

# Family-based index case testing to identify children with HIV

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## 01

### Rationale

Pediatric HIV treatment coverage is stagnating. The most recent estimates suggest that only 46% of children living with HIV are on treatment, well below the AIDS Free target of 1.6 million by the end of 2018.<sup>1</sup> A key challenge is to identify children who are living with HIV who have been missed through routine testing services. For children in the 0-14 year age group, over 95% of HIV infections are acquired as a result of vertical transmission. As a result, historical approaches to pediatric diagnosis have tended to focus on early infant diagnosis (EID) within the context of prevention of mother-to-child-transmission (PMTCT) programs.

Testing the family of adult or child 'index' cases can serve as an entry point for identification of children living with HIV not identified through PMTCT program testing. This type of family-based approach to HIV testing and service delivery enables parents and their children to access care as a unit. Such approaches may improve retention and offer a convenient service for families affected by HIV.

Unlike other types of routine approaches to pediatric HIV testing – such as testing in inpatient wards, sick child clinics, malnutrition centres or immunization clinics – index case testing is a potentially high-yield identification strategy irrespective of national seroprevalence. In fact, yield may be higher in low-prevalence countries where programs may be less mature and access to HIV testing and prevention services is lower, resulting in large gaps in PMTCT and EID coverage.

Furthermore, testing of a child whose parent is already known to be living with HIV is more likely to result in linkage to care if that child tests positive, since in most cases the parent will already be on antiretroviral therapy (ART).

## 02

### Barriers and facilitators of implementation

#### Barriers

- Adults tend to get tested at voluntary counseling and testing (VCT) centers, tuberculosis (TB) clinics and other service delivery points where providers may not be fully aware of the importance of family testing of the index case.
- While many women first get tested when they present for ANC services, there is often a shortage of human resources to offer testing to family members.
- In large or extended families there is difficulty in defining the biological children of the index case.
- Where systems to document and track follow-up are weak, and access to testing



needs to be initiated by the client, child contacts of an index case may not be brought to the facility for testing.

- Some adult providers are not comfortable with testing children, and there is confusion around appropriate tests to use, namely, rapid tests or infant diagnosis tests.
- Testing children may result in inadvertent disclosure of maternal status, which can lead to intimate partner violence or other harms for the mother and her child.
- Parents may be in denial of their status or not be ready to test children when they themselves are first identified as living with HIV. Offering family-based testing in such settings may make them less likely to attend for HIV care.
- Providers may feel that they lack time to counsel on the importance of testing children, identify children in the family who have not been tested, perform tests in children and ensure that they are linked to care.
- Lack of clear standard operating procedures (SOP) and monitoring tools to enable providers to correctly identify children to be tested and track them until they are linked to care.

### Facilitators

- Availability of tools and job aides for providers to facilitate family testing
- Defined policies promoting concepts of index case/contact testing
- Building relationship with primary client by inviting his/her family to access services
- Doing family testing of child and adult clients who are already in care/on ART, which ensures linkage to care for any newly identified positive individuals/children since they will have seen the positive impact of a close family member being linked to care and treatment
- Availability of outreach workers or community health workers to support home-based testing
- Availability of HIV self-test kits in pharmacies, which may make testing generally more accessible especially for adult and adolescent family members

## 03

### Policy and legal considerations

Testing children of index cases is an extension of policy guidance, which already recommends contact tracing of newly diagnosed people living with HIV (PLHIV)<sup>2</sup> and household contact tracing of people with tuberculosis (TB) in order to identify children and adults who may need evaluation for TB infection.<sup>3</sup>

Governments must assess the current policy environment and address any gaps, using the approach outlined in Section 4:

- Promote policy of universal family testing in the context of treatment programs for adults living with HIV, including women who are pregnant or breastfeeding.
- In settings where lower cadres and lay workers are not permitted to test children, consider specific legal or policy reform to permit trained staff to undertake testing.
- Frame index case testing of children as an opportunity to protect the rights of children affected by HIV to access prevention and care services.

## 04

### Steps for scale-up

There are four steps to implementing family-based testing in national programs:

#### Step 1:

Form an interest group of key stakeholders, community representatives and national technical working group (TWG) members. This is an essential first step to build consensus, identify possible concerns and agree on approaches to track and evaluate roll out.

## Step 2:

Assess the current policy environment and address any gaps. Key questions include:

- Is there existing national policy on family-based index case testing?
- If so, at what scale is this policy being implemented and what are the perceived challenges to scale-up?
- If there is no policy around family-based index case testing, is there existing guidance on contact tracing for newly diagnosed PLHIV and/or guidance on TB contact tracing for the children of known TB-positive cases?

If new policy/guidance is needed, this should be developed by stakeholders in collaboration with the HIV TWG.

## Step 3:

Identify target sites for roll out of index case testing in a phased manner, for example:

- Large PMTCT sites
- Large adult ART sites linked to sites where pediatric ART is available
- Pediatric treatment sites (for promotion of sibling testing)
- Outreach testing for children living in orphanages

Selecting existing treatment sites for initial roll out of index case testing is important:

- Treatment sites likely have more staff capacity for index case testing than testing sites. But it is important to ensure that testing technologies, including rapid testing and virologic testing for infants <18 months of age, are available.
- Linkage to care is more likely to happen for newly identified positives at treatment sites.
- Since index cases will be people on treatment, they are more likely to understand the importance of treatment and follow-up for their HIV-positive children.

Once sites have been selected, send out a circular to all sites to explain the importance of family testing, ensure providers have access to testing kits and materials, and define when and how they will receive site visits to provide initial training and follow-up supervision.

## Step 4:

Develop a detailed implementation plan, elements of which should include:

- For selected sites:
  - Reinforce the supply chain to ensure availability of test kits and optimal pediatric ARV formulations. Note that more testing reagents will be needed in the initial phase in order to test children of existing clients.
  - Send out communication to the sites so all management and staff are aware.
- Develop tools and job aides, including posters for clinic walls, to promote index testing and reinforce the fact that treatment for children is available and life-saving
- Develop an M&E plan and, if needed, data capture forms to track uptake of the policy, assess yield and determine the proportion of newly identified children linked to treatment.
- Develop a simple training and mentoring plan for on-site training of staff at roll-out sites with periodic site visits to assess progress, identify challenges and develop practical solutions and learning.
- Estimate the additional community-based staff that might be needed to expand to family-based index case testing in the home.

# 05

## Case example of successful implementation

The effectiveness and high yield of family-based index case testing was demonstrated in two recent UNICEF-led initiatives in the Democratic Republic of Congo (DRC) and Zimbabwe. Over a period of six months, a total of 170 children were identified as HIV positive and all but one were initiated on ART. The majority of these (161/170) were in DRC where the yield of family-based testing was very high at 30%. By contrast, in Zimbabwe, although the strategy was still valuable, yield was lower at 3%. This difference highlights the importance of context, and is likely driven by PMTCT coverage, EID coverage and the difference between the two programs in terms of maturity. This is an important consideration for national governments as they plan adoption and/or scale-up of this intervention. This example is described in more detail in the UNICEF annual results report: [https://www.unicef.org/publications/index\\_96412.html](https://www.unicef.org/publications/index_96412.html).

# 06

## Monitoring

Monitoring should be undertaken to assess yield of the intervention and the success of linkage to care and also to document provider and client perspectives. In many cases, index case testing will result in disclosure of the index case's HIV status. It is important to understand how index cases should be counselled and prepared for testing of their contacts and children. Negative experiences may have a detrimental impact on the uptake of index case testing.

# 07

## Conclusion

Index case testing has a high yield irrespective of the background of HIV prevalence in the country. Indeed may have a higher yield in the low-prevalence settings where it is also associated with poor PMTCT coverage. It is an intervention that reinforces concepts of family care and helps to build trust between clients and providers because it shows that providers and clinics care about their children. It is an intervention that may help to identify those children who have 'fallen through the cracks' in the system.

### References

1. UNAIDS. *Start Free Stay Free AIDS Free: 2017 Progress report*. Geneva: UNAIDS; 2018.
2. WHO. *Guidelines on HIV self-testing and partner notification: Supplement to consolidated guidelines on HIV testing services*. Geneva: WHO; 2016.
3. WHO. *Recommendations for investigating contacts of persons with infectious tuberculosis in low- and*

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