialized liaison in every insurance company so that our staff does not have to waste so much time navigating to a person with the knowledge and power to make authorization decisions.
- Enhance reimbursement.
- There should be fewer steps for patients to complete in order to be eligible for services.
- Insurance company's case manager should be more active in treatment plan .
- Funding for administrative costs was decreased by grantee imposing a hardship on the agency's ability to provide the support needed to ensure delivery of care.
- Help with copayment, get specialist that accept those insurances.
- Yes RWA can advocate for HIV patients not to be in a MMC or find selected few PCP that will collaborate better with the HIV community and the specialists we refer to.
- Well, I believe such will be hard because there is more than one HMO in the state.
- Would like to see an open dialogue between Ryan White and the Managed Care insurance companies. There are specialists that we frequently need to refer to yet are unable to link the patient with causing a delay in medically necessary care. This frustrates the patient and sometimes leads them to disengage in medical care completely. We can manage their HIV but not their specialty needs. We need access to a greater number of providers in areas such as neurology, dermatology, gastroenterology and ENT. I had a patient today who waited 5 months for an ENT appointment and by the time he got there, the problem had solved itself. He was

fortunate, some patients' problems are not solved, and they worsen. These patients then wind up hospitalized with complicated medical issues and exorbitant medical bills.

- With the addition to Medicaid Managed Care Networks to, it makes it very challenging for patients to connect with physicians without a protracted amount of waiting time. Therefore the patients are at the mercy of the medical networks limited list of specialist. As RW grantees there is no mechanism in place to alert healthcare networks in regard to finding a resolution.
- Easier prior approval for meds & services, which is less labor intensive and time consuming.
- Allowing DOT services, particularly with our children and adolescent clients.
- Improving the efficiency of MMC approved transportation services.
- Nothing operationally but it should be taken into account how lengthy this process is, particularly for medically complex patients, which takes away from hands on care for patients.

2.6 Conclusions and Recommendations

- It appears as though the MCM and CM-NM system is working well within the EMA. There are some glitches wherein and with (INSERT rest of the statement
- Other funding, including Ryan White Part B, appears to be available for outreach or nonmedical case management field services.

It would be helpful if the Council could contact N.J. Dept. of Health and get more information regarding what services Part B funds. (In the past, the EMA was told by NJDOH that Part B funded only agencies outside of the EMA's/TGA's, so that Ryan White funding could be spread around to the rest of the state. Apparently, this policy has changed. It would be nice to know what the state policy is regarding Part B funding and where the funding is allocated, i.e., can agencies within the New Jersey EMA/TGA's apply for this funding and what kind of services are funded, so that Part A and Part B could better coordinate services and funding and maximize the service continuum for PLWHA.

- Monitor expenditures and the need for lab funds – for both HIV-related and age-related tests. Increase funding for Primary Medical Care (outpatient medical care) which includes lab costs accordingly as needed.
- Continue to monitor expansion of Medicaid Managed Care and impact on patient access to medical care. Identify specific instances or trends.
- Continue to monitor impact of MMC on Ryan White Part A and F expenditures and use of MCM in ensuring that MMC individuals receive HIV care and are documented in CHAMP.
- If some of the start up glitches with MMC – prior approvals, prior authorizations, delay in medication and care – do not improve, seek to have the HIV system (to be determined) meet with some of the HMO case managers and others to educate them about HIV medical care and attempt to resolve some problems related to HIV treatment.
- These recommendations should become part of the work of the Continuum of Care (COC) Committee, with results reported to the NEMA Planning Council and Committees.

Part 3: Community Viral Load

3.1 Background

HIV **Viral Load (VL)** is a measure of the severity of HIV infection, and can be calculated by estimating the amount of virus in an involved body fluid per milliliter. The viral load in the blood is a good predictor of the likelihood of transmitting HIV to another. The higher the viral load value, the more viral elements there are in tissues and in circulating blood and other body fluids, and the more contagious is HIV infection.

“Community Viral Load (CVL)” is defined as mean or total VL (amount of the virus in the blood) of all HIV positive individuals receiving care in a given area.³ The CDC has just released a fact sheet entitled, "Using Viral Load Data to Monitor HIV Burden and Treatment Outcomes in the United States".⁴ The document lists four VL measures. **Measure #3: In-Care Viral Load**, will measure the "community viral load" of PLWHA receiving Ryan White medical care in the Newark EMA.

Viral Load Suppression is a measure of the percent of individuals with a VL < 200 copies/mL and is one of four In+Care Campaign measures. VL suppression is computed by CHAMP every two months for the EMA and for the EMA's Ryan White medical providers. HRSA HAB Core Clinical Performance Measures include VL suppression for persons on antiretroviral therapy (ARV) “below limits of quantification” which is < 200 copies/mL. CHAMP reports these data as "VL – HAART" for three VL thresholds: < 400, < 200, and < 50 copies/mL.

CVL in the Newark EMA will be measured using the following two indicators. See Table 5.

- #1 In+Care Viral Load Suppression**
- #2 HRSA HAB Viral Load Suppression.**

Research Question #3

What is the baseline community viral load in the Newark EMA for 2011, as measured by Viral Load Suppression?

Specific services include:

- **Data Collection and Analysis.** Obtain CHAMP data for 2011 on Viral Load Suppression for the EMA, geographical areas including the five counties and the five largest cities, zip codes where available, and demographic characteristics including race/ethnicity, age, gender and exposure category/mode of transmission.
- **Baseline Report.** Prepare report of findings including tables and graphs/figures showing VL suppression levels by geography and demographics. Identify any significant differences between areas and populations needing further review. This response port will serve as a baseline CVL for "In-Care" PLWHA.

³ Centers for Disease Control and Prevention. Division of HIV/AIDS Prevention. Strategic Plan 2011 through 2015. August 2011. <http://www.cdc.gov/hiv/strategy/dhap/pdf/DHAP-strategic-plan.pdf>.

⁴ CDC. February 2012. http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/viral_load.htm

Table 5: Viral Load Suppression Measures – In+Care Campaign and HRSA HAB Core Clinical Performance Measures

In+Care Campaign: VIRAL LOAD SUPPRESSION	HRSA HAB Core Clinical Performance Measure: VIRAL LOAD SUPPRESSION
Definition: Percentage of patients, regardless of age, with a diagnosis of HIV/AIDS with a viral load less than 200 copies/mL at last viral load test during the measurement year.	Definition: Percentage of patients, regardless of age, with a diagnosis of HIV/AIDS with viral load below limits of quantification(1) at last test during the measurement year.
Numerator: Number of patients with a viral load less than 200 copies/mL [2] at last viral load test during the measurement year [3]	Numerator: Number of patients with viral load below limits of quantification(1) at last test during the measurement year.
Denominator: Number of patients, regardless of age, with a diagnosis of HIV/AIDS with at least <u>one medical visit</u> with a provider with prescribing privileges [1] in the measurement year.	Denominator: Number of patients, regardless of age, with a diagnosis of HIV/AIDS who: <ul style="list-style-type: none"> • had at least <u>two medical visits</u> during the measurement year with at least 60 days in between each visit; and • were prescribed antiretroviral therapy for at least 6 months; and • had a viral load test during the measurement year.
Patient Exclusions: (1) documented deceased, (2) incarcerated for greater than 90 days, (3) relocated out of the service area or transferred medical care at any time in the measurement year.	Patient Exclusions: None.
Data Element: 1. Does the patient, regardless of age, have a diagnosis of HIV/AIDS? (Yes/No) <ul style="list-style-type: none"> a. If yes, did the patient have at least one medical visit during the measurement year? (Yes/No) <ul style="list-style-type: none"> i. If yes, did the patient have a viral load less than 200 copies/mL on the last viral load test? (Yes/No) 	Data Element: 1. Does the patient, regardless of age, have a diagnosis of HIV/AIDS? (Y/N) <ul style="list-style-type: none"> a. If yes, did the patient have at least two medical visits during the measurement year with at least 60 days in between each medical visit? (Y/N) <ul style="list-style-type: none"> i. If yes, was the patient prescribed antiretroviral therapy for at least 6 months? (Y/N) <ul style="list-style-type: none"> 1. If yes, was a viral load test drawn? (Y/N) <ul style="list-style-type: none"> a. If yes, did the patient have viral load below limits of quantification(1) on the last test? (Y/N) <ul style="list-style-type: none"> i. If yes, list date.
Note: [1] A “provider with prescribing privileges” is a health care professional who is licensed in their jurisdiction to prescribe ARV therapy (i.e., physician, physician assistant, and/or nurse practitioner). [2] DHHS guidelines and the AIDS Clinical Trials Group define virologic failure as a confirmed viral load greater than 200 copies/mL. [3] Patients with no viral load tests in the measurement year are to be included in the denominator.	Notes: (1) “Below limits of quantification” is defined as < 200 copies/mL. The Department of Health and Human (DHHS) guidelines and the AIDS Clinical Trials Group define virologic failure as a confirmed viral load >200 copies/mL. http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf .

3.2 Community Viral Load Results

This section shows statistics for Community Viral Load (CVL) or Viral Load Suppression by the two indicators – In+Care and HRSA HAB – and CY 2011 and FY 2011. The tables and figures show aggregate information. The reason that both CY11 and FY11 are used is that either time period can be used by the reader to determine the baseline.

Baseline CVL/Viral Load (VL) Suppression for Newark EMA

Baseline CVL/VL Suppression for the Newark EMA has been computed for 4 measures – CY 2011 HAB and In+Care and FY 2011 HAB and In+Care. These are shown in Table 6. For all four measures, VL suppression ranges from 62% to 66% for Newark EMA Ryan White Part A/F clients.

Table 6: Baseline CVL/VL Suppression for CY 2011 and FY 2011 for In+Care and HRSA HAB Measures

Measure	In+Care		HRSA HAB	
	CY 2011	FY 2011	CY 2011	FY 2011
PLWHA in Part A/F medical care			3,986	3,334
Numerator (VL <200)	2,448	2,271	2,133	1,983
Denominator	3,943	3,609	3,303	3,003
% Medical Care Clients in Measure			83%	90%
% VL Suppression	62%	63%	65%	66%

National VL Suppression Goals, Targets, Benchmarks

The question raised by the VL Suppression data is, “**How are we (Newark EMA) doing?**” Can we compare NEMA performance to national benchmarks, goals and targets? The answer is, yes we can, but benchmarks exist only for HRSA HAB core clinical performance measures.

In+Care. No national goals/targets/benchmarks have been established for “In+Care” Viral Load Suppression. The “In+Care” campaign is designed to encourage measurement and reporting of the VL data, and as such is an initial data collection project.

HRSA HAB Core Clinical Performance Measures. In contrast, the HRSA HAB indicators as measured by the National HIV QUAL data show a range of 89.4% as the most recent median goal/target/benchmark, with 94.2% achieved by the Top 25% of providers and 100% achieved by the Top 10% of providers. These measures are described more fully in the HRSA HAB Core Clinical Performance Measure of Viral Load Suppression in **Appendix D**.

The goal/target/benchmark for VL Suppression for the Newark EMA should be 89.4%.

Table 7: HRSA HAB Viral Load Suppression – National Goals/Targets/Benchmarks

NATIONAL HIV QUAL DATA (1)						
	2003	2004	2005	2006	2007	2009
Top 10%	100%	100%	100%	100%	98.9%	100%
Top 25%	97.1%	97.0%	95.7%	95.7%	95.5%	94.2%
Median*	89.7%	90.9%	89.6%	91.6%	90.3%	89.4%

*from HAB data base.

(1) HIVQUAL-US Indicator: Percent of patients who received a viral load test during each six-month semester
<http://hivqualus.org/index.cfm/22/9842> and <https://www.ehivqual.org/>

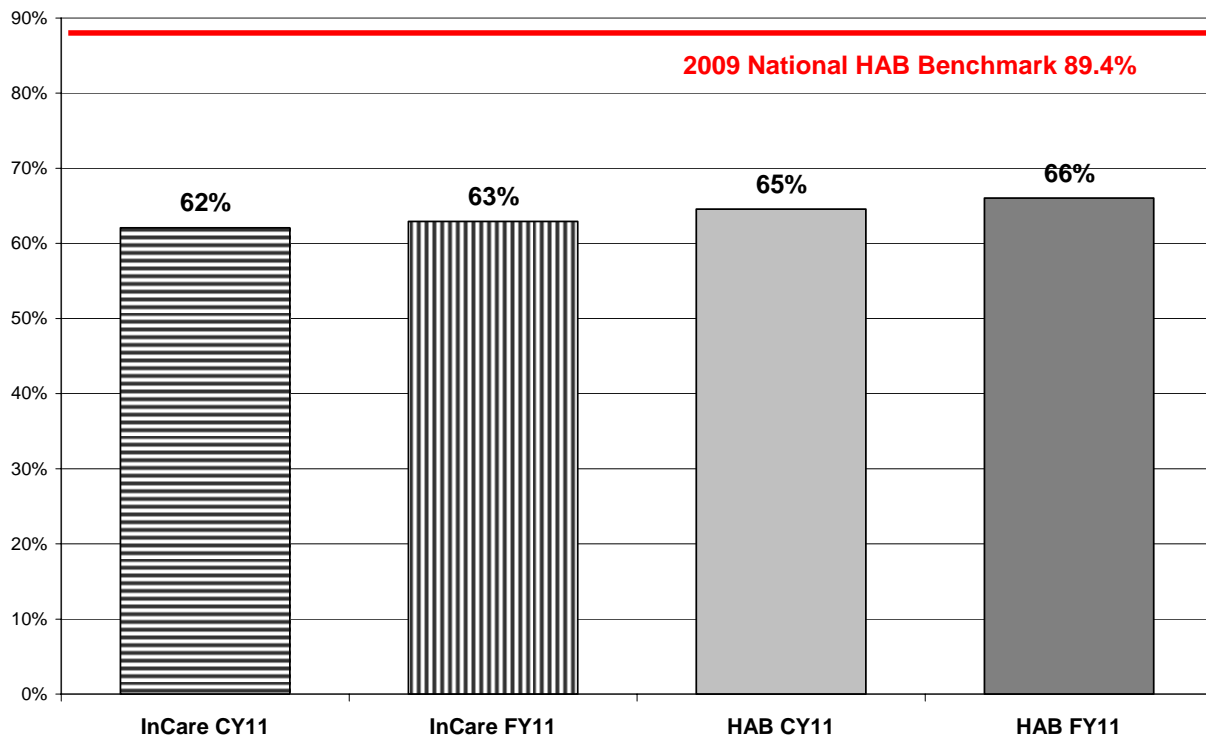
Based on this goal/target/benchmark, the Newark EMA at 66% has a way to go – and should improve VL suppression by 23 percentage points to reach the median HAB VL Suppression benchmark.

CVL by Demographics

Total

The figure below compares the Newark EMA VL suppression performance for all indicators as of CY11 and FY11.

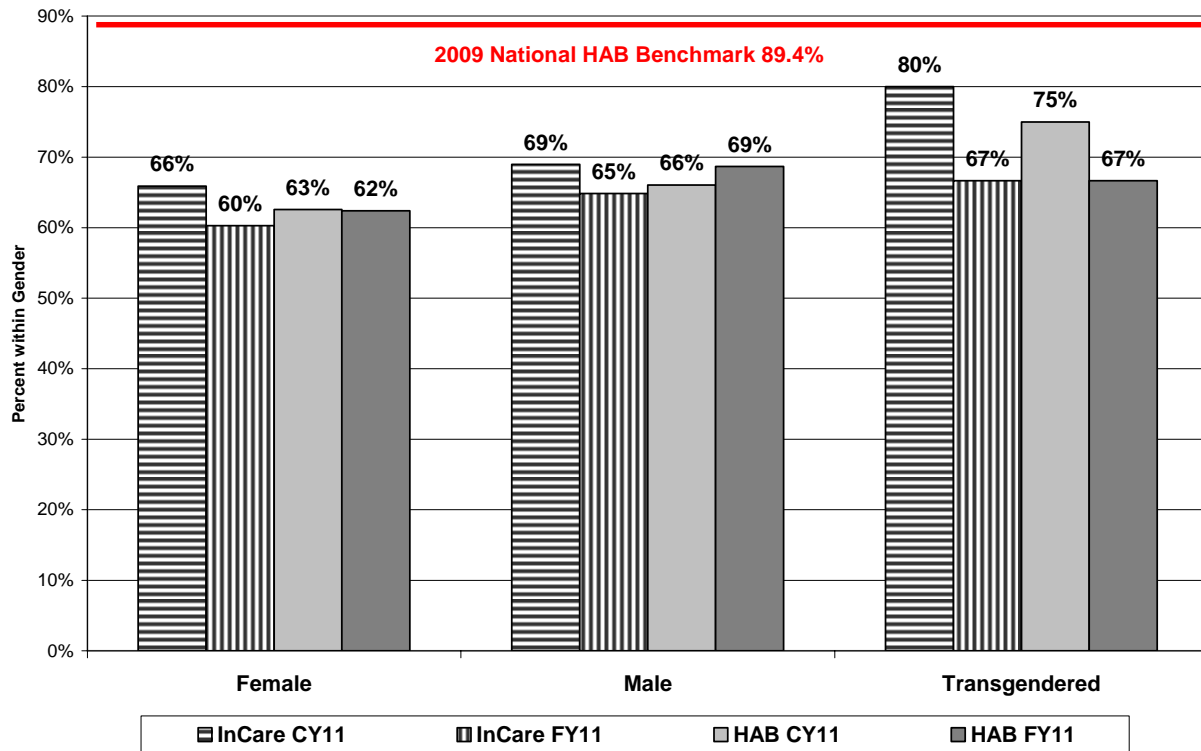
Figure 1: Viral Load Suppression for Newark EMA – InCare CY11 FY11 and HAB CY11 FY11



Gender

A slightly higher percentage of males had viral load <200 than females in all measures. In general, transgendered PLWHA had the highest percent of VL under 200. The higher percent of males is counterintuitive, because we tend to believe that women take care of their health more than men.

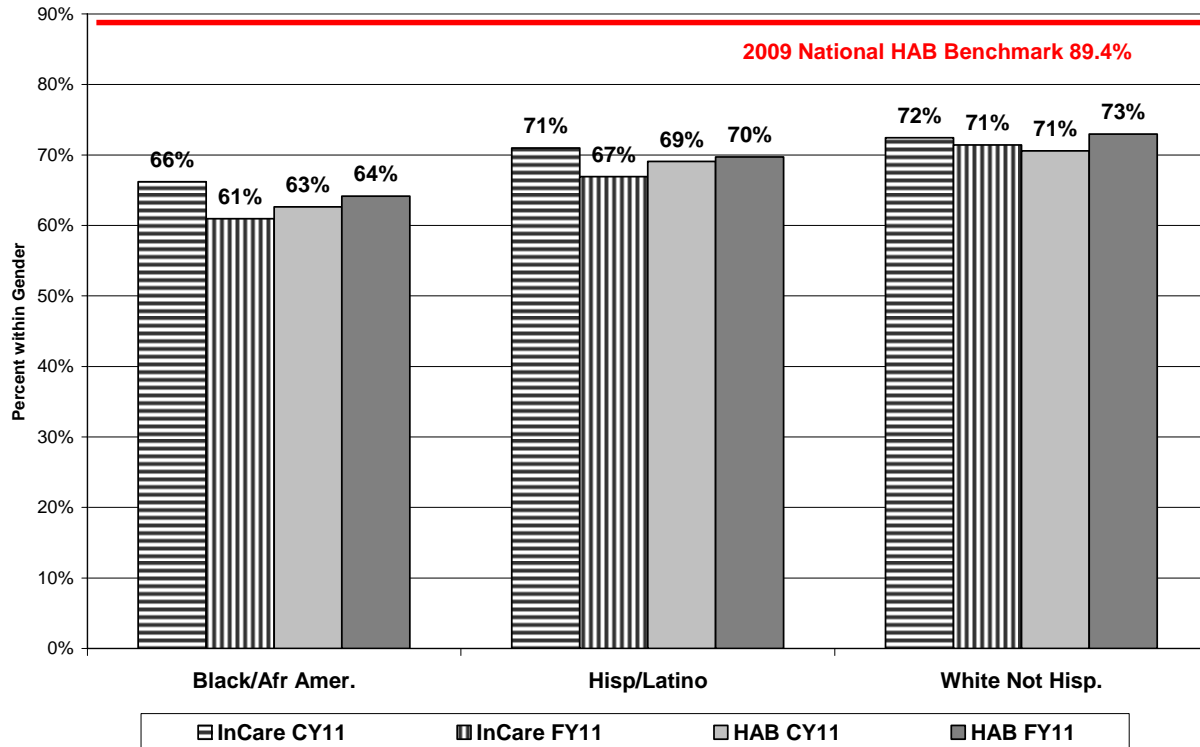
Figure 2: Viral Load Suppression for Newark EMA by Gender – InCare CY11 FY11 and HAB CY11 FY11



Race/Ethnicity

African Americans (Not Hispanic) had the lowest percent of Viral Load <200 at 61% to 66%. Rates were higher for Hispanic/Latino PLWHA at two thirds (67%) to 71%. Rates for White (Not Hispanic) PLWHA were slightly higher at 71%-73%.

Figure 3: Viral Load Suppression for Newark EMA by Race/Ethnicity – InCare CY11 FY11 and HAB CY11 FY11

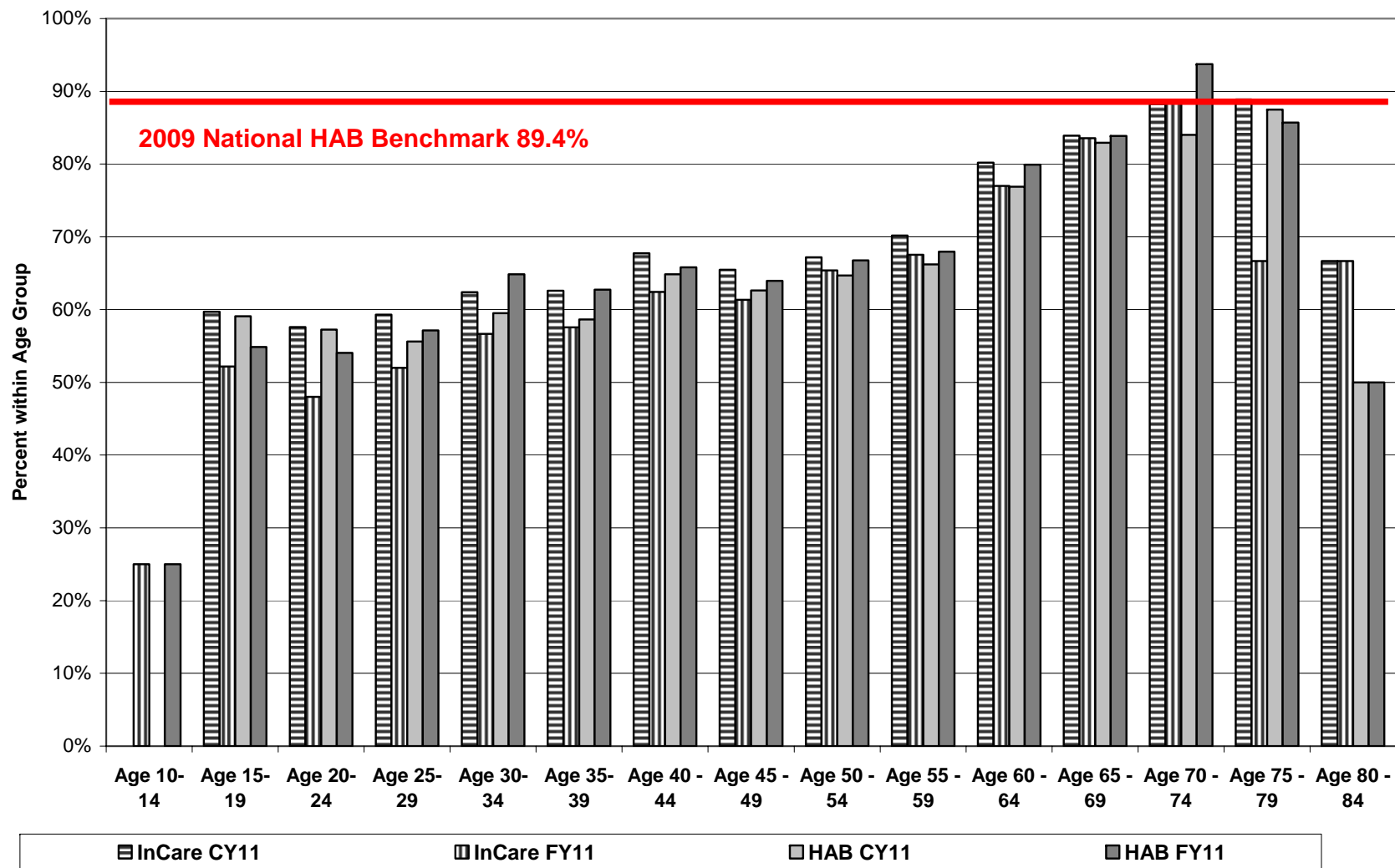


Age

As PLWHA age, an increasing percent have Viral Load <200. Over two thirds of PLWHA age 50 and older have VL <200. In contrast, a lower percentage of the younger population of VL <200. See the figure below. This trend can be due to noncompliance or other reasons, including those that are medically related.

In analyzing age, the reader should examine trends of all data. Also, at the very young and older ages, the denominator may be so small that the percentage is very low. (E.g., for Age 80-84 HAB CY11 FY11 the denominator is 2 PLWHA and one PLWHA had VL<200 resulting in 50%.)

Figure 4: Viral Load Suppression for Newark EMA by Age – InCare CY11 FY11 and HAB CY11 FY11



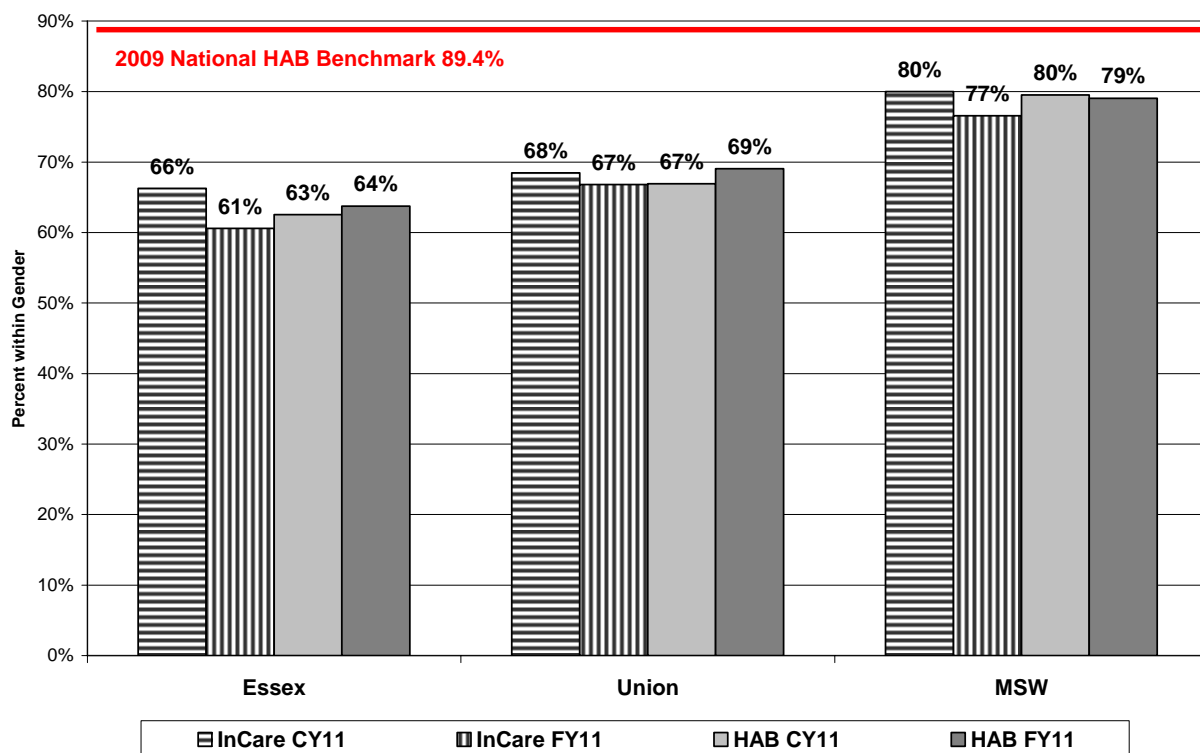
Geography

This section presents data by county/region of PLWHA residence as recorded on CHAMP.

Newark EMA

The Morris, Sussex, Warren (MSW) county region has the highest percent of PLWHA with suppressed viral load. Union County is lower and Essex County has the lowest percentage. Since Essex accounts for the majority (70%) of the PLWHA included in this indicator, it puts downward pressure on the EMA totals during all time periods.

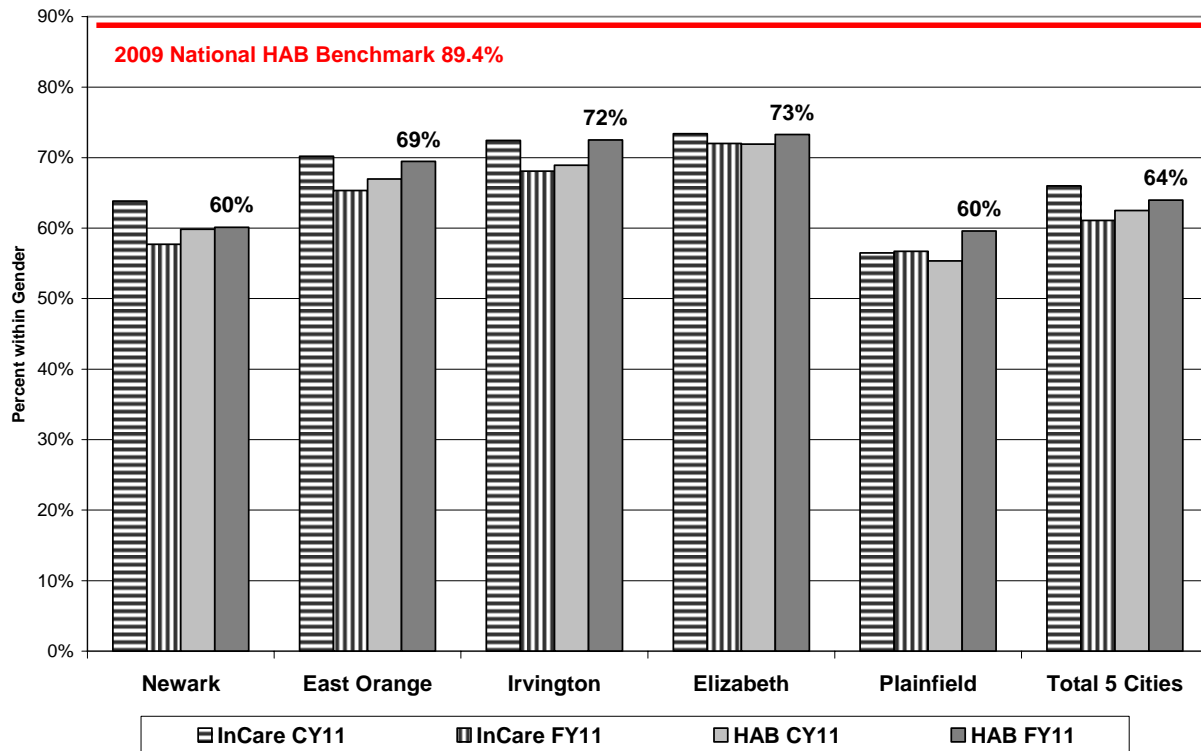
Figure 5: Viral Load Suppression for Newark EMA by County/Region – InCare CY11 FY11 and HAB CY11 FY11



5 Largest Cities

The EMA's 5 largest cities account for 74% of the PLWHA included in the CVL measurement. Newark by itself accounts for nearly half (45%) of the CVL PLWHA. For the 5 cities as a group, the VL <200 is approximately two thirds of PLWHA. There are differences between the cities. PLWHA in Elizabeth have the highest percent with VL <200 followed by Irvington and East Orange. Plainfield has the lowest percent of PLWHA with VL <200 followed by Newark.

Figure 6: Viral Load Suppression in the EMA’s 5 Largest Cities – InCare CY11 FY11 and HAB CY11 FY11



3.3 Conclusions and Recommendations

- By all measures, viral load suppression percentages are well below the National HIV QUAL goal/benchmark/targets. Achieving this target should be a top priority of Ryan White medical care in the Newark EMA.
- The following populations have lower rates of viral load suppression. Part A/F providers should target these populations to improve their viral load suppression percentages.
 - Women
 - Black/African American PLWHA
 - PLWHA under age 60
 - PLWHA residing in Essex County, Union County, Plainfield, Newark