Estimating Unmet Need for HIV Primary Medical Care
Frequently Asked Questions

Updated Unmet Need Methodology Overview

1. Why did HRSA HAB update the Unmet Need methodology for the Ryan White HIV/AIDS program?

In the years since the original Unmet Need methodology was put in place, the treatment of HIV disease has changed significantly due to the effectiveness of antiretroviral treatment (ART). In addition, the availability and quality of data used to estimate unmet need have improved. Given this, HRSA HAB began exploring ways to estimate unmet need more effectively—to meet both the legislative requirements and provide a better tool that jurisdictions can use to identify needs and develop interventions in response to those needs.

2. What are the main differences from the original methodology?

- The original methodology differentiated between HIV non-AIDS and AIDS whereas now we use people living with diagnosed HIV infection. This aligns with changes in how HIV surveillance data are presented.
- The new methodology uses a 5-year recent cohort for population size rather than all people living with diagnosed HIV. This 5-year cohort is defined using HIV surveillance data as the number of people living with diagnosed HIV infection in the jurisdiction based on most recent known address who had an HIV diagnosis or any other HIV-related lab data (e.g., CD4, VL, genotype, or HIV test even if already diagnosed) reported to the HIV surveillance program during the most recent five calendar year period. This makes it more likely that individuals who have moved or died are not included in the estimate.
- The definition for "In Care" in the estimates includes CD4 and Viral Load tests, but NOT antiretroviral prescriptions, as prescription data are not available in the HIV surveillance data.
- Most of the components of the new methodology use the most recent known address for the person rather than address at diagnosis. This is consistent with broader changes in how data are presented by Centers for Disease Control and Prevention (CDC) and better reflects where people are living now rather than when they were diagnosed.
- Added estimates for Late Diagnoses and In Care, Not Virally Suppressed to the new methodology.
- There are required and enhanced estimates. Required elements must be completed by all, but jurisdictions can also choose to do any or all of the additional enhanced estimates (see question below on differences between required and enhanced).

Unmet Need Definitions and Terms

3. How is Unmet Need for HIV Primary Medical Care defined?

Unmet Need is "the need for HIV-related health services by individuals with HIV who are aware of their HIV status but are not receiving regular primary [HIV] health care". (REF: Mosaica, "HRSA/HAB Definitions Relate to Needs Assessment," prepared for the Division of Service Systems, HIV/AIDS Bureau by Mosaica: The Center for Nonprofit Development and Pluralism, June 10, 2002.)

4. What is the difference between the *required* and *enhanced* estimates and analyses?

- The **required** estimates utilizes HIV surveillance data for **Late Diagnoses**, **Unmet Need,** and **In Care Not Virally Suppressed** totals as well as Priority Populations. These estimates and analyses must be submitted to HAB.
- The **enhanced** estimates includes all of the **required** estimates plus additional estimates and analyses that can be useful for RWHAP planning and resource allocation. In addition to HIV surveillance data, recipients may choose to use RWHAP data for **Unmet Need** and **In Care Not Virally Suppressed** as well as the same Priority Populations used for HIV surveillance data. Adding subpopulation analyses for HIV surveillance and RWHAP data is also an option. Finally, linked databases may be used. These additional estimates and analyses are optional but are recommended if feasible; how much of the enhanced estimates and analyses are completed is also up to the recipient.

HRSA
Ryan White HIV/AIDS Program

5. What is the difference between Late Diagnoses and New Diagnoses?

New diagnoses are people with HIV diagnosed in the most recent calendar year based on residence at time of diagnosis. Late diagnoses are a subset of all new diagnoses and represent people with new diagnoses whose first CD4 test result was <200 cells/mL (or a CD4 percentage of total lymphocytes of <14) or had documentation of an AIDS-defining condition ≤3 months after a diagnosis of HIV infection. If ≥2 events occurred during the same month and could thus qualify as "first," apply the same conditions used by CDC's Division of HIV/AIDS Prevention HIV Incidence and Case Surveillance Branch (DHAP HICSB).

6. How is this different from Data to Care?

While similar data may be used for analyses, the purpose of the Unmet Need Estimates and Analyses and Data to Care is different. The focus of Data to Care is on utilizing HIV surveillance and other data sources to determine who is potentially not in care and conduct investigations to either re-engage persons who are out of care or to update information in surveillance if a person is in care, has moved out of jurisdiction or is deceased.

Unmet Need also utilizes surveillance data to determine who has not recently been in care (no labs in the most recent year) but is also focused on other measures, including those with late diagnosed HIV and those who are in care but not virally suppressed. These additional estimates and analyses help to identify additional opportunities to increase testing and outreach opportunities as well as improve care engagement. Both Data to Care and Unmet Need provide information on persons with HIV (and specific priority populations) that can inform planning and intervention efforts to improve health outcomes for persons with HIV.

7. What is considered the most recent calendar year?

Jurisdictions are asked to use the most recent calendar year for which data are available. This means that a jurisdiction should have cleaned and reviewed the data and determined them to be complete, accurate and ready for release. This will vary by jurisdiction and should be assessed at the time that the estimates and analyses are being prepared. The HIV surveillance staff in a jurisdiction will likely make the determination on which data are ready for release.

8. Is there a difference between assessing unmet needs for priority setting and the NOFO?

Yes, there is a difference. Unmet Need is a component of the overall planning activities a RWHAP recipient engages in to address the needs of clients. The needs assessment is the main driver for the priority setting and resource allocation activities in Ryan White jurisdictions. Using needs assessment results, recipients (and Planning Councils/Bodies in RWHAP Part A programs) must set priorities and allocate resources to meet these needs. Based on needs assessment, utilization of services, and epidemiologic data recipients (and Planning Councils/Bodies in RWHAP Part A programs) decide what services are most needed by people living with HIV in the EMA or TGA (priority setting) and decide how much RWHAP funding should be used for each of these service categories (resource allocations).

9. What does RWHAP-related funded services include?

Services funded by pharmaceutical rebates and/or program income are considered RWHAP-related funded services. For estimates and analyses using RWHAP data, the denominator should include clients who received RWHAP or RWHAP-related funded services.

Preparing for Unmet Need Estimates and Analysis

10. When Should I Start Working on Unmet Need?

While the actual estimates are not due until the application submission, preparation for Unmet Need should start as soon as is feasible. This will ensure you have adequate time to contact and work with your HIV surveillance program as well as determine which approach you are using for Unmet Need (required or enhanced). Recipients are encouraged to develop a Preparation Plan to help them plan for completing the Unmet Need estimates and analyses.

11. How can the RWHAP Part A and Part B recipients ensure that HIV surveillance staff are prepared for running the Unmet Need estimates and analyses?

The Abt team presented Unmet Need on a CDC HIV surveillance call in January, so the surveillance contacts should be aware of this requirement. RWHAP staff should start working with HIV surveillance staff in their jurisdictions as early as possible to identify who will be responsible for running the estimates and analyses and ensure there is adequate time to complete the work.

Completing the Unmet Need Estimates and Analysis

12. If we are conducting estimates and analyses using RWHAP data, are we expected to merge RWHAP data across different Parts?

Jurisdictions are expected to use RWHAP data to which they already have access. If a jurisdiction already have data from different Parts in their data system, there is no requirement to filter the data. There is also no expectation to merge data across different Parts.

13. If we choose to do enhanced estimates and analyses, do I need to complete everything listed in the manual?

HRSA HAB encourages recipients to complete as much of the enhanced estimates and analyses as is possible. However, only the required estimates and analyses must be completed; any additional analyses are optional.

14. How would linked databases be possible if HIV surveillance is reluctant to share data with Ryan White?

HRSA HAB and CDC strongly encourage data sharing between HIV surveillance and the RWHAP in jurisdictions. As a reminder, linked databases are not used for the required Unmet Need estimates and analyses, only for the enhanced estimates and analyses.

15. Do you have any recommendations on how to coordinate priority populations across unmet need, Early Identification of Individuals with HIV/AIDS (EIIHA), and Ending the HIV Epidemic?

The selection of priority populations should be data driven. Specifically, data from the needs assessment, service utilization, and other component of your program (e.g., HIV Care Continuum, EIIHA strategy, Unmet Need data, etc.) should be used to make determinations on the selection of priority populations. To the extent possible, the activities to support selected priority populations should reflect the demonstrated need in the different components of the application (e.g., unmet need, EIIHA, etc.).

16. Do we have to use the subpopulation breakdowns in the Optional Calculation tables or is there flexibility?

Recipients may use breakdowns that are most useful locally, which may include demographics such as race and age and geographic areas such as counties or health districts. It is recommended the breakdowns for the RWHAP data be the same as those for HIV surveillance data as much as possible. The SAS program from CDC will run the estimates using the categories in the Optional Calculation Tables, except for Health Planning Areas and Priority Populations, which are determined by the jurisdiction.

17. We know COVID-19 has impacted service delivery systems and our client's ability to access care. We also see that lab reporting has been impacted. This will no doubt impact unmet need calculations. We are concerned that the HIV surveillance staff may not have updated data prepared for 2020 or even 2019 due to pandemic response. What advice do you have in this circumstance?

HAB understands that COVID-19 may have impacted lab reporting. RWHAP recipients should use the most recent data that is complete, accurate and ready for release, as determined by the HIV surveillance team.

Submitting the Unmet Need Estimates and Analysis

18. When is the new Unmet Need requirement being implemented?

HRSA HAB is implementing the new unmet need requirement in the FY 2022 Notice of Funding Opportunity (NOFO). As such, all RWHAP Parts A and B recipients will be required to submit unmet need estimates and analyses in their FY 2022 applications.

19. Is there a timeline to complete the unmet need project? Do you have a date for when the NOFO will be released?

Unmet Need Estimates and Analyses will need to be completed in time for inclusion in your jurisdiction's response to the NOFO. The NOFOs are anticipated to be released late summer 2021.

20. How will recipients submit the Unmet Need Estimates to HRSA HAB?

HRSA HAB has developed Required Reporting Templates for recipients to use to submit Unmet Need Estimates and analysis. Recipients will also need to include narrative responses specific to unmet need in their applications based on questions in the Notice of Funding Opportunity (NOFO). Recipients may also submit the Optional Calculation tables but this is not mandatory. Additional information can be found in the RWHAP Parts Part A and B NOFOs.

21. Will recipients be able to describe data system and other limitations as part of the narrative in the application?

Yes, recipients will be able to describe limitations in reporting Unmet Need estimates in the application.

Tools for Completing Unmet Need and Estimates

22. Do I have to use CDC SAS Code to conduct the analysis?

The SAS program (analytic software) was developed by the CDC's Division of HIV/AIDS Prevention HIV Incidence and Case Surveillance Branch (DHAP HICSB) to help jurisdictions analyze their HIV surveillance data, but recipients do not have to use it.

23. Does the SAS code assume the jurisdiction uses eHARS?

The SAS code does assume that eHARS is being used.

24. How do I get the CDC SAS Code?

The SAS program developed by CDC's Division of HIV/AIDS Prevention HIV Incidence and Case Surveillance Branch (DHAP HICSB) is available to the HIV surveillance staff in each jurisdiction and has been distributed through the CDC Sharepoint site.

25. When will the SAS code be available?

The SAS code is available now to HIV surveillance staff. The SAS code is available on the CDC Sharepoint site to HIV surveillance staff in each jurisdiction.

26. What is the difference between version 1 and version 2 of the Required Reporting Templates and Optional Calculation Tables?

While they both have the same templates and tables, what differs is how the different templates and tables relate to one another. In version 1, data auto-populates across different templates and tables. This means if you populate the Optional Calculation Tables, they will then automatically populate the applicable sections in the Required Reporting Templates. In version 2, this feature does not exist. Both versions have validations and auto-calculation fields (cells highlighted in yellow) to make things easier for recipients.

Technical Assistance

27. Is technical assistance available if I need help?

Training and technical assistance (TA) are available to HRSA HAB staff, RWHAP Parts A and B recipients, and state and local HIV surveillance staff by members of the Unmet Need Training and TA Team through May 31, 2021. Potential topics can include collection and use of data for estimating unmet need as well as conducting subpopulation analyses by key characteristics (e.g., age, gender, race/ethnicity, transmission risk category). Assistance is available via email or phone consultations, webinars, staff trainings, or through the provision of resource materials. After May 31, 2021, TA is available through your HRSA HAB project officer.

28. How do I request Technical Assistance for Unmet Need?

Reach out to your HRSA HAB Project Officer with any questions.

29. When is Technical Assistance available for Unmet Need?

Technical Assistance from the Abt team is available through May 31, 2021. After May 2021, technical assistance is available through your HRSA HAB Project Officer.

30. What resources are available to help me with the estimate?

HRSA HAB has provided several resources to assist Parts A and B recipients with completing the estimates. These are available on the TargetHIV website and include:

- ☑ Unmet Need Training Webinars Recordings and Slides
- ☑ Training Videos
- ☑ Methodology for Estimating Unmet Need: Instruction Manual
- ☑ Required Reporting Template and Optional Calculation Tables (Excel)
- ☑ The Required and Enhanced Estimates for RWHAP Unmet Need Reporting Fact Sheet
- ☑ Estimating Unmet Need for HIV Primary Medical Care Preparation Plan
- ☑ Feasibility of Required vs. Enhanced Estimates and Analysis for Estimating Unmet Need for HIV Primary Medical Care
- ☑ Using Unmet Need Estimates and Analysis for HIV Primary Medical Care to Inform Planning
- ☑ High-level Workflow Infographic for Estimating Unmet Need: Key Steps for RWHAP Part A and Part B Recipients
- ☑ Data Capacity Assessment

For detailed instructions and tools for calculating Unmet Need, visit **https://targethiv.org/library/topics/estimating-unmet-need-hiv-primary-medical-care**

HRSA
Ryan White HIV/AIDS Program