# Activities for Interpreting and Using Data Training

# Activity A:

# How Are We Doing? Assessing Data Availability and Use for PSRA

1. Work in a small group.
2. Choose people to fill the following roles:
   * **Facilitator,** to coordinate the work of the group and also participate
   * **Recorder/reporter,** to summarize the work of the small group and report to the full group (you may use two different people if you prefer)

3. Consider our earlier discussions, consider your responsibilities as a Planning Council for one of the following, as assigned to your group:

* **Priority setting** – determining what services people with HIV in this EMA/TGA who are eligible for Ryan White services are most likely to need, and the relative importance of these services
* **Resource allocation –** deciding how much Ryan White HIV/AIDS Program (RWHAP) Part A funding should be allocated to each service priority
* **Directives** – developing directives to the recipient on how best to meet the Council’s service priorities

4. As a group, discuss the following (You will have about 20 minutes):

1. What kinds of information does the Planning Council need to make sound decisions in the area assigned to your group?
2. To what extent does the Planning Council have the information/data it needs to make sound decisions in this assigned area? What other kinds of information do you feel are most needed?
3. How comfortable are you in reviewing, interpreting, and using available needs assessment data? Why?

5. Be prepared to share your answers with the full group.

# Activity B: Terms and Concepts

* 1. Spend a few minutes working individually on the attached worksheet, matching terms with definitions and descriptions.
  2. Now work together with your small group and see if you can agree on a set of answers. Identify any areas of disagreement or confusion and any concepts the group does not fully understand. You have about 15 minutes.
  3. Be prepared to share your work with the full group.

# Data Terms and Concepts Worksheet

Review the definitions and descriptions below and identify the term or concept described from the list at the bottom of the next page. Put the letter of the definition/description with the term. (Note: There are deliberately more terms than definitions/descriptions, just to make the activity interesting.)

1. Information about the service needs of people living with HIV/AIDS (PLWH), barriers to obtaining these services, and types and extent of needs that are not being met – one of the components of a comprehensive needs assessment.
2. The frequency of new cases of a disease that occur per unit of population during a defined period of time – such as the rate of new cases per 100,000 population in your EMA or TGA.
3. Information on the capacity of service providers in a specified geographic area to meet the needs of PLWH, including the extent to which services are available, accessible, and appropriate to PLWH overall and to specific subpopulations groups – a component of a needs assessment.
4. Information that can be expressed in numbers, counted, or compared on a scale – such as epi data or aggregated PLWH survey data.
5. Differences in service access to appropriate services based on where an individual lives – such as differences in access to primary medical care or mental health services for people living in a rural community or outlying county.
6. The extent to which available services meet the needs of particular subpopulations of PLWH – for example, whether service providers have staff who speak Spanish or other languages needed by PLWH in the EMA or TGA; whether providers have staff from various communities of color and knowledgeable about these cultures; whether providers are experienced with and sensitive to the needs of gay, lesbian, bisexual, and transgender (GLBT) PLWH; or whether providers have appropriate training to work with HIV-positive youth.
7. A listing and description of the providers of HIV-related services in a specified geographic area, what types of services they provide, where, and to whom, including both Ryan White and non-Ryan White funded providers – one of the components of a comprehensive needs assessment.
8. Information about people who know they are HIV-positive but are not receiving regular HIV-related primary medical care, including their characteristics, where they live within the EMA or TGA, their primary care needs, barriers that keep them out of care, and other service gaps.
9. The total or cumulative number of cases of a disease per unit of population as of a defined date – such as the rate of HIV cases per 100,000 population diagnosed through December 31, 2016 in your EMA or TGA.
10. A systematic process used to collect and analyze information about the number, characteristics, and needs of PLWH in and out of care, identify current resources available to meet those needs, and determine unmet needs and service gaps.
11. The level or number of specific service “slots” within a service category that exist in a specified geographic area – such as the total number of funded outpatient substance abuse treatment slots for PLWH within an EMA or TGA.
12. The process of comparing results from different needs assessment or research studies to see whether they report similar findings and giving greater weight to findings that are reported from several different studies or sources – for example, comparing PLWH survey, focus group, and epi profile trends and finding that all three indicate a growing rate of HIV/AIDS among youth aged 18-25.
13. Information about the use of RWHAP Part A services by service category; includes percent of total contract funds used by month and for an entire program year, number and characteristics of clients, overall and sometimes by type of service within the service category – for example, physician visits, laboratory tests.
14. Information that cannot easily be measured or expressed in numbers – such as narrative information from a focus group or consumer Town Hall meeting.
15. The extent to which services in a particular geographic area can be obtained conveniently by people who need them – for example, whether the location of services enables PLWH to get to the facility, whether the provider offers services at appropriate hours (e.g., during the day, in the evening, and on weekends), and whether child care services are available.
16. The estimated number of people in a specific geographic area who know they are HIV-positive but are not receiving regular HIV-related primary medical care.

**List of Terms and Concepts:**

1. Incidence
2. Prevalence
3. Incidence rate
4. Prevalence rate
5. Quantitative data
6. Qualitative data
7. Needs assessment
8. Epidemiologic profile
9. Assessment of service needs and barriers
10. Resource inventory
11. Profile of provider capacity and capability
12. Estimate of unmet need
13. Assessment of unmet need
14. Utilization data
15. Geographic disparities
16. Availability of services
17. Accessibility of services
18. Appropriateness of services
19. Triangulation
20. Client and unit costs

# Activity C: Identifying Data Needed for Specific Decisions

1. Work in a small group, with a facilitator and a recorder/reporter (you may split these two roles).
2. Review the background description and the area of decision making assigned to you and answer the questions provided. You will have about 30 minutes.
3. Be prepared to share your work with the full group.

**Background:**

The Southwest EMA RWHAP Part A Planning Council is preparing to carry out its priority setting and resource allocations process. The entire Planning Council will participate in priority setting and resource allocation and in identifying possible directives, but the Needs Assessment Committee and the Priority Setting and Resource Allocations Committee are taking a lead role in the preparations. You are the members of those committees.

**Epi Data Summary – Southwest EMA**

|  |  |  |  |
| --- | --- | --- | --- |
| **Population Group** | **% of EMA Population** | **% of EMA Population Living with HIV/AIDS** | **Prevalence per 100,000 as of 2016** |
| HIV/AIDS |
| White Non-Hispanic | 66 | 52 | 169 |
| African American | 5 | 14 | 609 |
| Hispanic | 24 | 28 | 257 |
| American Indian | 4 | 5 | 289 |
| Asian/Pacific Islander | 1 | <1 | 98 |

* As the chart indicates, 52% of PLWH in Southwest EMA are White non-Hispanic, although African Americans, American Indians, and Hispanics are all over-represented among HIV/AIDS cases. The prevalence rate for African Americans as of 2016 is more than three times the rate for White non-Hispanics, and the Hispanic and American Indian rates both more than 1½ times the White non-Hispanic rate.
* Highest risk factors in this EMA are men who have sex with men (MSM - 45% of recent cases) and injection drug use (IDU - 34%), but heterosexual transmission is increasing, as is the incidence rate among women with injection drug use and opioid addiction.
* The State estimates that 47% of PLWH in your EMA who know their status are not receiving HIV-related primary medical care (they are “not in care”).

**Needs Assessment:** The Planning Council conducts needs assessment on a three-year cycle:

**Each year,** the Planning Council obtains the following:

* 1. **An updated epidemiologic profile for the EMA,** with HIV and AIDS data for the five counties of the EMA, including incidence and prevalence data and trends for population groups by race/ethnicity, gender, age, and risk factor. Data are presented in the aggregate for the entire EMA, which includes one urban county and four “outlying” counties.
  2. **An updated estimate of unmet need, including some population data** – the number and percent of people in the EMA who know they are HIV-positive but are not receiving regular HIV-related primary medical care and some information about them. Since most of the data come from HIV/AIDS surveillance data and lab reports from people in care, the EMA has some basic information about people in care and not in care – where they lived when diagnosed, risk factor, age at diagnosis, date of diagnosis, HIV versus AIDS diagnosis, race/ethnicity, and gender.
  3. **Service utilization data from the Recipient** – including client demographic information (race/ethnicity, gender, and county of residence), total funds used, cost per client, and percent of contract funds used for each service category funded through RWHAP Part A.
  4. **Summary of other funding streams in the EMA –** a chart of data that specifies major non- RWHAP Part A funding amounts and sources (primarily public sources), for the six core service categories – primary medical care, medications, oral health, substance abuse treatment, mental health services, and medical and non-medical case management.

**During the past three-year cycle,** the Committee and PC support staff, using consultants as appropriate, have provided the PC with the following data and studies:

1. **A PLWH survey** conducted with the help of funded RWHAP Part A service providers and some other important service providers. It includes more than 500 PLWH in the EMA. The survey provides information on basic demographics, date of diagnosis, co-morbidities (e.g., substance use, mental health needs, homelessness), self-reported health status, HIV-related services received in the past 12 months (based primarily on the EMA’s priority service categories but including some services that are not currently prioritized), identification of up to three services most wanted but not received, satisfaction with services received, and perceived barriers to care. About 92% of those surveyed are receiving some kind of Ryan White funded services; 97% reported having been to see a physician for HIV-related care during the past 12 months.
2. **An assessment of service needs, gaps, and barriers to care for people are not in care** – individuals who know their HIV status but are not receiving HIV-related primary medical care. The EMA has had great difficulty obtaining this information through the PLWH survey, so last year funded a special study and worked with its Consumer Committee to find and interview people not in care. A quick three-month study was able to identify and interview 59 individuals not in care, 47 in the EMA’s central county and 12 in the outlying counties. Data include demographics, date of diagnosis, care history, barriers to care including primary reason for leaving care or for never entering care after diagnosis, and priority service needs and gaps. All individuals were also given information about how to obtain services, and at least 15 accepted referrals and were connected to primary care or case management services.
3. **A report on seven focus groups** of 6-12 individualseach, for six disproportionately affected and/or historically underserved populations of PLWH in the EMA, including individuals who tend to be underrepresented in the PLWH survey: (1) young African American men who have sex with men, aged 16-25, (2) African American women, (3) Hispanic men, (4) PLWH with opioid addiction, (5) American Indian men, (6) transgender PLWH, and (7) residents of the EMA’s outlying counties. Nearly everyone in the focus groups is receiving HIV-related primary medical care. The focus groups provide qualitative data on perceived service needs and gaps, including barriers to care, as well as level of satisfaction with the HIV/AIDS-related services they receive, including cultural competence issues.
4. **Quality management data,** including data on HIV/AIDS Bureau performance measures, with a special focus on linkage to care, doctor visits, use of anti-retrovirals and adherence to those medications, and viral suppression, as well as results of quality improvement projects to improve completion of mental health assessments and annual pap smears.
5. **A special study** of PLWH living in rural parts of the EMA, focusing on demographics, HIV and broader health status, service needs and gaps, access and barriers, where the individual would prefer to receive services, and transportation issues.
6. **A resource inventory** that identified 63 providers within the EMA that offer services in 15 service categories considered particularly important for PLWH. Information is limited, but includes service locations, types of services provided, target populations, number of “slots,” major sources of funding, whether the entity has any formal agreements/MOUs with RWHAP Part A providers, approximate percent of clients who are HIV-positive, whether staff have training in HIV/AIDS, and whether there is a waiting list for services.

**Situation and Assignment:**

In preparation for the priority setting and resource allocations process, the Committees are reviewing and assessing available data reports. Three work groups have been established, focusing on data needs for the following:

* **Setting service priorities** for the EMA
* **Allocating resources** to service categories that have been identified as priorities for this EMA
* **Developing directives** for the Recipient to help in implementing the EMA’s service priorities

**Answer the questions below** from the perspective of your assigned work group:

1. Which of the types of data sources/reports listed in the Background description are likely to be most useful in decision making in your assigned area – which are most likely to provide information needed for that type of decision making? How and why will they be important?
2. Which, if any, are *not* needed or unlikely to be very useful? Explain your answer.
3. What additional types of data would help the Planning Council to make sound decisions in your assigned area of decision making? Explain how/why.

# Activity D: Assessing Data Reports

1. Work in a small group, with a facilitator and a recorder/reporter (you may split these last two roles if desired).
2. Imagine yourselves as members of the Southwest EMA Planning Council who are reviewing data reports in preparation for priority setting and resource allocations. Quickly review the background information and list of data reports provided for Activity C. Then review the information provided below about the data report assigned to your group (PLWH Survey, Focus Group Report, or Report on the Unmet Need Study).
3. For your data report, answer the following questions. Make additional assumptions as needed. You will have about 20 minutes.
   * 1. What are the strengths and weaknesses of this data report as described?
     2. What “weight” would you give this report – how confident are you about its quality and value for use in decision making?
     3. How might you use “triangulation” to make the best use of these data? What other data reports might you use for comparison?
4. Be prepared to present your answers to the full group.

**1. PLWH Survey**

The EMA conducted a PLWH survey this past winter with the help of funded RWHAP Part A service providers and non-funded service providers such as counseling and testing sites, prevention for positives programs, emergency rooms, homeless shelters, and substance abuse treatment centers. The survey includes data from 520 PLWH in the EMA.

A contractor was hired to develop the survey questionnaire in coordination with the Needs Assessment Committee and to coordinate data collection. Except for about 75 interviews conducted at homeless shelters, emergency rooms, and other non-Ryan White sites, the survey involved self-administered questionnaires in English and Spanish made available at service sites.

The consultants developed a list of the targeted number of surveys from PLWH with varying characteristics, based on the demographics of the local epidemic, plus the need to oversample traditionally underserved populations. There was also a targeted minimum number of surveys to be obtained from each provider site, but no maximum was set. Results indicate that the number of completed surveys was hard to control since the surveys were made available to all clients over a 30-day period. Following is a comparison between planned and actual composition of the PLWH surveyed.

**Targeted and Actual Breakdown of Survey Respondents – Southwest EMA PLWH Survey**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Characteristic** | **Desired # and %**  **(N=500)** | | **Actual # and %**  **(N=520)** | |
| **Gender** | # | % | # | % |
| Male | 375 | 75 | 437 | 84 |
| Female | 100 | 20 | 78 | 15 |
| Transgender | 25 | 5 | 5 | 1 |
| **Race/Ethnicity** |  |  |  |  |
| White non-Hispanic | 200 | 40 | 302 | 58 |
| Hispanic | 100 | 20 | 73 | 14 |
| African American | 100 | 20 | 78 | 15 |
| American Indian | 75 | 15 | 62 | 12 |
| Asian/Pacific Islander | 25 | 5 | 5 | 1 |
| **County of Residence** |  |  |  |  |
| Central County | 425 | 85 | 499 | 96 |
| Outlying Counties | 75 | 15 | 21 | 4 |
| **Other Targeted Characteristics** |  |  |  |  |
| Youth 16-24 | 40 | 8 | 16 | 3 |
| White non-Hispanic MSM | 100 | 20 | 187 | 36 |
| MSM of Color | 100 | 20 | 120 | 23 |
| White non-Hispanic IDUs/Substance Users | 75 | 15 | 73 | 14 |
| IDUs/Substance Users of Color | 100 | 20 | 36 | 7 |
| Sex workers | 35 | 7 | 14 | 3 |
| Homeless | 50 | 10 | 21 | 4 |
| Not “in care” | 75 | 15 | 16 | 3 |

As the table indicates, in general, funded RWHAP Part A providers had a larger number of surveys completed than non-RWHAP Part A providers. Efforts were made to involve sites likely to provide a diverse group of PLWH, and this effort was largely successful. The survey was not successful in reaching people who are not receiving primary medical care. Other groups for which targeted numbers were not reached include people who live in the outlying counties or are homeless, sex workers, or IDUs or other substance users of color.

The survey provides information on basic demographics, date of diagnosis, co-morbidities (e.g., substance use, mental health needs, homelessness), self-reported health status, HIV-related services received in the past 12 months (based primarily on the EMA’s priority service categories but including some services that are not currently prioritized), identification of up to three services most wanted but not received, satisfaction with services received, and perceived barriers to care.

Following are some of the key findings from the report:

* **Primary medical care:** About 97% of respondents reported having been to see a physician at least once for HIV-related care during the past 12 months, although the State estimates that 27% of PLWH in the EMA are “not in care.” Half (51%) report receiving medical care from a private physician or clinic, 34% report care from one of the five county clinics funded by RWHAP Part A, and 92% of American Indians report care from the Indian Health Service clinic funded by RWHAP Part A.
* **Insurance and related assistance:** 39% report receiving Medicare, and 53% receive Medicaid. Hispanics are less likely than other groups to be receiving either of these – 19% receive Medicare and 44% receive Medicaid. While 29% of White non-Hispanics have some form of private insurance (employer or individual), only 12% of African Americans and 10% of Latinos have such insurance.
* **Viral suppression:** 83% of all respondents and 72% of African Americans report they are virally suppressed.
* **Substance use:** 75% report past use of an illegal drug, 19% report using an illegal drug in the past week, and 23% report use in the past month. Eleven percent report having received substance abuse treatment.
* **Mental health services:** 29% report that they were diagnosed with or treated for depression during the past year, and 62% report having taken medications prescribed for psychological or behavioral conditions at some point in their lives. About two-thirds (69%) report receiving individual or group counseling in the past year, and 11% have seen a psychiatrist or clinical psychologist. African Americans and Hispanics are less likely than White non-Hispanics to report having seen a clinician in the past year.
* **Housing:** 6% report homelessness or unstable housing conditions during the past year; 17% report unstable housing in the past two years.
* **Service priorities:** The top ten service priorities – “the most important services for PLWH in this EMA” – are primary medical care, oral health, medications, medical case management, mental health services, emergency financial assistance (for food, utilities, and rent), transportation assistance, insurance premium and cost-sharing assistance, substance abuse treatment, and housing.
* **Service gaps overall and by race/ethnicity:** The service categories most often identified among the top three “wanted but not received” in the past year for all respondents include oral health services, medications, mental health services (individual counseling), insurance premium and cost-sharing assistance, and emergency financial assistance. For White non-Hispanics, the top three are oral health, insurance premium and cost-sharing assistance, and mental health services. For African Americans, they are medications, oral health, and emergency financial assistance. For Hispanics, they are medications, emergency financial assistance, and housing services. For American Indians, they are medications, mental health services, and oral health services.
* **Service gaps for specific populations:** Individuals reporting a history of substance use other than marijuana identify detoxification services and substance abuse treatment for opioid addiction as key service gaps, along with mental health and case management services. Women are more likely than men to identify transportation, nutritional services, and medical case management as service gaps, as well as respite care and child care. Rural dwellers are most likely to identify unmet transportation needs and lack of access to substance abuse treatment.
* **Satisfaction with services:** Overall, respondents are “moderately” satisfied with services received. White non-Hispanics generally report the highest level of satisfaction with services received, while African Americans report the lowest level, with Hispanics and American Indians in the middle. Services with the highest level of reported client satisfaction include primary medical care and oral health, with more than 75% of clients reporting a high or moderate level of satisfaction. Services with the lowest level of satisfaction include medical case management and transportation, with 42% and 37% of clients, respectively, reporting dissatisfaction.
* **Barriers:** Communities of color report more barriers to services than white non-Hispanics. Most frequently identified barriers include transportation problems, not enough bilingual provider staff, and lack of evening or weekend hours.

**2. Focus Group Report**

Southwest EMA hired a consultant to conduct a series of 7 focus groups targeting disproportionately affected and/or historically underserved populations of people with HIV and AIDS in the EMA, including individuals underrepresented in the PLWH survey. The Planning Council’s RFP specified that the focus groups should include individuals in all three EMA counties, and that together the focus groups reach at least 70 people (an average of 10 per focus group). It required that at least two focus groups be conducted in Spanish. The contractor was expected to obtain some minimum demographic data on each participant, including age, race/ethnicity, gender, zip code of residence, HIV or AIDS status, and whether the individual had “seen a doctor for HIV-related medical care in the past 12 months.” The RFP identified 12 possible population groups and required that at least 6 of them be targeted; 7 were chosen.

The consultant conducted one focus group for each of the following 7 population groups; the number of participants is provided for each group (total number = 59):

* + - 1. Young African American MSM – 9
      2. African American women – 11
      3. Hispanic men (conducted bilingually) – 6
      4. PLWH with an opioid addiction - 12
      5. American Indian men (conducted in an outlying county on a reservation) – 13
      6. Transgenders – 3
      7. Residents of the EMA’s four outlying counties (conducted in an outlying county) - 5

The focus groups provide qualitative data on perceived service needs and gaps, including barriers to care, as well as level of satisfaction with the HIV-related services they receive, including cultural competence issues. The contractor wrote a separate report on each focus group and then an aggregate summary of key findings, which include the following:

* **Access to appropriate medical care:** Demographic data indicate that nearly everyone in the focus groups (96%) saw a doctor for HIV-related medical care last year, but at least one member of every focus group reported some barriers to obtaining needed HIV-related medical care. Transgender PLWH and Hispanic males reported the *least* difficulty, and people from the outlying counties (regardless of race/ethnicity) reported the *most* difficulty in obtaining medical care. All other groups had varying responses about access to medical care, but reported being able to obtain services.
* **Access to medications:** Obtaining needed medicationswas seen as a problem for Hispanics, some of whom may not be documented and are afraid to seek services from public entities, and for people with a history of opioid abuse. At least one person in 6 of the focus groups (all but transgender PLWH) reported some difficulties in obtaining needed medications.
* **Service gaps:** The majority of people in the opioid use focus groups and at least one person in each focus group reported difficulty in obtaining substance abuse services. At least one person in all 7 focus groups reported difficulty in obtaining mental health services and oral health services.
* **Awareness of service availability:** All groups indicated that many people do not receive services because they are unaware that Ryan White services exist or that services are available without cost to low-income people. About half of Hispanics reported personal language barriers (most of those in the focus groups speak English), and most indicated that many Hispanics in the EMA have limited English literacy or limited literacy in both languages.
* **Other service barriers:** Most often identified other barriers to care were lack of convenient or adequate transportation assistance (mentioned in 6 of the 7 focus groups), lack of evening and weekend hours for providers (mentioned in 5 groups), negative experiences with providers, some of whom “don’t respect clients with HIV” (mentioned in 3 groups), and lack of providers located in outlying areas (mentioned in 2 groups). Women reported considerable challenges in finding child care so they can obtain care, especially substance abuse treatment and mental health services.
* **Transportation:** Transportation needs appear as great for people living in the central county of the EMA as for those in outlying counties. Only focus group with a rural focus and the American Indian focus group had more than one rural resident in them. The American Indian group reported minimal transportation needs, indicating that they receive needed services on or near the reservation. Women with children most often reported transportation problems. Use of bus tokens is seen as difficult when one or more transfers are required, especially for women with children and people who describe their health status as “poor,” and rural dwellers noted that there is minimal public transportation in their areas.
* **Case management:** Nearly all participants indicated receiving some medical case management services, which is expected since in this EMA, referrals to most services other than primary medical care must be made through either medical care providers or medical case managers. There was a higher level of dissatisfaction with medical case management services than with other services, with participants in 5 of the focus groups indicating that it is very hard to reach their case manager and get a call back or appointment, and that medical case managers often are not able to provide needed referrals for supportive services. Women most often reported that case managers seem to have caseloads that are too large.
* **Culturally appropriate services:** All groups reported some difficulties in obtaining culturally appropriate or population-appropriate services. Hispanics reported difficulty in finding provider staff who speak Spanish when seeking transportation, nutrition, case management, and oral health services. Transgender PLWH reported an overall lack of sensitivity to their population among providers including physicians. African Americans reported few African American provider staff. American Indians reported receiving primary care largely through an Indian Health Service clinic, but having some difficulties with cultural competence when they seek other kinds of services, especially mental health services. Young African American MSM reported that few services include staff knowledgeable about youth and young adults and insufficient confidentiality in some large clinics and other service facilities.

**3. Report on the Unmet Need Study**

The Planning Council recently completed a quick three-month assessment of service needs, gaps, and barriers to care for people are not in care – individuals who know their HIV status but are not receiving HIV-related primary medical care. Because the PLWH survey and focus groups were not successful in including people out of care, at the end of last year the Planning Council funded its first special study of people not in care. A consultant was hired, and the Needs Assessment Committee and contractor worked closely with the Consumer Committee to find and interview people not in care.

The HIV/AIDS Bureau (HAB) has defined a person as “out of care” when there is no evidence that a person who knows s/he is HIV-positive has had any of the following during a recent 12-month period:

* A CD4 count
* A viral load test
* A prescription for anti-retroviral therapy (ART)

In addition, a PLWH is considered not to be retained in care when s/he does not have evidence of at least 2 HIV-related doctor visits (or 2 viral load tests and/or CD4 counts) 3 months apart during the past 12 months.

The EMA has what it considers a solid estimate of the number and percent of people not in care in the EMA, based on an analysis prepared by the State epidemiologist. The State used the HAB operational definition in estimating unmet need for the EMA. However, the Planning Council’s PLWH survey and the focus groups used a less specific question – “Have you seen a doctor for HIV-related medical care in the past year?”

The contractor reviewed and summarized the State’s estimate and assessment on unmet need as part of its work on unmet need. Among the key findings:

* Overall, 37% of PLWH in the EMA’s three counties are not in care, using the HAB definition. The outlying counties each have over 45% of PLWH out of care, while the central county (which has more than 85% of living HIV/AIDS cases in the EMA) has about 34% out of care.
* PLWH whose mode of transmission was Injection Drug Users (IDUs) are much more likely than men who have sex with men (MSM) to be out of care. About 52% of IDUs are out of care, compared to 32% of MSM.
* People of color, especially African Americans, are more likely to be out of care than White non-Hispanics. The State estimates that 45% of African American PLWH, 43% of Hispanics, 38% of American Indians, and 29% of White non-Hispanics are not in care.
* Men are slightly more likely than women to be out of care. An estimated 39% of men and 34% of women are not in care.
* People under 25 (52%) are more likely to be out of care than older PLWH, and people 55 and over (27%) are least likely to be out of care.

To identify PLWH not in care, the contractor worked closely with consumers on the Planning Council, counseling and testing sites, and service providers that are likely to be points of entry into care. The contractor developed a mini-survey, and provided stipends to consumers in various locations and with various characteristics to locate people not in care, conduct the mini-survey with them, and then provide them information about available services. Outreach workers funded through the Minority AIDS Initiative (MAI) were asked to provide assistance as well and completed most of the surveys in the outlying counties.

Through this method, during a two-month data collection period, the contractor as able to identify and interview 59 individuals not in care, 47 in the EMA’s central county and 12 in the four outlying counties. All individuals interviewed were also given information about how to obtain services.

Data from the mini-survey include demographics, date of diagnosis, HIV versus AIDS status, care history, barriers to care, and priority service needs and gaps. The findings indicate that:

* 39% of those identified are White non-Hispanic, 32% African American, 27% Latino, and 2% American Indian.
* 90% are male, 8% female, 2% transgender.
* 32% were diagnosed in the past two years, 39% 2-5 years ago, and 29% more than five years ago.
* 68% have received HIV-related medical care at some point in the past.
* 51% have been incarcerated in the past two years.
* 19% were diagnosed while living in another State.
* 76% report at least one of the following co-morbidities within the past two years: substance use, mental health issues, or homelessness.
* 71% say they are low income.
* The most frequently reported barriers to care, all mentioned by at least 20% of respondents, are: co-morbidities (especially substance use) that make it hard to adhere to treatment and lead to negative experiences with some medical personnel (51%), lack of information about available services or lack of awareness that free medical care is available to those without insurance (43%), not feeling ill and therefore not feeling in need of medical care (34%), inability to access medical care because the individual works during the day (27%), and lack of transportation (22%).
* Services viewed as most needed are: primary medical care (68%), medications (59%), substance abuse treatment (59%), housing assistance (29%), help in “navigating the system" (25%), and oral health services (25%).
* After the interview, 34% accepted a referral to primary care or case management, and 25% kept an appointment with a service provider.