

# Urgent action needed on point-of-care early infant diagnosis

Point-of-care diagnostic machines are a critical breakthrough in HIV early infant diagnosis. In the countries where they are being used, they are already saving the lives of infants living with HIV. The technology has been shown to work, we know it is cost-effective, now is the time to scale up - all HIV-exposed infants should have access to point-of-care diagnosis.

The Global Fund (GF) proposal development process and the USA President's Emergency Plan for AIDS Relief (PEPFAR) country operational plan (COP) processes are taking place right now - they are important opportunities to - all HIV-exposed infants should have access to point-of-care diagnosis (POC EID).

### Why is early diagnosis so important?

When infants living with HIV are untreated, the disease progresses quickly. Without treatment, up to 50% of children living with HIV die before their second birthday. Untreated infants living with HIV are particularly vulnerable in the first three months of their life. To have the best chance of survival they need to be tested and started on treatment. So, the World Health Organisation (WHO) recommends EID, which means testing infants born to mothers living with HIV within the first 6 weeks of life.

















## What is point-of-care early infant diagnosis (POC EID)?

POC EID is a test done at a health facility. A blood sample is taken from the infant, put in a simple machine that tests it and produces the result so that it can be returned to the parent/caregiver, usually on the same day. If the infant is found to be living with HIV, they can begin antiretroviral therapy (ART) immediately. As such, point-of-care machines are a breakthrough!

**Point-of-care vs conventional lab-based testing:** Many countries still use EID tests that can only be carried out in laboratories. In these countries, blood samples are taken, transported to the lab, tested and then the results are sent back to the health facility. Over 40% of caregivers never receive the test results and even when results are returned, the process is slow <sup>3</sup>- often taking more than 50 days. <sup>4</sup>

Now that point-of-care machines exist and have been shown to work, we need to get national programmes to switch most of their HIV testing in infants to POC machines; we need to be sure that parents and caregivers know about POC EID, can access this service and are supported throughout the process.

### Where is it available?

In 2015, <sup>5</sup> a set of projects began to introduce and scale up POC EID in 15 African countries - Cameroon, Côte d'Ivoire, the Democratic Republic of the Congo, Eswatini, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Rwanda, Senegal, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe. Each country is at a different stage in its implementation of POC technology. There are also 10 countries in West and Central Africa that are now being given technical support to scale up POC EID - Burkina Faso, Cabo Verde, Central African Republic, Chad, Congo, Equatorial Guinea, Gabon, Ghana, Mali, and Nigeria. <sup>6</sup>

<sup>&</sup>lt;sup>1</sup> "Closing the Early Infant HIV Diagnosis (EID) and Treatment Gaps for Infants and Children: The Point-of-Care EID (POC EID) Scale-up in WCA" IQLS, IRESSEF and Unicef, 2019

<sup>&</sup>lt;sup>2</sup> UNAIDS Update - Only half of HIV-exposed babies are tested for HIV, 25 March 2019.

<sup>&</sup>lt;sup>3</sup> Based on EGPAF POC EID implementation data from 8 countries and a weighted average of 8 studies

<sup>&</sup>lt;sup>4</sup> Based on EGPAF POC EID implementation data from eight countries (March 2018) and two studies: Jani, Ilesh, et al. 'Effect of Point-of-Care Testing on Antiretroviral Therapy Initiation Rates and Retention of Patients: A clustered randomized trial', AIDS, 8 May 2018; and, Mwenda, Reuben, et al., 'Significant Patient Impact Observed upon Implementation of Point-of-Care Early Infant Diagnosis Technologies in an Observational Study in Malawi', Clinical Infectious Diseases, 27 February 2018

<sup>&</sup>lt;sup>5</sup> The projects are funded by Unitaid and delivered by African Society for Laboratory Medicine (ASLM), Clinton Health Access Initiative (CHAI), Elizabeth Glaser Paediatric AIDS Foundation (EGPAF), and UNICEF

<sup>&</sup>lt;sup>6</sup> This project is being led by UNICEF, in collaboration with the Institut de Recherche en Santé, de Surveillance Epidémologique et de Formation (IRESSEF), Réseau Africain de Recherche sur le SIDA (RARS)

## What are the issues?

- Not all decision-makers are well enough informed about POC and give it the priority that it needs in their programmes and budgets;
- Many service providers face technical problems due to the limited availability of point of care tests, supply chain problems, staffing shortages, and weak health care infrastructure;
- At the community level, parents lack the information they need about EID, testing and treatment options. Some people also face practical problems accessing health facilities, including the long distances and costs of traveling to the nearest facility.
- HIV-related, as well as gender-based stigma and discrimination are still a major barrier to EID, as well as to treatment, care and support.



### What must we demand?

Funding - Increased financial commitment is needed to introduce POC machines where needed based on a detailed analysis of the organisation of the laboratory network, provide the supplies needed for existing machines, and to make sure that there is enough operational and social support including:



- trained health workers with enough time to talk to increased commitment to fully fund;
- information for parents/caregivers to understand why it's important to test their infants, support for mothers living with HIV to make an informed choice about infant testing that meets their needs and financial support to be able to take their children to a health facility for the test;
- grants for NGOs, CBOs and networks of people living with and affected by HIV to encourage health-seeking behaviour by developing and disseminating information materials, holding community health days to reduce stigma around infant testing and coordinating group and one-toone peer-to-peer support for parents/caregivers.

Integration - Infant testing must be part of a wider package of health services for families affected by HIV. Services should be integrated to create more opportunities to identify infants exposed to HIV, connect them to testing and treatment and prevent loss to follow-up. One solution is to have combined clinics, where mothers living with HIV and their infants can access family planning, maternal and child health and prevention of mother-to-child transmission (PMTCT) services, all in one place. POC testing machines can have more impact and be more cost-effective if they are also used to test for other diseases such as TB. Integrated policies are also needed so, for example, child-friendly medicines are available as well as infant testing.

### How do we do it?

Here are some of the ways you can advocate for the inclusion of POC EID services in Global Fund and PEPFAR grants:

#### **Global Fund:**

- Raise the issue during the country dialogue processes or when your National Strategic Plan (NSP) is being developed;
- Contact your community representatives in the GF Country Coordinating Mechanism (CCM) and get information about key dates for your country application find out how to get involved; and,
- Each CCM has one People Living with HIV (PLHIV) representative and one alternate member. They are in the best strategic position to raise grassroots issues and need to be actively involved in developing the country proposal to the GF. Use these representatives, along with civil society representatives on the CCM to demand POC for all HIV-exposed infants.

#### **PEPFAR COP:**

- Engage in the 2020 COP discussions in your country/region. If you are unable to be involved directly you can contact your local network or national umbrella organisation and call for this issue to be raised during the COP meetings; and,
- These are the important dates for 2020 COP processes:
  - February 17th-21st in Johannesburg (Group 1: Nigeria, Cameroon, Côte d'Ivoire, Ukraine, DRC, West Africa Region)
  - February 24th-28th in Johannesburg (Group 2: South Africa, Lesotho, Eswatini, Namibia, Angola, Botswana, Zimbabwe, Zambia, Mozambique, Haiti/Dominican Republic)
  - March 2nd-6th in Johannesburg (Group 3: Ethiopia, Kenya, Tanzania, Uganda, Burundi, Rwanda, South Sudan, Malawi, Vietnam)
  - March 9th in Bangkok (Asia Region)
  - March 23rd in Washington DC (Western Hemisphere region)

## Any questions? Who to ask and where to look

If you need more information or would like guidance as you advocate for POC EID, please contact us at Global Network of People of Living with HIV (GNP+) at info@gnpplus.net and we will get back to you very quickly.

The top four materials we suggest you refer to for more info are:

- 1) Start Free, Stay Free, AIDS Free, 2019 Report
  https://www.unaids.org/sites/default/files/media asset/20190722 UNAIDS SFSFAF 2019 en.pdf
- 2) UNICEF HIV website, with a dedicated section on POC EID, including many resources. https://www.childrenandaids.org/point-of-care
- 3) Now more than ever! A need to reach the youngest children affected by HIV and AIDS, The Coalition for Children Affected by AIDS
  - https://childrenandhiv.org/wp-content/uploads/2017/06/NowMorethanEverECDandHIVbrochure.pdf
- 4) Early Infant Diagnosis: Understanding the Perceptions, Values and Preferences of Women living with HIV in Kenya, Namibia and Nigeria
  - https://www.gnpplus.net/new-icw-and-gnp-study-on-early-infant-diagnosis-calls-for-quality-information-and-informed-choices-for-women-living-with-hiv
- 5) The Kigali Declaration: Wake Up! Our Children are Dying! https://healthgap.org/children-with-hiv-are-dying/