







AN ETHNO-EPIDEMIOLOGICAL STUDY TO ASSESS EARLY INFANT DIAGNOSIS (EID) OF HIV INFECTION PROGRAMME

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EXECUTIVE SUMMARY

Globally, the World Health Organisation (WHO) has recommended the implementation of Early Infant Diagnosis (EID) and treatment among HIV exposed infants to achieve the 2030 goal of HIV elimination. The EID programme is aimed at early HIV diagnosis and subsequent initiation of Anti-Retroviral Treatment (ART); consequently, DNA Polymerase Chain Reaction (PCR) tests are conducted at 6 weeks of age and onwards.

An ethno-epidemiological study was conducted to assess gaps and barriers to the implementation of the EID programme at various levels. The assessment of EID programme was conducted across 11 states detecting more than 90% of HIV positive pregnancies and comprised primary and secondary data collection across 62 Integrated Counselling and Testing Centres (ICTCs), 30 Anti-Retroviral Treatment Centres (ARTCs), 11 State AIDS Control Societies (SACSs), 4 Regional Reference Laboratories (RRLs) and National AIDS Control Organisation (NACO) (secondary data).

The main findings of this study were that children are either not brought or brought late for HIV testing, or that the follow-up of children for confirmatory testing and treatment is suboptimal. These findings recommend that EID programme coverage should be improved, by providing alternative choices for service utilisation, services at grass root level; user-friendly EID testing algorithms should be utilized; leverage existing viral load testing centres for EID testing; and improve programme management through streamlining supply chain management and intra NACO convergence via efficient inter-department coordination.



Globally, WHO has recommended the implementation of EID and treatment among HIV exposed infants to achieve the 2030 goal of HIV elimination. In response to this, the Government of India initiated implementing EID services through the National AIDS Control Programme (NACP) in 2010 which was scaled up in fourth phase -NACP-IV (2012-2017) in a step-wise manner. EID programme is aimed at early HIV diagnosis and subsequent initiation of ART; hence, DNA PCR tests are conducted at age of 6 weeks and onwards. Stand Alone (SA) ICTCs under Prevention of Parent to Child Transmission (PPTCT) programme function as dried blood sample collection sites and are linked to RRLs.



An ethno-epidemiological study was conducted to assess gaps and barriers in the implementation of EID programme at different levels.



The assessment of EID programme was conducted across 11 states (Figure 1) detecting more than 90% of HIV positive pregnancies and involved primary and secondary data collection across 62 ICTCs, 30 ARTCs, 11 SACSs, 4 RRLs and NACO (secondary data).

At the ICTC-level, mother-baby pair data was collected from PPTCT and Exposed Infant/Child (EIC) registers. In Depth Interviews (IDI) were conducted among service providers and carer were interviewed to assess gaps in EID services (Figure 2).

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At the SACS and District AIDS Prevention and Control Unit (DAPCU) levels, programme managers were interviewed to assess challenges in implementation of EID programme and secondary Strategic Information Management System (SIMS) data was collected (Figure 3). From NACO, secondary programme data was collected pertaining to HIV positive pregnancy detection and HIV testing conducted at RRLs.



Figure1: EID study – Selected States and Districts



RRL-Regional Reference Laboratory, NACO-National AIDS Control Organisation, SACS-State AIDS Control Society, IDIs-In Depth Interviews, ARTc -Anti Retroviral Treatment Centre





- There were a total of 816 HIV positive pregnant women with 675 live births and an additional 351 children were referred from other ICTCs. 881 children were tested for HIV, including 18 month antibody tests.
- EID service utilisation
 - » One fourth infants (24%, 161/675) born to HIV-positive pregnant women did not have any HIV test under EID programme.
- » EID testing facility was available only at 42.4% of SA-ICTCs (Figure4).
- Delay for EID test
 - » Only half of those tested infants (51%, 448/881), had the test done within two months of age.



Key gaps in EID programme



- Inappropriate selection of tests
 - » In 24% children, age appropriate EID test was not done.
- Incomplete EID cascade
 - » Nearly 40% (337/881) of infants enrolled under the programme did not have their 18 month antibody test.
- Lost-to -follow-up for confirmatory DNA PCR Test
 - » Analysis of secondary data collected at RRL showed that after first DNA PCR positive test, 40% of infants are lost-to-follow-up for second confirmatory DNA PCR test (820/1885).



Figure 4: Loss to follow-up cases after 1st EID test

- High Turn-Around-Time for EID Testing
 - » Only 6 laboratories (RRL) across the country have the facility to process the EID samples.
 - » The median turn-around-time for conduction of EID test (Figure 5) varied from 29 days to 53 days (2013 to 2016) across different states.
- » Median sample transport time from ICTC to RRL was 11 to 14 days nationally but it was more (19 days to 33 days) for those states without testing laboratory.



Figure 5: Turn-around-time for EID test in selected states

- Children born to HIV positive mothers need to be tested early for HIV and those who are diagnosed positive need to be provided treatment but:
 - » Children are not brought or brought late for HIV testing.

"There can be financial problem. One child came at 12 months, his mother was expired. Child didn't receive NVP (Nevirapine) and didn't test for HIV. I did tests and child was positive at the age of 12 months. I had sent DBS (Dried Blood Sample) sample to RRL, now report has come. But after 2-3 months of test, child died. So, because of family conditions, lack of awareness, they are not coming for tests."

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Qualitative findings revealed:

- » Sample collection services are available only at selected facilities.
- » Follow up of children for confirmatory testing and treatment is sub-optimal. Qualitative finding revealed:

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"We are also following these children. There is one issue very prominent looking into migration. Once delivered, they take their baby and go away. So, one thing is migration, another thing is refusal. It is very crucial to convince them to draw blood from such a little baby. And another reason is social stigma."

- State official



RECOMMENDATIONS

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Improve EID testing coverage

Alternate choices for service utilisation As HIV positive mothers access ART centres for treatment, ART centres can be equipped with additional EID testing facilities. This will increase utilisation of services and decrease drop out cases. Additionally, ICTC centres could be equipped and medical staff trained to provide ART to paediatric cases:

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".....for baby at least this should not be the scenario where there is a doctor who is placed in the ICTC what is if we strengthen those doctors who are signing the report for the babies, they themselves start the treatment at that facility itself. Why can't our ICTCs start functioning as ART centres for paediatric cases? It is just a thought process in context of better operationality... because every month we are asking babies to travel... because already this rapport between the ICTC counsellors has been developed for 18 months...it's just about who prescribes them the medicines and who follows up for adherence."

» HIV testing services are available at limited facilities leading to burden on regional laboratories and delaying testing time.

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Qualitative findings revealed:

"It takes more time for EID testing if the RRL laboratory is not available in concerned state. One person has to travel 700 to 800 km, it will take 2 days for somebody to take the sample and reach there and there is no courier. The lab technician has to go there, take the sample."

- State Official

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» Inappropriate DNA PCR test selection for ICTC level EID testing leading to increase RRL burden.

Providing services at doorstep

ICTCs can collaborate with frontline workers for tracking HIV exposed children and for sample collection at beneficiary's residence. Travel allowance to laboratory technician and incentives to Accredited Social Health Activist (ASHA) workers can be provided for each EID test.

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"There are gaps in follow-up, one case is there, and they are not ready for follow-up at any cost, I and technician, we went to their home, contacted them through ASHA and got baby tested there itself at their home, only then they come here for next follow-up. These kinds of gaps are seen, so if something through system can be done or through NGOs, it would be beneficial."

- ICTC Counsellor, Karnataka

"We used to pay the money from our pocket. There is no special provision for that."

– ICTC LT, Odisha

- State official

User friendly tool:

As the EID testing algorithm is complex at the counsellor and laboratory technician level, there is unnecessary samples collected for DNA PCR test leading to additional burden on RRLs. Algorithm should be simplified and there should be a provision for user friendly software for selection of appropriate test. The software tool should also be friendly in order to generate the monthly reporting format as the current practice is to record EID testing in individual format while reporting is in monthly format. This will improve the data management issues at ICTC level.

Leverage existing viral load testing centres for EID testing:

Upgrading state-level laboratories to perform DNA PCR tests will reduce turn-around-time for EID testing and will reduce burden on RRL facilities.

Evidence generation for alternative test -Whole Blood Finger Prick Test (WBFPT):

an alternative to routine antibody testing can be conducted. Once validated, WBFPT can be initiated at peripheral levels – Facility Integrated (FI) ICTCs to improve EID service coverage.

Programme Management:

» Streamlined Supply Chain Management Procurement of logistics and distribution at facility level should be streamlined to ensure availability of logistics.

"Challenges for DBS kits shortage is that if baby comes here for testing and we send them back because of no kits available then there are highly any chances of baby returning back for the tests again"

- ICTC counsellor, Karnataka

» Intra NACO Coordination

Coordination between Basic Service Division (BSD) and Care Support and Treatment (CST) divisions of NACO can be established for smooth functioning of diagnosis and treatment services delivery.

» Inter-departmental Coordination

Interdepartmental coordination between Reproductive & Child Health (RCH) and NACO can be established to increase coverage and penetration of EID services. Efficient follow-up mechanism can be established to decrease lost to follow-up cases.

There were a total of **816 HIV positive pregnant women** with **675 live births** and an additional **351 children** were referred from other **ICTCs**. **881 children** were **tested for HIV**, including 18 month antibody

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Across the Continuum of HIV Services for Key Populations











