U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration

HAB HIV Performance Measures
Pediatric FAQs

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The document focuses on questions related to the HIV/AIDS Bureau's pediatric performance measures that are most frequently asked by programs that receive funds under the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Ryan White HIV/AIDS Program). FAQs will be updated as necessary.

Questions that relate to the various types of performance measures can be found at: http://www.hab.hrsa.gov/special/habmeasures.htm.

The following categories of questions have been frequently asked and the corresponding answers are detailed in this document:

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Scope of Pediatric Measures

Question: The number of pediatric clients is relatively small in comparison to the cost it would take to build a centralized reporting system. Why aren't there fewer pediatric measures?

Answer: Grantees are encouraged to select and utilize those measures that are pertinent to their program. The number of measures selected will vary by program.

Question: My program serves both children and adolescents. Which measures should I use?

Answer: A table (available at [insert link]) has been created to identify which set of measures to use for which population. Because the HAB performance measures align with the Public Health Service guidelines, the adult and adolescent core clinical measures (Groups 1-3) should be used for children > 13 years of age.

Adherence Assessment & Counseling

Question: I see both pediatric and adolescent patients. Do I use the pediatric or the adult/adolescent adherence measure?

Answer: If the program serves both pediatric and adolescent patients using one measure consistently is the easiest and cleanest approach. Either measure can be used for the adolescent population; however, the pediatric measure should be used with the pediatric population.

Question: Do I have to talk and/or include the parent or guardian in the discussion?

Answer: The answer varies based on the age and maturation of the child. If the patient is a child, the parent or guardian should be included in the discussion. If the patient is a young teen both parties would likely be involved in the discussion. If the patient is an older adolescent or young adult the parent or guardian may be involved in the discussion but does not have to be.

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ARV Therapy

Question: How do we account for patients who were prescribed medication but choose not to take them?

Answer: It is understood that patients, for many reasons, may choose not to fill or take a prescribed treatment. While programs may not attain 100% compliance on the measure, it is, however, important to capture the actual percentage of clients that are on a prescribed treatment regimen and identify opportunities for improvement. Often times when programs begin to track and trend data, they find unexpected levels of performance and new opportunities for improvement.

CD4 Value

Question: The CD4 measure allows for both a CD4 count and percentage. Why?

Answer: Clinicians interpreting CD4 count for children must consider age as a variable. CD4 count and percentage values in healthy infants who are not infected with HIV are considerably higher than values observed in uninfected adults and slowly decline to adult values by age 5 years. In children younger than 5 years of age, the absolute CD4 count tends to vary more with age within an individual child than does CD4 percentage. Therefore, in HIV-infected children younger than 5 years of age, CD4 percentage is preferred for monitoring immune status, whereas absolute CD4 count can be used in older children. (Pediatric Guidelines August 16, 2010)

Question: How do I count children who turn five (5) years old during the measurement year?

Answer: For those children who turn 5 years old during the measurement year, either a CD4 count or CD4 percentage can be used. Both methods should be included in the numerator as having met the criteria.

Question: The measure states that the CD4 value must be performed at least three months apart. This misses some people who are seen right before or right after the three month mark. Can this be modified?

Answer: All of the measures can be modified to make them more useful to the program. Some programs have suggested using the three month time period with a plus or minus two (2) week leeway. This strategy may be helpful in capturing additional patients within this time frame but it introduces another level of complexity for running electronic reports.

Developmental Surveillance

Question: Why are HIV-exposed children included in the development surveillance measure?

Answer: The rate of developmental delays is significantly higher in both the HIV-infected and HIV-exposed children compared to the general population. Therefore it is important for delays to be identified as soon as possible and appropriate referrals made.

Question: Who can conduct the developmental surveillance? Does it count if a general pediatrician completes it and not the HIV team?

Answer: Yes, another pediatrician or other members of the team can complete the surveillance; however, the results must be documented in the HIV health team's record. This allows the HIV team to be aware of the results, identify developmental delays and make appropriate referrals.

Question: What is the difference between developmental surveillance and developmental screening?

Answer: Developmental surveillance is the process of identifying children at risk for developmental delays. The observations should be age appropriate and can include both formal and informal clinic assessments. Developmental screening utilizes standardized tools to identify and refine the recognized risk. The Denver Developmental Screen is one such example of a standardized tool.

Question: How am I supposed to use the developmental surveillance measure? What should I be looking for and what counts as an improvement?

Answer: Developmental surveillance should be conducted annually on all HIV-infected and exposed children. The measure is designed to track the number and percentage of children who receive the surveillance. If

the rates are low this may be an appropriate issue to be addressed through a quality improvement project. An improvement would be represented by an increase in the percentage of children who received developmental surveillance on an annual basis.

Health Care Transition Planning for HIV-Infected Youth

Question: What are the core elements to consider in a transition plan for youth?

Answer: The following elements should be included in a comprehensive transition plan: a) where to go; b) when transition would take place; c) who will be involved from the health care team and family; d) assessment of readiness for adult program. A multidisciplinary team may be best suited to create the plan.

Question: Can we start the discussion about transition before the adolescent is 17 years old?

Answer: Yes. The health care team should assess the readiness of each adolescent and understand that everyone matures at a different rate. Discussion should have begun for all adolescents by the age of 17 years at the latest.

Question: Why wasn't discussion with a parent or guardian included in the measure?

Answer: The focus of the measure is to plan and prepare the youth for transition from a pediatric/adolescent program to an adult program. For some youth it will be important and beneficial to include the parent or guardian, but it is not required.

Question: If my program takes care of patients throughout the lifespan, is this an appropriate performance measure for us?

Answer: Some programs, often referred to as "lifespan clinics", care for patients throughout the course of their lives. While the primary provider may change, the team as a whole remains the same. This measure may not be appropriate for use in programs such as these.

Question: Who can conduct the discussion about health care transition planning?

Answer: Any member of the HIV team can conduct the discussion about health care transition planning. The discussion must be documented in the HIV health team's record.

Question: Should we exclude adolescents who have already transitioned into adult care?

Answer: If the adolescent was enrolled in your program at the beginning of the measurement period they should be included in the denominator and the numerator.

HIV Diagnostic Testing to Exclude HIV Infection in Exposed Infants

Question: What is an "HIV-exposed infant"?

Answer: All children born to HIV-infected women are considered "HIV-exposed."

Question: When should HIV testing be performed for HIV-exposed infants?

Answer: According to current national guidelines, virologic diagnostic testing for HIV-exposed infants should be performed at 14-21 days, at age 1-2 months and at age 4-6 months. Additional information can be obtained at http://aidsinfo.nih.gov/ContentFiles/PediatricGuidelines.pdf.

Question: Is viral culture acceptable for this measure?

Answer: While viral culture is not the preferred method of diagnostic testing, it is acceptable.

Question: Why can't I use two antibody test results for diagnosis?

Answer: Although two negative antibody tests conducted $\geq$ 6 months also definitively excludes HIV infection, the focus of this measure is on

infants < 6 months of age for whom antibody tests are not appropriate.

Question: What if a child is breastfed? Should the child be tested and are they definitively diagnosed?

Answer: Breastfeeding is not recommended for HIV-infected women in the United States as transmission of HIV can occur. If a child is breastfed, he/she should continue to be re-tested until after breastfeeding has ceased (see WHO guidelines available at: http://www.who.int/child_adolescent_health/documents/9789241599535/en/index.html). Testing during breastfeeding cannot definitively exclude HIV because the child is exposed to HIV every time he/she is breastfed.

Question: What happens if a patient presents at ≥ 6 months of age? Should the patient be included in the denominator?

Answer: No. Because the measure is focusing on your program's process of HIV diagnostic testing, exposed children who present older than 6 months of age are excluded. Testing, however, should still be performed if it has not been completed.

HIV Drug Resistance Testing Before Initiation of Therapy

Question: A resistance test was performed in 2009 but ARV therapy wasn't initiated until 2010. Does the 2009 test count?

Answer: Yes. Resistance testing must be performed at any time prior to initiating ARV therapy for the tests to be included in the numerator.

Question: What do I do if a resistance test was performed by another agency? Does it count?

Answer: Any test would be included in the numerator if the source documentation or a complete record of the resistance test findings is available.

Question: Does resistance testing apply to patients on neonatal prophylaxis?

Answer: No. The measure focuses on the initiation of therapy after a diagnosis with HIV infection has been confirmed.

Question: If ARV therapy has been stopped and then re-started, should they be included?

Answer: No. The measure focuses on resistance testing before therapy is initiated for the first time.

Question: Where do I find documentation of resistance testing?

Answer: If the lab results are not electronically available, a chart review may be required.

Medical Visit

Question: Why does the medical visit measure not include HIV-exposed children?

Answer: Children infected with HIV are at risk for rapid immunologic and clinical progression. For this reason, it is imperative that these children are seen by a provider. The measure is intended to examine the engagement in care for the HIV infected population.

Question: Why do the medical visit and CD4 value measure require the timeframe of "at least 3 months apart"?

Answer: The measures focus on a patient's engagement in care over time. If the timeframe was not defined a patient with a visit January 3, January 13 and January 23 and no other visit for the rest of the year would be counted as having met the criteria. The timeframe establishes a minimum time frame between visits to demonstrate engagement in care.

Question: The medical visit measure states that the visit must be performed at least three months apart. This misses some people who are seen right before or right after the three month mark. Can this be modified?

Answer: All of the measures can be modified to make them more useful to the program. Some programs have suggested using the three month time period with a ± two (2) weeks leeway. This strategy may be helpful in

capturing additional patients within this time frame but it introduces another level of complexity for running electronic reports.

Question: Our system captures data from providers outside of the HIV care setting. Can we still use the medical visit measure?

Answer: If appropriate for your program the HIV care setting can be defined as broader than those programs receiving Ryan White Program funds.

MMR Vaccination

Question: Why was MMR vaccination included when no other immunizations are included in the list of pediatric performance measures?

Answer: MMR immunization was chosen to be included in the pediatric performance measures for a variety of reasons: 1) recommendations for MMR immunization with HIV-infected patients are clearly defined; 2) MMR serves as a marker of immunization in general; 3) MMR immunization creates the greatest confusion among providers as to whether or not the immunization should be administered.

Question: If the CD4% is < 15% should I give the MMR vaccination?

Answer: No. Children with CD4% < 15% should not receive the MMR vaccine.

Question: Can live vaccines be given to HIV-indeterminate children?

Answer: MMR is made from a live-attenuated strain. The CDC recommends providing MMR to children with CD4 values $\geq$ 15%. Vaccination schedules are the same for HIV-exposed or indeterminate children.

Question: The CDC recommends that 2 doses of the MMR vaccine be given by the time the child is 6 years old. Why doesn't the measure address this?

Answer: It is important to understand the doses must be given at the appropriate time and cannot be given together. The CDC recommends that 1 dose be provided by age 2 and the 2nd dose provided by age 6. For simplicity, the performance measure focuses on the first dose.

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Question: What happens if a child turned 2 or 4 years old in the measurement year? Should they be counted in the denominator?

Answer: Yes, the child should be included in the denominator.

Question: Why weren't HIV-exposed children included in the measure?

Answer: HIV-exposed children who are not HIV-infected should be immunized based on the general immunization schedule, which can be found at http://www.cdc.gov/vaccines/recs/schedules.

Neonatal Zidovudine Prophylaxis

Question: My program isn't responsible for prescribing ZDV prophylaxis at birth. Why is this measure important?

Answer: While administration of ZDV prophylaxis at birth may not fall under the direct purview of your program, a child born with HIV infection represents a sentinel event where the system of care can be positively impacted.

Question: Why was 12 hours of birth included as part of the measure?

Answer: The effectiveness of ZDV prophylaxis is dependent on the timing of administration. Current guidelines recommend that ZDV should be initiated as close to the time of birth as possible, preferably within 6 to 12 hours of delivery. Additional information can be found at http://aidsinfo.nih.gov.

Question: Some providers are using a 4-week course of ZDV for neonatal prophylaxis. Why isn't this allowed for the performance measure?

Answer: The current PHS guidelines require a 6-week course of treatment.

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PCP Prophylaxis

Question: Why do two measures focus on PCP prophylaxis?

Answer: The recommendations for PCP prophylaxis are different for HIV-infected and HIV-exposed children. For simplicity, a separate measure was created to focus on each population.

Question: Do I include pediatric patients who have been presumptively excluded for HIV?

Answer: No, pediatric patients who have been presumptively excluded for HIV are considered HIV-negative and would not receive PCP prophylaxis. They would not be included in either the numerator or the denominator.

Planning for Disclosure of HIV Status to Child

Question: The disclosure measure only includes children ≥ 12 years of age. Shouldn't we be discussing disclosure before this time?

Answer: The actual timing of disclosure is dependent on the maturation of the child. The American Academy of Pediatrics strongly encourages disclosure to school-age HIV-infected children. At a minimum, preliminary discussions about disclosure should be held with the guardian by the time the child is 12 years. If your program consistently plans for disclosure prior to age of 12 years, the measure can be modified to reflect the target age.

Question: Why aren't children with developmental delays excluded from the disclosure measure?

Answer: Regardless of whether a child has a developmental delay, members of the health care team still need to talk with the parent or guardian about disclosure. Children with developmental delays can benefit from discussions about disclosure and their HIV status.

Question: What does "documented" mean in the disclosure measure?

Answer: "Documented discussion" means that the provider or another member of the medical team has talked with the guardian and/or child about disclosure and the discussion is noted in the health record.

TB Screening

Question: Why does the performance measure require annual TB screening for children?

Answer: Children infected with HIV are more likely to develop active TB disease compared to the rest of the population. Because children with HIV infection are at high risk for tuberculosis, annual testing is recommended.

Question: Why isn't IGRA recommended for the pediatric population?

Answer: Because of uncertainty about test sensitivity of IGRA, the routine use for finding LTBI or diagnosing TB in HIV-infected children is not recommended.