

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT - 2016

TABLE OF CONTENTS

LIST OF	TABLES	;	ii
LIST OF	FIGURE	S	iv
LIST OF	ABBRE	VIATIONS	vi
INTROD	UCTION	ν	viii
	Legisla	tive Background - Planning Council Duties	viii
	HAB E>	xpectations	x
PURPOS	SE, RESE	EARCH QUESTIONS AND METHODOLOGY	xi
	Purpos	se	xi
	Resear	rch Questions	xi
	Metho	odology	xii
PART 1:	GAPS	IN MEETING OUTCOMES ALONG THE HIV CARE CONTINUUM	1
1.1	Introd	uction	1
1.2	Metho	odology	1
	1.2.1	Measures	1
		Viral Load Suppression (VLS)	2
		Retention In Care (RIC)	2
	1.2.2	Five Target Populations	3
1.3	Baselir	ne Findings	3
	1.3.1	Baseline Findings – Viral Suppression	3
	1.3.2	Baseline Findings – Retention In Care	6
1.4	Viral L	oad Suppression by Retention In Care	9
1.5	Viral L	oad Suppression by Length of Time in RWHAP Care	10
1.6	Viral L	oad Suppression and Retention In Care by Services	13
	1.6.1	Mental Health Services	13
	1.6.2	Outpatient Substance Abuse Services	13
	1.6.3	Medical Transportation Services	14
	1.6.4 1.6.5	Housing Services	14
	1.0.5		14
			10
			20
			20
		RESIDENTIAL SUBSTANCE ARUSE SERVICES BY SUBTYPE	21
1.7	Conclu	isions and Recommendations	
,	Target	Ponulations Still Need Targeting!	
	It's the	• New Clients Including Newly Diagnosed!	
	But A	Also Those in RWHAP for 6+ Years!	
	Import	tance of Accurate Data	
	And	Look at Specific Service Subtypes as Points to Intervene	

PART 2:	CONSU	MER SUR	VEY	26
2.1	Introdu	ction		26
2.2	Demogr	aphic Ch	aracteristics of Respondents	26
2.3	Viral Lo	ad		29
	2.3.1	Knowled	dge of Viral Load and Viral Load Suppression (VLS)	.29
		2.3.1.1	Knowledge of term "Viral Load"	.29
		2.3.1.2	Knowledge of Your (Respondent) Viral Load	.30
		2.3.1.3	Reported Viral Load Values	.30
	2.3.2	Respond	Jents' [Individual] Viral Load Suppression	.31
		2.3.2.1	Viral Suppression	.31
		2.3.2.2	Not Virally Suppressed	.33
		2.3.2.3	Maintain or Improve VLS	.33
2.4	Medical	Visits/R	etention In Care (RIC)	35
	2.4.1	HIV Med	dical Appointments in the Past Year	.35
		2.4.1.1	Scheduled Medical Appointments	.35
		2.4.1.2	Scheduled Medical Appointments Kept	.35
		2.4.1.3	Scheduled Medical Appointments Having to be Rescheduled	.36
		2.4.1.4	Scheduled Medical Appointments that were Missed	.38
	2.4.2	Assistan	ce in Keeping Medical Appointments	.39
2.5	Conclus	ions and	Recommendations re VLS and RIC	40
PART 3:	LATE HI	V DIAGN	OSIS – SURVEY OF LATE TESTERS	41
3.1	Introdu	ction		41
3.2	Method	lology		41
3.3	Findings	5		42
	3.3.1	Demogr	aphic and Socioeconomic Characteristics (N=27)	.42
	3.3.2	Late Tes	ting Responses – Reasons & Other Characteristics (N=33)	.43
3.4	Conclus	ions and	Recommendations	45

APPENDICES

APPENDIX A-1:	Additional Figures for Part 1 - Gaps in Meeting Outcomes Along the HIV Care Continuum 46
APPENDIX A-2:	Additional Tables for Part 1 - Gaps in Meeting Outcomes Along the HIV Care Continuum71
APPENDIX B:	Consumer Survey Tools
APPENDIX C:	Oral Health Consumer Focus Group

LIST OF TABLES

Table 1: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP	11
Table 2: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Target	
Population (Count)	12
Table 3: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Target	
Population (Percent Distribution of VLS)	12
Table 4: 2015 RWHAP Clients Virally Suppressed and Retained In Care by Services Received – Newark	
ЕМА	15
Table 5: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Mental Health Service Subtype	
(Services Received) – Number of Clients	18

Table 6: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Mental Health Service Subtype	
(Services Received) – Percent Distribution	18
Table 7: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by OP Substance Abuse Service	
Subtype (Services Received) – Number of Clients	19
Table 8: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by OP Substance Abuse Service	
Subtype (Services Received) – Percent Distribution	19
Table 9: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Medical Transportation Service	
Subtype (Services Received) – Number of Clients	20
Table 10: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Medical Transportation	
Service Subtype (Services Received) – Percent Distribution	20
Table 11: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Housing Service Subtype	
(Services Received) – Number of Clients	21
Table 12: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Housing Service Subtype	
(Services Received) – Percent Distribution	21
Table 13: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Residential Substance Abuse	
Service Subtype (Services Received) – Number of Clients	22
Table 14: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Residential Substance Abuse	
Service Subtype (Services Received) – Percent Distribution	22

APPENDIX A-2

Table 15: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Mental Health Services Count)	73
Table 16: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Mental Health Services (Percent Distribution of VLS)	73
Table 17: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services Count)	74
Table 18: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services (% Dist of VLS)	74
Table 19: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Count)	75
Table 20: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Percent Distribution of VLS)	75
Table 21: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Count)	76
Table 22: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Percent Distribution of VLS)	76
Table 23: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Residential Substance Abuse Services (Count)	70
Table 24: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Posidential Substance Abuse Services (Percent Distribution of VLS)	,,
Table 25: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C	77
Table 26: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C	70
Disparity Categories (Percent Distribution of VLS)	79

LIST OF FIGURES

Figure 1: Viral Load Suppression in Newark EMA by NA Target Populations – Year Ending 12/31/15	4
Figure 2: Viral Load Suppression in Newark EMA by Race/Ethnicity – Year Ending 12/31/15	4
Figure 3: Viral Load Suppression in Newark EMA by Gender – Year Ending 12/31/15	4
Figure 4: Viral Load Suppression in Newark EMA by Age Category – Year Ending 12/31/15	4
Figure 5: Viral Load Suppression in Newark EMA by Health insurance – Year Ending 12/31/15	5
Figure 6: Viral Load Suppression in Newark EMA by County of Residence – Year Ending 12/31/15	5
Figure 7: Viral Load Suppression in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15	5
Figure 8: Viral Load Suppression in Newark EMA by Housing Status – Year Ending 12/31/15	5
Figure 9: Retention In Care in Newark EMA by NA Target Populations – Year Ending 12/31/15	7
Figure 10: Retention In Care in Newark EMA by Race/Ethnicity – Year Ending 12/31/15	7
Figure 11: Retention In Care in Newark EMA by Gender – Year Ending 12/31/15	7
Figure 12: Retention In Care in Newark EMA by Age Category – Year Ending 12/31/15	7
Figure 13: Retention In Care in Newark EMA by Health Insurance – Year Ending 12/31/15	8
Figure 14: Retention In Care in Newark EMA by County of Residence – Year Ending 12/31/15	8
Figure 15: Retention In Care in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15	8
Figure 16: Retention In Care in Newark EMA by Housing Status – Year Ending 12/31/15	8
Figure 17: Viral Load Suppression of Target Populations by Whether Retained in Care – CY 2015	9
Figure 18: VLS by Length of Time in RWHAP and Target Population – CY 2015	10
Figure 19: Viral Load Suppression in 2015 by New Clients and Years Active in RWHAP	11
Figure 20: Percent 2015 RWHAP Clients Virally Suppressed by Service Received – Newark EMA	16
Figure 21: Percent 2015 RWHAP Clients Retained In Care by Service Received – Newark EMA	17

APPENDIX A-1

Figure 22: Viral Load Suppression in Newark EMA by Race/Ethnicity – Year Ending 12/31/15	47
Figure 23: Viral Load Suppression in Newark EMA by Gender – Year Ending 12/31/15	47
Figure 24: Viral Load Suppression in Newark EMA by Age Category – Year Ending 12/31/15	48
Figure 25: Viral Load Suppression in Newark EMA by Health Insurance – Year Ending 12/31/15	48
Figure 26: Viral Load Suppression in Newark EMA by County of Residence – Year Ending 12/31/15	49
Figure 27: Viral Load Suppression in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15	49
Figure 28: Viral Load Suppression in Newark EMA by Housing Status – Year Ending 12/31/15	50
Figure 29: Viral Load Suppression among Youth by Race/Ethnicity – Year Ending 12/31/15	51
Figure 30: Viral Load Suppression among Youth by Gender – Year Ending 12/31/15	51
Figure 31: Viral Load Suppression among Youth by Age Category – Year Ending 12/31/15	52
Figure 32: Viral Load Suppression among Youth by Health Insurance – Year Ending 12/31/15	52
Figure 33: Viral Load Suppression among Youth by County of Residence – Year Ending 12/31/15	53
Figure 34: Viral Load Suppression among Youth by Residence in 5 Largest Cities – Year Ending 12/31/15	53
Figure 35: Viral Load Suppression among Youth EMA by Housing Status – Year Ending 12/31/15	54
Figure 36: Viral Load Suppression among MSM of Color by Race/Ethnicity – Year Ending 12/31/15	55
Figure 37: Viral Load Suppression in among MSM of Color by Gender – Year Ending 12/31/15	55
Figure 38: Viral Load Suppression among MSM of Color by Age Category – Year Ending 12/31/15	56
Figure 39: Viral Load Suppression among MSM of Color by Health Insurance – Year Ending 12/31/15	56
Figure 40: Viral Load Suppression among MSM of Color by County of Residence – Year Ending 12/31/15	57
Figure 41: Viral Load Suppression among MSM of Color by Residence in 5 Largest Cities – Year Ending	
12/31/15	57
Figure 42: Viral Load Suppression among MSM of Color by Housing Status – Year Ending 12/31/15	58
Figure 43: Viral Load Suppression among People Age 45+ by Race/Ethnicity – Year Ending 12/31/15	59
Figure 44: Viral Load Suppression among Persons Age 45+ by Gender – Year Ending 12/31/15	59
Figure 45: Viral Load Suppression among Persons Age 45+ by Age Category – Year Ending 12/31/15	60

Figure 46: Viral Load Suppression among Persons Age 45+ by Health Insurance – Year Ending 12/31/15	60
Figure 47: Viral Load Suppression among Persons Age 45+ by County of Residence – Year Ending 12/31/15	61
Figure 48: Viral Load Suppression among Persons Age 45+ by Residence in 5 Largest Cities – Year Ending	
12/31/15	61
Figure 49: Viral Load Suppression among People Age 45+ by Housing Status – Year Ending 12/31/15	62
Figure 50: Viral Load Suppression among Women by Race/Ethnicity – Year Ending 12/31/15	63
Figure 51: Viral Load Suppression among Women by Gender – Year Ending 12/31/15	63
Figure 52: Viral Load Suppression among Women by Age Category – Year Ending 12/31/15	64
Figure 53: Viral Load Suppression among Women by Health Insurance – Year Ending 12/31/15	64
Figure 54: Viral Load Suppression among Women by County of Residence – Year Ending 12/31/15	64
Figure 55: Viral Load Suppression among Women by Residence in 5 Largest Cities – Year Ending 12/31/15	65
Figure 56: Viral Load Suppression among Women by Housing Status – Year Ending 12/31/15	66
Figure 57: Viral Load Suppression among Late Diagnoses by Race/Ethnicity – Year Ending 12/31/15	67
Figure 58: Viral Load Suppression among Late Diagnoses by Gender – Year Ending 12/31/15	67
Figure 59: Viral Load Suppression among Late Diagnoses by Age Category – Year Ending 12/31/15	68
Figure 60: Viral Load Suppression among Late Diagnoses by Health Insurance – Year Ending 12/31/15	68
Figure 61: Viral Load Suppression among Late Diagnoses by County of Residence – Year Ending 12/31/15	69
Figure 62: Viral Load Suppression among Late Diagnoses by Residence in 5 Largest Cities – Year Ending	
12/31/15	69
Figure 63: Viral Load Suppression among Late Diagnoses by Housing Status – Year Ending 12/31/15	70

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)
ADAP	AIDS Drug Assistance Program
ADDP	(New Jersey) AIDS Drug Distribution Program
ARV	Anti-Retroviral (therapies)
CARE Act	Comprehensive AIDS Resources Emergency (CARE) Act
СВО	Community Based Organization
CDC	U.S. Centers for Disease Control and Prevention
СНАМР	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 or managers)
Cmte	Committee
COC	Continuum Of Care Committee of NEMA Planning Council
CQM	Clinical Quality Management
CPC	Comprehensive Planning Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DAYAM	Division of Adolescent and Young Adult Medicine (formerly at UMDNJ, now at Rutgers University)
DCHW	Newark Department of Health and Community Wellness (formerly Department of Child and Family Well Being)
DMAHS	Division of Medical Assistance and Health Services ("Medicaid Division" within the N.J. Department of Human Services)
DHTSS	Division of HIV/AIDS, TB and STD Services, formerly the Division of HIV/AIDS Services
EIIHA	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
FG	Focus Group
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
HCC	HIV Care Continuum
HIPAA	Health Insurance Portability and Accountability Act
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
IHAP	Integrated HIV/AIDS Prevention and Care Plan 2017-2021
КІ	Key Informant [interviews]
LGBTQ	Lesbian, Gay, Bisexual, Transgendered, Questioning
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)
МСМ	Medical Case Management
МН	Mental Health
MMC	Medicaid Managed Care (NJFC for categorically eligible individuals also receiving Temporary Assistance to Needy Families (TANF) or Supplemental Security Income (SSI))
MNT	Medical Nutritional 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
NJCRI	North Jersey Clinical Research Initiative (New Jersey AIDS Partnership)
NJDHS	N.J. Department of Human Services (administers NJ Medicaid and DMAHS)
NJDOH	N.J. Department of Health (formerly NJDHSS – NJ Department of Health and Senior Services)
NJDS	New Jersey Dental School (at Rutgers University)
NJFC	New Jersey Family Care (Medicaid Expansion)
NJ-CLAS	New Jersey Culturally and Linguistically Appropriate Standards
PLWHA	People Living With HIV or AIDS
PPACA	Patient Protection and Affordable Care Act (also known as the "Affordable Care Act"
REC	Research and Evaluation Committee of NEMA Planning Council
RIC	Retention In Care
RW	Ryan White [Program]
RWHAP	Ryan White HIV/AIDS 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)
TGA	Transitional Grant Area
VLS	Viral Load Suppression
WICY	Women, Infants, Children and Youth
YMSM	Young Men who have Sex with Men

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).

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));
(ii) demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;

(iii) priorities of the communities with HIV/AIDS for whom the services are intended;
(iv) coordination in the provision of services to such individuals with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;

(v) availability of other governmental and non-governmental resources, including the State medicaid plan under title XIX of the Social Security Act [42 U.S.C. 1396] et seq.] and the State

Children's Health Insurance Program under title XXI of such Act [42 U.S.C. 1397aa et seq.] to cover health care costs of eligible individuals and families with HIV/AIDS; and (vi) capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities;

(D) develop a comprehensive plan for the organization and delivery of health and support services described in <u>section 300ff–14 of this title</u> that—

(i) includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;

(ii) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse);

(iii) is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS; and

(iv) includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in <u>section 300ff–14 of this title</u>, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities;

(E) assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area, and at the discretion of the planning council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs;

(F) 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 of this subchapter;

(G) establish methods for obtaining input on community needs and priorities which may include public meetings (in accordance with paragraph (7)), conducting focus groups, and convening ad-hoc panels; and

(H) 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
- 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 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 2016 was twofold. First, to continue to assess the ongoing impact of the changing healthcare landscape on the Ryan White HIV/AIDS Program (RWHAP), and build upon the results of previous 2015 Update and 2014 Assessment. Second, and more importantly, to shift the approach of previous assessments and align assessment of patient needs with respect to achieving outcomes along the HIV Care Continuum (HCC).

The HIV Care Continuum, formerly called the HIV Treatment Cascade, was formalized in President Obama's Executive Order of August 2013 as the framework for HIV/AIDS among all federal agencies. The National HIV/AIDS Strategy 2020 issued in July 2015 incorporated the HCC as the measurement framework. The diagnosed-based HCC has five measures: (1) diagnosed, (2) linkage of newly-diagnosed to medical care, (3) retention in care, (4) antiretroviral use, and (5) viral suppression. The 2016 Needs Assessment focuses on **retention in care and viral load suppression.**

The 2014 Needs Assessment focused on implementation of the Affordable Care Act (ACA) including Medicaid Expansion in New Jersey starting on January 1, 2014. The major issue of the 2015 Needs Assessment Update to was the impact of the ACA on the Ryan White HIV/AIDS Program (RWHAP) after one full year of operation - as of the end of 2014. The EMA began to identify the core medical and support service gaps and needs of PLWHA newly enrolled in the ACA and what was needed to help achieve Viral Load Suppression (VLS) including data on linkage to care and retention.

The 2016 Needs Assessment examined the health outcomes post-ACA implementation and especially with respect to the key indicators of the HCC – retention and viral suppression – needed to reduce HIV transmission rates and improve health outcomes which are equivalent to containing the HIV epidemic.

The results of the 2016 Needs Assessment will be used as baseline information for implementation of the Newark EMA Integrated HIV/AIDS Prevention and Care Plan for 2017-2021 (IHAP).

Research Questions

<u>Part 1:</u> What are the gaps in meeting outcomes along the HIV care continuum among our target groups (youth, MSM of color, 45 and older) and other high risk populations - women, late diagnoses?

<u>Part 2:</u> What do RWHAP consumers know about viral load, viral suppression, their own viral status, and what is there experience with medical visit and appointments kept, rescheduled and missed - as indicators of Viral Load Suppression (VLS) and Retention in Care (RIC). These results will be compared to the CHAMP results in Part 1.

Part 3: What are the characteristics of people who test late for HIV?

- What are the reasons they are testing late?
- How many times did clients see a provider in the last year and did not receive testing?

Methodology

The Needs Assessment 2016 includes use of both quantitative and qualitative research methods. Quantitative methods included a review of the Comprehensive HIV/AIDS Management Program (CHAMP) Client Level Database(CLD) regarding outcomes along the HIV Care Continuum including viral load suppression and retention in care by demographics, geographic area, and service utilization for CY 2015, and tabulation of a survey of 854 consumers regarding their knowledge of and experience with viral load suppression and medical visits/retention in care. Another survey of 33 consumers who were "late testers" (diagnosed with Stage III HIV – AIDS) identified the reasons they delayed entry into HIV medical care. A supplemental focus group of 20 consumers provided feedback on experience on oral health. **All tools – consumer health survey, and late tester survey - are in Appendix B.**

Data on utilization of Part A and MAI (Part F) services was obtained from the Newark EMA Recipient (formerly, Grantee) and the CHAMP system. The Consumer Health Survey was distributed across a wide geographical area throughout the EMA. The Late Tester survey was distributed to agencies who had served the new clients according CHAMP. Results of both consumer surveys were entered into an excel spreadsheets and were tabulated using SPSS software. There was extensive coding, data cleaning and verification involved with the survey responses.

PART 1: GAPS IN MEETING OUTCOMES ALONG THE HIV CARE CONTINUUM

1.1 Introduction

The research question to be answered is:

What are the gaps in meeting outcomes along the HIV care continuum among our target groups (youth, MSM of color, 45 and older) and other high risk populations - women, late diagnoses?

The goal of this question is to assess 2015 service utilization on the CHAMP data files by the HIV Care Continuum (HCC) measures – viral load suppression (VLS) and retention in care (RIC). President Obama's Executive Order of August 2013 confirmed that the HCC would be the framework for HIV/AIDS among all federal agencies. The National HIV/AIDS Strategy 2020 issued in July 2015 incorporated the HCC as the measurement framework.

This Needs Assessment 2016 changes the approach of previous assessments and aligns assessing patient needs with respect to outcomes along the HIV Care Continuum (HCC).

The purpose of this section was to graph data on achievement of Viral Load Suppression (VLS) and Retention in Care (RIC) by the EMA in total and by the five target populations for the year ending 12/31/15. For 2015 the EMA achieved a rate of viral load suppression of 80% (79.81%) and 88% (87.6%) retention in care.

1.2 Methodology

The method used in Part 1 was a comprehensive review and analysis of data from the EMA's Ryan White HIV/AIDS Program (RWHAP) client level data system, CHAMP, for Calendar Year (CY) 2015. Variables included but were not limited to: demographic characteristics, viral load suppression (VLS), retention in care (RIC), by RWHAP services received and give target populations. This was an extensive data review.

1.2.1 Measures

The two measures used for the HIV Care Continuum are based on HRSA HAB Core Performance Measures and the CDC HIV Care Continuum and NJDOH Diagnosis-Based HIV Care Continuum. Sources are indicated in footnotes.

Viral Load Suppression (VLS)

HIV Viral Load Suppression (HRSA HAB)¹

Definition	Percentage of patients, regardless of age, with a diagnosis of HIV with a HIV viral load less than
Demnition	200 copies/mL at last HIV viral load test during the measurement year
Numeratori	Number of patients in the denominator with a HIV viral load less than 200 copies/mL at last HIV
Numerator:	viral load test during the measurement year
Deneminatory	Number of patients, regardless of age, with a diagnosis of HIV with at least one medical visit in
Denominator:	the measurement year
Patient Exclusions:	None

Retention In Care (RIC)

Retained in Care (CDC)

The percentage of diagnosed individuals who had two or more documented medical visits, viral load tests or CD4 tests, performed at least three (3) months apart in the observed year.

Continuously Retained in Care (NJDOH)²

Gap in HIV Medical Visits (HRSA HAB)¹

The definition used by New Jersey to measure being continuously retained in care is "PLWHA having at least two CD4 or VL tests at least three months apart in 2015.

•	
Definition	Percentage of patients, regardless of age, with a diagnosis of HIV who did <u>not have</u> a medical visit in the last 6 months of the measurement year
Numerator:	Number of patients in the denominator who did <u>not have</u> a medical visit in the last 6 months of the measurement year
Denominator:	Number of patients, regardless of age, with a diagnosis of HIV who had at least one medical visit in the first 6 months of the measurement year
Patient Exclusions:	Patients who died at any time during the measurement year
Retention in Care -	"Reverse of Gap" [in HIV Medical Visits] – Newark EMA
Definition	Percentage of patients, regardless of age, with a diagnosis of HIV who had a medical visit in the last 6 months of the measurement year
Numerator:	Number of patients in the denominator who had a medical visit in the last 6 months of the measurement year
Denominator:	Number of patients, regardless of age, with a diagnosis of HIV who had at least one medical visit in the first 6 months of the measurement year
Patient Exclusions:	Patients who died at any time during the measurement year

The "Reverse" of the Gap measure is the HRSA HAB measure that is closest to the CDC/NJDOH measure – in terms of measurement period (one year) and frequency of measures of CD4, VL or medical visits.

¹ HRSA. HAB. <u>http://hab.hrsa.gov/deliverhivaidscare/coremeasures.pdf</u>. Accessed 10/2/16.

² New Jersey HIV Care Continuum Among Persons Living with HIV/AIDS in 2015. Abdel R. Ibrahim and John Ryan. Epidemiologic Services/DHSTS. April 2016

1.2.2 Five Target Populations

The Needs Assessment - 2016 was to focus on five target populations:

- 1. Youth (Age 13-24)
- 2. Men who have Sex with Men (MSM) of Color
- 3. Women (Age 18 and older)
- 4. Individuals age 45 and older
- 5. Late Testers Individuals newly diagnosed (within the past 12 months) with Stage III HIV disease that is, **AIDS diagnosis.**

1.3 Baseline Findings

1.3.1 Baseline Findings – Viral Suppression

As expected, there were variations within the target populations. Youth had an overall lower rate of VLS despite having medical visits. Persons age 45 and older had higher rates of VLS. These findings are typically due to the nature and behavior of adolescents and young adults compared to those age 45 and older who are typically more stable and careful in their health behaviors.

Lower rates of VLS were seen in the following groups. Much of this is expected based on experience within the EMA and nationwide.

- <u>Target Populations</u> Youth have lower rates of VLS, particularly those age 19-24 and African American. Among MSM of Color, African-Americans have lower VLS, and those with Medicaid or who are uninsured, and unstably housed. Among Women, younger women have lower rates of VLS, as well as those in temporary or unstable housing. Persons with Late Diagnoses (AIDS) have lower VLS for all demographic categories.
- **<u>Race/Ethnicity</u>** African Americans have lower VLS than others.
- <u>Gender</u> women are slightly lower than men VLS.
- <u>Age</u> younger populations under age 45 have lower VLS.
- Health Insurance Medicaid beneficiaries and the uninsured have lower VLS rates.
- **<u>Residence</u>** VLS is lower among residents of Essex County, Newark and East Orange.
- Housing Status those in temporary or unstable housing arrangements have lower VLS.

The individual figures for each of the target groups are in **Appendix A-1**.

TARGET POPULATIONS





Figure 3: Viral Load Suppression in Newark EMA by Gender – Year Ending 12/31/15



TOTAL RWHAP CLIENTS





Figure 4: Viral Load Suppression in Newark EMA by Age Category – Year Ending 12/31/15





Figure 5: Viral Load Suppression in Newark EMA by Health insurance – Year Ending 12/31/15

Figure 7: Viral Load Suppression in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15



Figure 6: Viral Load Suppression in Newark EMA by County of Residence – Year Ending 12/31/15



Figure 8: Viral Load Suppression in Newark EMA by Housing Status – Year Ending 12/31/15



1.3.2 Baseline Findings – Retention In Care

Results of retention in care – two medical visits per year in each 6 month period - were slightly different than viral suppression. It is difficult to assess gaps because the **percentage variations between the EMA-wide average of 87.6% were so small**. However, the following are noted.

- <u>Target Populations</u> MSM of Color and Women (Age 18+) have RIC rates slightly below the EMA. Youth RIC exceeds the EMA by three percentage points and RIC for persons age 45+ exceeds the EMA percentage by one percentage point. Late testers (Late Diagnoses-AIDS) have a 100% RIC rate which is due to their new diagnosis and need to get their medical care and ARVs stabilized.
- <u>Race/Ethnicity</u> Hispanic/Latino PLWHA have the highest rates of RIC followed by Whites. African Americans have slightly lower RIC rates than EMA-wide. However, since Blacks account for 70% of persons retained in care, their numbers weight the total so the measure may not be fully accurate.
- <u>Gender</u> At 87.3% women have slightly lower RIC than men, whose rate of 87.9% is slightly higher than the EMA's 87.6%.
- <u>Age</u> RIC by age shows the most contrast with VLS. Younger populations under age 24 have higher retention than older populations. For those children under age 18, 100% RIC rate is due to parents/caregivers bringing them to the provider. For those age 18-24, the 90% RIC rate is attributable to the special RWHAP-funded programs in the EMA targeting youth. The surprise is PLWHA age 25-34, where 407 of 499 or 81% of young adults were retained in care. Persons age 35-64 have higher percentages of RIC. However, RIC at 86% for those age 65+ is lower than the EMA percentage. This is surprising because most age 65+ have Medicare or are dual eligibles (Medicare and Medicaid). This may be due to a data entry issue, and that medical visits paid by Medicare are not recorded in CHAMP.
- <u>Health Insurance</u> In contrast to VLS, Medicaid beneficiaries have a higher percent of RIC at 88.9% than the EMA. Medicare is the same as the EMA; private insurance is lower (possibly due to data entry issues or lack of information). The uninsured who receive RWHAP medical care have RIC rates of 85.8% two percentage points lower than the EMA.
- <u>Residence</u> As with VLS, retention in care is lower among residents of Essex County and the cities of Newark, East Orange and Irvington. Persons living outside of the EMA have slightly lower RIC but that is to be expected due to access issues or finding an HIV provider closer to home.
- <u>Housing Status</u> As with VLS, those in **temporary housing arrangements have slightly lower** retention in care (86.9%) than those in stable and even unstable housing (87.7%-87.9%). The reason for RIC that equals the EMA average for those in unstable housing – emergency shelters, homeless, jail/prison – is that RWHAP funds special medical care programs targeting these populations, including discharge planning for jails/prisons.

TARGET POPULATIONS





Figure 11: Retention In Care in Newark EMA by Gender – Year Ending 12/31/15



TOTAL RWHAP CLIENTS



Figure 10: Retention In Care in Newark EMA by Race/Ethnicity – Year Ending 12/31/15

Figure 12: Retention In Care in Newark EMA by Age Category – Year Ending 12/31/15



Page 7



Figure 13: Retention In Care in Newark EMA by Health Insurance – Year Ending 12/31/15

Figure 15: Retention In Care in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15



Figure 14: Retention In Care in Newark EMA by County of Residence – Year Ending 12/31/15



Figure 16: Retention In Care in Newark EMA by Housing Status – Year Ending 12/31/15



1.4 Viral Load Suppression by Retention In Care

This section compared viral suppression rates with retention in care –whether the target groups showed differences in VLS outcomes if they had 2 or more medical visits per year (in CY 2015). All target groups who were retained in care in CY 2015 showed higher rates of viral suppression.

- Among **Youth** (n=147), VLS rates were higher if they were retained in care but still lower than the EMA rate -70% versus 80%.
- **MSM of Color** (n=591) retained in care had VLS rates of 82% compared with 75% if not retained.
- Persons Age 45 and older (n=2,471) had VLS rates exceeding the EMA average regardless of retention in care.
- 82% of **Women** (n=1,458) retained in care achieved viral suppression versus 74% of those not retained.
- Late Testers (n=13) had VLS rates of 77% lower than the EMA-wide rate which is to be expected given delayed entry into medical care.



Figure 17: Viral Load Suppression of Target Populations by Whether Retained in Care – CY 2015

1.5 Viral Load Suppression by Length of Time in RWHAP Care

Since the previous section found that PLWHA who were Retained In Care with at least 2 medical visits in the year had better Viral Suppression than those without two visits, we decided to examine if whether VLS varied by the length of time in the RWHAP system. That is, does VLS improve the longer a person is in Ryan White?

The answer was not clear. See the table below. As expected, new clients in RWHAP for one year or less had much lower VLS at 58% compared with 80% EMA-wide. These "one year" clients include (1) those never before in the RWHAP system regardless of date of diagnosis, and (2) the Early Intervention Services (EIS) clients who were newly diagnosed within the past 12 months and linked to RWHAP care in CY 2015. EIS clients achieved VLS of 52%.

Clients in RWHAP for 2-3 years achieved an overall VLS rate of 82%. This percentage continued for those RWHAP clients active for 4-5 years and 6 years and longer. It could be **expected that the VLS rate for "long-term" RWHAP clients would trend upward and increase above 82%, but CY 2015 data do not show this.** See Figure 19.

The target populations show more variations as shown in the tables below (Table 2 and Table 3).

- For **youth**, VLS starts at 44% for new clients, rises to 81% and then declines to 66% for long term clients.
- For **MSM of Color**, initial VLS is 59% and rises to 80%-85% then drops to 80%.
- For those age 45 and older, initial VLS is 62% rising to 86% and settling in at 85%.
- For women, the initial VLS rate of 57% rises to 82% and settles in at 79%.
- For Late Testers, the initial VLS rate was 54%. (These are new client so there is no data beyond their first year in RWHAP.)



Figure 18: VLS by Length of Time in RWHAP and Target Population – CY 2015

Length of Time in NFMA	# Clien	ts (End of CY 2	2015)	9	% Distribution				
RWHAP	VL Suppressed	Not VL Suppressed	Total	VL Suppressed	Not VL Suppressed	Total			
Years Active in RWHAP									
(Total # years incl gaps)									
1 year	226	161	387	<mark>58.4%</mark>	41.6%	100.0%			
2-3 years	543	120	663	81.9%	18.1%	100.0%			
4-5 years	442	104	546	81.0%	19.0%	100.0%			
6 and above years	2,459	543	3,002	81.9%	18.1%	100.0%			
Total	3,670	928	4,598	79.8%	20.2%	100.0%			
<u>New Client 2015</u> (Never in CHAMP/NEMA RWHAP before)	221	157	378	58.5%	41.5%	100.0%			
<u>Early Intervention (EIS)</u> <u>Client 2015</u> (Newly diagnosed & never in CHAMP/NEMA RWHAP before)	70	65	135	51.9%	48.1%	100.0%			

Table 1: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP

Figure 19: Viral Load Suppression in 2015 by New Clients and Years Active in RWHAP



					Years /	Active In	NEMA	RWHAF	D				Nov	Client	2015	EIS Client 2015		0015
Target		1 year			2-3 year	ſS		4-5 year	ſS	6 and	d above	years	ivev	Client	2015	EIS	Client 2	2015
Population		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Youth (13-24)	15	19	34	30	11	41	18	4	22	59	30	89	15	19	34	7	11	18
MSM of Color	68	48	116	152	38	190	124	21	145	236	60	296	67	48	115	20	21	41
Age 45+	101	63	164	256	40	296	243	47	290	1918	347	2265	98	61	159	23	18	41
Women	69	52	121	183	40	223	132	39	171	1040	273	1313	68	48	116	16	19	35
Late Dx AIDS	27	23	50	0	0	0	0	0	0	0	0	0	27	23	50	27	23	50
Total NEMA	226	161	387	543	120	663	442	104	546	2459	543	3002	221	157	378	70	65	135

Table 2: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Target Population (Count)

Page 12

 Table 3: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Target Population (Percent Distribution of VLS)

			Year	s Active In	NEMA RW	/HAP			Now Clie	ont 2015	EIS Client 2015		
Target	1 ye	ear	2-3 y	ears	4-5 y	/ears	6 and abo	ove years		2015	LIS CITE	111 2015	
Population		Not		Not		Not		Not		Not		Not	
	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	Total
Youth (13-24)	44.1%	55.9%	73.2%	26.8%	81.8%	18.2%	66.3%	33.7%	44.1%	55.9%	38.9%	61.1%	100%
MSM of Color	58.6%	41.4%	80.0%	20.0%	85.5%	14.5%	79.7%	20.3%	58.3%	41.7%	48.8%	51.2%	100%
Age 45+	61.6%	38.4%	86.5%	13.5%	83.8%	16.2%	84.7%	15.3%	61.6%	38.4%	56.1%	43.9%	100%
Women	57.0%	43.0%	82.1%	17.9%	77.2%	22.8%	79.2%	20.8%	58.6%	41.4%	45.7%	54.3%	100%
Late Dx AIDS	54.0%	46.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	54.0%	46.0%	54.0%	46.0%	100%
Total NEMA	58.4%	41.6%	81.9%	18.1%	81.0%	19.0%	81.9%	18.1%	58.5%	41.5%	51.9%	48.1%	100.0%

1.6 Viral Load Suppression and Retention In Care by Services

The purpose of this section was to analyze CHAMP data from CY 2015 on Viral Load Suppression (VLS) and Retention In Care (RIC) by Ryan White HIV/AIDS Program (RWHAP) services received during 2015. This analysis might indicate the services in which VLS and RIC were high and low, and where to target RWHAP efforts to improve VLS and RIC outcomes.

CHAMP data were obtained for 6,640 RWHAP clients in 2015 as follows: 4,598 for VLS and 3,703 for Retention In Care.

- 3,670 or 79.8% had Viral Load Suppression (VLS) and 3,245 or 87.6% were Retained In Care.
- The VLS percentages were <u>lower</u> than the EMA average in 5 service categories mental health, outpatient substance abuse, medical transportation, housing and residential substance abuse. It was decided to review the service subtypes within each of these categories.
- Tables showing Viral Suppression and Retention in Care for the remaining nine service categories are in **Appendix A-2.**

1.6.1 Mental Health Services

A total of 1,866 (28%) clients received RW-funded Mental Health services in 2015 – with 1,262 reporting Viral Load Suppression (VLS) and 1'055 Retention In Care (RIC).

995 or 78.8% had Viral Load Suppression (VLS) and 937 or 88.8% were Retained In Care.

- By service subtype, lower rates of VLS were experienced among those receiving Individual Family Counseling services (76.9%) and Mental Health Assessment (75.3%).
- Likewise, lower rates of Retention In Care were experienced by these two subtypes at 69.2% (Individual Family Counseling) and 68.5% (Mental Health Assessment).

1.6.2 Outpatient Substance Abuse Services

A total of 1,040 (16%) clients received RW-funded Outpatient Substance Abuse services in 2015 – with 732 reporting Viral Load Suppression (VLS) and 639 Retention In Care (RIC).

568 or 77.7% had Viral Load Suppression (VLS) and 601 or 94.1% were Retained In Care.

- By service subtype, lower rates of VLS were experienced among those receiving Individual Counseling-Level II Intensive Outpatient services (62.5 %), Methadone Treatment (68.8%), Suboxone Treatment (75.6%) and Substance Abuse Assessment (68.4%).
- However, there were no low rates of Retention In Care by subtype. All were at least 94% or greater. This is likely because substance abuse services are connected directly with medical care.

1.6.3 Medical Transportation Services

A total of 1,191 RW clients (17.9%) received transportation services in 2015. Of those, 923 received RW medical care and had information about VLS and 822 had information about RIC.

Of those clients receiving transportation, 729 or 79% were virally suppressed and 777 or 93.7% were retained in care.

- By service subtype, those who had **door-to-door transportation (taxi reimbursement or agency van transport)** had higher rates of VLS and RIC than those who received bus or train passes.
 - Those receiving **bus/train passes** had a **slightly lower VLS at 77.5% than EMA-wide average VLS of 79.0%.** This lower rate may be associated with less stable living arrangements, difficulty in making connections, etc. But the variation is small.
 - Retention In Care was good for all. Even those receiving bus/train passes had RIC at 93.1% which was lower than taxi reimbursement (100%) and agency van transport (95.6%) but is still a very good RIC rate.

1.6.4 Housing Services

PLWHA receiving emergency or short-term Housing Services are expected to have lower compliance and outcomes than those in stable housing arrangements. A total of 189 individuals receiving housing services reported viral load data and 170 reported retention in care data.

- Over three quarters (75.7%) of RW clients receiving housing services were virally suppressed. **73.5% receiving transitional housing were virally suppressed.**
- 92.4% of RW clients receiving housing services were Retained In Care -and 95% received transitional housing. Only 84.2% of those receiving security payments were retained in care.
- New clients receiving RWHAP housing services have by far the lowest rates of viral load suppression at 58.3%. However those who have been in Ryan White for six years and above have lower VLS rates at 74.6%.

Payment for emergency and short-term housing services by RWHAP shows benefits – in terms of reasonable viral load suppression and higher retention in care than the overall EMA percentage of 87.6%. The RW HAP transitional housing programs also include case management and linkage to care which help PLWHA achieve good health outcomes.

1.6.5 Residential Substance Abuse Services

Only 16 PLWHA received RWHAP funded Residential Substance Abuse services. Only 53.8% were virally suppressed but 90.9% were Retained In Care, exceeding the EMA wide percentage. Of course, retention is due to on-site or nearby access to regular medical care as part of the treatment program.

There was no statistically measurable difference in VLS based on the length of time in RWHAP services due to small numbers. However, those in RWHAP for two years or more had higher rates of VLS than new clients.

		# Clients						% Distribution with Service Category						
	Viral	Load Suppress	ion	Reter	ntion In Care	(Gap)		Viral I	.oad Suppre	ssion	Reten	tion In Care	(Gap)	
RWHAP Services Received in 2015	VL Suppressed	Not VL Suppressed	Total	Retained in Care	Not Retained in Care	Total		VL Suppres sed	Not VL Suppres sed	Total	Re- tained in Care	Not Re- tained in Care	Total	
Primary Medical Care	3,670	928	4,598	3,245	458	3,703	Ī	79.8%	20.2%	100%	87.6%	12.4%	100%	
Mental Health	995	267	1,262	937	118	1,055		78.8%	21.2%	100%	88.8%	11.2%	100%	
OP Substance Abuse	569	163	732	601	38	639		77.7%	22.3%	100%	94.1%	5.9%	100%	
Oral Health	687	120	807	625	72	697		85.1%	14.9%	100%	89.7%	10.3%	100%	
Medical Case Mgt	3,514	858	4,372	3,245	458	3,703		80.4%	19.6%	100%	87.6%	12.4%	100%	
Medical Nutr. Therapy	417	96	513	417	30	447		81.3%	18.7%	100%	93.3%	6.7%	100%	
Non-Medical Case Mgt	838	204	1,042	850	62	912		80.4%	19.6%	100%	93.2%	6.8%	100%	
Housing Services	143	46	189	157	13	170		75.7%	24.3%	100%	92.4%	7.6%	100%	
Residential Subst. Abuse	7	6	13	10	1	11		53.8%	46.2%	100%	90.9%	9.1%	100%	
Food/Nutritional	181	41	222	197	7	204		81.5%	18.5%	100%	96.6%	3.4%	100%	
Transportation	729	194	923	770	52	822		79.0%	21.0%	100%	93.7%	6.3%	100%	
Legal Services	127	26	153	130	9	139		83.0%	17.0%	100%	93.5%	6.5%	100%	
Emergency Fin. Asstc.	133	25	158	129	13	142		84.2%	15.8%	100%	90.8%	9.2%	100%	
Health Ins. Prem. Asstc	117	18	135	114	4	118		86.7%	13.3%	100%	96.6%	3.4%	100%	
Medical Visits ³	3,072	779	3,851	2,881	305	3,186		79.8%	20.2%	100%	90.4%	9.6%	100%	
Total 2015	3,670	928	4,598	3,245	458	3,703		79.8%	20.2%	100.0%	87.6%	12.4%	100.0%	

Table 4: 2015 RWHAP Clients Virally Suppressed and Retained In Care by Services Received – Newark EMA.

³ Medical Visits = RWHAP clients who had a medical visit in CY 2015. Primary Medical Care may have included services that were NOT medical visits billed to RWHAP.



Figure 20: Percent 2015 RWHAP Clients Virally Suppressed by Service Received – Newark EMA



Figure 21: Percent 2015 RWHAP Clients Retained In Care by Service Received – Newark EMA

MENTAL HEALTH SERVICES BY SUBTYPE

Table 5: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Mental Health Service Subtype (Services Received) – Number of Clients

	H4C Vira	al Load Suppre	ssion	Retent	ion (Revers	e Gap)
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Indiv Counseling	723	174	897	663	82	745
Indiv Counseling-IOP						
Indiv-Psychiatric	244	53	297	255	16	271
Indiv-Family Counseling	10	3	13	9	4	13
Indiv-COOD	10		10	10		10
MH Assessment	171	56	227	111	51	162
Group Counseling	67	9	76	68	4	72
Group-Family						
MH Screening	191	48	239	199	10	209
Total MH Services	995	267	1262	937	118	1055

Table 6: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Mental Health Service Subtype (Services Received) – Percent Distribution

	H4C Vira	al Load Suppre	ession	Retent	tion (Revers	e Gap)
				Retained	Not Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	lotal
Indiv Counseling	80.6%	19.4%	100.0%	89.0%	11.0%	100.0%
Indiv Counseling-IOP	0%	0%	0%	0%	0%	0%
Indiv-Psychiatric	82.2%	17.8%	100.0%	94.1%	5.9%	100.0%
Indiv-Family Counseling	76.9%	23.1%	100.0%	69.2%	30.8%	100.0%
Indiv-COOD	100.0%	0.0%	100.0%	100.0%	0.0%	100.0%
MH Assessment	75.3%	24.7%	100.0%	68.5%	31.5%	100.0%
Group Counseling	88.2%	11.8%	100.0%	94.4%	5.6%	100.0%
Group-Family	0%	0%	0%	0%	0%	0%
MH Screening	79.9%	20.1%	100.0%	95.2%	4.8%	100.0%
Total MH Services	78.8%	21.2%	100.0%	88.8%	11.2%	100.0%

OUTPATIENT SUBSTANCE ABUSE SERVICES BY SUBTYPE

Table 7: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by OP Substance Abuse Service Subtype (Services Received) – Number of Clients

	H4C Vira	al Load Suppre	ession	Reten	tion (Revers	e Gap)
	VL Suppressed	Not VL Suppressed	Total	Retained in Care (Gap)	Not Retained in Care (Gap)	Total
Indiv Counsel-Level I	331	101	432	369	20	389
Indiv Counsel-Level II IOP	5	3	8	7		7
Indiv Counsel-Level III Partial Care	2		2	1		1
Group Counsel - Level I	177	45	222	195	8	203
Group Counsel - Lev I - Indiv Billed	4	1	5	5		5
Group Counsel - Level II – IOP	72	17	89	74	3	77
Methadone Treatment	11	5	16	11		11
Suboxone Treatment	31	10	41	37	2	39
SA Screening	230	66	296	236	15	251
SA Assessment	80	37	117	96	5	101
Total SA Services (Clients)	568	163	731	601	38	639

Table 8: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by OP Substance Abuse Service Subtype (Services Received) – Percent Distribution

	H4C Vira	al Load Suppre	ession	Retent	tion (Revers	e Gap)
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Indiv Counsel-Level I	76.6%	23.4%	100.0%	94.9%	5.1%	100.0%
Indiv Counsel-Level II IOP	62.5%	37.5%	100.0%	100.0%	0.0%	100.0%
Indiv Counsel-Level III Partial Care	100.0%	0.0%	100.0%	100.0%	0.0%	100.0%
Group Counsel - Level I	79.7%	20.3%	100.0%	96.1%	3.9%	100.0%
Group Counsel - Lev I - Indiv Billed	80.0%	20.0%	100.0%	100.0%	0.0%	100.0%
Group Counsel - Level II – IOP	80.9%	19.1%	100.0%	96.1%	3.9%	100.0%
Methadone Treatment	68.8%	31.3%	100.0%	100.0%	0.0%	100.0%
Suboxone Treatment	75.6%	24.4%	100.0%	94.9%	5.1%	100.0%
SA Screening	77.7%	22.3%	100.0%	94.0%	6.0%	100.0%
SA Assessment	68.4%	31.6%	100.0%	95.0%	5.0%	100.0%
Total SA Services (Clients)	77.7%	22.3%	100.0%	94.1%	5.9%	100.0%

MEDICAL TRANSPORTATION SERVICES BY SUBTYPE

Table 9: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Medical TransportationService Subtype (Services Received) – Number of Clients

	H4C Vir	al Load Suppre	ession	Retention (Reverse Gap)			
					Not		
				Retained	Retained		
	VL	Not VL		in Care	in Care		
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total	
Bus/Train Passes	569	165	734	607	45	652	
Taxi Reimbursement	56	8	64	59	0	59	
Van/Agency based Transport	183	42	225	195	9	204	
Total Transp Services (Clients)	729	194	923	770	52	822	

Table 10: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Medical Transportation Service Subtype (Services Received) – Percent Distribution

	H4C Vira	al Load Suppre	ession	Retent	tion (Revers	e Gap)
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Bus/Train Passes	77.5%	22.5%	100.0%	<mark>93.1%</mark>	6.9%	100.0%
Taxi Reimbursement	87.5%	12.5%	100.0%	100.0%	0.0%	100.0%
Van/Agency based Transport	81.3%	18.7%	100.0%	95.6%	4.4%	100.0%
Total Transp Services (Clients)	79.0%	21.0%	100.0%	93.7%	6.3%	100.0%

HOUSING SERVICES BY SUBTYPE

Table 11: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Housing Service Subtype (Services Received) – Number of Clients

	H4C Vira	al Load Suppre	ession	Retention (Reverse Gap)			
					Not		
				Retained	Retained		
	VL	Not VL		in Care	in Care		
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total	
Transitional	86	31	117	96	5	101	
Coordination/Assistance	1		1	1		1	
Rental Assistance-Short Term	34	8	42	38	3	41	
Security Payment	30	10	40	32	6	38	
Total Housing Services (Clients)	143	46	189	157	13	170	

Table 12: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Housing Service Subtype (Services Received) – Percent Distribution

	H4C Viral Load Suppression			Retention (Reverse Gap)		
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Transitional	73.5%	26.5%	100.0%	95.0%	5.0%	100.0%
Coordination/Assistance	100.0%	0.0%	100.0%	100.0%	0.0%	100.0%
Rental Assistance-Short Term	81.0%	19.0%	100.0%	92.7%	7.3%	100.0%
Security Payment	75.0%	25.0%	100.0%	84.2%	15.8%	100.0%
Total Housing Services (Clients)	75.7%	24.3%	100.0%	92.4%	7.6%	100.0%

RESIDENTIAL SUBSTANCE ABUSE SERVICES BY SUBTYPE

Table 13: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Residential Substance Abuse Service Subtype (Services Received) – Number of Clients

	H4C Viral Load Suppression			Retention (Reverse Gap)		
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Residential Substance Abuse	7	6	13	10	1	11
Total Resid. SA Services (Clients)	7	6	13	10	1	11

Table 14: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Residential Substance Abuse Service Subtype (Services Received) – Percent Distribution

	H4C Viral Load Suppression			Retention (Reverse Gap)		
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Residential Substance Abuse	53.8%	46.2%	100.0%	90.9%	9.1%	100.0%
Total Resid. SA Services (Clients)	53.8%	46.2%	100.0%	90.9%	9.1%	100.0%

1.7 Conclusions and Recommendations

The CHAMP data analysis provides considerable information on the target populations and all others receiving RWHAP services. This Needs Assessment provides some indication of where and what areas and populations to target to improve outcomes of Retention In Care and Viral Load Suppression along the HIV Care Continuum. However, more detailed analysis is needed and indicated in the recommendations.

Target Populations Still Need Targeting!

Data show that the five "target" populations still need special attention and interventions to improve viral suppression and retention in care – or retention in care to achieve VLS. See the tables in Appendix A that show VLS for each of these target populations by demographics and geographic areas which can improve understanding of successes and gaps in VLS.

Recommendation – Youth and "Former Youth". Despite high rates of retention (2+ medical visits/year), the rates of viral suppression are well below all other populations. The numbers of youth client are small and can be addressed on an individual basis. It is recommended that the EMA develop strategies to improve viral suppression of individual youth clients, identifying barriers and recommendations for improvement including innovative approaches like an antiretroviral vaccine given once a month or longer. Agencies that work with youth should also combine prevention activities including PrEP with care and treatment. *Individuals age 25-34, aka "former youth" who also have both low VLS and retention rates and engage in high risk activities should be included in these interventions.*

Recommendation – MSM of Color. Viral suppression is lowest among Black/African American MSM at 74% compared to Hispanic/Latino MSM at 83%. Also MSM age 25-44 (75% VLS) and those on Medicaid (76%) and uninsured (74%) on RWHAP medical care. It is recommended that the EMA "drill down" the data to identify more specifically the location (county/city of residence) of Black MSM, ages and other characteristics and develop targeted approaches to reach these individuals and improve VLS. This could be done as part of the Newark EMA QM Plan and the Integrated HIV/AIDS Plan 2017-2021.

Recommendation – Persons Age 45 and older. The viral suppression rates for this large population differ by age category, length of time in care, and other factors. It is recommended that the EMA stratify data for this population by demographic and geographic subgroups to better identify the groups and locations of individuals needing assistance in VLS.

Recommendation – Women. The same recommendation for persons age 45 and older is made for women. Stratify data for this large population to identify smaller populations who can benefit from targeted interventions.

Recommendation – Late Testers. These individuals with Stage III HIV (AIDS) achieve higher rates of VLS than the other target populations when in care for two or more visits. The efforts should be identifying those at risk, getting them tested, and linking to care immediately – and ensuring
retention during the first several years. This is discussed in Part 3 – but the regional EIRCs should develop and implement both identification and retention strategies appropriate for their regions, at risk populations, and providers.

It's the New Clients Including Newly Diagnosed!

When we looked at new clients – they have lowest VLS. Their low VLS also lowers the EMA-wide rate of viral suppression. This is to be expected because they have not received medical care or antiretrovirals which would improve viral load.

VLS improves to over 80% after a person has been in RWHAP for 2+ years. But there is no increase in VLS the longer a person has been in RWHAP. In fact, as demonstrated by some service subtypes, VLS actually declines after a person has been in RWHAP for six years or more.

The trends in VLS improvement from the first year to years two to three and beyond show the impact of RWHAP medical care and retention in care.

Recommendation. All entities involved in linkage of new clients to care must be marshaled as a team to ensure retention in RWHAP past the first and second years. Whether the patient has public insurance (Medicaid) or private insurance or they are uninsured and receive RWHAP-funded medical care, the care team must ensure follow up, treatment adherence and retention of these new clients. Every provider agency and MCM support agency must implement and follow retention protocols for these new patients.

...But Also Those in RWHAP for 6+ Years!

If Newark EMA RWHAP wants to improve VLS, it must target those who have been in the RW system for more than 1 year. The data show that those who have been in RWHAP for **6 years or longer have** slightly lower VLS than those in RWHAP from 2-5 years.

Recommendation. The agency care teams must also follow up on Viral Suppression of those clients in the RWHAP system for a long time – 6 or more years. These individuals may be resistant to medications or have other issues that impact improvement in viral suppression. This could be a project for the Newark EMA QM committee.

Importance of Accurate Data

It is possible that some issues regarding measurement of VLS and retention are the result of issues with data recording – inaccurate, incomplete or no data entered into CHAMP. CHAMP is the Newark EMA's client level data system that is relied upon by HRSA HAB to capture and report correct information about RWHAP outcomes.

Recommendation. To ensure that the Newark EMA is getting credit for successes in VLS and retention – and can correctly areas needing improvement – all agencies – medical care, medical

case management, non-medical case management – must accurately medical visits of PLWHA regardless of funding source.

...And Look at Specific Service Subtypes as Points to Intervene

It is posited that substance abuse and mental health issues interfere with medical care and Improvement with health of PLWHA. While these data do not confirm this position, the CHAMP service utilization data show that RWHAP clients who are receiving RW funded mental heath services or substance abuse services do have VLS lower than other clients. But this is not the only real answer!

Lower viral loads are present at time of "intake" for behavioral services – Mental Health Screening, Substance Abuse Screening, Mental Health Assessment, and Substance Abuse Assessment. It s at these points that the RW HAP system can begin to educate clients about viral load and good health and to engage clients in their medical care. However, it is recognized that at these points the primary goal is to get the client into behavioral care and to treat the underlying issues so that they can enter medical care and engage in the treatment.

Recommendation. The EMA should identify tools or strategies that can be used at these points to start the process of education and engagement in retention in care and improving viral load and overall health.

Recommendation – Transportation and Retention/Medical Visits. There should be closer examination of the relationship between transportation (bus tickets) and kept medical visits and retention in care. Do RWHAP clients who get transportation assistance (bus tickets) keep their medical appointments? If so, what is their viral suppression? This would help assess outcomes along the HIV Care Continuum. This can be done as part of the Newark EMA QM Committee.

PART 2: CONSUMER SURVEY

2.1 Introduction

The purpose of the consumer health survey was to obtain data from consumers regarding their knowledge of Viral Load, good Viral Load and Viral Load Suppression (VLS), and their medical care, specifically medical visits and compliance. A total of **854 surveys were received** from consumers throughout the Newark EMA. The Consumer Survey is in <u>Appendix XX.</u>

2.2 Demographic Characteristics of Respondents

 Gender – Of the 854, 528 (62%) were male, 321 (38%) were female, two (2) were transgender (<1%), two were "Other" and one did not answer.

Gender of respondents reflects distribution of PLWHA in Newark EMA.

Sexual Behavior – The majority (520 or 61%) responded as heterosexual, 156 (18%) indicated Men who have Sex with Men (MSM), 51 (6%) indicated Bisexual, 19 or 2% indicated Women who have Sex with Women (WSW). The remaining 13% gave other answers – Other (15 or 2%), None/None of the Above (5 or 1%), and No Answer (88 or 10%).

Sexual behavior responses reflect more heterosexual transmission than in EMA's HIV epidemic, but that is OK given that respondents may not want to indicate behavior on a survey.

 Race/Ethnicity – This variable combined two questions – Hispanic/Latino and Race. 513 (60%) of respondents reported they were Black/ African-American, followed by 222 (26%) Hispanic/Latino, 76 (9%) White, Not Hispanic, 23 (3%) Other Race/Ethnicity, and 20 (2%) who did not respond.

A higher percent of survey respondents are Hispanic/Latino than in NEMA Epidemic (21%).

1. Gender	#	%
Male	528	61.8%
Female	321	37.6%
Transgender	2	0.2%
Other	2	0.2%
No Answer	1	0.1%
Total	854	100.0%

2. Sexual Behavior	#	%
Heterosexual	520	60.9%
MSM	156	18.3%
WSW	19	2.2%
Bisexual	51	6.0%
Other	15	1.8%
None/None of Above	5	0.6%
No Answer	88	10.3%
Total	854	100.0%

34. Race/Ethnicity	#	%
White, Not Hispanic	76	8.9%
African American	513	60.1%
Hispanic/Latino	222	26.0%
Other	23	2.7%
Unknown/Not Reported	20	2.3%
Total	854	100.0%

	#	%
Puerto Rico	63	28.4%
México	11	5.0%
Ecuador	7	3.2%
Costa Rica	2	0.9%
Trinidad & Tobago	2	0.9%
Dominican Republic	6	2.7%
Honduras	8	3.6%
Peru	5	2.3%
Cuba	6	2.7%
Guatemala	2	0.9%
Venezuela	3	1.4%
El Salvador	2	0.9%
Colombia	13	5.9%
Brazil	13	5.9%
El Salvador	1	0.5%
No Answer	78	35.1%
Total	222	100.0%

3A Country of Origin (3. Hispanic Answer "Yes")

With respect to **Country of Origin** of the Hispanic/Latino respondents, the highest number/percent indicated Puerto Rico, followed by Colombia and Brazil, the Mexico, Honduras and Ecuador. Over one third did not answer the question.

Age. There was a good distribution of respondents by age. 28 (3%) Youth (Age 13-24), 85 (10%) age 25-34, 113 (13%) age 35-44, 267 (31%) age 45-54, 241 (28) age 55-64, 70 (8%) age 65-74, and 3 (<1%) age 75-84. 47 (5%) gave no answer.

Age Category shows 3 respondents under age 13. This may be a coding error. 68% of respondents were age 45+ which is consistent with 71% of NEMA epidemic.

5. Age Category	#	%
Age 0-12	3	0.4%
Age 13-24	28	3.3%
Age 25-34	85	10.0%
Age 35-44	113	13.2%
Age 45-54	267	31.3%
Age 55-64	241	28.2%
Age 65-74	70	8.2%
Age 75-84	3	0.4%
No Answer	44	5.2%
Total	854	100.0%
Age 45+	581	<u>68.0%</u>

6. County of Residence	#	%
Essex	568	66.5%
Union	108	12.6%
Morris	113	13.2%
Sussex	11	1.3%
Warren	9	1.1%
Outside NEMA	41	4.8%
No Answer	4	0.5%
Total	854	100.0%
Morris, Sussex, Warren	133	15.6%

- 7. ZIP Code 5 Cities # % 384 45.0% Newark East Orange 71 8.3% 3.9% Irvington 33 Elizabeth 48 5.6% Plainfield 0.7% 6 Total - 5 Cities 542 63.5% Outside of 5 Cities 312 36.5% 854 Total 100.0%
- When Diagnosed with HIV. The highest percent of individuals (43%) were diagnosed 15 or more years ago, followed closely by 11-15 years ago and 5-10 years ago. Length of time living with HIV disease based on when diagnosed has implications for the rest of the survey.

Six were not HIV positive – so the **total of 848 HIV Positive respondents will be used for the rest of this consumer survey report.**

 County of Residence. Two thirds (568) reported Essex as county of residence, 133 (16%) Morris Sussex Warren region, 108 (13%) Union County, 41 (5%) outside NEMA, and 4 (<1%) gave no answer.

Responses by county of residence are a little different than the epidemic (70% Essex, 21% Union, 9% Morris Sussex Warren.)

• **ZIP Code of Residence.** Tabulation by ZIP code shows that 2/3 of respondents were from 5 largest EMA Cities, compared to 71% of epidemic. But 45% were from Newark which is consistent with epidemic.

8. When Diagnosed	#	%
Within past year	33	3.9%
2-4 years ago	87	10.2%
5-10 years ago	158	18.5%
11-15 years ago	166	19.4%
15+ years ago	369	43.2%
Not HIV+	6	0.7%
No Answer	35	4.1%
Total	854	100.0%
HIV Positive	848	

2.3 Viral Load

One goal of NHAS 2020 is universal viral suppression among people living with HIV. A second is that improving outcomes at every step of the HIV Care Continuum (HCC) must remain a priority. As a step to achieving these goals of viral suppression and improving outcomes at the HCC endpoint measured by viral suppression, the goal of this section was to determine the extent to which persons living with HIV/AIDS (PLWHA) and RWHAP consumers were working toward achieving Viral Load Suppression (VLS).

The universe of respondents from this point forward is 848 HIV+ individuals.

2.3.1 Knowledge of Viral Load and Viral Load Suppression (VLS)

2.3.1.1 Knowledge of term "Viral Load"

The baseline question was asked: Do you know what Viral Load is? The purpose was to see whether the individuals who were HIV+ had any idea of the measure of optimal HIV health.

¼ (25%) of HIV+ respondents did not know what Viral Load was!

We thought this might be prevalent among those newly

diagnosed and living with HIV disease for < 5 years. So we then did a cross-tabulation of knowledge of Viral Load by Length of Time Living with HIV disease. We found that **30% of those living with HIV** disease for **11+ years did not know what Viral Load was!**

This finding raises the question: How can Newark EMA hope to reduce HIV incidence by reducing HIV transmission (through suppression of Viral Load if 1/4 of PLWHA do not know what Viral Load is and may not understand its importance?

8 When Diagnosed		9. Know What VL is? (#)		9. Know What V		at VL is? (%	VL is? (%)	
8. When Diagnosed	Yes	No	No Ans.	Total	Yes	No	No Ans.	Total
Within past year	23	7	3	33	69.7%	21.2%	9.1%	100%
2-4 years ago	64	22	1	87	73.6%	25.3%	1.1%	100%
5-10 years ago	117	33	8	158	74.1%	20.9%	5.1%	100%
11-15 years ago	117	38	11	166	70.5%	22.9%	6.6%	100%
15+ years ago	261	95	13	369	70.7%	25.7%	3.5%	100%
No Answer	9	14	12	35	25.7%	40.0%	34.3%	100%
Total	591	209	48	848	69.7%	24.6%	5.7%	100%

Knowledge of Viral Load by Length of Time Living with HIV

9. Viral Load - Do You Know What Viral Load is?

	#	%
Yes	591	69.7%
No	209	24.6%
No Answer	48	5.7%
Total	848	100.0%

2.3.1.2 Knowledge of Your (Respondent) Viral Load

The questionnaire attempted to drill down to respondents' knowledge of their own Viral Load. Since the Council did not know how individuals would respond, we allowed a number of responses, which would be analyzed and refined as results were tabulated.

With respect to respondents' answers to the question **"Do You Know what Your Latest Viral Load Is?** the answers to this question were all over and were internally inconsistent.

When cross tabs were run between Viral Load (VL) value and the "undetectable" term, there were inconsistencies. Likewise, some entered "No" but did enter a VL value.

This could be the result of the survey tool design, but more likely that clients are not familiar with the terms Viral Load, undetectable, and values. Only 68% of HIV+ respondents reported some Viral Load.

10. Do Tou know what four latest what load is:				
	#	% HIV+		
10A. No Answer	63	7.4%		
10B. Yes	259	30.5%		
10C. VL Value Entered	126	14.9%		
10D. Undetectable	269	31.7%		
10E. Undetectable (<200)	62	7.3%		
10F. Undetectable (<50)	52	6.1%		
10G. Undetectable (<20)	186	21.9%		
10H. No	151	17.8%		
TOTAL Responses	1,168			
Total Reporting Some VL	579	68.3%		
TOTAL HIV+	848			

10. Do You Know What Your Latest Viral Load Is?

- <u>Viral Load Reporting.</u> A total of 579 or 68% of total 854 respondents reported some Viral Load. 126 (15%) provided a number and the remaining 453 (53%) provided a range, e.g., Under 200, Under 50, Under 20. There were some duplicates in the range categories, for example, a person with a VL of 49 might answer both Under 200 and Under 50. So we took an unduplicated count of persons.
 - It is important to highlight that 275 or one-third did NOT provide any VL information. This may indicate that the questions were confusing, but more likely that consumers do not know what Viral Load is.

2.3.1.3 Reported Viral Load Values

Question 10C asked respondents to enter their numerical Viral Load Value. We ran a cross tabulation of these numerical values with VL categories ("undetectable") to see if there was a match or some correspondence, indicating that respondents understood the relationship between their VL number and VL category (undetectable). To better analyze the data, the reported VL values were grouped by range. The ranges were set to enable comparison with "undetectable" categories. **126 (15%) HIV+** respondents reported their Viral Load value. **80 of these 126 also reported a VL category which is the universe for this tabulation.**

PLWHA with low Viral Loads (66%) appear to understand "undetectable" where as those with higher VL (401+) do not (30%).

VIRAL LOAD RANGE (Based on Reported VL Value)	VL Undetectable	VL Under 200	VL Under 50	VL Under 20	Total	% Dist.
VL Under 20	2	0	0	2	4	5%
VL = 20	10	1	5	26	42	53%
VL 21-49	2	0	2	1	5	6%
VL = 50	0	0	1	0	1	1%
VL 51-199	0	1	0	0	1	1%
VL = 200	0	0	0	0	0	0%
VL 201-399	2	0	1	0	3	4%
VL = 400	0	0	0	0	0	0%
VL 401+	10	3	2	9	24	<mark>30%</mark>
Total	26	5	11	38	80	100%

This knowledge gap is indicated by Question **11: Do You** Know What Viral Load Suppression Or A Good Viral Load Is?

 Know what Good VL of VLS is?
 #
 %

 Yes
 490
 57.8%

 No
 259
 30.5%

 No Answer
 99
 11.7%

 Total
 848
 100.0%

Know What Good VL or

Only 58% of respondents knew. **42% either did not know (30%) or did not answer (12%)!**

2.3.2 Respondents' [Individual] Viral Load Suppression

The remaining series of questions asked about respondents' individual viral load and viral load suppression. Overall, despite varying numerical responses, it is clear that **respondents know what is important to maintain their health and manage their HIV disease, and understand where they may need improvement.**

2.3.2.1 Viral Suppression

Question 11 asked "Do You Have Viral Load Suppression Or Are Virally Suppressed?

The disturbing answer was that over ¼ (27%) did not know and another 7+% did not answer. In other words, over 1/3 (35%) do not know if they are HIV healthy as measured by VLS.

Question 11A asked **how respondents got their VL to this good level** and provided 3 possible responses as well as "Other." Nearly all answered that they took their medications as the way to achieve VLS. 2/3 kept medical appointments.

#	%
451	53.2%
101	11.9%
232	27.4%
64	7.5%
848	100.0%
#	%
431	95.6%
288	63.9%
115	25.5%
451	
	# 451 101 232 64 848 # 431 288 115 451

Respondents who indicated they were **NOT virally suppressed** also answered this question. This indicated **their understanding of the importance of these three methods to their HIV health.**

	Survey Respondents					
Strategy to Achieve VLS/HIV Health	Not Virally Suppressed		Did not know if VLS		No answer to VLS question	
	#	%	#	%	#	%
Took medications	26	25.7%	79	34.1%	31	48.4%
Kept medical appts	17	16.8%	52	22.4%	20	31.3%
Living arrangements	5	5.0%	16	6.9%	3	4.7%
TOTAL NOT VLS	101		232		64	

55 consumers provided additional responses and comments about how they managed their HIV disease.

Additional Reasons or Methods For Maintaining VLS (55 Responses)		
Category	Individual Responses	
Adherence	Adherence.	
Family/Friends	Annoying boyfriend always on my case. Having a great support system. Support	
	from my family and support groups. Wife keeps me on my toes.	
Support Groups	Attend support groups. Support groups. Workshops.	
Provider/Agency	Broadway House helped. Listen to all the doctors. Listen to my doctor and try to eat	
	right. My doctor, Wanda Figueroa.	
Medications	Change in medication. Changed prescriptions. Not on meds. Patient states being	
	adherent however MD in the process of evaluating regime. Started clinical trials at	
	St. Michaels Medical Center at diagnosis.	
Healthy Eating/Diet	Diet. Eat healthier. Eat healthy. Eating. Eating healthy. Eating right as well.	
	Eating/exercise. Healthy diet. Herbal supplements. Nutrition.	
Lifestyle Change	Change the way I was living. Doing the right thing. Doing the things that are most	
	important in life while living with HIV. Eat, take meds, rest. Eating well, rest.	
	Exercise, good eating, taking care of myself. Proper rest and exercise. Exercise.	
Housing	Exercise and my own place to live. Living arrangement stinks.	
Take Care of Myself	Loving myself. Taking care of myself. Taking care of self. Taking good care of myself.	
Reduce Stress	Low stress intake. No stress, exercise. Stress free.	
Faith	My faith in God. Plenty of prayer and eating well. Trusting and believing God, the	
	Creator. Practicing to pray and have more faith. Tengo fe que Dias El todo poderoso	
	tiene control de me vida.	
Substance use	No unprotected sex. No drugs. Quit smoking. No alcohol. No alcohol, smoking, and	
	sexual activity. Stop getting high. Stop using.	
Unknown	Do not know. I do not know. Just know it's good. Don't know. I don't know anything	
	about it, but to stay away. I don't know. Good numbers without meds.	

2.3.2.2 Not Virally Suppressed

For those who were not virally suppressed, Question 11B asked "What Happened to Prevent or Interfere with VL Improvement?"

The primary reason was missing medications (73%) followed by missing medical appointments (42%).

Prevent/Interfere with VL Improvement	#	%
Missed medications	74	73.3%
Missed medical appts	42	41.6%
Living arrangements	31	30.7%
No Answer	37	36.6%
Total No VLS	101	

25 consumers provided additional responses and comments about why they did not maintain good VL.

Additional Reasons or Methods For Not Maintaining Good VL (25 Responses)		
Category	Individual Responses	
Substance Use	Using drugs. Drug use. Was homeless for the past few years. I had a bad substance abuse addiction.	
Take HIV Medications	Always take HIV Meds. Just began medication. Maybe resistant. Waiting for bloodwork results to change meds. Not on meds. Not sure. I take my medications daily. Resistant to medication. Been on the same medication since I was diagnosed. Waiting for bloodwork.	
Stop/Forget HIV Medications	Because I forget. Had stopped taking meds. Just forgot. Stop taking meds.	
Access to HIV Medications	Cannot get medications.	
Lack of Provider/Health	Closure of infectious diseases clinic where I was for 24 years a patient. Not	
Insurance	having health insurance at the time, it was difficult to receive treatment. Don't have and can't afford insurance. Problem with welfare.	
Don't Know	Don't know. I just don't understand.	
Retention – Dropped Out	Dropped out of care.	
Family Issues	Family problems.	
Other	If I am right about what I think it is, I'm on my way to get it suppressed. (almost undetectable). Just got here and the doctor has not spoken about my viral stuff. Taking care of myself.	

2.3.2.3 Maintain or Improve VLS

Question 12 asked all respondents how they were going to maintain or improve their Viral Load? The vast majority indicated they would **keep taking medications (84%) and more than half would keep medical appointments (59%).**

How Maintain/Improve VL?	#	%
Keep taking medications	716	84.4%
Keep medical appts	504	59.4%
Do Not Know	1	0.1%
Total	848	

76 consumers provided additional responses and comments about how they would maintain VLS or improve their Viral Load.

Pag	е	34
	~	

Additional Methods for Maintaining VLS or Improving VL (76 Responses)		
Category	Individual Responses	
Healthy Eating/Diet/ Exercise	Exercise and rest well. Change in diet. Continue to take vitamins, herbs, and supplements for immune system. Correct diet; exercise, walking. Diet and exercise. Eat healthy. Eat healthy, exercise, drug free. Eat healthy. Exercise. Eat well. Eat, take meds, rest. Eating good. Eating healthy. Eating healthy. Eating right, and no stress. Exercise. Exercise, eat healthy. Exercise, eat healthy. Exercise. Good diet. Health choices and lifestyle. Keep eating right. Keeping healthy. Living right. Eating right. Nutrition. Relaxation, Exercise. Stay healthy.	
Education	And by getting information.	
Medication	Change in medication.	
Sexual Behavior	Continue practicing safe sex. Have been abstinent for about 5 years. No drinking. No drugs. Not sexually active. Not having sex without protection. Practice sex with condoms. Safe sex when it happens. Stay healthy and eat healthy. Safe sex. Safe sex. No sex.	
Lifestyle Change	Continue to do what's necessary to keep my levels maintained. Continue to live the best I know how. Doing right thing. Keep doing the right things. Keep living a good healthy lifestyle. Life style change. Low stress, wear condoms, take meds, on time, don't skip. Stability. Stay focus. Staying stress free. Taking care of self. Taking good care of myself. Try stress free.	
Medical Care	Continue with clinical trials. Doing what the doctor tells me to do. Making sure I get my bloodwork done too. Repeat what got me undetected.	
Housing	Exercise and keep my apartment. Keep stable home environment.	
Don't' Know	Don't know anything about viral loads. No Answer.	
Substance Use	Eat healthy, exercise, do not use drugs. Exercise, eat good, don't use drugs. No drinking. No drugs. Not sexually active. Not getting high or using drugs. Stay clean from drugs. Stay clean. Stop smoking. Try not to use drugs or any other poison.	
Support	Family support. Good support group, family.	
Spiritual	Maintain healthy diet and pray. My faith in God. Not engaging in any harmful activity - staying spiritual. Plenty of prayer, eating properly and a great support system. Praying, staying focus doing what is right to suppress the virus.	

2.4 Medical Visits/Retention In Care (RIC)

The purpose of this section was to assess the number of medical visits that PLWHA have for their HIV disease and to assess Retention In Care (RIC), which is one of the outcome measures on the HIV Care Continuum. The EMA's CHAMP system has data on medical visits, but we wanted to hear directly from consumers on their HIV-medical appointments, kept appointments and reasons for rescheduling and not keeping appointments. In addition to taking HIV medications as prescribed, keeping medical appointments and assessing health status – as measured in RIC - are key to achieving Viral Load Suppression (VLS).

2.4.1 HIV Medical Appointments in the Past Year

2.4.1.1 Scheduled Medical Appointments

Question 13 asked: "How many scheduled appointments for your HIV medical care did you have in the past year? (NOT things like foot care, diabetes, heart, lung, etc.)"

The range of responses to number of medical appointments was zero (none) to 52. For ease of analysis, ranges were computed. The majority of respondents (82%) had at least one HIV medical appointment in the past year. However, nearly one in five (18%) had no HIV medical appointments.

# Scheduled Appts	#	%
1-6	490	57.8%
7-12	177	20.9%
13-24	25	2.9%
25-52	5	0.6%
None	11	1.3%
No Answer	140	16.5%
Total	848	100.0%
Total Pts w/ Med Appts	697	82.2%

2.4.1.2 Scheduled Medical Appointments Kept

Question 14 asked, "Of these [scheduled] appointments, how many did you keep?"

We were able to measure "kept" appointments for only 621 respondents because the remaining 76 of the 697 did not answer the question.

81% of patients said they kept all of their scheduled medical appointments and 19% said they missed one or more scheduled appointments. This finding is consistent with previous Needs Assessments showing that up to 20% of scheduled appointments are either missed or must be rescheduled.

# Scheduled Appts KEPT	#	%
1-6	455	53.7%
7-12	150	17.7%
13-24	14	1.7%
25-52	2	0.2%
None	36	4.2%
No Answer	191	22.5%
Total	848	100.0%
Total Pts Kept Med Appts	621	73.2%

Kept All Appts	501	80.7%
Missed 1 or more Appt	120	19.3%

Page 36

Question 14a asked **Why did you keep your HIV medical appointments?** (Check all that apply and add reasons). All 848 respondents provided reasons for keeping Scheduled Appointments.

The #1 reason was to stay healthy (77%), to get blood work done (55%), because they need medications or to get prescription refills (53% -51%), to keep VL low (49%) and stay Virally Suppressed (40%).

Reasons for Kept Appts	#	%
To Stay Healthy	656	77.4%
Need Medications	450	53.1%
To Get Prescription Refills	433	51.1%
To Get Bloodwork Done	465	54.8%
To Keep Viral Load Low	417	49.2%
To Stay Virally Suppressed	337	39.7%
Total HIV+ Respondents	848	

Additional Reasons for Keeping Appointments (57 Responses)		
Category	Individual Responses	
Keep apprised of health status	Help doctors follow how meds are doing for me. Because I needed to know about my situation. For health reasons - Keeping ahead of any problems that may rise. To learn more about condition from doctor. I got to my primary care every month, and my specialist every 3-4 months. To make sure that I was and stayed undetectable. To be healed completely.	
Overall Health	Because I want to live. Diet + exercise. Don't want to die. Good eating. Remain as healthy as possible. Live as long as I can. To stay alive. Stay away from people and things.	
Support	Need support from doctors and other medical staff, case managers. Support.	
Medical Team	Great doctor. I love coming to see my treatment team. See DM.	
Medications	Change medication.	
Medical Referrals	Got referred to Dr. Wenzler. Wanted to change doctors and heard she was a good doctor.	
Specific Medical Care	I was on a study for Hep-C. Surgery.	
Access to Care	Live in nursing home. Medical staff on premises.	

2.4.1.3 Scheduled Medical Appointments Having to be <u>Rescheduled</u>

Question 15 asked, "Of these [scheduled] appointments, how many did you have to reschedule?"

Responses were received from 695 patients with scheduled medical appointments. Approximately **1/3** (32% or 274) said their appointments had to be scheduled.

# Rescheduled Appts	#	%
None	421	49.6%
One	114	13.4%
Two	93	11.0%
Three to five	55	6.5%
Six or more	12	1.4%
No Answer	153	18.0%
Total	848	100.0%
Total Pts w/ Med Appts	695	82.0%
Total Rescheduling Visits	274	32.3%

The primary reason for rescheduling the
appointment was that the patient
forgot (36%). The second highest
reason was transportation problems
(29%), followed by feeling ill (26%),
conflicts with other medical
appointments (20%) and delays in
rescheduling (14%). 11% just did not
feel like going. Other reasons for

Reasons for Rescheduling Previously Scheduled Medical Visits (N = 274)	#	%
Transportation problems	80	29.2%
Feeling ill	71	25.9%
Conflicts with other medical appointments	56	20.4%
Delays in rescheduling	37	13.5%
Forgot	98	35.8%
Did not feel like going	29	10.6%

rescheduling scheduled appointments are shown below. The **primary reason is conflict with work schedule.**

Other Reasons for Rescheduling Scheduled Medical Appointments (73 Responses)		
Category	Individual Responses	
Work/Employment	Work. Working. Conflict with work hours. Couldn't get off work. Did not want to take off work or be late. Issues with work schedule. Job schedule. New job schedule. Work. Work and office rescheduled. Work conflict. Work reasons and family. Work Schedule. Work schedule conflict. Work schedule conflicts. Work schedule. Work. Overtime. Working.	
Minimal Rescheduling	Always go to HIV Doctor. Not many.	
Bloodwork Issues	Did not get bloodwork done on time. Didn't get bloodwork done on time. Didn't get bloodwork done. Need to get bloodwork done.	
Personal Problems/	Conflicts with personal problems. Death in family. Problems at home. Childcare.	
lssues	Spouse not feeling well. Taking care of ill mother. To make up my son's appointment.	
Scheduling Issues	Conflicts with schedule. School issues. School schedule. School. Making appointments on my day off. Estoy en un programa de reabilitation, y no puderion traeme por falta de staff.	
Provider/Clinic Issues	Doctor rescheduling. The clinic was overbooked.	
Other Health Issues	Had surgery for cancer. Was in the hospital.	
Insurance Issues	Insurance Change. Insurance lapsed. Insurance problems. Insurance reasons. No insurance. The insurance card didn't have the doctor's name on it. Welfare.	
Out of State/Country	Had to leave the country. I had to go to Columbia. Out of state. Out of town. On vacation. Was out of town a lot.	
Mistake	Mistake about the date.	
Homelessness	I was homeless due to legal issues with the landlord.	
Incarceration	In jail	
Weather	Snow. Weather.	
Traffic	Traffic	
No Answer	No Answer.	

2.4.1.4 Scheduled Medical Appointments that were <u>Missed</u>

Question 16 asked, "Of these [scheduled] appointments, how many did you miss? Missed appointments for HIV medical care has been a persistent issue not only in the Newark EMA but nationwide.

Of the 686 respondents with medical visits who answered this question, **170 or 20% had missed scheduled appointments for HIV medical care.** This is consistent with findings of prior Needs Assessments.

The main reason was that the **patient forgot (nearly ½ or 47%)**. One third had transportation problems or felt ill. 19% had conflicts with other medical appointments, and 18% did not fee like going. Only 12% experienced delays in rescheduling the appointment and so missed it.

# Missed Appts	#	%
None	516	60.8%
One	62	7.3%
Тwo	58	6.8%
Three to five	41	4.8%
Six or more	9	1.1%
No Answer	162	19.1%
Total	848	100.0%
Total Pts w/ Med Visits	686	80.9%
Total Pts w/ Missed Appts	170	20.0%

Reasons for Missing Previously Scheduled Medical Visits (N = 170)	#	%
Transportation problems	60	35.3%
Feeling ill	56	32.9%
Conflicts with other medical appointments	33	19.4%
Delays in rescheduling	20	11.8%
Forgot	80	47.1%
Did not feel like going	30	17.6%

Other reasons for missing scheduled appointments are shown below. While conflicts with employment/ work schedule are important, one of the main reasons was due to **health insurance problems** – **insurance lapsed, patient did not have insurance, or changing health insurance.**

Other Reasons for Missing Scheduled Medical Appointments (34 Responses)		
Category	Individual Responses	
Work/Employment	Job. School, work. Saturday appointments because I have work. Traveling, working.	
	Work. Work schedule. Work. Working.	
Bloodwork Issues	Bloodwork had to be done.	
Personal Problems/	Childcare. Death in family. Personal issues with family and housing. Problems at home	
lssues	with kids.	
Scheduling Issues	Confused with another date. Mistake about the date. Estoy en un programa de	
	reabilitation, y no puderion traeme por falta de staff.	
Provider/Clinic Issues	Dr. being on time.	
Other Health Issues	Was in the hospital. Was in the hospital.	
Insurance Issues	Because of my insurance. Didn't have insurance. Insurance lapsed. Insurance problems.	
	Keeping my insurance. No insurance. I missed appointments because I was changed from	
	one hospital to another.	
Out of State/Country	I had to go to Columbia. Out of town.	
Homelessness	Homeless	
Behavior	Running streets.	
Weather	Weather	

2.4.2 Assistance in Keeping Medical Appointments

The final question asked, **What would help you keep your HIV medical appointments in the future?** The item cited most by the total 848 respondents was "appointment reminders" (38%), followed by Phone Calls (34%). One quarter suggested that transportation would help, 17% said text messages, and 8% said support from others.

Help Keep Appointments	#	%
Transportation	213	25.1%
Appointment reminders	322	38.0%
Text messages	141	16.6%
Phone calls	287	33.8%
Support from others	71	8.4%

However, responses were different in the open-ended question. Many respondents felt that they (the individual) was responsible for their own health and had to take on that responsibility. We see this attitude throughout surveys, focus groups and other needs assessment methods – the dichotomy between those who [can] care for themselves and feel they do not need assistance versus those who need support, as well as a subgroup of those who use lack of support as an excuse for non-adherence or noncompliance. These three attitudes/positions are not restricted to HIV disease, but exist throughout the general population for a wide range of life issues! Others cited issues related to operation of clinics and support systems. It is up to the EMA to try to assist those who need support to engage in HIV medical care and improve their health.

Additional Things that Would Help You Keep Your HIV Medical Appointments (34 Responses)		
Category	Individual Responses	
I manage my health	Don't need help. I remember my appts. I do it by myself. I don't need reminders. Put on	
myself	calendar. Remind myself how important treatment is. Staying focused. Gangvas de	
	vivir. (Joy of life). My will to be healthy and not spread HIV. My mythe programe.	
I receive good health	Excellent, good doctor, great staff as well as case manager. Getting help from NJAS.	
care & services	Good healthcare providers are also very important. That also is why I am doing good.	
Work/Employment	Work Schedule	
Reminder Calls	Continue calls. I already receive phone calls as a reminder. Office always calls. Peter Ho	
	Call faithfully. Reminders and phone calls are an excellent idea.	
Better Clinic Hours	Late night appointments. I wish that they had more of a flexible schedule and stayed up	
	later. Making the clinic's schedule more flexible and staying open until later. Staff being	
	more flexible. Doctors having more hours available.	
Clinic Staff/Operational	Change the appointment sheet to make more clear and easier to read. It's confusing to	
Issues	many especially when there's 3-4 sheets. Medical case manager has been very helpful.	
	Some staff who pick up the phone to schedule appts are nasty. Not to be judgmental.	
	The telephone communication can be tough to get through. Sometimes, I'm not able to	
	leave voicemails. Trying to contact people in the office.	
Transportation	Better communication since one time my transportation came late and I was 2 hours	
	late.	
Coordination of health	Dental appointment.	
care		
Insurance Issues	Insurance concerns (maintaining it). Insurance.	
Personal Stability	Housing stability. Finance. Money.	
None	None	

2.5 Conclusions and Recommendations re VLS and RIC

- **Consumer Lack of knowledge re VL or VLS.** 30% of PLWHA and RWHAP consumers who had been living with HIV disease for 5+ years did not know what Viral Load or Viral Load Suppression were. Universal viral suppression is a goal of NHAS 2020.
 - <u>Recommendation</u>: The EMA must decide whether this knowledge gap is an impediment to increasing VLS among RWHAP patients.
 - <u>Recommendation</u>: The EMA's Continuum Of Care (COC) Committee should review this issue and knowledge gap and make recommendations for the relevant Service Standards – Outpatient/ Ambulatory Care, Medical Case Management (Treatment adherence counseling). That is, should RWHAP providers educate patients on the meaning of VLS or is just the number enough?
- Missed Appointments. 20% of PLWHA and RWHAP consumers continue to miss their scheduled HIV medical appointments. Some are rescheduled and others are not. While the reasons are mostly legitimate and typical of non-HIV individuals, regular HIV medical care is essential to (1) improving patient health, (2) reducing viral load, and hence (3) reducing the spread of HIV and controlling – and even eliminating – the epidemic. Intense follow up on patients who miss appointments is a focus of HAB and the National Quality Center (NQC).
 - <u>Recommendation</u>: The Newark EMA should consider doing an EMA-wide Quality Improvement Project (QIP) for Missed Appointments. This includes stratifying the issues related to missed appointments, identifying possible interventions, developing a Plan-Do-Study-Act (PDSA) cycle/model or several models, and implementing the QIP for missed appointments. This could be under the leadership of the Newark EMA Quality Management Committee with input from the Continuum Of Care (COC) Committee.
 - <u>Recommendation</u>: Under supervision of the Grantee and its RWHAP contract for services, provider agencies should review their customer services - hours of operation, front desk personnel, appointment scheduling, etc., and identify areas of improvement. Also, examine the transportation issues especially those of Medicaid Expansion (NJ Family Care) and report problems or barriers. Identify where improvements can be made and implement as many as possible.

PART 3: LATE HIV DIAGNOSIS – SURVEY OF LATE TESTERS

3.1 Introduction

The National HIV-AIDS Strategy (NHAS 2020) calls for identifying individuals who do not know their status and bringing them into care for their HIV disease. Within the EMA's RWHAP, we have found that approximately one third of individuals newly diagnosed with HIV disease coming into RWHAP Part A have Stage III HIV – which is AIDS. The Planning Council wanted to survey these individuals anonymously and learn what factors might have led to delaying HIV testing, and hence identify the points at which the Newark EMA could intervene for earlier testing.

Research Question

What are the characteristics of people who test late for HIV?

- What are the reasons they are testing late?
- How many times did clients see a provider in the last year and did not receive testing?

It was felt that answers to these questions would identify the services that are needed to meet the gaps - and improve access to testing before HIV disease escalates to Stage III (AIDS).

3.2 Methodology

This section utilized CHAMP data regarding late testers in 2015. The consultant identified the universe of RWHAP clients who received Early Intervention Services (EIS) in Calendar Year (CY) 2015 - that is, RWHAP clients diagnosed with HIV disease within the preceding 12 months. There were a total of **184 EIS clients in CY 2015**. Within this CY 2015 EIS universe, the consultant extracted a list of **66 (36%)** individuals by CHAMP Client ID who had been diagnosed with Stage III HIV disease (AIDS) a.k.a. **"Late Testers"**. These ID numbers were linked with medical providers and other agencies who had delivered service in 2015 and the resulting client ID and provider list given to the Council. The Research and Evaluation Committee (REC) developed a questionnaire for this population and the Planning Council staff sent this questionnaire out to agencies identified in CHAMP as having seen these Late Testers during CY 2015. The agencies in turn were to identify these clients by name and to distribute this survey confidentially to these Late Tester clients. Respondents were assured that their surveys would be anonymous.

Planning Council staff compiled results using a coding book developed by the consultant. Staff prepared a preliminary report of findings regarding HIV testing and medical are and presented it to the REC. The consultant developed a data base of responses, matched it with CHAMP files for demographics and socioeconomic characteristics. This report is the result of the responses, matching and analysis.

3.3 Findings

Of the total 66 late testers, we received **responses from 33 clients – 50% of the total late testers in 2015 who entered the RWHAP system**.⁴ Of these, **27 (82%) had CHAMP ID** which enabled us to capture demographic information.

Responses were received from 8 provider agencies as shown below. This is a good response rate for a survey that was anonymous, relied solely on voluntary client participation, and asked clients to discuss personal issues regarding HIV testing. Other agencies that did not get the participation or provide responses are not to be faulted.

Agency	Total	Responses	% Response
Morristown Memorial Hospital	3	3	100%
Neighborhood Health Center	4	3	75%
Newark Beth Israel Medical Center	8	6	75%
Newark Homeless	11	5	45%
Rutgers IDP	10	6	60%
St. Michael's Peter Ho	5	3	60%
Smith Center	4	5	125%
Trinitas	5	2	40%
Subtotal	50	33	66%
Other Agencies	16	0	0%
TOTAL	66	33	50%

3.3.1 Demographic and Socioeconomic Characteristics (N=27)

The 27 respondents with CHAMP ID had the following are the demographic/socioeconomic characteristics:

- Gender. 78% (21) male, 22% (6) female, 0% transgendered.
- Race/Ethnicity. 59% (16) Black/African-American, 37% (10) Hispanic/Latino, 0% white, 4% (1) of other racial/ethnic minorities.
- Age. 0% < age 25, 33% (9) age 25-34, 22% (6) age 35-44, 26% (7) age 45-54, 15% age 55-64 (4) and 4% (1) age 65+.
- County of Residence. 70% (19) Essex County, 15% (4) Union County, 11% (3) Morris/Sussex/ Warren region, 4% (1) outside of the EMA.
- Self-Reported Exposure Category. 63% (11) Heterosexual contact, 30% (8) Men who have Sex with Men (MSM), 7% (2) Unknown/risk not reported.

⁴ The Planning Council received responses from 35 clients but two individuals did not match up to any CHAMP client ID in either 2015 or 2016 – that is, the ID was invalid. So these two were removed from the analysis.

- Income/Poverty Level. The majority 23 or 85% had incomes below 138% of the Federal Poverty Level (FPL) which is the income threshold for Medicaid Expansion. Three (11%) had incomes between 139%-400% FPL. One (4%) had incomes above 500% FPL.
- Health Insurance. The majority 56% (15) were uninsured. 37% (10) had Medicaid and two (7%) had private insurance.
- Housing Status. 59% (16) were in Stable Permanent housing. The remaining 41% (11) were in Temporary Housing.
- Special Populations/EIIHA Populations.

Youth age 13-24	0	(0%)
MSM of Color	8	(30%)
Persons age 45 and older	12	(45%)
Women of Color	6	(22%)

3.3.2 Late Testing Responses – Reasons & Other Characteristics (N=33)

Responses from the **33 the 66 clients were received from eight (8) of the 16 agencies** who had served the 66 clients. All 8 were **RWHAP medical provider agencies**.

1. Before your most recent positive HIV test, did anyone tell you that you had HIV? The majority of late testers <u>had never been told they were HIV+.</u>

No	29 (88%)	
No Answer	1 (3%)	
Yes	<u>3 (9%)</u>	<u># Years Ago You Were Told HIV+:</u>
Total	33 (100%)	1 = 1 year ago
		1 = 9 years ago
		1= 10 years ago in Mexico

2. In the past year, how many visits did you have with a doctor or healthcare provider? Of the 33 respondents, 31 answered and 24 (73%) had one or more visits with a medical provider in the past year. Nearly half of those (11 or 46%) had never been told to have an HIV test.

# Visits	#	%
None	7	21%
1	1	3%
2	9	28%
3	4	12%
4	3	9%
6 or more	7	21%
No Answer	2	6%
Total	33	100%
Total 1+ Visit	24	73%

2a. If one or more, how many of those visits did the healthcare provider suggest you have an HIV test?

No Time	11	46%
Once	9	38%
Twice	3	13%
Total Answers	23	97%
No Answer	1	3%
Total	24	100%

2b. If one or more, during that year, did you see a healthcare provider for any of the following symptoms (check all that apply)? Of the 24 respondents who had seen a healthcare provider in the past year, they reported the following symptoms which are indicative of HIV.

Symptom	#	% (24)
Fatigue	9	38%
Fever	4	17%
Weight Loss	9	38%
Trouble Breathing	4	17%
Frequent Infections	5	21%
Breaks outs on the skin	2	8%
Diarrhea	4	17%
Swollen lymph nodes	7	29%
Sores in the mouth	5	21%
Muscle pain	3	13%
OTHER	20	83%
Swelling in ankles	1	4%

3. What are the reasons you did not get tested for HIV earlier (check all that apply)? The 33 respondents gave a variety of reasons for not getting tested for HIV earlier. The one most cited was that they did not feel they were at risk for HIV (55%). The next reason was that the respondent did not feel sick (48%) or did not know the symptoms of HIV. Some (15%) thought they might be infected but did not want to know for sure – due to fear or other reasons. Others did not know where to get tested, cited cultural reasons, fear and lack of knowledge about HIV.

Reason	#	% (33)
I didn't think I was at risk for HIV	18	55%
I didn't feel sick	16	48%
I didn't know the symptoms of HIV infection	15	45%
I thought I might be infected but didn't want to know for sure	5	15%
I didn't know where to go to get tested	3	9%
I was afraid someone might find out I was infected	1	3%
I didn't think I could afford the treatment if tested positive	4	12%
Other reasons (please Explain)	12	36%
Afraid	1	3%
Cultural	1	3%
I didn't know much about it	1	3%

4. What made you finally decide to get an HIV test (check all that apply)? The primary reason that the respondents finally got an HIV test was due to recommendation by a health care provider (21 or 64%). The second reason was that the respondent started to feel sick (7 or 21%). Others went because a friend or family member recommended an HIV test, or that they had a test at free testing event, or they got insurance. The health care provider plays the most important role in getting at risk individuals tested for HIV.

Reason	#	% (33)
I started to feel sick	7	21%
A friend or a family member convinced me I should get tested	1	3%
Someone close to me tested positive for HIV	2	6%
A doctor or other health care provider recommended an HIV test	21	64%
I got insurance coverage	2	6%
I was offered a test at a free testing event	3	9%
Other reasons (please explain)	11	33%
ER doctor recommended HIV test	1	3%
Sent to hospital for passing out at work, labs showed HIV+	1	3%

3.4 Conclusions and Recommendations

- The top reasons for not getting tested for HIV disease earlier were did not feel at risk for HIV or did not feel sick. This indicates the need for identifying and educating persons at high risk for HIV sexually active, substance users (all substances).
 - <u>Recommendation</u>: The EMA should work with the prevention and counseling and testing agencies through the EIRCs and other venues to identify, test and link to care the high risk individuals – as recommended in the Newark EMA Integrated HIV Prevention and Care Plan (IHAP).
- The top reason that led respondents to get an HIV test was the recommendation of the health care provider. This is probably the result of a risk assessment (sexual and other behaviors) performed during a routine physical exam or to treat an illness that was symptomatic of HIV.
 - <u>Recommendation</u>: Non-HIV providers should continue to be educated on HIV, symptoms, the rapid test and ease of testing and access to treatment.
- While not mentioned in the survey, these "late testers" with Stage III HIV disease have high viral loads and HIV disease is highly contagious to their sexual partners. Even after they get into HIV medical care, their partners are still at risk.
 - <u>Recommendation</u>: Both HIV prevention and RWHAP must continually educate clients about HIV transmission, and preventing transmission via treatment adherence counseling and education on Pre-Exposure Prophylaxis (PrEP). This is also recommended in the Newark EMA IHAP.

APPENDIX A-1: ADDITIONAL FIGURES FOR PART 1 - GAPS IN MEETING OUTCOMES ALONG THE HIV CARE CONTINUUM

LIST OF FIGURES

Figure 22: Viral Load Suppression in Newark EMA by Race/Ethnicity – Year Ending 12/31/15	47
Figure 23: Viral Load Suppression in Newark EMA by Gender – Year Ending 12/31/15	47
Figure 24: Viral Load Suppression in Newark EMA by Age Category – Year Ending 12/31/15	48
Figure 25: Viral Load Suppression in Newark EMA by Health Insurance – Year Ending 12/31/15	48
Figure 26: Viral Load Suppression in Newark EMA by County of Residence – Year Ending 12/31/15	49
Figure 27: Viral Load Suppression in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15	49
Figure 28: Viral Load Suppression in Newark EMA by Housing Status – Year Ending 12/31/15	50
Figure 29: Viral Load Suppression among Youth by Race/Ethnicity – Year Ending 12/31/15	51
Figure 30: Viral Load Suppression among Youth by Gender – Year Ending 12/31/15	51
Figure 31: Viral Load Suppression among Youth by Age Category – Year Ending 12/31/15	52
Figure 32: Viral Load Suppression among Youth by Health Insurance – Year Ending 12/31/15	52
Figure 33: Viral Load Suppression among Youth by County of Residence – Year Ending 12/31/15	53
Figure 34: Viral Load Suppression among Youth by Residence in 5 Largest Cities – Year Ending 12/31/15	53
Figure 35: Viral Load Suppression among Youth EMA by Housing Status – Year Ending 12/31/15	54
Figure 36: Viral Load Suppression among MSM of Color by Race/Ethnicity – Year Ending 12/31/15	55
Figure 37: Viral Load Suppression in among MSM of Color by Gender – Year Ending 12/31/15	55
Figure 38: Viral Load Suppression among MSM of Color by Age Category – Year Ending 12/31/15	56
Figure 39: Viral Load Suppression among MSM of Color by Health Insurance – Year Ending 12/31/15	56
Figure 40: Viral Load Suppression among MSM of Color by County of Residence – Year Ending 12/31/15	57
Figure 41: Viral Load Suppression among MSM of Color by Residence in 5 Largest Cities – Year Ending	
12/31/15	57
Figure 42: Viral Load Suppression among MSM of Color by Housing Status – Year Ending 12/31/15	58
Figure 43: Viral Load Suppression among People Age 45+ by Race/Ethnicity – Year Ending 12/31/15	59
Figure 44: Viral Load Suppression among Persons Age 45+ by Gender – Year Ending 12/31/15	59
Figure 45: Viral Load Suppression among Persons Age 45+ by Age Category – Year Ending 12/31/15	60
Figure 46: Viral Load Suppression among Persons Age 45+ by Health Insurance – Year Ending 12/31/15	60
Figure 47: Viral Load Suppression among Persons Age 45+ by County of Residence – Year Ending 12/31/15	61
Figure 48: Viral Load Suppression among Persons Age 45+ by Residence in 5 Largest Cities – Year Ending	
12/31/15	61
Figure 49: Viral Load Suppression among People Age 45+ by Housing Status – Year Ending 12/31/15	62
Figure 50: Viral Load Suppression among Women by Race/Ethnicity – Year Ending 12/31/15	63
Figure 51: Viral Load Suppression among Women by Gender – Year Ending 12/31/15	63
Figure 52: Viral Load Suppression among Women by Age Category – Year Ending 12/31/15	64
Figure 53: Viral Load Suppression among Women by Health Insurance – Year Ending 12/31/15	64
Figure 54: Viral Load Suppression among Women by County of Residence – Year Ending 12/31/15	64
Figure 55: Viral Load Suppression among Women by Residence in 5 Largest Cities – Year Ending 12/31/15	65
Figure 56: Viral Load Suppression among Women by Housing Status – Year Ending 12/31/15	66
Figure 57: Viral Load Suppression among Late Diagnoses by Race/Ethnicity – Year Ending 12/31/15	67
Figure 58: Viral Load Suppression among Late Diagnoses by Gender – Year Ending 12/31/15	67
Figure 59: Viral Load Suppression among Late Diagnoses by Age Category – Year Ending 12/31/15	68
Figure 60: Viral Load Suppression among Late Diagnoses by Health Insurance – Year Ending 12/31/15	68
Figure 61: Viral Load Suppression among Late Diagnoses by County of Residence – Year Ending 12/31/15	69
Figure 62: Viral Load Suppression among Late Diagnoses by Residence in 5 Largest Cities – Year Ending	
12/31/15	69
Figure 63: Viral Load Suppression among Late Diagnoses by Housing Status – Year Ending 12/31/15	70

TOTAL RWHAP CLIENTS

Figure 22: Viral Load Suppression in Newark EMA by Race/Ethnicity – Year Ending 12/31/15







#1 Viral Load Suppression in Newark EMA By Gender - Year Ending 12/31/15



Figure 24: Viral Load Suppression in Newark EMA by Age Category – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Age Category - Year Ending 12/31/15

Figure 25: Viral Load Suppression in Newark EMA by Health Insurance – Year Ending 12/31/15





Figure 26: Viral Load Suppression in Newark EMA by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15

Figure 27: Viral Load Suppression in Newark EMA by 5 Largest Cities of Residence – Year Ending 12/31/15





Figure 28: Viral Load Suppression in Newark EMA by Housing Status – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Housing Status - Year Ending 12/31/15

YOUTH

Figure 29: Viral Load Suppression among Youth by Race/Ethnicity – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Race/Ethnicty - Year Ending 12/31/15 <u>YOUTH</u>

Figure 30: Viral Load Suppression among Youth by Gender – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Gender - Year Ending 12/31/15 YOUTH



Figure 31: Viral Load Suppression among <u>Youth</u> by Age Category – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Age Category - Year Ending 12/31/15 <u>YOUTH</u>







Figure 33: Viral Load Suppression among <u>Youth</u> by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15 <u>YOUTH</u>



#1 Viral Load Suppression in Newark EMA By 5 Largest Cities of Residence -Year Ending 12/31/15 <u>YOUTH</u>



Figure 35: Viral Load Suppression among <u>Youth</u> EMA by Housing Status – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Housing Status - Year Ending 12/31/15 YOUTH



MSM OF COLOR

Figure 36: Viral Load Suppression among <u>MSM of Color</u> by Race/Ethnicity – Year Ending 12/31/15





Figure 37: Viral Load Suppression in among MSM of Color by Gender – Year Ending 12/31/15





Figure 38: Viral Load Suppression among <u>MSM of Color</u> by Age Category – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Age Category - Year Ending 12/31/15 <u>MSM OF COLOR</u>

Figure 39: Viral Load Suppression among <u>MSM of Color</u> by Health Insurance – Year Ending 12/31/15





Figure 40: Viral Load Suppression among <u>MSM of Color</u> by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15 MSM OF COLOR



#1 Viral Load Suppression in Newark EMA By 5 Largest Cities of Residence -Year Ending 12/31/15 <u>MSM OF COLOR</u>



Figure 42: Viral Load Suppression among <u>MSM of Color</u> by Housing Status – Year Ending 12/31/15





AGE 45 AND OLDER

Figure 43: Viral Load Suppression among <u>People Age 45+</u> by Race/Ethnicity – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Race/Ethnicity - Year Ending 12/31/15 AGE 45+



Figure 44: Viral Load Suppression among Persons Age 45+ by Gender – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Gender - Year Ending 12/31/15 <u>AGE 45+</u>


Figure 45: Viral Load Suppression among <u>Persons Age 45+</u> by Age Category – Year Ending 12/31/15





Figure 46: Viral Load Suppression among <u>Persons Age 45+</u> by Health Insurance – Year Ending 12/31/15





Figure 47: Viral Load Suppression among <u>Persons Age 45+</u> by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15 <u>AGE 45+</u>

Figure 48: Viral Load Suppression among <u>Persons Age 45+</u> by Residence in 5 Largest Cities – Year Ending 12/31/15





Figure 49: Viral Load Suppression among <u>People Age 45+</u> by Housing Status – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Housing Status - Year Ending 12/31/15 <u>AGE 45+</u>



WOMEN (AGE 18+)

Figure 50: Viral Load Suppression among Women by Race/Ethnicity – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Race/Ethnicity - Year Ending 12/31/15 WOMEN (AGE 18+)

Figure 51: Viral Load Suppression among Women by Gender – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Gender - Year Ending 12/31/15 WOMEN (AGE 18+)



Figure 52: Viral Load Suppression among <u>Women</u> by Age Category – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Age Category - Year Ending 12/31/15 <u>WOMEN (AGE 18+)</u>







Figure 54: Viral Load Suppression among <u>Women</u> by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15 <u>WOMEN (AGE 18+)</u>

Figure 55: Viral Load Suppression among <u>Women</u> by Residence in 5 Largest Cities – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By 5 Largest Cities of Residence -Year Ending 12/31/15 <u>WOMEN (AGE 18+)</u>



Figure 56: Viral Load Suppression among <u>Women</u> by Housing Status – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Housing Status - Year Ending 12/31/15 <u>WOMEN (AGE 18+)</u>

LATE DIAGNOSIS (AIDS)

Figure 57: Viral Load Suppression among <u>Late Diagnoses</u> by Race/Ethnicity – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Race/Ethnicity - Year Ending 12/31/15 LATE DIAGNOSIS (AIDS)

Figure 58: Viral Load Suppression among Late Diagnoses by Gender – Year Ending 12/31/15

#1 Viral Load Suppression in Newark EMA By Gender - Year Ending 12/31/15 <u>LATE DIAGNOSIS (AIDS)</u>



Figure 59: Viral Load Suppression among <u>Late Diagnoses</u> by Age Category – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Age Category - Year Ending 12/31/15 <u>LATE DIAGNOSIS (AIDS)</u>

Figure 60: Viral Load Suppression among <u>Late Diagnoses</u> by Health Insurance – Year Ending 12/31/15





Figure 61: Viral Load Suppression among <u>Late Diagnoses</u> by County of Residence – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By County of Residence - Year Ending 12/31/15 <u>LATE DIAGNOSIS (AIDS)</u>



#1 Viral Load Suppression in Newark EMA By 5 Largest Cities of Residence -Year Ending 12/31/15 <u>LATE DIAGNOSIS (AIDS)</u>



Figure 63: Viral Load Suppression among <u>Late Diagnoses</u> by Housing Status – Year Ending 12/31/15



#1 Viral Load Suppression in Newark EMA By Housing Status - Year Ending 12/31/15 <u>LATE DIAGNOSIS (AIDS)</u>

APPENDIX A-2: ADDITIONAL TABLES FOR PART 1 - GAPS IN MEETING OUTCOMES ALONG THE HIV CARE CONTINUUM

LIST OF TABLES

Table 15: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Mental Health Services Count)	73
Table 16: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Mental Health Services (Percent Distribution of VLS)	73
Table 17: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services Count)	74
Table 18: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services (% Dist of VLS)	74
Table 19: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Count)	75
Table 20: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Percent Distribution of VLS)	75
Table 21: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Count)	76
Table 22: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Percent Distribution of VLS)	70
Table 23: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Residential Substance Abuse Services (Count)	70
Table 24: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Residential Substance Abuse Services (Percent Distribution of VLS)	,
Table 25: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C	77
Table 26: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C	70
Disparity Categories (Percent Distribution of VLS)	/9

DATA TABLES - SERVICE CATEGORY SUBTYPE SHOWING LENGTH OF TIME IN NEMA RYAN WHITE AND VIRAL LOAD SUPPRESSION

					Years /	Active In	NEMA	RWHAF)				Nou	(Cliont	2015	EIC	Client	2015
Service Subtype		1 year			2-3 year	'S	4	4-5 year	ſS	6 and	d above	years	New	/ Client	2015	EIS	Chefft 2	2015
Service Subtype		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Indiv Counsel	47	27	74	121	26	147	77	16	93	478	105	583	47	27	74	17	14	31
Indiv Coun-IOP																		
Indiv-Psych	14	1	15	28	8	36	29	6	35	173	38	211	14	1	15	3		3
Indiv-FC	1		1	3		3	2	1	3	4	2	6	1		1	1		1
Indiv-COOD				2		2	1		1	7		7						
MH Assess	13	9	22	29	9	38	27	10	37	102	28	130	13	9	22	5	4	9
Group Counsel		1	1	7	2	9	6	1	7	54	5	59		1	1			
Group-Family																		
MH Screen	16	2	18	26	4	30	20	7	27	129	35	164	16	2	18	7	1	8
Total NEMA	226	161	387	543	120	663	442	104	546	2459	543	3002	221	157	378	70	65	135

Table 1: Viral Load Suppression (VLS) in CY 2015 b	y New Clients and Years Active in RWHAP -	By Mental Health	Services Count)
			· · · · · · · · · · · · · · · · · · ·

 Table 2: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Mental Health Services (Percent Distribution of VLS)

			Year	s Active In	NEMA RW	'HAP			Now Cliv	ont 2015	EIS Clio	nt 2015	
Service Subtype	1 y	ear	2-3 y	/ears	4-5 y	/ears	6 and ab	ove years		2015		111 2015	
	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	Total
Indiv Counsel	63.5%	36.5%	82.3%	17.7%	82.8%	17.2%	82.0%	18.0%	63.5%	36.5%	54.8%	45.2%	100%
Indiv Coun-IOP	0	0	0	0	0	0	0	0	0	0	0	0	0
Indiv-Psych	93.3%	6.7%	77.8%	22.2%	82.9%	17.1%	82.0%	18.0%	93.3%	6.7%	100.0%	0.0%	100%
Indiv-FC	100.0%	0.0%	100.0%	0.0%	66.7%	33.3%	66.7%	33.3%	100.0%	0.0%	100.0%	0.0%	100%
Indiv-COOD	0	0	100.0%	0.0%	100.0%	0.0%	100.0%	0.0%	0	0	0	0	0
MH Assess	59.1%	40.9%	76.3%	23.7%	73.0%	27.0%	78.5%	21.5%	59.1%	40.9%	55.6%	44.4%	100%
Group Counsel	0.0%	100.0%	77.8%	22.2%	85.7%	14.3%	91.5%	8.5%	0.0%	100.0%	0	0	0
Group-Family	0	0	0	0	0	0	0	0	0	0	0	0	0
MH Screen	88.9%	11.1%	86.7%	13.3%	74.1%	25.9%	78.7%	21.3%	88.9%	11.1%	87.5%	12.5%	100%
Total NEMA	67.0%	33.0%	79.5%	20.5%	80.5%	19.5%	79.9%	20.1%	67.0%	33.0%	61.5%	38.5%	100%

					Years /	Active In	NEMA	RWHAP)					Ne		EIC	Client	2015
Service Subtype		1 year			2-3 year	'S		4-5 yeaı	ſS	6 and	l above	years	w	Client 2	015	EIS	Chefft 2	2015
		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Indiv Counsel-Lev I	8	7	15	40	13	53	46	8	54	237	73	310	8	7	15	1		1
Indiv Counsel-Lev II IOP					1	1	1		1	4	2	6						
Indiv Counsel-Lev III Partial Care	1		1	1		1							1		1			
Group Counsel - Level I	3	3	6	14	8	22	23	2	25	137	32	169	3	3	6			
Group Counsel – Lev I Indiv Billed							1		1	3	1	4						
Group Counsel – Lev II IOP	4	1	5	7	2	9	13		13	48	14	62	4	1	5			
Methadone		1	1					1	1	11	3	14		1	1			
Suboxone				2	1	3	4		4	25	9	34						
SA Screening	12	2	14	16	4	20	17	6	23	185	54	239	12	2	14	5	1	6
SA Assessment	6	6	12	13	8	21	9	1	10	52	22	74	6	6	12	2	3	5
Total OP SA CLIENTS NEMA	27	13	40	59	19	78	66	14	80	416	117	533	27	13	40	8	4	12

Table 3: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services

Table 4: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Substance Abuse Services (% Dist of VLS)

			Year	s Active In	NEMA RW	/HAP			New Clie	ant 2015	FIS Clie	nt 2015	
Service Subtype	1 y	ear	2-3 y	rears	4-5 y	vears	6 and abo	ove years		2015	LIS CITE	111 2015	
Service Subtype		Not		Not		Not		Not		Not		Not	
	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	Total
Indiv Counsel-Lev I	53.3%	46.7%	75.5%	24.5%	85.2%	14.8%	76.5 %	23.5%	53.3%	46.7%	100.0%	0.0%	100%
Indiv Counsel-Lev II IOP	0	0	0.0%	100.0%	100.0%	0.0%	<mark>66.7%</mark>	33.3%	0	0	0	0	100%
Indiv Counsel-Lev III Partial Care	100.0%	0.0%	100.0%	0.0%	0	0	0	0	100.0%	0.0%	0	0	100%
Group Counsel - Level I	50.0%	50.0%	63.6%	36.4%	92.0%	8.0%	81.1%	18.9%	50.0%	50.0%	0	0	100%
Group Counsel - Lev I Indiv Billed	0	0	0	0	100.0%	0.0%	75.0%	25.0%	0	0	0	0	100%
Group Counsel - Lev II IOP	80.0%	20.0%	77.8%	22.2%	100.0%	0.0%	77.4%	22.6%	80.0%	20.0%	0	0	100%
Methadone	0.0%	100.0%	0	0	0.0%	100.0%	78.6%	21.4%	0.0%	100.0%	0	0	100%
Suboxone	0	0	66.7%	33.3%	100.0%	0.0%	73.5%	26.5%	0	0	0	0	100%
SA Screening	85.7%	14.3%	80.0%	20.0%	73.9%	26.1%	77.4%	22.6%	85.7%	14.3%	83.3%	16.7%	100%
SA Assessment	50.0%	50.0%	61.9%	38.1%	90.0%	10.0%	70.3%	29.7%	50.0%	50.0%	40.0%	60.0%	100%
Total OP SA CLIENTS NEMA	67.5%	32.5%	75.6%	24.4%	82.5%	17.5%	78.0%	22.0%	67.5%	32.5%	66.7%	33.3%	100%

					Years	Active In	NEMA	RWHAF)				Nou	Client	2015	EIC	Client	0015
Service Subtype		1 year			2-3 yeaı	rs	4	4-5 year	'S	6 and	l above	years	INEW	/ Client	2015	EIJ	Chefft 2	2015
		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Bus/Train Passes	40	14	54	86	22	108	94	17	111	349	112	461	39	13	52	8	2	10
Taxi Reimbursement	6		6	7	2	9	11	1	12	32	5	37	6		6	3		3
Van/Agency based Transport	7	5	12	18	9	27	24	2	26	134	26	160	7	5	12	1	1	2
Total NEMA	49	18	67	105	28	133	116	20	136	459	128	587	48	17	65	12	3	15

Table 5: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Count)

 Table 6: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Medical Transportation Services (Percent Distribution of VLS)

			Year	s Active In	NEMA RW	′НАР			Now Clie	ont 2015	EIS Clie	at 2015	
Service Subtype	1 y	ear	2-3 y	rears	4-5 y	vears	6 and abo	ove years		2015	LIS CITE	11 2015	
		Not		Not		Not		Not		Not		Not	
	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	Total
Bus/Train Passes	74.1%	25.9%	79.6%	20.4%	<mark>84.7%</mark>	15.3%	75.7%	24.3%	75.0%	25.0%	80.0%	20.0%	100%
Taxi Reimbursement	100.0%	0.0%	77.8%	22.2%	91.7%	8.3%	86.5%	13.5%	100.0%	0.0%	100.0%	0.0%	100%
Van/Agency based Transport	58.3%	41.7%	66.7%	33.3%	92.3%	7.7%	83.8%	16.3%	58. 3 %	41.7%	50.0%	50.0%	100%
Total NEMA	73.1%	26.9%	78.9%	21.1%	85.3%	14.7%	78.2%	21.8%	73.8%	26.2%	80.0%	20.0%	100.0%

					Years	Active In	NEMA	RWHA)				Nou	Client	2015	EIC	Client	0015
Service Subtype		1 year			2-3 yeai	rs		4-5 yeai	ſS	6 and	d above	years	New	/ Client	2015	EIS	Client	2015
		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Transitional	6	5	11	21	7	28	9	2	11	50	17	67	6	5	11	1		1
Coordination/										1		1						
Assistance										Ŧ		Т						
Rental Assistance-	1		1	10		10	G	1	7	17	7	24	1		1			
Short Term	L		L	10		10	0	L	/	17	/	24	T		T			
Security Payment				6	2	8	3	2	5	21	6	27						
Total NEMA	7	5	12	34	8	42	17	4	21	85	29	114	7	5	12	1	0	1

Table 7: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Count)

Table 8: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Housing Services (Percent Distribution of VLS)

			Years	s Active In	NEMA RW	НАР			Now Clic	ont 2015		at 2015	
Service Subtype	1 ye	ear	2-3 y	ears	4-5 y	ears	6 and abo	ove years		2015		11 2015	
		Not		Not		Not		Not		Not		Not	
	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	Total
Transitional	54.5%	45.5%	75.0%	25.0%	84.7 %	15.3%	75.7%	24.3%	54.5%	45.5%	100.0%	0.0%	100.0%
Coordination/ Assistance	0	0	0	0	81.8%	18.2%	74.6%	25.4%	0	0	0	0	100.0%
Rental Assistance- Short Term	100.0%	0.0%	100.0%	0.0%	0	0	100.0%	0.0%	100.0%	0.0%	0	0	100.0%
Security Payment	0	0	75.0%	25.0%	85.7%	14.3%	70.8%	29.2%	0	0	0	0	100.0%
Total NEMA	58.3%	41.7%	81.0%	19.0%	81.0%	19.0%	74.6%	25.2%	58.3%	41.7%	100.0%	0.0%	100.0%

 Table 9: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Residential Substance Abuse (Count)

					Years	Active In	NEMA	RWHA)				Nov	Client	2015	EIC	Client 2	001 E
Service Subtype		1 year			2-3 yeaı	ſS	4	4-5 yeaı	ſS	6 and	d above	years	New	Client	2015	EIS	Client 2	2015
		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Residential	1	4	E	1		1	1	1	2	4	1	5		4	4			
Substance Abuse	T	4	J	T		T	T	T	2	4	L L	J		4	4			
Total NEMA	1	4	5	1		1	1	1	2	4	1	5		4	4			

 Table 10: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By Residential Substance Abuse (Percent Distribution of VLS)

			Year	s Active In	NEMA RW	/HAP			Now Cliv	ont 2015		nt 2015	
Service Subtype	1 y	ear	2-3 y	vears	4-5 y	/ears	6 and abo	ove years	New Cite	2015	EIS CITE	111 2015	
Service Subtype		Not		Not		Not		Not		Not		Not	
	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	VLS	Total
Residential	20.0%	80.0%	100.0%	0.0%	50.0%	50.0%	80.0%	20.0%	0.0%	100.0%	0%	0%	100%
Substance Abuse	20.070	00.070	100.070	0.070	30.070	50.070	00.070	20.070	0.070	100.070	0,0	0,0	100/0
Total NEMA	20.0%	80.0%	100.0%	0.0%	50.0%	50.0%	80.0%	20.0%	0.0%	100.0%	0%	0%	100.0%

	Years Active In NEMA RWHAP									Nou	(Cliont	2015	EIS Client 2015					
H4C "Disparity"		1 year		2-3 years		4	4-5 yeaı	ſS	6 and	l above	years			2015				
Category		Not			Not			Not			Not			Not			Not	
	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total	VLS	VLS	Total
Race/Ethnicity																		
Black Not Hispanic	133	111	244	360	96	456	289	79	368	1703	444	2147	130	107	237	37	43	80
Hispanic/Latino	74	41	115	123	19	142	103	18	121	513	67	580	72	41	113	26	20	46
White Not Hispanic	9	7	16	48	3	51	40	5	45	177	24	201	9	7	16	4	2	6
Other	10	2	12	12	2	14	10	2	12	66	8	74	10	2	12	3	0	3
<u>Gender</u>																		
Male	152	107	259	358	78	436	307	63	370	1393	266	1659	148	107	255	53	44	97
Female	69	53	122	185	40	225	133	40	173	1055	276	1331	68	49	117	16	20	36
Transgender	5	1	6	0	2	2	2	1	3	11	1	12	5	1	6	1	1	2
Age Category																		
Age 0-12	0	1	1	0	1	1	0	1	1	11	2	13	0	1	1	0	1	1
Age 13-18	0	0	0	2	1	3	1	0	1	14	6	20	0	0	0	0	0	0
Age 19-24	15	19	34	28	10	38	17	4	21	45	24	69	15	19	34	7	11	18
Age 25-34	63	46	109	130	41	171	83	27	110	168	73	241	62	44	106	29	15	44
Age 35-44	47	32	79	127	27	154	98	25	123	303	91	394	46	32	78	11	20	31
Age 45-54	58	35	93	132	25	157	142	30	172	832	202	1034	57	34	91	13	9	22
Age 55-64	36	22	58	95	11	106	76	12	88	807	119	926	34	21	55	7	6	13
Age 65+	7	6	13	29	4	33	25	5	30	279	26	305	7	6	13	3	3	6
Health Insurance																		
Medicaid	89	66	155	260	63	323	196	58	254	1268	325	1593	86	64	150	23	27	50
Medicare	12	7	19	43	7	50	55	8	63	496	75	571	12	7	19	4	2	6
Private Insurance	25	17	42	82	11	93	54	9	63	244	31	275	25	17	42	10	5	15
Uninsured	99	71	170	157	39	196	137	29	166	446	112	558	97	69	166	33	31	64
Other	1	0	1	1	0	1	0	0	0	5	0	5	1	0	1	0	0	0
Total NEMA	226	161	387	543	120	663	442	104	546	2459	543	3002	221	157	378	70	65	135

Table 11: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C "Disparity" Categories (Count)

Table 12: Viral Load Suppression (VLS) in CY 2015 by New Clients and Years Active in RWHAP – By H4C "Disparity" Categories (Percent Distribution of VLS)

HAC "Dispority"			Year	rs Active In		New Client 2015		EIS Client 2015					
	1 y	ear	2-3 y	/ears	4-5 y	rears	6 and ab	ove years		2015			
cutegory	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	VLS	Not VLS	Total
Race/Ethnicity													
Black Not Hispanic	54.5%	45.5%	78.9%	21.1%	78.5%	21.5%	79.3%	20.7%	54.9%	45.1%	46.3%	53.8%	100%
Hispanic/Latino	64.3%	35.7%	86.6%	13.4%	85.1%	14.9%	88.4%	11.6%	63.7%	36.3%	56.5%	43.5%	100%
White Not Hispanic	56.3%	43.8%	94.1%	5.9%	88.9%	11.1%	88.1%	11.9%	56.3%	43.8%	66.7%	33.3%	100%
Other	83.3%	16.7%	85.7%	14.3%	83.3%	16.7%	89.2%	10.8%	83.3%	16.7%	100.0%	0.0%	100%
<u>Gender</u>													
Male	58.7%	41.3%	82.1%	17.9%	83.0%	17.0%	84.0%	16.0%	58.0%	42.0%	54.6%	45.4%	100%
Female	56.6%	43.4%	82.2%	17.8%	76.9%	23.1%	79.3%	20.7%	58.1%	41.9%	44.4%	55.6%	100%
Transgender	83.3%	16.7%	0.0%	100.0%	66.7%	33.3%	91.7%	8.3%	83.3%	16.7%	50.0%	50.0%	100%
Age Category													
Age 0-12	0.0%	100.0%	0.0%	100.0%	0.0%	100.0%	84.6%	15.4%	0.0%	100.0%	0.0%	100.0%	100%
Age 13-18	0.0%	0.0%	66.7%	33.3%	100.0%	0.0%	70.0%	30.0%	0.0%	0.0%	0.0%	0.0%	100%
Age 19-24	44.1%	55.9%	73.7%	26.3%	81.0%	19.0%	65.2%	34.8%	44.1%	55.9%	38.9%	61.1%	100%
Age 25-34	57.8%	42.2%	76.0%	24.0%	75.5%	24.5%	69.7%	30.3%	58.5%	41.5%	65.9%	34.1%	100%
Age 35-44	59.5%	40.5%	82.5%	17.5%	79.7%	20.3%	76.9%	23.1%	59.0%	41.0%	35.5%	64.5%	100%
Age 45-54	62.4%	37.6%	84.1%	15.9%	82.6%	17.4%	80.5%	19.5%	62.6%	37.4%	59.1%	40.9%	100%
Age 55-64	62.1%	37.9%	89.6%	10.4%	86.4%	13.6%	87.1%	12.9%	61.8%	38.2%	53.8%	46.2%	100%
Age 65+	53.8%	46.2%	87.9%	12.1%	83.3%	16.7%	91.5%	8.5%	53.8%	46.2%	50.0%	50.0%	100%
Health Insurance													
Medicaid	57.4%	42.6%	80.5%	19.5%	77.2%	22.8%	79.6%	20.4%	57.3%	42.7%	46.0%	54.0%	100%
Medicare	63.2%	36.8%	86.0%	14.0%	87.3%	12.7%	86.9%	13.1%	63.2%	36.8%	66.7%	33.3%	100%
Private Insurance	59.5%	40.5%	88.2%	11.8%	85.7%	14.3%	88.7%	11.3%	59.5%	40.5%	66.7%	33.3%	100%
Uninsured	58.2%	41.8%	80.1%	19.9%	82.5%	17.5%	79.9%	20.1%	58.4%	41.6%	51.6%	48.4%	100%
Other	100.0%	0.0%	100.0%	0.0%	0.0%	0.0%	100.0%	0.0%	100.0%	0.0%	0.0%	0.0%	100%
Total NEMA	58.4%	41.6%	81.9%	18.1%	80.9%	19.1%	81.9%	18.1%	58.5%	41.5%	51.9%	48.1%	100%

DATA TABLES – RYAN WHITES SERVICES BY SUBTYPE, VLS AND RIC

OUTPATIENT/PRIMARY MEDICAL CARE SERVICES BY SUBTYPE

Table 13: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Outpatient/Primary Medical Care Service Subtype (Services Received) – Number of Clients

	H4C Vira	al Load Suppre	ession	Retent	tion (Revers	e Gap)
					Not	
				Retained	Retained	
	VL	Not VL		in Care	in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Physician - Initial/Med Assess.	167	108	275	126	19	145
Physician - Medical Visit	2,183	546	2,729	2,103	178	2,281
Nurse - Initial Intake	113	56	169	67	27	94
Nurse - Medical Visit	474	98	572	445	53	498
Nurse - Phlebotomy/Labs/Vitals	279	69	348	255	37	292
GYN/Reproductive Medical Visit	433	83	516	386	39	425
Laboratory /Diagnostic Testing	485	111	596	419	60	479
Physician – Specialty Care Visit	71	18	89	58	6	64
Nurse Pract./Phys. Assist. Visit	951	261	1,212	851	123	974
Physician – Spec. Care Visit/ID	1,075	227	1,302	743	227	970
Anoscopy	3	1	4	4		4
Total PMC Services	3,670	928	4,598	3,245	458	3,703

Table 14: Viral Load Suppression (VLS) and Retention In Care in CY 2015 by Outpatient/Primary Medical Care Service Subtype (Services Received) – Percent Distribution

	H4C Vira	al Load Suppre	ession	Retent	tion (Revers	e Gap)
	VL	Not VL		Retained in Care	Not Retained in Care	
	Suppressed	Suppressed	Total	(Gap)	(Gap)	Total
Physician - Initial/Med Assess.	60.7%	39.3%	100%	86.9%	13.1%	100%
Physician - Medical Visit	80.0%	20.0%	100%	92.2%	7.8%	100%
Nurse - Initial Intake	66.9%	33.1%	100%	71.3%	28.7%	100%
Nurse - Medical Visit	82.9%	17.1%	100%	89.4%	10.6%	100%
Nurse - Phlebotomy/Labs/Vitals	80.2%	19.8%	100%	87.3%	12.7%	100%
GYN/Reproductive Medical Visit	83.9%	16.1%	100%	90.8%	9.2%	100%
Laboratory /Diagnostic Testing	81.4%	18.6%	100%	87.5%	12.5%	100%
Physician – Specialty Care Visit	79.8%	20.2%	100%	90.6%	9.4%	100%
Nurse Pract./Phys. Assist. Visit	78.5%	21.5%	100%	87.4%	12.6%	100%
Physician – Spec. Care Visit/ID	82.6%	17.4%	100%	76.6%	23.4%	100%
Anoscopy	75.0%	25.0%	100%	100.0%	0.0%	100%
Total PMC Services	79.8%	20.2%	100%	87.6%	12.4%	100%

APPENDIX B: CONSUMER SURVEY TOOLS

Consumer Health Survey (Viral Suppression and Medical Visits/Retention In Care)

Consumer Survey – Late Testers (Anonymous)

Consumer HEALTH ISSUES Survey

For O	ffice	Use	
Date:			
Site			

We are conducting a survey on the needs of people regarding health issues. The purpose is to determine the need for HIV medical care and how best we can allocate [Ryan White and other] resources for medical care. This will take only a few minutes to complete. Your participation is <u>voluntary</u>, your responses will be kept <u>confidential</u>, and you can <u>decline</u> to answer any of the questions. **Have you answered this survey before? If YES, please do not complete another survey form.**

1.	Gender Male Female Transgender Other
2.	Sexual Behavior Heterosexual Men who have sex with men Women who have sex with women Bisexual Other
3.	Are you Hispanic or Latino? No Yes Country:
4.	Race American Indian/Alaska Native Asian Black or African American Native Hawaiian/Other Pacific Islander White Other
5.	Current Age: (Please list your age in years)
6.	In what county do you live? Essex Union Morris Warren Sussex Other
7.	What is your ZIP Code where you currently live? (Enter)
8.	When were you diagnosed with HIV/AIDS?Within the past year2 to 4 years ag5 to 10 years ago11 to 15 years ago15+ years agoNot HIV+
VIRA	LLOAD (VL)
9.	Do you know what Viral Load is? Yes No
10.	Do you know what your latest Viral Load is?YesYes, my number isYes, undetectableYes, Undetectable (< 200)
11.	Do you have Viral Load Suppression or a good Viral Load (VL) (VL < 200 or undetectable)? Yes No Do not know
	 a. If Yes, how did you get your VL to this good level? (check all that apply) Took medications Kept medical appointments Other (explain)
	 b. If No, what happened to prevent or interfere with VL improvement?(check all that apply) Missed medications Missed medical appointments Other (explain)
	PLEASE CONTINUE ON THE OTHER SIDE

	How are you going to maintain undetectable VL or continue to improve your VL? (check all the apply) Image: Second secon
ED	ICAL CARE
3.	How many scheduled appointments for your HIV medical care did you have in the past year?(NOT things like foot care, diabetes, heart, lung, etc.)Insert the Number:
ŀ.	Of these appointments, how many did you keep?Insert the Number:
	14a. Why did you keep your HIV medical appointments? (Check all that apply and add reasons) Keep healthy Need medications Get bloodwork done Keep Viral Load low Other (explain) Stay Virally Suppressed
	15a. Why did you have to reschedule? (Check all that apply and add reasons) Transportation problems Feeling ill Delays in rescheduling Forgot Other (explain) Other (explain)
5.	Of these appointments, how many did you miss? Insert the Number:
	16a. Why did you miss the appointment(s)? (Check all that apply and add reasons) Transportation problems Feeling ill Delays in rescheduling Forgot Other (explain) Other (explain)
7.	What would help you keep your HIV medical appointments in the future?

Thank you for participating! Your responses will help the Newark EMA HIV Health Services Planning Council make recommendations about the needs of individuals with HIV in the counties of Essex, Morris, Sussex, Union and Warren. If you would like to see the results of this survey, they will be available by contacting the Newark EMA HIV Health Services Planning Council at (973) 485-5220 after July 31, 2016.

Diagnosis Questionnaire

For Office Use
Date: _____
Site: _____

We are conducting a questionnaire on the needs of people regarding health issues. The purpose is to determine the need for HIV medical care and how best we can allocate [Ryan White and other] resources for medical care. This will take only a few minutes to complete. Your participation is <u>voluntary</u>, your responses will be kept <u>confidential</u>, and you can <u>decline</u> to answer any of the questions.

1. Before your most recent positive HIV test, did anyone ever tell you had HIV? (if no, go to question 2)

If yes:

- 1a. How many years ago was that?
- 2. In the past year, how many visits did you have with a doctor or other health care provider? ______ visits (if zero, go to question 3)

If 1 or more visits:

- 2a. In how many of those visits did the health care provider suggest you have an HIV test?
- 2b. During that year, did you see a health care provider for any of the following symptoms (check all that apply)?
 - _____ Fatigue (feeling more tired than usual)
 - _____ Fever
 - _____ Weight loss
 - _____ Trouble breathing
 - _____ Frequent infections (for example, throat infections)
 - _____ Break outs on the skin
 - ____ Diarrhea
 - _____ Swollen lymph nodes

____ Sores in the mouth

- ____ Muscle pain
- 3. What are the reasons that you did not get tested for HIV earlier (check all that apply)?
 - _____ I didn't think I was at risk for HIV
 - _____ I didn't feel sick
 - _____ I didn't know the symptoms of HIV infection
 - _____ I thought I might be infected but didn't want to know for sure
 - _____ I didn't know where to go to get tested
 - _____ I was afraid someone would find out I was infected
 - _____ I didn't think I could afford the treatment if I tested positive
 - _____ Other reason (please explain)
- 4. What finally made you decide to get an HIV test (check all that apply)?
 - _____ I started to feel sick
 - _____ A friend or family member convinced me I should get tested
 - _____ Someone close to me tested positive for HIV
 - _____ A doctor or other health care provider recommended an HIV test
 - _____ I got insurance coverage
 - _____ I was offered a test at a free testing event
 - _____ Other reason (please explain)

APPENDIX C: ORAL HEALTH CONSUMER FOCUS GROUP

Oral Health Care Verbal Consumer Survey

The following "focus group" was held on April 20, 2016 at Hope House in Dover, NJ. It followed a
presentation by a dentist to 20 consumers in the Morris, Sussex, Warren region. The purpose was to
obtain views of PLWHA about [their] oral health care – and possible barriers to oral health.Facilitator:
Summary:Caroline Schenkman, Linkage to Care Coordinator, Family Health CenterAllison Delcalzo-Berens, Clinician, Family Health Center

- 1. Who has been to the dentist in the past year? 11 of the 20 consumers said that they had.
- 2. If yes, why? Attendees gave the following reasons. (There was no tally of the number of respondents for each reason)
 - Comfort of dentures
 - Issues with dentures
 - Fitting of dentures
 - Teeth cleaning (preventative)
 - X-rays (preventative)
 - Because "they" tell me to come back.
 - Crowns
 - Root canal
- 3. If no, why not?
 - Don't like the dentist
 - Nothing is bothering me. I only go when I have a problem.
- 4. We have a program that pays for dental care. We want to use this money. What would it take to get you to see the dentist if it did not cost you anything?
 - Some said that they will still only go if something is bothering them.
 - Many seemed surprised that Ryan White pays for dental care, even those who raised their hands that they had been to the dentist in the last year or those who reported verbally that they go on a regular basis.
 - Transportation. (it was noted by providers in the room that transportation is available through all four RW funded agencies and those agencies were listed by name.)
 - Case manager does all the work to get them there. (This is paraphrasing but basically one consumer said that if someone else made the appointment and scheduled his transportation and reminded him the day before, he would go.)

(Continued on next page)

Additional Comments

Multiple consumers expressed that they feel their oral health care is something they take pride in tending to. Some reported that they enjoy going to the dentist and like the feeling they get when they leave and one consumer stated that it improved the "quality" of his life.

One consumer recommended the use of incentives as it may get more out of care people into the dentist chair. This sparked an intense reaction from another consumer who reported he was "offended" that the first consumer would suggest that he or anyone else get an incentive for taking care of themselves. This consumer stood up somewhat aggressively (in my opinion) and I judged it best to end the conversation.

Conclusions

The reasons for not going to the dentist – don't like dentists and going only when there is a problem – are issues we have heard throughout the EMA. And not just among PLWHA!

It is agreed within the RWHAP that **considerable education** must continue about the benefits of preventive dental care, health risks of poor oral health, ad especially the new painless treatment options and methods. Some biases against routine oral health care are also cultural, which also involves education.

With respect to **providing incentives** for keeping oral health appointments – the use of incentives for [routine] medical care and other personal care is always a controversial topic. Some feel that incentives help in treatment adherence and other compliance, and others feel just like some of the participants – that each person is responsible for their own personal care.

Those involved in the EMA's RWHAP (providers, administrators, consumers) have found that when PLWHA understand the value of taking care of their health, and make one trip to the dentist, they keep going and keeping oral health appointments. This is due to a combination of better health and less pain, new treatment methods, and feeling health – as some participants stated As one dentist in the EMA said, "Once a person comes in for their first visit and sees that they feel better and it is not painful, they keep coming!" This is the goal and challenge for the EMA's Oral Health care.