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 now 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.)

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4. **What is the difference between Late Diagnoses and New Diagnoses?**
   New Diagnoses are people in the jurisdiction 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 <1) 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 applied by CDC's Division of HIV/AIDS Prevention HIV Incidence and Case Surveillance Branch (DHAP HICSB).

5. **What is considered the most recent calendar year?**
   It's 2021 now, so would it be 2020 data due in the Fall? 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.

6. **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 recipient engages in to address the needs clients have in the jurisdiction. The needs assessment is the main driver for the priority setting and resource allocation activities in Ryan White jurisdictions. Based upon 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 decides how much RWHAP funding should be used for each of these service categories (resource allocations).

Preparing for Unmet Need Estimates and Analysis

7. **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 that you have adequate time to contact and work with your HIV surveillance program and 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.

8. **How can the RWHAP Part A and Part B recipients ensure that HIV surveillance is 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.

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Completing the Unmet Need Estimates and Analysis

9. **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.

10. **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.

11. **Do you have any recommendations on how to coordinate priority populations across unmet need, 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 focus on. To the extent possible, the activities to support selected priority populations should reflect the demonstrated need in the reflected in the different components of the application (e.g., unmet need, EIIHA, etc.).

12. **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 Area and Priority Population, which are determined by the jurisdiction.

13. **We know COVID-19 has impacted service delivery systems and our client's ability to access care. We also see that lab reporting itself has been impacted as well. This will no doubt impact unmet need calculations. We are concerned that the 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 complete data that is available, which will be determined by the HIV surveillance team.

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Submitting the Unmet Need Estimates and Analysis

14. **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.

15. **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.

16. **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.

17. **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

18. **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.

19. **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 will be distributed to those contacts via their listserv.

20. **When will the SAS code be available?**
    The SAS code should be available by March 2021. It will be distributed by CDC to the HIV Surveillance contacts in each jurisdiction.

Technical Assistance

21. **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. 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.

22. **How do I request Technical Assistance for Unmet Need?**
    Email requests for assistance to the Abt Unmet Need Training and TA Team: https://targethiv.org/ta-org/estimating-unmet-need-training-and-ta-team. A response will be sent within 48 hours of the request.

23. **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.

    https://targethiv.org/library/topics/estimating-unmet-need-hiv-primary-medical-care