

**Newark EMA
HIV Health Services Planning Council**



**NEEDS ASSESSMENT
UPDATE 2023**

September 2023

This page left blank.

NEEDS ASSESSMENT UPDATE – 2023

TABLE OF CONTENTS

INTRODUCTION	i
A. Legislative Background - Planning Council Duties.....	i
B. HAB Expectations.....	ii
PURPOSE, RESEARCH QUESTIONS AND METHODOLOGY	iii
Purpose	iii
Research Question and Methodology.....	iii
NEEDS ASSESSMENT - UPDATE 2023	1
INDIVIDUALS NEWLY-DIAGNOSED WITH HIV NOT LINKED TO HIV MEDICAL CARE WITHIN 1 MONTH OF	
DIAGNOSIS - 2022	1
1.1 Purpose of Needs Assessment – Update 2023	1
1.2 Background and Importance of Linkage to HIV Medical Care following HIV Diagnosis	1
1.3 Population Studied for Needs Assessment Update 2023	2
1.3.1 Demographics of the Newly Diagnosed Not Linked to Care within 30 Days of Diagnosis	2
SURVEY FINDINGS	4
1.4 Time Between HIV Diagnosis and First Medical Visit	4
Question #2: Date of HIV Diagnosis.....	4
1.5 Location of HIV Diagnosis	5
Question #3: Was the Client Diagnosed in Your Agency? If not, at what agency/where?	5
1.6 Activities from Diagnosis to Receipt of Medical Care	8
Question #4: Describe the activities and process from date of diagnosis to receipt of medical care by this client at your agency	8
1.7 Factors Delaying Medical Care following Diagnosis at Your Agency	14
Question #5: If the client was diagnosed at your agency, what was/were the factor(s) for the delay in receiving a first medical visit within 30 days of diagnosis?.....	14
1.8 Issues Involved in Linkage to Care Following HIV Diagnosis – Systems/Agency/Client	16
Question #6: What types of issues were involved in linkage to care following HIV diagnosis for this client – or for all clients not linked to care within 30 days?	16
1.9 Access to HIV Medical Care Following HIV Diagnosis	17
Question #7: Please provide the following information about your clinic.	17
1.10 Recommendations for Improvements in Linkage to Care	23
Question #8: What recommendations do you have to improve linkage to care within 30 days of HIV diagnosis including how the EMA can improve linkage to care?	23
1.11 Telehealth as Option for Linkage to Care	25
Question #9: Would a telehealth medical visit – contact with a provider by video – following diagnosis help improve linkage to care within 30 days?	25
1.12 Other Comments or Recommendations	25
Question #10: Please insert any other comments or recommendations.	25
CONCLUSIONS AND RECOMMENDATIONS	26

LIST OF TABLES

Table 1: Demographic Characteristics of Newly-Diagnosed PLWH not Linked to Care within 30 Days of Diagnosis3
Table 2: Clients Not Linked within 30 Days by Location of HIV Diagnosis7
Table 3: Clients Diagnosed Outside of New Jersey by Location and Not Linked within 30 Days.....7
Table 4: Case-Specific Activities from Date of Diagnosis to Receipt of Medical Care – by Location of HIV Diagnosis8
Table 5: Reasons Clients Diagnosed in Agency were Not Linked within 30 Days (Summary)14
Table 6: Reasons Clients Diagnosed in Agency were Not Linked within 30 Days (Detailed)15
Table 7: List of Agencies and Their Hours of Operation (as of May 2023)18
Table 8: Types of Agencies by Extended Hours of Operation (as of May 2023).....19
Table 9: List of Agencies by Extended Hours of Operation (as of May 2023).....19
Table 10: Number of Days to Your Clinic’s First Available Medical Appointment from Today - by Type of Agency20
Table 11: Number of Days from HIV Diagnosis to Medical Appointment by Type of Agency21
Table 12: Sources of Documentation of ID (Hospital Based Clinics).....22
Table 13: Use of Telehealth to Improve Linkage to Care by Type of Provider Agency25
Table 14: Summary of Challenges to Linkage to Care within 30 Days of Diagnosis and Recommendations26
Table 15: Conclusions and Recommendations for Improving Linkage to Care within 30 Days of HIV Diagnosis27

LIST OF FIGURES

Figure 1: Linkage to Care More than 30 Days – CY 20225

APPENDICES

- APPENDIX A: Federal Linkage to Care Documentation**
- APPENDIX B: Agency Survey Tool**
- APPENDIX C: NJDOH Dear Colleague Letter – Universal HIV Testing**
- APPENDIX D: NJDOH Charity Care Program and Eligibility**

INTRODUCTION

The information below was extracted from the Ryan White Part A Manual published by HRSA/HAB in 2013 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).

A. Legislative Background - Planning Council Duties

Completion of the needs assessment is a significant part of the **eight duties of the planning council**, as shown in federal law, most recently updated by the Ryan White Treatment Extension Act. Five sections - (4)(A), (B), (F), (G) and (H) - speak directly to the needs assessment. The purpose of the needs assessment is to assist the planning council in meeting Section (4)(C) – establish service priorities for the allocation of funds within the eligible area – and (4)(D) - develop a comprehensive plan for the organization and delivery of health and support services.

42 U.S. Code § 300ff–12 - Administration and planning council

(b) HIV health services planning council

(4) Duties: The planning council established or designated under paragraph (1) shall—

(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;

(C) establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant based on the—

- (i) size and demographics of the population of individuals with HIV/AIDS (as determined under subparagraph (A)) and the needs of such population (as determined under subparagraph (B));
- (Additional language not included)**

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

- 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."

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

PURPOSE, RESEARCH QUESTIONS AND METHODOLOGY

Purpose

The purpose of the Needs Assessment - Update 2023 is to determine needs of People Living with HIV (PLWH) particularly as related to the goals of the National HIV/AIDS Strategy (NHAS) 2021-2025 and the Integrated HIV Prevention and Care Plan 2022-2026 (IHP 22). Specifically, these goals are by providing access to care for HIV, to improve HIV-related outcomes for persons with HIV and to reduce HIV-related disparities and health inequities.

This assessment focuses on individuals newly diagnosed with HIV and ensuring their access to HIV medical care immediately/as soon as possible after diagnosis. Access to HIV medical care will improve their health, reduce risk of transmission of HIV, and hence move toward ending the HIV epidemic. Results will improve the Newark EMA's progress toward achieving the goals of the IHP 22 and Ending the HIV Epidemic (EHE) in Essex County.

Research Question and Methodology

Research Question:

- What are the reasons that individuals newly diagnosed for HIV who are served by the Newark EMA Ryan White HIV/AIDS Program (RWHAP) are not linked to HIV medical care within one month of diagnosis – which is a goal of the National HIV/AIDS Strategy (NHAS) 2021-2025? The baseline measure is Calendar Year (CY 2022) – those diagnosed in 2022 but not linked to HIV medical care within one month of diagnosis.
 - Where are these individuals diagnosed with HIV (which may impact their linkage to care)?
 - What are the reasons for delayed linkage to care – agency-related, client related, systems-related?
 - Would use of telehealth improve linkage to care within one month of diagnosis?
 - What recommendations do you have for improving linkage to HIV medical care within one month of HIV diagnosis?

Approach:

The scope of research will include:

- (1) Using the CHAMP data base, identifying by client ID the number of RWHAP clients diagnosed with HIV in 2022 who were not linked to care within one month of diagnosis.
- (2) Identifying the RWHAP-funded agencies who served these newly-diagnosed clients. This list would be used for the survey.
- (3) Developing a survey tool to obtain information for each client and agency regarding linkage to care – where the client was tested and received the HIV diagnosis, date of HIV diagnosis, date of first medical visit, and steps taken by the agency to link the individual

to HIV medical care following diagnosis. Additional information included the reasons for non-linkage, e.g., due to the agency, client or systems issues, access measured by hours of operation and extended hours, specific questions for hospital-based clinics regarding documentation and barriers to care, and recommendations for the RWU and EMA to improve linkage to care.

- (4) Administering the survey to agencies and collecting responses via survey monkey or hard copy.
- (5) Tabulating results,
- (6) Reporting findings,
- (7) Identifying gaps within agencies as well as their overall healthcare systems as applicable, and gaps in linkage which may be outside of the control of the agency, and
- (8) Identifying the potential percent of clients whose linkage to care may be outside of the control of the agencies and EMA, and
- (9) Making recommendations for improving linkage to HIV medical care for newly diagnosed individuals and hence medical outcomes.

NEEDS ASSESSMENT - UPDATE 2023

INDIVIDUALS NEWLY-DIAGNOSED WITH HIV NOT LINKED TO HIV MEDICAL CARE WITHIN 1 MONTH OF DIAGNOSIS - 2022

1.1 Purpose of Needs Assessment – Update 2023

The purpose of the Needs Assessment – Update 2023 is to better understand the characteristics of newly diagnosed individuals who have not been connected to HIV medical care within one month of diagnosis, and to identify which circumstances are within control of the RW-funded agencies through corrective action and which are not. Thus, the findings will estimate the extent the EMA can achieve the NHAS 22-25 goal of 95% linkage to care within one month of HIV diagnosis - through agency action, and those outside of agency influence – because of client non-compliance or diagnosis outside of New Jersey and associated delay in accessing HIV medical care in the EMA.

1.2 Background and Importance of Linkage to HIV Medical Care following HIV Diagnosis

Background:

Ensuring that individuals newly-diagnosed with HIV have access to HIV medical care to treat their HIV disease and improve their health outcomes has been a priority of the federal government since 2013, and even earlier. This is reflected in the following areas.

HHS HIV Performance Measures. Linkage to routine HIV medical care is a “universal standard” covering all individuals diagnosed with HIV regardless of age. Initially in 2013, the measure was linkage to care within 90 days of diagnosis. In March 2017, the time period was reduced to linkage within 30 days of diagnosis. Linkage to care within one month of diagnosis was reaffirmed in the HIV Performance Measures issued in 2019. **(See Appendix A.)**

National HIV/AIDS Strategy (NHAS). The NHAS 2016-2020 and NHAS 2021-2025 have included Linkage to Care within month of HIV diagnosis as their Indicators. For NHAS 2016-2020 the goal was 85% linkage within one month of HIV diagnosis. NHAS 2021-2025 raised this target to 95% linkage within one month of HIV diagnosis.

Ryan White Services Report (RSR). All agencies receiving RWHAP for Outpatient/Ambulatory Health Services (OAHS) – HIV medical care – are required to submit directly to HRSA/HAB a RSR report. This report includes two measures related to Linkage to Care within one month of diagnosis:

- (1) Positive HIV Test Date
- (2) Outpatient/ambulatory health service link date (required for all clients with new HIV diagnosis in the reporting period who received Outpatient/Ambulatory Health services)

For the Newark EMA, these data are extracted from the CHAMP client level data (CLD) system based on dates entered by agencies. CHAMP provides an extract file for every RWHAP funded agency. Each agency reviews and verifies its data. Any corrections are made by the agency in consultation with Ryan White Unit (RWU)/Recipient and CHAMP vendor. Once the changes are approved and made, **THE AGENCY SUBMITS THE FINAL RSR DATA** (not CHAMP or RWU/Recipient). Thus, **it is essential for newly diagnosed individuals that both the dates of HIV diagnosis and first medical visit are entered correctly in CHAMP.**

Integrated HIV Prevention and Care Plan 2022-2026 (IHP 22). The IHP 22 has required states and local jurisdictions to develop a plan for addressing the HIV epidemic in 2022-2026 using four pillars of the Ending the HIV Epidemic (EHE) - #1 Diagnose, #2 Treat, #3 Prevent and # Respond. The Newark EMA's IHP 22 submitted December 9, 2022 and approved by HRSA HAB and CDC includes Linkage to Care within one month **to 95% by 2026.** Bimonthly CHAMP Performance Reports measuring the EMA's progress on achieving this indicator are distributed to all entities - Recipient, EMA CQM Committee, EHE Coordinator, the Planning Council and all committees –and is posted on the Planning Council website.

1.3 Population Studied for Needs Assessment Update 2023

“Newly diagnosed” are those individuals diagnosed with HIV disease for the first time (previously HIV-negative) within the past 12 months when they presented to the Ryan White HIV/AIDS Program (RWHAP) for treatment.

In 2022, a total of 187 individuals who were newly-diagnosed presented to RWHAP agencies as recorded in CHAMP. Of these, 132 or 70.6% were linked to HIV medical care within 30 days and 55 or 29.4% were not. However, there were several data sources with more clients not linked. These were added in.

For purposes of this Needs Assessment Update 2023, a total of **67 newly diagnosed RWHAP clients were not linked care within 30 days of HIV diagnosis.** Because some of these clients were served by more than one agency, a total of **77 responses** were received from **17 agencies.**

1.3.1 Demographics of the Newly Diagnosed Not Linked to Care within 30 Days of Diagnosis

The table below shows the demographic characteristics of those newly diagnosed with HIV but not linked to care within 30 days of diagnosis. The characteristics are similar to those newly diagnosed linked to care within 30 days and the total newly diagnosed in 2021. A few key points:

- 30% of non-linked were Hispanic/Latino, slightly higher than total PLWH of 25% in 2022 but less than the 37% newly diagnosed PLWH in 2021.
- 76% were male, similar to newly diagnosed PLWH in 2021.
- Nearly 70% were age 25-34 and 35-44, similar to those newly diagnosed PLWH in 2021.

- By health insurance, while a high percent were Medicaid recipients or uninsured – 43% and 37% - a surprising 16% had private insurance.
- By county of residence, the non-linked reflected the distribution of PLWH in 2022. Two thirds (67%) resided in the EMA’s 5 largest cities, with 34% in Newark – same as the epidemic.
- By housing status, half (46%) lived in Stable Permanent Housing including 43% in their own rented or owned apartment/house, and 54% lived in Temporary Housing with 52% doubling up or staying with family/friends.
- By income, nearly all 85% had income at/below 100% poverty, 3% 100-193% FPL, and 10% had incomes 139%-400% FPL.

The conclusion is that non-linkage to care within 30 days of HIV diagnosis is not related to standard demographic characteristics, but other factors.

Table 1: Demographic Characteristics of Newly-Diagnosed PLWH not Linked to Care within 30 Days of Diagnosis

Demographic/Geographic Characteristic		# Clients	% Distn
Total Not Linked to Care within 30 Day		67	100.0%
Race/Ethnicity	Black Not Hispanic	39	58.2%
	Hispanic/Latino	20	29.9%
	White Not Hispanic	4	6.0%
	Other	4	6.0%
Gender	Male	51	76.1%
	Female	14	20.9%
	Transgender (Total)	2	3.0%
Age Category	Age 0-12	1	1.5%
	Age 13-18	2	3.0%
	Age 19-24	6	9.0%
	Age 25-34	29	43.3%
	Age 35-44	17	25.4%
	Age 45-54	6	9.0%
	Age 55-64	4	6.0%
	Age 65+	2	3.0%
	Age Unknown	0	0.0%
Health Insurance	Medicaid	29	43.3%
	Medicare	2	3.0%
	Private Insurance	11	16.4%
	Uninsured	25	37.3%
	Other	0	0.0%
County of Residence	Essex	43	64.2%
	Union	14	20.9%
	MSW	3	4.5%
	Outside NEMA	7	10.4%

Demographic/Geographic Characteristic		# Clients	% Distn
Total Not Linked to Care within 30 Day		67	100.0%
5 Cities	Newark	23	34.3%
	East Orange	3	4.5%
	Irvington	11	16.4%
	Elizabeth	7	10.4%
	Plainfield	1	1.5%
	Total (5 Cities)	45	67.2%
Housing Status	Stable Permanent Housing	31	46.3%
	<i>House/Apartment - Rent or Own Unsubsidized</i>	29	43.3%
	<i>House/Apartment - Subsidized Non HOPWA</i>	2	3.0%
	Temporary Housing	36	53.7%
	<i>House/Apartment - Doubling up, staying with family/friends</i>	35	52.2%
	<i>Institution (Hospital, Psych.)</i>	1	1.5%
	Unstable Housing	0	0.0%
Total	67	100.0%	
Poverty Level	</= 100% FPL	57	85.1%
	101%-138% FPL	2	3.0%
	139%-400% FPL	7	10.4%
	401%-500% FPL	1	1.5%

SURVEY FINDINGS

1.4 Time Between HIV Diagnosis and First Medical Visit

Question #2: Date of HIV Diagnosis

The first question asked respondents for the Date of HIV Diagnosis. Responses were compared to the Date of HIV Diagnosis that was recorded in CHAMP by the agency and the Date of First Medical Visit.

A total of four (4) or 6% of the 67 clients reported a HIV Diagnosis Date different than the HIV Diagnosis Date recorded in CHAMP. This is a data entry issue by agencies.

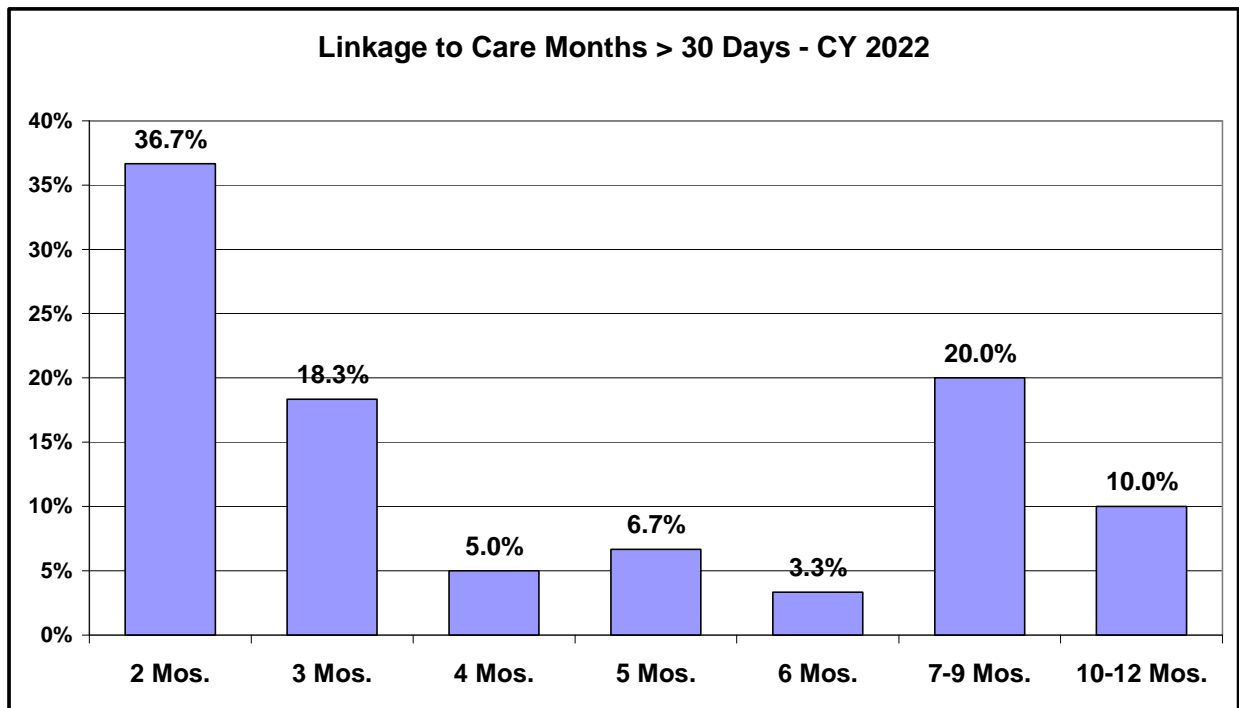
Question #2 Follow up: Definition of Linkage to Care Following HIV Diagnosis

One agency said that a client (1.5% of total) had been diagnosed with HIV and **seen by a provider who works with HIV and that this qualifies as linkage to care.** Unfortunately, this is **not the definition of linkage to care unless the medical visit with the provider not funded by RW is entered into CHAMP (client level data system).**

Time between HIV Diagnosis to Medical Visit

Of the 63 clients with correct dates of HIV diagnosis, the **median time between HIV Diagnosis and Medical Visit was 61-90 days**. (Median is the midpoint – 50% above and 50% below the midpoint.) The **average time between diagnosis and first medical visit was 4.56 months** but this is skewed by the high number of linkages occurring 6 or more months.

Figure 1: Linkage to Care More than 30 Days – CY 2022



1.5 Location of HIV Diagnosis

Question #3: Was the Client Diagnosed in Your Agency? If not, at what agency/where?

Tested within the agency/health care system. A total of eight (8) (12%) clients not linked to care within 30 days were diagnosed at the agency providing RWHAP medical care. Another 12 (18%) were diagnosed within the health care system of the RWHAP medical provider entity. This is a **total of 20 or (30%)** of clients not linked to care who were diagnosed within the agencies and health systems funded by RWHAP.

Tested within the EMA. An additional **12 or 18% of clients were tested elsewhere in the Newark EMA.** Three (3) or 4.5% were tested in a Counseling and Testing (CT) agency and another nine (9) (14%) were tested at a hospital located in the EMA.

Tested within the EMA but outside “traditional” HIV venues. Six (6) or 9% of clients were tested in these circumstances – one by HIV Home Test kit and five (5) or 8% by non-RWHAP providers including private Primary Care Providers (PCPs) and Urgent Care centers.

Testing location unknown. A total of 12 or 18% of newly-diagnosed clients reported that the location of their HIV test was unknown. **This may be an issue of documentation which needs to be addressed.**

-
- The above circumstances for the **44 or 66% can be considered within the control of the agencies and RWHAP system of care.** Hopefully they can improve internal linkage to care with effort and creative approaches and solutions.
-

Tested within New Jersey outside of the EMA. Three (3) individuals (4.5%) were diagnosed outside of the EMA but in New Jersey – one (1) was incarcerated and diagnosed in prison, (2) one in a NJ state institution, and (3) the third diagnosed in a county outside of the EMA.

-
- These individuals may be assisted or linked to care in coordination with any regional or statewide initiatives promoted by the **NJ Universal HIV Testing** initiative.
-

Tested outside of New Jersey. One in five – 14 or 21% - were diagnosed outside of New Jersey including seven (10.5%) diagnosed in another state and seven (10.4%) a county outside of the United States.

-
- These **14 or 21% can be considered outside of the control of the agencies within the RWHAP system of care.** The best agencies can do is to get them into care ASAP after they present to the agency, and provide support to help them achieve viral load suppression.
-

The tables below provide the detailed information on testing location.

Table 2: Clients Not Linked within 30 Days by Location of HIV Diagnosis

Location of HIV Diagnosis	#	% Distn	Totals	
<u>Controllable</u>			44	65.7%
In Our Agency	8	11.9%		
Within Our Healthcare System	12	17.9%		
In EMA - CT Agency	3	4.5%		
In EMA – Hospital	9	14.4%		
Unknown/Not Documented	12	17.9%		
<u>Needs Work on RW Resources</u>			6	9.0%
In EMA - Non RW - Private PCP/Urgent Care	5	7.5%		
Home Test Kit	1	1.5%		
<u>NJ Universal Testing Initiative</u>			3	4.5%
Incarceration in NJ	1	1.5%		
Outside EMA – NJ	2	3.0%		
<u>Not Controllable</u>			14	20.9%
Outside EMA – NYC	3	4.5%		
Outside EMA - Other State	4	6.0%		
Outside EMA - Other Country	7	10.4%		
Total	67	100.0%		

SUMMARY OF TESTING VS LINKAGE TO CARE

Controllable by RW-Funded Agencies	44	65.7%
Needs Work w/n EMA & w/ NJDOH	9	13.4%
Not Controllable (Outside NJ)	14	20.9%

Table 3: Clients Diagnosed Outside of New Jersey by Location and Not Linked within 30 Days

DIAGNOSES OUTSIDE OF NJ	By Location		Subtotal	
	#	%	#	%
<i>New York City</i>	3	4.5%	3	4.5%
<i>Outside EMA - Other State</i>			4	6.0%
Arizona	2	3.0%		
Florida	1	1.5%		
Tennessee	1	1.5%		
<i>Outside EMA - Other Country</i>			7	10.4%
Brazil	1	1.5%		
Chile	1	1.5%		
Guatemala	2	3.0%		
Ecuador	2	3.0%		
India	1	1.5%		
Total	13	20.9%		

1.6 Activities from Diagnosis to Receipt of Medical Care

Question #4: Describe the activities and process from date of diagnosis to receipt of medical care by this client at your agency (from client chart/case record).

The activities and processes from diagnosis to treatment should follow specific agency protocols and client circumstances. The table below is organized by location of HIV test, so the reader can follow the patient flow from this point to the medical visit. The cases/clients are listed in order of the CHAMP Client ID (not shown) so the RWU can follow.

(NOTE: A corresponding chart with the client ID and agency will be used by RWU for follow up by EMA Clinical Quality Management (CQM) and the Early Intervention and Retention Collaboratives (EIRCs).)

Table 4: Case-Specific Activities from Date of Diagnosis to Receipt of Medical Care – by Location of HIV Diagnosis

Note: Abbreviations are at the end of this table.

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
OUR AGENCY (8)		
1	Our agency	Client requested an HIV test on 4/29/2022. Test came back positive on 5/02/2022. Client saw ID provider on 6/8/2022.
2	Our agency	Patient came in for rapid HIV test for possible PrEP intake. Immediately following positive test appointment was scheduled with ID provider on 2/17/22 to discuss diagnosis. Patient was scheduled to meet with Linkage Coordinator on 2/18/22 to complete Ryan White enrollment paperwork and appropriate screenings. Intensive counseling and support was given as well as laboratory blood work was ordered.
3	Our agency	Patient came in for a CPE on 2/23/2022. LAB ordered 2/23/2022 and collected on 3/2/2022. Results received 3/5/2022 and was prescribed Ergocalciferol 1.25 mg. Comment: HIV diagnosis date was 12/1/21 in CHAMP.
4	Our agency	Patient came in for a sick visit on 6/15/22. HIV test ordered 6/15/2022. Results 7/7/2022. Patient saw ID provider on 7/19/2022 and prescribed Delstrigo 100/300/300 1 daily.
5	Our agency	Client was seen at Counseling and Testing Center at our agency, completed lab work on June 20, 2022. Upon testing positive for HIV, client had follow up appointments at PHC on July 1, 2022; however the patient was a no show. They had their first appointment on July 25, 2022.
6	Our agency	Patient's wife tested positive in OB/GYN so he came in and was tested and seen the same day. (Agency: Did not receive late care. HIV diagnosis date incorrectly entered.)
7	Our agency	Patient came in for gender affirming care on 12/6/2022. She had her blood test. Results returned 12/7/2022. Staff was unable to reach her to give her the results for several months. 7 attempts to contact her are in the medical record.
8	Our agency	Patient initially seen for TB. HIV test done at that visit. Several attempts made to schedule appointments. Patient missed initial appointment on 11/16/22 and came in and saw provider 11/18/22. Comment: HIV diagnosis date was 10/17/22 in CHAMP.

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
IN OUR HEALTH SYSTEM (12)		
9	In our Health System (Internal Medicine)	Client saw internal medicine for STD screen 5/27/2022. Client had follow up 5/31/2022, learned of positive HIV diagnosis. Client completed lab work and initial appointment at PHC on 6/01/2022.
10	In our Health System (Lattimore TB Clinic)	Patient was seen at Lattimore (TB) Clinic by a physician who also works in HIV until her other issue stabilized and she was transferred to FXB. FXB had been in contact with other provider since the time of diagnosis. Other provider began ARVs. Patient transferred to FXB 10/3/2022. (Agency: Date in CHAMP for first HIV test was incorrect. It was corrected today 5/17/2023.)
11	In our Health System (NBIMC Women's Health Center)	Client was diagnosed 02/23/2022 during prenatal care and was referred to Dr. Taylor. Client did not follow up with appointments or meds. No ART! Client delivered via C-Section at NBIMC on 06/29/2022 and was referred to this agency 07/11/2022. Client missed several scheduled appointment due to barriers. Initial visit 08/04/2022. ART Descovy started.
12	In our Health System (Gynecology Clinic)	Client tested positive for HIV at a GYN clinic in June 2022 (6/23/22). Client had first appointment at PHC on July 26, 2022. Therefore the client was linked to care within the appropriate time. Comment: 7/26/22 is more than 30 days from 6/23/22.
13	In our Health System (NBIMC Emergency Department)	Client was seen in Emergency Department for ESRD care and was initially diagnosed 05/16/2022. HAART Biktarvy started. Client was referred to ID clinic and initial appointment was 05/19/2022. Comment: HIV diagnosis date was 3/11/22 in CHAMP.
14	In our Health System (Family Health Center)	Client was diagnosed 11/15/21 at PCP office during primary care visit and was referred to Infectious Disease clinic. Client failed to return due to some existing barriers and work schedule. Initial visit was 01/18/2022. ART Dovoto started 01/18/2022.
15	In our Health System (NBIMC Labor and Delivery)	Client was diagnosed 3/05/2022 during labor and c-section delivery. Client initial visit for medical care was 03/14/2022. ART started same day. Baby started AZT with pediatric ID. Comment: First medical visit date was 5/9/22 in CHAMP.
16	In our health system (NBIMC Inpatient)	Client was initially diagnosed 01/28/22 during hospital day admission and received ART Dovato. Client discontinued medication after discharge. Initial visit medical visit was 02/14/2022. ART Dovato restarted. Comment: HIV diagnosis date was 11/21/21 in CHAMP.
17	In our Health System (NBIMC Adult Health Center/Family Health Center)	Client initially diagnosed at PCP office 01/19/2022. Referred to ID clinic. Due to some barriers client initial visit was 02/15/2022 in which ART Bictegravir/Emtricitabine/Tenofovir was started. Comment: HIV diagnosis date was 1/2/22 in CHAMP.
18	In our Health System (NBIMC Inpatient)	Client was admitted 11/17/2021 and was diagnosed while inpatient. ART not clinically indicated during initial admission due to disseminated histoplasmosis and active HBV infection. Client was discharged 12/09/2021 initial medical appointment was 12/14/2021. Client missed appointment. Several phone calls were made to client to reschedule as well as home visits were done. Unable to locate client. Eventually was able to locate client weeks later. Initial visit 01/20/22 ART Biktarvy started same day.
19	In our Health System (TB Clinic)	Patient unaware of positive HIV diagnosis until he was seen in University Hospital Emergency Dept. and informed on 9/22/22. He then called and obtained an appointment at IDP for 10/19/22. Comment: HIV diagnosis date was 6/9/22 in CHAMP.

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
20	In our Health System (NBIMC Adult Health Center/Family Health Center)	Client was newly diagnosed on 08/08/2022 but also diagnosed with Latent TB. Client was immediately referred to the Lattimore Clinic for TB (Rutgers University) which resulted in a delay for HIV Care and Treatment. Client initial visit was 10/28/2022 in which ART started. Descovy, and anti TB medication.
ANOTHER AGENCY IN EMA (17)		
21	Another Agency in EMA (Rutgers/University Hospital)	Patient linked to NJCRI on 7/5/22 when discharged. Patient was seen by MCM on 7/5/22. Saw provider and began rapid start ART. Patient is presently returned in care at NJCRI. Next lab appointment on 6/7/23, next medical is 6/15/23. Comment: HIV diagnosis date was 6/2/22 in CHAMP.
22	Another agency in EMA (Private Care Provider - (ID Care Associates)	Client was referred to support services (Case Management and Behavioral Health) in March 2022. Intake was completed on 3/29/2022. The client did not receive diagnosis and is not in medical care at EDGE NJ. (Client linked to private care provider.) Comment: HIV diagnosis date was 2/1/22 and first medical visit 3/28/22 in CHAMP.
23	Another agency in EMA (Counseling & Testing)	8/24/2022 client had a CPE visit with Internal Medicine. 9/7/2022 client had a CPE visit with Infectious Disease. Client prescribed SYMTUZA 800/150/200 10 tabs 1 oral daily. Comment: HIV diagnosis date was 1/1/22 in CHAMP.
24	Another Agency in EMA (Rutgers/University Hospital)	Client was admitted to Rutgers University Hospital 12/20/21 with severe COVID and was diagnosed. ART started during admission 01/15/2022 (Descovy and Prozcobix). Client was referred to this agency 01/20/22 and initial visit was 02/01/2022.
25	Another agency in EMA (St. Barnabas)	IDP NP saw patient on 10/4/22 after a University Hospital ED hospital admission. Appointment scheduled and kept in IDP for 10/31/22. Comment: HIV diagnosis date was 5/15/22 in CHAMP.
26	Another agency in EMA (St Barnabas)	This is baby born to a woman with HIV infection. He was in the hospital as a newborn for 17 days and then followed by the Barnabas ID physician. He was transferred to FXB and seen at FXB on 2/23/2022. He had already been on ARV medications and the FXB team was in touch with the family and the previous physician during this time period. He received lab work 2/16/2022, between the hospital discharge and the first FXB appointment. Comment: HIV diagnosis date was 1/17/22 in CHAMP.
27	Another agency in EMA (Urgent Care)	Patient completed intake w/ MCM on 4/27/22. Appointment to see provider on 5/3/2022 but patient rescheduled for 6/12/2022. Patient saw provider 1st at NJCRI 6/12/22. Patient never returned for care until recently due to patient is on HOPP w/ NJCRI. Patient seen by MCM 5/3/23 to relink and complete labs. Patient seen for medical appt and follow up on 5/8/23. Comment: HIV diagnosis date was 1/1/22 in CHAMP.
28	Another agency in EMA (Primary Care Provider - PCP)	As per Case Management note, patient was seen by Primary Care Provider (outside of SMMC PHC) and was then referred to SMMC PHC likely upon diagnosis. Client's first PHC appointment was on May 13, 2022. Comment: HIV diagnosis date was 9/29/21 in CHAMP.
29	Another Agency in EMA (Counseling & Testing)	Registration. Nursing Assessment. MCM Intake. Screening With Mental Health Clinician. Charity Care Application. Comment: HIV diagnosis date was 11/21/22 and first medical visit 12/16/22 in CHAMP.
30	Another Agency in EMA (Urgent Care)	Client was newly diagnosed 5/03/2022 at an urgent care facility and was prescribed ART Biktarvy. Client initial appointment at this agency was 5/19/2022. ART plan was switched to Davato on 05/19/2022. Comment: HIV diagnosis date was 4/28/22 in CHAMP.
31	Another agency in EMA	Was initially seen and engaged in University Hospital ED by our PN on 3/4/22. An

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
	(Clara Maass during a hospital admission)	initial visit in IDP occurred 3/16/22. (Client also applied for the HOPP program in August 2022. Client was linked to care by the time he reached the HOPP program.) Comment: HIV diagnosis date was 9/1/21 in CHAMP.
32	Another agency in EMA (Appears to be Clara Maass Hospital)	Client was receiving outreach by RWJ Barnabas Health Family Practice. Had a cancelled appointment and walk-in to the IDP on 11/7/2022 to establish care. From date of diagnosis till walk-in at IDP, client self reported to go to the hospital and subacute rehab a few times and not sure of what diseases he has or what medications he is supposed to take. Comment: HIV diagnosis date was 6/15/22 in CHAMP.
33	Another agency in EMA (St Barnabas Medical Center)	Our medical provider saw client at St Barnabas Medical Center September 2022. Gave samples of Dovato that he began taking at discharge. Provider saw client for follow up appt at The Smith Center 10/12/22. Obtained labs at this appt. VL<20. Comment: HIV diagnosis date was 9/1/22 in CHAMP.
34	Another agency in EMA (Counseling & Testing)	Date of first medical visit 12/20/2022. Comment: HIV diagnosis date was 7/2/22 in CHAMP.
35	Another agency in EMA (St Barnabas Hospital)	Client was diagnosed at St. Barnabas in August 2022 and was referred to SMMC PHC. Client's first appointment at SMMC PHC was 10/12/2022
36	Another agency in EMA (Primary Care Physician – PCP)	Client was initially tested and diagnosed 10/20/2022 at PCP office. Client transferred to this facility (NBIMC) and initial visit was 12/07/2022. ART Biktarvy prescribed and started.
37	Another agency in EMA (Mountainside Medical Center)	On 9/22/22 patient seen by Rutgers TB unit and indicated per NJDOH patient known to have HIV for 2 years but not on treatment. Patient referred on 9/22/22 to Rutgers IDP and seen for initial visit 10/7/22. Comment: HIV diagnosis date was 11/13/20 in CHAMP.
IN HOME TEST KIT (1)		
38	At Home Test Kit	Patient tested positive January 2022 via home kit sent by NAP. On 2/10/22 patient called and scheduled an appt for 2/12/22 at Rutgers University Hospital. Was started on ART (BIKTARVY). Client was then referred to Charity Care but was denied coverage. University contacted us (Newark DHCW Special Care Clinic) and an appointment was made for client to be seen at our clinic within a week (2/23/22).
UNKNOWN/NOT DOCUMENTED (12)		
39	Unknown	First appointment was done on 12/29/2021 CPE visit. Patient taking SYMTUZA 800/150/200/10 oral daily. Comment: HIV diagnosis date was 12/21/21 and first medical visit date was 6/14/22 in CHAMP.
40	Unknown	Patient came into to see ID provider CPE on 6/28/2022, first appointment. Patient is taking Atripla 600-200-300mg. Comment: HIV diagnosis date was 1/1/22 in CHAMP.
41	Unknown	Patient referred after positive test. Patient was scheduled for an ID appointment on 2/22/2022. There was a reschedule for 2/23/2022. Patient canceled appointment. Client made his appointment on 3/15/2023. Comment: HIV diagnosis date was 2/4/22 in CHAMP.
42	Unknown	Registration. Nursing Assessment. MCM Intake. Charity Care Application. Comment: HIV diagnosis date was 8/8/22 and first medical visit date was 9/13/22 in CHAMP.
43	Unknown	Registration. Nursing Assessment. MCM Intake. Screening With Mental Health. Comment: HIV diagnosis date was 7/11/22 and first medical visit date was 7/15/22 in CHAMP.

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
44	Not documented.	Patient was scheduled for 4/12/22 new patient appointment and reminded of appointment which he kept. Comment: HIV diagnosis date was 3/1/22 in CHAMP.
45	Unknown	Registration Nursing Assessment MCM Intake Screening With Mental Health Comment: HIV diagnosis date was 1/15/21 and first medical visit date was 2/25/21 in CHAMP.
46	Unknown	Registration Nursing Assessment MCM Intake Mental Health Screening Comment: HIV diagnosis date was 11/1/22 and first medical visit date was 12/1/22 in CHAMP.
47	Unknown	Registration. Nursing Assessment. MCM Intake. Screening With Mental Health. Comment: HIV diagnosis date was 6/15/22 and first medical visit date was 8/18/22 in CHAMP.
48	Unknown	Registration Nursing Assessment MCM Intake Charity Care Application Comment: HIV diagnosis date was 3/17/22 and first medical visit date was 4/14/22 in CHAMP.
49	Unknown	According to records, client was diagnosed in 2002. Upon intake at PHC, client was retested to confirm diagnosis in December 2022. Comment: HIV diagnosis date was 1/1/2000 in CHAMP.
50	Unknown	Registration. Nursing Assessment. MCM Intake. Charity Care Application. Comment: HIV diagnosis date was 6/27/22 and first medical visit date was 8/18/22 in CHAMP.
AGENCY OUTSIDE OF EMA (3)		
51	Another Agency outside of EMA (Planned Parenthood New Brunswick)	Registration. Nursing Assessment. MCM Intake. Screening With Mental Health Clinician. Comment: HIV diagnosis date was 7/15/22 and first medical visit date was 9/26/22 in CHAMP.
52	State of NJ (client was diagnosed while incarcerated in State of New Jersey 2022)	Client admits to knowing before being diagnosed by our clinic (DHCW). He states he was in denial; but was suffering with some medical issues. Patient was treatment naïve (never took ARVs). Comment: HIV diagnosis date was 7/25/22 and first medical visit date was 9/16/22 in CHAMP.
53	Agency outside of EMA	Hospital records show that patient was receiving HAART while in Greystone since March 2022. IDP PN scheduled initial appointment for 7/7/22 but patient missed appt as she was discharged from Greystone and could not be contacted/found. (Patient with long history of severe mental illness) . Once she was re admitted to Greystone, PN able to schedule a new appointment for 11/2/22 which was kept.
OUTSIDE OF NJ TOTAL = 14		
OUTSIDE OF NJ WITHIN US (7)		
54	Outside of NJ (Florida)	Patient moved to NJ in October 2022. Came to NJCRI for transfer of care for RW services. Patient was seen to have medical records requested from previous provider. Records were received 10/26/22. patient began ART with provider in 10/26/22. Patient currently retained in care at NJCRI. Next appointment for labs were completed 5/1/23, RW follow up 5/22/23.
55	Outside of NJ (Somewhere in NYC in 2020)	Patient transferred care from NYC and was initially seen 11/11/2022.

#	Where Diagnosed	Activities and processes from date of diagnosis to receipt of medical care by this client at your agency
56	Outside of NJ (My House Clinic, Nashville, TN)	8/1/22- Diagnosed in Nashville, TN. Patient prescribed Biktarvy 10/18/22. Nashville TN Medical Visit 10/27/22.- Patient suddenly moved to NJ without medical records and sought immediate medical care from Morristown Medical Center. HIV test done by Sexual Health Center 11/1/22.- Medical Case Manager does Ryan White Intake. 11/2/22- Medical records received from TN 11/9/22- Ryan White Medical Visit and Labs(both paid for by the grant) done by APN. Patient was given for continuation of treatment two weeks of Biktarvy samples. 11/10/22 - ADDP approved 11/14/22 - APN received a Prior Authorization notice from Gainwell. Patient's HIV medication approved. 1/1/23 - Patient was enrolled in Private Insurance Exchange 1/25/23 - Medical Visit with ID specialist . 5/2/23 - Patient notified Medical Case Manager that he moved to NY and he was linked to care Queens Hospital Center 5/18/23 - NJ State Dept of Health requested HIV RNA PCR and CD4 lab results faxed to State.
57	Outside of NJ (Facility in Arizona)	Patient was diagnosed in Arizona and moved to be with family in NJ. Work began with case coordination before patient came to NJ. Care Coordination and obtaining financial assistance began when patient got to NJ and then patient officially received medical care and prescriptions. Patient on ARVs from PA. FXB covered the copay for labs until other financial arrangements were made.
58	Outside NJ (Apichac HC, Manhattan, NY)	Patient linked to NJCRI for HOPP services 11/18/22; linked for transfer of RQ care to NJCRI on 11/28/22. Saw provider same day and presented ART same day. Patient saw provider last 1/30/23 and was to complete labs on 5/1/2023, but was a no show.
59	(Outside of NJ) Arizona	Client was diagnosed in the State of Arizona in 2021 and was started on ART (BIKTARVY) after 2nd HIV was done. When she came to our clinic; she had only 2 pills left. treatment was continued.
60	Outside of NJ (Village Park Medical NYC)	Patient was in care in NYC until he was seen on 10/13/22 in IDP. He was seen again in November 2022 and then cancelled February 2023 appointment.
OUTSIDE OF NJ & US (7)		
61	Outside of NJ (Guatemala his home country)	Client is currently enrolled in our Hyacinth Wellness Clinic. When client reached out for HIV services, he was scheduled for bloodwork and seen by our provider within 30 days.
62	Outside of NJ (Ecuador)	Client was diagnosed in Ecuador and was started on HIV treatment. He is a refugee and was out of meds on his first visit with us.
63	Outside of NJ (Medical facility in Brazil)	Client was diagnosed in Brazil in February 2021 and began treatment immediately. Client came to the US at the end of 2021. Client's first PHC appointment was 1/24/2022
64	Outside of NJ (Chile approximately 2020/2021)	Patient found ZHC online and called to be linked into care after moving to the U.S. 6 months ago and not having HIV medications. Met with Linkage to care coordinator on 2/17/2022 Initial bloodwork was ordered and appointment was scheduled for ID Care appointment on 2/17/2022. Patient came with other medical STI issues so was scheduled for follow-up on 2/22/2022. Patient attended all of these appointments.
65	Outside of NJ (Medical facility in India)	Client was diagnosed in India in March 2022. Client moved to the US and promptly sought care. First PHC appointment occurred on 11/16/2022.
66	Outside of NJ (Client was diagnosed with HIV in Guatemala.)	Upon program enrollment, this client received medical case management, psychosocial assessment, medical appointment (10/18/2022, verified as attended) and ongoing follow up medical case and support services.
67	Outside of NJ (Ecuador)	Registration. Nursing Assessment. MCM Intake. Screening With Mental Health Clinician. Charity Care Application.

ABBREVIATIONS:

APN = Advanced Practice Nurse	NBIMC = Newark Beth Israel Medical Center
DHCW = Dept of Health & Community Wellness (Newark)	NJCRI = North Jersey Clinical Research Initiative
HOPP = Housing Opportunities for Priority Populations	PHC = Peter Ho Clinic (SMMC)
ID = Infectious Disease	PN = Patient Navigator
IDP = Infectious Disease Practice (Rutgers)	SMMC = St. Michael's Medical Center
MCM = Medical Case Management	ZHC = Zufall Health Center

1.7 Factors Delaying Medical Care following Diagnosis at Your Agency

Question #5: If the client was diagnosed at your agency, what was/were the factor(s) for the delay in receiving a first medical visit within 30 days of diagnosis? (e.g., client did not return/want to go, agency did not follow up, etc.). List as many factors as applicable.

Agencies gave a range of responses to this question. There were a total of 26 responses – **11 or 42% were agency-related/caused and 15 or 58% were client-related.** Data entry errors were the chief reason that agencies did not record timely linkage to care. On the client side, the majority was **client did not follow up.** However, other client needs are health-related and others could be better managed within the agency.

Table 5: Reasons Clients Diagnosed in Agency were Not Linked within 30 Days (Summary)

Reason Types	#	%
<i>AGENCY-RELATED</i>	11	42%
Data Entry Errors	6	23%
Misunderstanding of "Linkage to Care"	1	4%
Did not Communicate within Health system	1	4%
No delay - no reason given	2	8%
Late scheduling of Medical Appointment	1	4%
<i>CLIENT-RELATED</i>	15	58%
Other Client Needs	6	23%
Client Did Not Follow Up	9	35%
TOTAL RESPONSES	26	100%

Table 6: Reasons Clients Diagnosed in Agency were Not Linked within 30 Days (Detailed)

Reasons
AGENCY RELATED
Data Entry Errors (6)
N/A patient was linked into care within 1 day documentation error when entering data within CHAMP by case manager. (2)
There was no delay in care. Client initial appointment was 3 days after diagnosis
There was no delay. Date of HIV diagnosis incorrectly entered.
Did not receive late care-HIV diagnosis date incorrectly entered.
We entered the initial date of diagnosis from another agency.
Misunderstanding of "Linkage to Care" (1)
There was no delay in receiving care. It was received at other non RW program immediately.
Did not Communicate within Health System (1)
TB clinic did not advise us of the HIV result. We did not see the positive result in lab data
No delay - no reason given
None. Diagnosed on 11-21-2022 blood work done at Trinitas EFP on 12-1-2022 First Doctor's visit at Trinitas EFP on 12-16-2022
There was no delay in care.
Late scheduling
Yes, client scheduled after 30 days after the date of diagnosis
CLIENT-RELATED
Other Client Needs
Family matters, newborn baby, Charity Care
Client was hospitalized at TRMC and also missed his initial appointment.
Client was dealing with other issues: pregnant wife, Both Client and wife tested positive, and immigration status (trafficking)
Dx on 11/1/2022. Client was seen by MD on 11/25/2022. Client was hospitalized -- Discharged on 11/23/2022.
Client was hospitalized and per MCM's notation, client was depressed about his diagnosis.
Client was diagnosed with Latent TB. Referred to Lattimore Clinic for care. Client initial visit was 10/28/2022.
Client Did Not Follow Up
Client missed scheduled appointment due to work schedule
Due to client barriers he failed to return as instructed.
Client no showed and cancelled various appointments scheduled. However they were still linked to care almost within 30 days.
No answer voicemail full, certified letter sent; email sent; we learned that patient most easily reached by email.
Client had barriers and discontinued ART.
Client had some barriers the caused a delay in care. Although linkage was in place IBH services were required due to diagnosis and other factors
Client did not return and missed initial appointment. Agency was unable to reach client telephone and well as not able to locate during home visits.
Patient canceled appointment two times before coming in for an ID appointment. (2)

1.8 Issues Involved in Linkage to Care Following HIV Diagnosis – Systems/Agency/Client

Question #6: What types of issues were involved in linkage to care following HIV diagnosis for this client – or for all clients not linked to care within 30 days?

The responses to this question were very specific to the cases at hand but provide more detail about the issues of data entry, communications, and client response.

a. Systems issues (e.g., delay between diagnosis in hospital ER/discharge planning or other entity, etc. to outpatient/community medical provider, etc.)

The following **Systems Issues** were identified. The **issues of data entry, communication and client response** can be addressed via the recommendations at the end.

- Initial date of his diagnosis was entered as 3/1/22 but MD only wrote "March 2022" so it could have been later in the month which would mean he was engaged within 30 days.
- Yes; delay in update on diagnosis in client chart.
- When we are aware, we enter the date of diagnosis that precedes our confirmatory testing. This may need clarification as it shows up as not engaged within 30 days when in fact we consistently engage patients in care within 30 days from the time we are aware of the positive diagnosis.
- Clara Maass notes document linkage to ID care but client motivation caused delay.
- Unclear why client first medical appointment was two months from date of diagnosis. His first appointment is documented for October 2022. I believe the lack availability with providers is the issue. COVID etc. Client requested to have his care at Rutgers because his wife is HIV positive and receives Pre-natal there.
- Diagnosing agency didn't provide proper information to link client.

b. Agency issues (e.g., not timely follow up, etc.)

The following responses indicate one issue between a non-RW funded agency, data entry, and need for improved scheduling of medical visits after new HIV diagnosis.

- Date of diagnosis incorrectly entered as 3/20/22. It was 2 years before patient was seen by our physician.
- Diagnosed at St Barnabas and had follow up at our agency. Was given meds at discharge. Office scheduled follow up for following month to obtain labs. Client followed through with appointment. Labs were undetectable.
- Likely was the first available appointment at the time.
- Client scheduled after the 30 days window after diagnosis.
- Date of diagnosis not documented in chart progress report.

c. Client issues (e.g., not returning for medical care, etc.)

The following responses were consistent with earlier reports. Clients were diagnosed out of the country and new to the US and navigating systems. Many patients failed to follow up and keep scheduled appointments. Patients were not doing well after HIV diagnosis or were hospitalized or referred for TB care.

- Client new to the states; was trying to obtain several necessary services at the same time.
- Client was not in the country 30 days after diagnosis, however was receiving treatment in Brazil upon initial diagnosis.
- Client was not in the country within 30 days of diagnosis.
- Patient diagnosed elsewhere, patient took time to process his diagnosis
- Client did not follow up for treatment of positive HIV status for reasons unspecified
- Client failure to follow up as instructed
- Patient non adherent to care.
- Client failure to follow up as instructed (2)
- Client never returned for HIV care
- Client did not attend initial scheduled follow up appointment
- Did not keep scheduled appointment (2)
- Per client, he was not doing well after he was diagnosed.
- Client discontinued ART due to barriers
- No issues; client was provided with appointment within 1 week of call
- Patient was linked to care within 22 days of (our) diagnosis. several phone calls made and letters were sent to clients home for return visits
- Client motivation - not returning, drug use, no social support, need for home health aid, transportation issues
- Hospitalization dealing with his new diagnosis
- Client was hospitalized with COVID.
- Client was diagnosed with TB and referred to Lattimore Clinic for care

1.9 Access to HIV Medical Care Following HIV Diagnosis

Question #7: Please provide the following information about your clinic.

Question #7a: What are your clinic's days and hours of operation? Do you have extended hours (evenings and weekends) of operation? Please list all.

The hours of each agency are shown below.

Of the 16 agencies surveyed in the Needs Assessment, **11 or 69% have extended hours of operation.** This includes four (80%) of hospital-based clinics, four (100%) Federally Qualified Health Centers (FQHCs) which are required by HRSA BPHC to have extended hours for all patients, and two (50%) community based providers. One (33%) non-medical community based provider has extended hours of operation.

Table 7: List of Agencies and Their Hours of Operation (as of May 2023)

Type of Agency	Weekdays	Saturday	Sunday
<i>Hospital Based Clinics</i>			
Newark Beth Family Treatment	M-F. 8:00am - 4:00pm		
Morristown Medical Center	M-F. 8am-4pm		
Rutgers FXB	Tue. 8am - 12N. Fri. 8am - 4pm		
Rutgers IDP	M & F. 8am – 4pm Tue & Wed. 8am - 5pm Thu. 8am – 7pm		
St. Michael's Medical Center	M & F. 6am - 4pm Tue-Thu. 8am – 4pm		
Trinitas	M-F. 8am – 4:30pm		
<i>FQHCs</i>			
Neighborhood Health Services	M, W, Th, F. 8am - 5pm. Tues 8am - 6pm.	Sat. 9am - 2pm.	
DHCW Special Care Clinic	M-F. 8:30am-4:30pm		
Newark CHC	M-F. 9:00am-7:00pm		
Zufall Health Center	M. 8am – 7pm Tue. 8am- 6pm Wed. 8am – 7pm Thu. 8am – 6pm Fri. 8am – 5pm	Sat. 8am- 1pm	
<i>Community-Based Providers</i>			
Hyacinth	M-F. 9am-6pm		
NJAS/EDGE	M-Th. 9:30am-9:00pm Fri. 9am-5pm. <u>CAN Wellness Center:</u> M- Thu 8:30am-5:30pm Fri. 8:30am-12:30pm		Sun. 10am-4pm
NJCRI	Mon. 10am-5:30pm Tues-Fri 9am - 4:30pm		
Smith Center for Infectious Disease	M – Th. 8:45am - 12N Tue. 4pm - 7pm		
<i>Not a Medical Provider</i>			
AIDS Resource Foundation (ARFC)	No Answer		
Community Health Law (CHLP)	No Answer		
PROCEED	M, W. 8:30am-8pm Fri 8:30am - 5pm Tue & Thu. 8:30am-9pm		

Table 8: Types of Agencies by Extended Hours of Operation (as of May 2023)

Type of Agency	No	Yes	Yes by Appt	TOTAL	% Extended Hours
Hospital Based Clinic (5)	1	3	1	5	80%
FQHC (4)		4		4	100%
Community-Based Provider (4)	2	2		4	50%
Subtotal	3	9	1	13	77%
Non-Medical Providers (3)	2	1		3	33%
TOTAL	5	10	1	16	69%

Table 9: List of Agencies by Extended Hours of Operation (as of May 2023)

Type of Agency	Weekdays	Weekends
<u>Hospital Based Clinics</u>		
Newark Beth Family Treatment		Saturday 8am - 12pm
Rutgers IDP	Thu. 8am – 7pm	Every other Saturday our mobile unit is in the community from 9am-4pm
St. Michael's Medical Center	Tuesday 10am – 6pm	
Trinitas	Last Wednesday of every month 8am-6pm	
<u>FQHCs</u>		
Neighborhood Health Services	Tues 8am - 6pm.	Sat. 9am - 2pm.
DHCW Special Care Clinic	3 rd Thursday of the month 8:30am -7:30pm	3rd Saturday of the month 9am-1pm.
Newark CHC	M-F. 9:00am-7:00pm	Saturdays 9am – 5pm
Zufall Health Center (West Orange)	Tue. 8am- 6pm	2nd & 4th Saturday of the month 8am-1pm
<u>Community-Based Providers</u>		
NJAS/EDGE	M-Th. 11am - 8pm	Saturday 9am – 12pm
NJCRI	Mon. 10am-5:30pm	
Smith Center for Infectious Disease	Tue. 4pm - 7pm for psychiatrist hours	
<u>Not a Medical Provider</u>		
PROCEED		Saturdays 9:00 am-2:00 pm

Question #7b: How many days to your clinic’s first available medical appointment for a newly diagnosed person - from today?

Agencies had appointments available very quickly but the results were difficult to quantify and categorize by number of days. However, at least 86% reported that the first medical appointment was available within 7 days from today for a newly-diagnosed person.

Table 10: Number of Days to Your Clinic’s First Available Medical Appointment from Today - by Type of Agency

Days to First Available Medical Appt from Today	Type of Agency			Total	% Distn
	Hospital Based Clinic (5)	FQHC (4)	Community-Based Provider (4)		
Immediately/Same Day			1	1	7%
1 Day		3	1	4	29%
1-2 Days	1			1	7%
2 Days	1			1	7%
1-3 Days		1		1	7%
1-5 Days			1	1	7%
3-7 Days			1	1	7%
Within a week	1			1	7%
Rapid Linkage within 7 days	1			1	7%
7-14 Days	1			1	7%
First Opening	1			1	7%
Total	6	4	4	14	100%
Distn by Agency Type	43%	29%	29%	100%	
Non-Medical Providers				3	

Question #7c: Number of days from diagnosis to medical appointment.

For many agencies, newly diagnosed individuals had a medical visit either immediately, same day or within one day. However, a number of agencies include a range of several days (e.g., from 1 through 5 or 7) so it was difficult to determine the actual timeframe. The table below shows the responses by type of agency. Thee (3) agencies were not medical providers so the question was not applicable.

Table 11: Number of Days from HIV Diagnosis to Medical Appointment by Type of Agency

Days from Dx to Medical Visit	Type of Agency			Total	% Distn
	Hospital Based Clinic (5)	FQHC (4)	Community-Based Provider (4)		
Immediately/Same Day		1	1	2	15%
0-1 Day			1	1	8%
1 Day		1			8%
1-2 Days	2				15%
3 Days	1		1	2	15%
1-4 Days		1		1	8%
1-5 Days			1	1	8%
1-7 Days		1		1	8%
5-7 Days	1			1	8%
7-14 Days	1			1	8%
No Answer ("Depends")	1			1	8%
Total	5	4	4	13	100%
Distn by Agency Type	38%	31%	31%	100%	
Non-Medical Providers				3	

Question #7d: For hospital-based clinics only (3 questions)

Question #7di: What is required for your charity care documentation?

Agencies provided a list of documents/information required to confirm eligibility for **New Jersey Hospital Care Payment Assistance aka "Charity Care."** These requirements issued by the N.J. Department of Health (NJDOH) are shown in **Appendix D**. They include: (1) documentation of insurance or lack of insurance, (2) income and resources below stated thresholds. Charity care pays for "necessary hospital care" and other services may not be eligible for payment.

1. Agency-specific "charity care checklist"
2. List of items (that could be included on such a charity care checklist):
 - a. Identification
 - b. Proof of residency (must have NJ address)
 - c. Proof of address
 - d. Proof of income, social security income, bank statement, any other income papers*
 - e. Proof of assets (as of the date of service)
 - f. Signed statement of support
 - g. Proof of insurance (if any) - Medical insurance card (including Medicaid)
 - h. Any immigration paperwork. (They cannot be here on a tourist visa.)

*Some agencies specified income documentation including: last year's income taxes (if no current income, bank statement), if income is paid in cash employer must provide letter documenting this income.

Question #7dii: Documentation of ID – How do you get documentation of identification if needed?

A number of agencies did not provide answers because charity care is not provided by community based agencies. FQHCs provide medical care regardless of immigration status and have special documentation requirements for Letter of Agreement (LOA) for NJDOH funding.

Table 12: Sources of Documentation of ID (Hospital Based Clinics)

Hospital Clinic Location	Where to Obtain Documentation
Essex County	Referrals to: <ul style="list-style-type: none"> City of Newark for a Newark ID (Newark residents) Bridges Outreach, Inc. (agency serving the homeless) in Newark which assists with documentation Other: <ul style="list-style-type: none"> By mail. If do not have ID with them on the first visit, asked to bring it with them on the second visit.
Union County	Referrals to: <ul style="list-style-type: none"> City of Elizabeth for an Elizabeth ID (Elizabeth residents) Public library for assistance with documentation St. John’s Church Appropriate agency
Morris County	<ul style="list-style-type: none"> Provide an application for a Morris County ID. Referrals to: <ul style="list-style-type: none"> Morris County library for assistance with documentation City of Morristown for a non-driver’s ID Case management for residents outside of Morris County

Question #7diii: Would you see a newly-diagnosed client if they don’t have ID?

Five of the six hospital-based clinics will see a newly-diagnosed client if they do not have ID.

Yes	3 Clinics (50%)
Yes, if the client has a birth certificate	1 Clinic (16%)
Yes, will start the process	1 Clinic (16%)
No	1 Clinic (16%)

1.10 Recommendations for Improvements in Linkage to Care

Question #8: What recommendations do you have to improve linkage to care within 30 days of HIV diagnosis including how the EMA can improve linkage to care?

Question #8a: Systems Issues.

Six agencies provided the following. Two require clarification with the CHAMP CLD system, and two are related to the eligibility process for charity care. The **recommendation** is to clarify the scope of CHAMP and system resources for documentation for charity care and other eligibility.

Hospital-Based Clinics

- Patients who have transferred or reengaged in care are not billable in CHAMP.
- Increase funding to assist patients in obtaining birth certificates and ID's

Community Medical Providers

- Major systems issue in incorporating private care providers in CHAMP.

Community-Based Organizations (CBO) – Nonmedical Agencies

- Lately some hospitals' charity care approval takes longer. They should speed up the process.
- Enforce accountability; mandate proof of linkage to care for services.
- Not sure because clients are already linked when they come to us for assistance.

Question #8b: Agency Issues.

Seven (7) agencies identified the following agency issues affecting Linkage to Care which could be improved. The **recommendation** is that the Ryan White Unit (RWU) investigate these issues with each of the agencies responding and seek to develop regional or EMA-wide solutions and clarifications.

Hospital-Based Clinics

- Limited labs because of high demand and limited RW funds
- Transportation for clients

FQHCs

- Agencies should support each other in seeing newly diagnosed patients ASAP. At times we have a full schedule for the day; it would be nice to know I can send the patient to another clinic that day w/o an appointment.
- Regular training of staff on CHAMP data entry. Running reports to check/verify accuracy of information inputted.

Community Medical Providers

- Non traditional hours
- Referrals to our agency. Clients are immediately linked to care

Community-Based Organizations (CBO) – Nonmedical Agencies

- Lack of follow up, provide more resources for linkage

Question #8c: Client Issues.

Seven (7) agencies answered but identified barriers facing clients which must be fixed to improve linkage to care. These are:

- (1) Lack of documentation including undocumented immigrants,
- (2) Lack of education,
- (3) Social disparities,
- (4) Limited transportation, and
- (5) Not ready for treatment, even though they were connected with services of Ending the HIV Epidemic (EHE) in Essex County.

However, these same barriers face the remaining 76% of newly-diagnosed clients but they are successfully linked to care! **The recommendation is to identify the best practices used in the EMA, develop innovative approaches and partnerships, continue to implement them, and continue to track newly-diagnosed individuals not linked to care within 30 days.**

Hospital-Based Clinics

- Documentation and limited transportation
- Social disparities
- Undocumented clients are hesitant to provide information for fear of deportation.

FQHCs

- Some clients are not able to show proper documentation due crossing the southern border as asylum-seekers

Community Medical Providers

- Not yet ready for treatment. Patient not returning for follow up care after being linked for HOPP (Ending the HIV Epidemic (EHE) in Essex County, Housing Opportunities for Priority Populations)
- Patient must receive continued adherence counseling on the importance of maintaining care

Community-Based Organizations (CBO) – Nonmedical Agencies

- Lack of support, lack of education
- Not having the necessary documentation to apply for charity care

1.11 Telehealth as Option for Linkage to Care

Question #9: Would a telehealth medical visit – contact with a provider by video – following diagnosis help improve linkage to care within 30 days?

Of the 17 agencies responding, the majority - 11 or (65%) - said a telehealth visit would improve linkage to care following HIV diagnosis, four (24%) said it would not, and two (12%) did not answer. One (6%) reported that telehealth visits are not recommended for the newly diagnosed or for initial medical visits.

Table 13: Use of Telehealth to Improve Linkage to Care by Type of Provider Agency

Type of Provider Agency (n=17)	Yes	No	No Ans.	Total
Hospital	24%	12%	6%	41%
FQHC	18%	0%	6%	24%
Community Medical Provider	12%	6%	0%	18%
CBO	12%	6%	0%	18%
Total	65%	24%	12%	100%

Over half (nine or 53%) of the agencies reported that they had the capability to perform this kind of telehealth visit. Likewise, nine or 53% of the agencies said they would be willing to explore this option.

1.12 Other Comments or Recommendations

Question #10: Please insert any other comments or recommendations.

Only one comment was provided.

- “Additional resources for housing opportunities for our homeless population would be beneficial.”

CONCLUSIONS AND RECOMMENDATIONS

This section summarizes conclusions from the Needs Assessment - Update 2023 and corresponding recommendations for improvement in Linkage to Care within 30 Days of HIV Diagnosis. This is important because Linkage is a Key Indicator in the National HIV/AIDS Strategy (NHAS) 2021-2025 and the Newark EMA Integrated HIV Prevention and Care Plan 2022-2026. There are two tables – summary and detailed - for ease of reference and follow up.

Table 14: Summary of Challenges to Linkage to Care within 30 Days of Diagnosis and Recommendations

CHALLENGES TO LINKAGE TO CARE WITHIN 30 DAYS OF DIAGNOSIS

Agency-related issues:

1. Data entry issues
2. Lack of clear agency protocols/procedures on linkage to medical care for newly diagnosed.
3. Communication within agency's health care system – e.g., between hospital and HIV clinic.

Client-related issues:

4. Do not show for appointments
5. Complicated health/family/insurance issues involving multiple entities within (and outside of) health system.

Other:

6. Client diagnosed by a non-RWHAP-funded entity in the EMA (hospital, private PCP, urgent care)
7. Client diagnosed outside of New Jersey.

RECOMMENDATIONS FOR IMPROVEMENT:

Agency-related issues:

1. Each agency follows and monitors its CHAMP data entry protocols to ensure timely entry of accurate date regarding HIV diagnosis date and first medical visit.
2. Agency-specific protocols to ensure linkage for newly-diagnosed.
3. Communication/training “blitz” within each health system on what to do with newly diagnosed HIV patient (refer to RWHAP funded entity).

Client-related issues:

4. Implement and/or continue best practices for appointment confirmation and follow up. Counseling client on need for medical care to improve their health.
5. MCM Care Plan and care coordination to ensure timely service referrals, follow up and linkage to care as soon as possible.

Other

6. Communication blitz/marketing campaign by EMA Planning Council & RWU to all medical entities in the EMA by email, brochure, etc., alerting them to availability of RWHAP-funded HIV-specific services (no cost & billable to insurance) for patients and to make referrals.
7. Link to care as soon as possible to ensure client is receiving ARVs and is on the path of VLS.

Report to RWU any clients (number) newly-diagnosed outside of NJ so we can assess their impact on overall Linkage to Care performance.

CONCLUSION: The EMA - through the RWU, EIRCs and programmatic/CQM monitoring, etc. - must continue to monitor performance on Linkage to Care within 30 Days of Diagnosis by each case/client not linked – to determine reasons and plans for improvement until the EMA achieves the goals of 95% Linkage to Care within one month.

Table 15: Conclusions and Recommendations for Improving Linkage to Care within 30 Days of HIV Diagnosis

Conclusions	Recommendations
<p>Linkage to Care – 2/3 Are Within Agency Control</p>	
<p>1. Data entry errors continue. A total of four (4) clients or 6% of those not linked to care had incorrect date of HIV Diagnosis in CHAMP. This adversely affects the linkage percentage and shows that the EMA is underperforming. Each agency reports its HIV diagnosis date directly to HRSA/HAB by the annual RSR – so if the HIV diagnosis date is incorrect, it shows non-linkage by that agency.</p>	<p>1. Agencies must have written CHAMP data entry protocols in place to ensure correct entry of HIV diagnosis date into CHAMP for newly diagnosed clients. Ryan White Unit (RWU) should measure data entry by: (1) requiring agencies to submit CHAMP data entry protocols (already done via RFP), (2) RWU checking these protocols and accuracy of diagnosis date vs CHAMP as part of site monitoring, (3) quality assurance by EIRC meetings, (4) FXB comparing HIV diagnosis confirmation vs CHAMP data as part of its CQM review.</p>
<p>2. Agencies are not clear on definition of “linkage to care”. Some stated “linked” when CHAMP & their own data showed more than 30 days between date of diagnosis and date of medical visit. Linkage is measured from the date of diagnosis to the date of the first medical visit per HRSA rules for the RSR - regardless of which client level data (CLD) system the agency uses.</p>	<p>2. All agencies must be trained and knowledgeable on the definition of Linkage to Care – which is the federal definition. Use the attachments in Appendix A . This can be done by RWU or other entity.</p>
<p>3. The median time between HIV diagnosis and medical visit is 61-90 days (within 3 months). The average is higher at 4.56 months because of the high number linked in more than 6 months.</p>	<p>3. Median linkage months to care is good. The averages show the range of months linkage. RWU and agencies should further analyze reasons for recent and later linkage, decide which clients to target, & develop and implement strategies for reducing linkage times.</p>
<p>4. Some agencies appear to have clear protocols on linkage to care following HIV diagnosis and others do not.</p>	<p>4. All agencies must have documented protocols/procedures for linkage to medical care following HIV diagnosis. The RWU should assess presence of these protocols during programmatic and CQM monitoring.</p>
<p>5. Agencies do not know where 18% (12) of clients were diagnosed. This lack of information and/or documentation affects total agency performance and that of the EMA.</p>	<p>5. Agencies must document location of HIV diagnosis (i.e., where tested by agency or geography) in client record based on the documentation of HIV positive diagnosis. Agencies must be required to identify and report location of HIV diagnoses – especially if outside of agency control - if the EMA is to achieve 95% linkage to care within 30 days by 2026.</p>
<p>6. For agencies within healthcare systems, there were some delays</p>	<p>6. RWHAP-funded HIV medical clinics within larger health care</p>

Conclusions	Recommendations
<p>between diagnosis at one healthcare system entity and linkage to care with the HIV medical care entity.</p>	<p>systems should develop protocols for linkage to care within the system and communicate these to all entities.</p>
<p>7. For agencies newly-diagnosing individuals with HIV – the chief agency-related reason for not linkage within 30 days was data entry errors and the chief client-related reason was clients’ not following up.</p>	<p>7. See above. CHAMP Data entry protocols. Protocols for reaching individuals. Better agency coordination and communication between testing entity and other components of health care system.</p>
<p>Linkage to Care – 1/3 Are Outside of Agency Control</p>	
<p>8. One in five (14 or 21%) were diagnosed outside of New Jersey, including 7 or 10% in another country. They came to the EMA RWHAP more than 30 days later, but were engaged in HIV medical care as soon as they came to the RWHAP-funded agency.</p>	<p>8A. Agencies must continue to engage these individuals in medical care as soon as possible, even though they may not “count” as linkage within 30 days. 8B. Also continue to report to RWU and PC the number of these individuals and circumstances to enable tracking of any increase due to immigration, etc.. This will enable the EMA to: (1) better allocate RW resources as payor of last resort to support any medical care and other services needed to achieve VLS, and (2) determine if the EMA ever will be able to achieve 95% linkage to care within 30 days – which may not be possible due to the mobility of individuals and steady influx of PLWH diagnosed outside of NJ.</p>
<p>Access to Medical Care Following HIV Diagnosis</p>	
<p>9. Agencies’ hours of operation including extended hours appear to provide sufficient access to medical care for those newly-diagnosed throughout the EMA.</p>	<p>9. The availability of these HIV medical care resources should be publicized throughout the EMA and New Jersey (by Planning Council support staff) in collaboration with the Ending the HIV Epidemic (EHE) in Essex County and New Jersey Universal HIV Testing Initiative. Hours of operation should be confirmed.</p>
<p>10. 86% of agencies reported that the time to the first medical appointment for a newly-diagnosed individual was within 7 days per the Rapid Treatment protocol. Many had appointments immediately or within 1-2 days. This shows the structural availability of medical care and availability to be seen by a medical provider. While good, this does not confirm the medical visit.</p>	<p>10. The time between HIV diagnosis and medical visit must continue to be tracked. Patient “no shows” for medical appointments and reasons must be tracked as well.</p>
<p>11. Agencies reported that the time between HIV diagnosis and</p>	<p>11. The time between HIV diagnosis date and medical visit must be</p>

Conclusions	Recommendations
<p>medical appointment was same day, many within 5 days, up to a maximum of 14 days. It is unknown if this is the date the medical appointment is scheduled or the actual medical visit.</p>	<p>continued to be tracked. Where the timeframes are greater than those shown in the report, the differences must be followed up and the reasons identified, with improvements made where possible.</p>
<p>Telehealth Visits to Improve Linkage within 30 Days</p>	
<p>12. A majority (65%) of agencies said a telehealth visit would improve linkage to care following HIV diagnosis. However, one noted that telehealth visits are not recommended for the newly diagnosed or for initial medical visits. Nine (9) or 53% would be willing to explore this telehealth option.</p>	<p>12. Use of telehealth for the initial linkage to care medical visit should be explored within the EMA. This is optional for agencies.</p>
<p>Overall</p>	
<p>13. The EMA performance on the percentage of Linkage to Care within 30 days of diagnosis is trending upward but we are not on the trajectory to achieve at the 95% goals of NHAS 2021-2025 and the Newark Integrated HIV Prevention and Care Plan 2022-2026 by 2026.</p>	<p>13. The RWU and EMA agencies must continue to monitor performance on the outcome Linkage to Care within 30 Days, identify the reasons for non-linkage, correct those within the agencies' control, and document those outside control of the agency, EMA, and NJDOH – seeking system-wide solutions where needed. Also, provide intensive support to those not linked within 30 days to ensure they are on a path to VLS.</p>

This page left blank.