NO TIME TO WAIT!

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

unicef for every child

Unitaid Innovation in Global Health

Actions to support point-of-care early infant diagnosis: a strategic framework for community-based organisations

Contents

Acronyms 03

1. Introduction 04
   - Standing by our children 04
   - Our aims 04
   - Intended users 05
   - How to use this strategic framework 05

2. Early infant diagnosis – The facts 06
   - A worldwide problem 06
   - Why is early infant diagnosis (EID) so important? 06
   - What barriers limit the uptake of EID? 07
   - Why are point-of-care (POC) machines a breakthrough for EID? 08
   - Are POC machines in use in your country? 09
   - The flexibility of POC machines 10
   - What must be done now? 10
   - We need you 12

3. How community-based organisations can support early infant diagnosis 13
   - Communities and the HIV response 13
   - What can you do to bring the benefits of POC EID into your community? 13
   - Advocating for access to quality EID testing services 14
   - Supporting parents and caregivers 15
   - Creating communities that support infant testing 15
   - Delivering health services 16
   - Conducting community-led research 16

4. Guide to developing an action plan 18
   - The 7 Key stages 18
   - Define your goal 18
   - Assess the situation 19
   - Consider your capacity 20
   - Choose your audience 21
   - Identify specific objectives 22
   - Create an action plan 23
   - Implement, monitor and evaluate 24
   - Action plan summary 25

5. Time to get to work 27

6. About us 28

7. Useful resources 29

8. Acknowledgments 30

9. Annexes 31

10. References 41

Acronyms

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
C4D	communication for development
CSO	civil society organisation
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
EID	early infant diagnosis
GIPA	greater involvement of people living with HIV/AIDS
GNP+	Global Network of People Living with HIV
HIV	human immunodeficiency virus
ICW	International Community of Women Living with HIV
MNCH	maternal, neonatal (newborn) and child health
NGO	non-governmental organisation
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
POC	point-of-care
UNAIDS	The Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organization

Key

Quote

Early Infant Diagnosis (EID)

Point-of-care (POC) technology

Community in action

Key information

Research

Advocacy and policy

Resources

1.

Introduction

Standing by our children

It is believed that 1.7 million children around the world are living with HIV. [1] If these children are not found, put on treatment and given the care that they need, they will not live long, healthy lives.

Whether your organisation is already working to support HIV testing among children or you would like to become more actively involved, this framework is here to help.

This framework focuses on early infant diagnosis (EID). What does that mean? In short, any child that could have been exposed to HIV before, during or after their birth, needs to be tested for HIV as soon as possible. Without treatment, HIV progresses very rapidly in young children and they can become unwell and die young. If they are tested and get an early HIV diagnosis, they can be given the treatment they need and their families can be supported to help make sure that they stay healthy.

New infant diagnosis tools now exist called point-of-care (POC) machines that make it easier to test infants for HIV. Using a POC machine, a small drop of blood can be taken from the infant's foot and the results given to the family on the same day.

Now that these machines exist and have been shown to work, we need more of them in strategic places and we need to be sure that parents and caregivers know about them, can access them, and are supported throughout the process. Community-based civil society organisations (CSOs) like yours can play an important part in working with communities to help make the most of this opportunity to improve the lives of infants living with HIV.

Our aims

This framework has been designed for CSOs to help you plan your work around infant HIV testing. There is a particular focus on Africa, as programmes to introduce point-of-care machines have so far focused on African countries, but we hope that the framework can be used by anyone wanting to work on early infant diagnosis of HIV.

It aims to help you to:

1. know more about early infant diagnosis and, in particular, point-of-care early infant diagnosis.
2. identify ways to work with communities to increase demand for early infant diagnosis and point-of-care early infant diagnosis by
   - informing, educating and supporting parents/caregivers about EID; and
   - influencing wider society to create an environment where testing infants for HIV is encouraged and stigma and discrimination are eliminated.
3. advocate for improvements to services, policies and funding relating to EID.
4. actively play a part in the implementation and monitoring of EID in your community.

Intended users

This strategic framework is designed to be used by civil society organisations (CSOs). CSOs bring people together to achieve change and improve the lives of ordinary people. They include: charities, international NGOs, religious-based groups, human rights groups, local NGOs, community self-help groups and many more. The framework is particularly focused on all community-based CSOs that want to work on issues surrounding HIV or paediatric health. That includes networks or groups of people living with HIV, key population networks, women's groups, organisations supporting children and health activists.

It may also be useful for implementing partners (organisations working to provide services for parents and caregivers of infants living with HIV), religious groups, government officials and other stakeholders to inform their work on early infant diagnosis.

How to use this strategic framework

The framework is not designed to be a fixed set of instructions. Instead we hope it will help guide you towards developing your own action plan to work on early infant diagnosis or to include it in your existing work.

Section 2 – turn to this section for the facts about early infant diagnosis. You can read this to make sure you have all the information you need about POC EID, you may also want to share it with other stakeholders to inform their work on POC EID.

Section 3 – gives specific guidance on the role that civil society organisations can play in supporting the uptake and implementation of POC EID.

Section 4 – is the heart of the framework, it guides you step by step through the different stages involved in developing an action plan for your organisation to work on EID and POC EID.

Section 7 has links to other resources and the Annexes have extra documents that might be helpful.

The framework is for you, so we hope you will use it in any way that you find helpful.

2.

Early infant diagnosis – the facts

A worldwide problem

Let's start with the good news. The number of new HIV infections in children is going down every year. 2.4 million new infections have been averted among children (0–14 years) since 2000, thanks to major advances in treatment for pregnant women and mothers living with HIV.[6] The bad news is, progress is slow and global targets to end new HIV infections among children are being missed.

Infants can be exposed to HIV in the womb, at birth or during breastfeeding. Efforts to prevent vertical transmission of HIV (sometimes called mother-to-child transmission) have had a positive impact, but more still needs to be done.

The *Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive*[7] helped to improve the health of mothers living with HIV and their babies. It led to more interventions to prevent mother-to-child transmission (PMTCT), as well as improvements in HIV testing and treatment for mothers and their babies. In 2016, UNICEF and UNAIDS launched a new initiative to build on this work, called the *Start Free, Stay Free, AIDS Free* framework[8], which has three key goals:

In 2018…

160 000 children were newly infected with HIV[2]

59% of infants exposed to HIV were tested by the age of two months[3]

54% of children living with HIV were receiving antiretroviral therapy[4]

72 000 AIDS related deaths in children aged 0-4[5]

- **Start Free** aims to end new HIV infections among children, partly by reaching 95% of pregnant women living with HIV and sustaining them on lifelong antiretroviral treatment (ART) by 2018.
- **Stay Free** focuses on reducing the number of adolescent girls and young women aged 10-24 years acquiring HIV to fewer than 100 000 annually by 2020.
- **AIDS Free** aims to ensure that 95% of all children and adolescents aged 10-19 years living with HIV receive ART by 2020.

Although there has been progress towards each goal, not enough has been done and the first target has already been missed. Children living with HIV are being left behind in the HIV response – they are now less likely to be on treatment than adults living with HIV.[9]

Why is early infant diagnosis so important?

When infants living with HIV are not treated, the disease progresses quickly. Without treatment, up to 50% of children living with HIV die before their second birthday.[10] Untreated infants are particularly vulnerable in the first three months of their life.[11] To have the best chance of survival, they need to be tested and started on treatment as soon as possible after infection occurs. The World Health Organization (WHO) recommends "early infant diagnosis" (EID) – testing infants born to mothers living with HIV within the first six weeks of life.

The tests that are used to detect HIV in adults measure antibodies in the body: antibodies that are produced by the immune system to attack the HIV virus. These tests cannot be used in infants under the age of 18 months, because they can find antibodies that were produced by the mother and passed on to the baby during pregnancy or through breastmilk. Instead a specific type of test that measures the virus itself is needed, called a virological test.

The WHO guidelines on testing for HIV-exposed infants states:[12]

- All infants exposed to HIV should be tested at six weeks and rapidly linked to care and treatment if positive.
- Virological testing at birth is also recommended for those at high risk of HIV infection.
- Infants who test positive at birth should be linked promptly to effective ART for newborns.
- Infants initially found to be negative should be retested using a virological test at nine months.
- All infants exposed to HIV should have a repeat test at the end of the breastfeeding period to detect HIV infections that occur during breastfeeding.

What barriers limit the uptake of EID?

Ever since 2010, WHO has been recommending that all HIV-exposed infants are tested for HIV at 4-6 weeks of age. But, in reality, this often does not happen. The percentage of infants being tested has steadily increased but by 2018, only 59% of infants exposed to HIV were being tested by the age of two months.[13] The number is even lower if you look specifically at Western and central African countries – just 27%. This table shows some of the country to country variations.[14]

Some country examples of Infant testing and treatment rates from 2018.

	% of HIV exposed infants tested before 2 months of age	% of children living with HIV on treatment
Côte d'Ivoire	56%	40%
DRC	20%	25%
Tanzania	47%	65%
Zimbabwe	63%	76%

Research carried out by the International Community of Women living with HIV (ICW) and GNP+ showed that mothers do want to know the HIV status of their child,[15] so what are the barriers that stop them accessing the tests?

Fear and Stigma

Parents/caregivers are afraid that their child's HIV status will be disclosed to other family members, friends and the wider community and that they will face stigma and discrimination. Some mothers living with HIV are also worried that their own HIV status will become known if they take their baby for a test. This is a problem especially for women who have not told their partner that they are living with HIV. Then there are other worries, including whether they will be able to cope practically and emotionally with having a child living with HIV and the fear that they will be prevented from breastfeeding.

Lack of information
Parents and caregivers do not always have the information they need to understand which tests are available and when they need to happen. There is also a lack of awareness of the HIV treatment options and outcomes for children. If they are not aware that treatment exists that can keep children healthy, where is the motivation to have them tested?

Health system weaknesses
When parents/caregivers do take their infant to be tested for HIV, they often have to wait a very long time for test results, up to three months or even longer. Worse still, some results are lost and never returned at all. Parents are then expected to make repeat visits to clinics, and this is not always easy. It can be difficult to get to the clinics where the tests are conducted. Only certain health facilities offer infant testing and they can be very far away. The time needed to travel to the clinic and the cost of transport are a major barrier for many people.

Why are point-of-care machines such a breakthrough for early infant diagnosis?

Point-of-care early infant diagnosis (POC EID) is a test done using a simple machine at the health facility. A blood sample is taken from the infant, put in the machine and the test results are produced and usually returned to the parent caregiver on the same day. If the infant is found to be living with HIV, they can begin ART immediately.

Point-of-care vs lab-based testing

Many countries still depend on conventional tests for infant diagnosis that can only be carried out in certain laboratories. In these countries, blood samples are taken, transported to the lab, tested and then the results are sent back to the original health facility. Over 40% of caregivers never receive the test results and even when test results are returned, the process is slow. [16] WHO recommends that there should never be more than a four-week turnaround time from collecting the blood sample to the results being given to a caregiver. [17] In reality, the turnaround time for test results using normal EID tests is often more than 50 days. [18] These delays can have terrible consequences as infants are most at risk of dying around the age of 2 to 3 months. To save their lives, results must be returned quickly and treatment begun without delays.

A 2019 study in eight African countries compared lab-based early infant diagnosis with point-of-care testing and found major advantages to using POC machines: [19]

- **Results were returned to caregivers much more quickly:** 98% of POC test results were returned to caregivers within 30 days, compared with only 19% of lab-based results.
- **The time between taking a blood sample and starting an infant on ART was significantly reduced:** 92% of infants diagnosed using POC technology began ART within 60 days of sample collection, compared with 43% of those diagnosed using lab-based EID.
- **Infants began ART sooner and at a younger age:** Infants diagnosed with POC technology started ART much more rapidly (same day compared with 49 days) and at a younger age (1.6 months compared with 3.3 months) than those diagnosed through lab-based EID.

The evidence already shows how well POC technology works. If it is made available in more health facilities and placed in strategic settings, it could lead to a real breakthrough in EID and move the world a step towards ending paediatric AIDS.

Improved treatment initiation in Mozambique[20]

A study in Mozambique compared the results of standard lab testing with POC testing. It found that POC testing led to better levels of retention in care and ART initiation.

- 89.7% of infants who tested positive with a POC test started ART within two months of diagnosis, compared with only 12.8% of those tested by a standard test.
- Six months after testing, 90.3% of infants who had received a POC test were still on treatment, compared to 40.2% of children who had received standard lab tests.

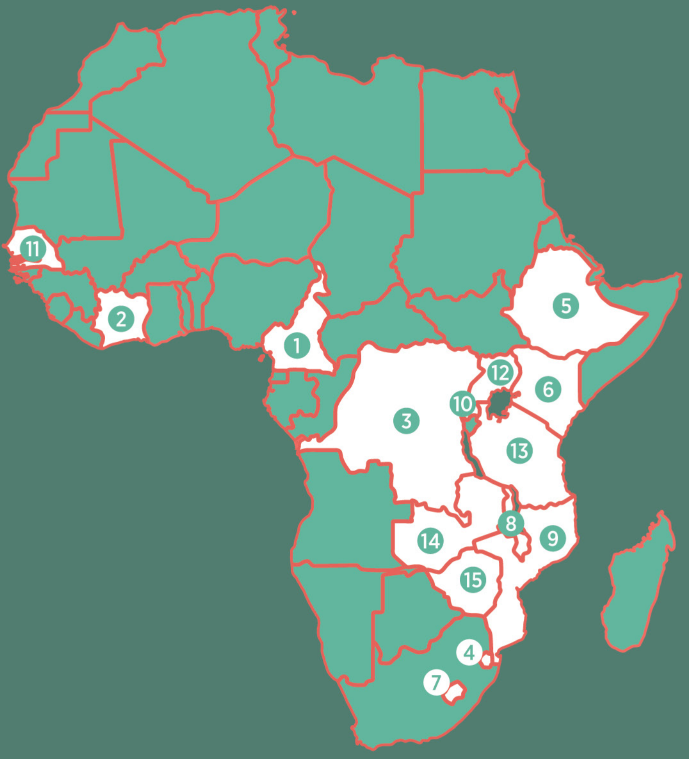
Are POC machines in use in your country?

In 2015, a project began to include POC EID technologies in national infant diagnostic programmes.[21] Through this initiative, POC EID has been introduced and scaled up 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.[22]

POC EID machines in 15 African countries

In 2015, a project began to include POC EID technologies in national infant diagnostic programmes. Through this initiative, POC EID has been introduced and scaled up in 15 African countries.

1. Cameroon
2. Côte d'Ivoire
3. Democratic Republic of the Congo
4. Eswatini
5. Ethiopia
6. Kenya
7. Lesotho
8. Malawi
9. Mozambique
10. Rwanda
11. Senegal
12. Uganda
13. Tanzania
14. Zambia
15. Zimbabwe



Can we afford POC EID?

Some worry about the cost of POC machines but they are very cost effective if you take into account the money wasted on conventional lab-based tests where the results never make it back to the parent. One study showed that the total cost of running a test and returning the result to the caregiver within 30 days was much less with POC technology (US$27.24) than traditional lab-based methods (US$131.02).

The flexibility of POC machines

POC devices are already being used in various ways in different countries. Various combinations of these placement and testing strategies can be used to suit the setting, make the best use of resources and to make sure that there are strong linkages to care.

Testing strategies:

- One POC machine can be used to test for multiple diseases (including tuberculosis (TB), HIV viral load, human papilloma virus (HPV), hepatitis and ebola).
- A POC machine can be placed in a health facility and used to test samples from any entry point within that facility (e.g. newborn and child health clinics, paediatric wards, nutrition units, specialist HIV clinics etc.)

Placement strategies:

- Stand-alone sites: where a machine is placed in one health facility and used to test samples from clients visiting that facility. This placement strategy works well for health facilities that need to conduct a high number of tests such as a maternal, newborn and child health clinics.
- Hub and spoke sites: the POC machine is placed at one site (the 'hub') where it is used to test samples from clients at that site, but it also receives samples from clients at other nearby facilities (the 'spokes') and tests them and then returns the results to those 'spokes'. These 'spoke' sites are likely to be facilities that have low levels of demand for EID testing.

Integrated TB and HIV testing in Zimbabwe[23]

A study in Zimbabwe used GeneXpert machines that were usually used to test for TB to also test for HIV. The spare capacity was used to carry out EID tests and viral load tests. In sites where the low demand for EID tests would not justify a stand-alone machine, they were able to increase access to EID testing services by using the spare capacity on the GeneXpert machine.

This reduced the turnaround time for EID tests (the time from sample collection to receipt of results) and all the infants that were found to have HIV were successfully initiated on to treatment. Importantly, the shared use of the POC machine made testing more cost efficient.

What must be done now?

Point-of-care diagnostic machines are an exciting breakthrough in early infant diagnosis.
In the countries where they are being used, they are already saving the lives of infants living with HIV.
Now is the time to scale up! The technology has been shown to work and we know it is cost effective.

There are still some challenges standing in the way:

- 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 such as a lack of machines, supply chain problems, staffing shortages, and a weak health care infrastructure.
- At the community level, some people are reluctant to test their infants and lack the information they need about HIV 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.
- In the wider community, stigma and discrimination are still a major barrier.

The next step is to remove these barriers to infant testing. All stakeholders involved in providing health care for HIV-exposed infants need to look at their own role and work out what they can do to make sure that these obstacles are overcome.

Political commitment: Decision makers need to recognise the potential of POC EID and prioritise it in their policies and programmes.

Funding: Sustained financial commitment is needed to introduce more POC machines, provide the supplies needed for existing machines and to make sure that there is enough operational support (including trained staff with enough time to talk to each client).

Support CSOs: Organisations like yours, that are community-led and operate in the heart of communities are ideally placed to engage people in HIV testing. Some CSOs will not have much experience in this area and will need information and training to be able to work to support infant HIV testing. Others may lack resources, such as money for simple things such as bicycles for peer workers to use, mobile phone credit, leaflets, support group meetings etc. CSOs need to work together to make a bigger impact and governments and funders need to recognise their importance and support their work.
Community Health Days

Integration: Infant testing must be seen as part of a wider package of health services for families affected by HIV. If services are integrated more opportunities are created to identify infants exposed to HIV, to connect them to testing and treatment and to 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 PMTCT services all in one place. POC technology can help to support integration between services as the testing machines can be used to test for more than one disease. There are also benefits to integrating policies so, for example, child-friendly medicines are made available alongside infant testing.

Community Health Days [24]

EGPAF holds "Community Health Days" – that bring together a whole package of services and deliver them right in the heart of communities. During the day, they offer services for HIV, MNCH and primary health. They also organise educational activities and community dialogues to encourage uptake of HIV and MNCH services, provide linkages to other health services, and reduce HIV stigma and discrimination. These activities empower communities to come together to remove the social and cultural barriers that limit uptake of HIV services.

Engage with parents/caregivers: POC technology can only make a difference if people choose to have their children tested. Information on infant testing and treatment options needs to be available so that parents can make informed decisions. Parents' concerns need to be listened to and services adapted to make it easier for parents to access HIV tests and treatment for their children. In some cases, they may need practical help, such as financial support for travel expenses for families who live far from their nearest health facility. Or they may have other concerns, for example around confidentiality or the consequences of a positive test result.

Encourage health seeking behaviour: Much more can be done to encourage people across the community to actively seek out health care, in addition to supporting individual families. In particular, schemes are needed to encourage men to engage not only in their own healthcare, but also the health needs of their family. They need to be provided with information around HIV testing, treatment and care and shown positive role-models.

> **"The aim is to counsel, test and initiate, but this only works well if work has already been done to ensure there is a basic level of awareness about HIV. Pre-education needs to happen across the wider community."**
>
> Edna Tembo,
> *Community of Women Living with HIV/AIDS (COWHLA), Malawi, 2019*

Reduce stigma: This remains the biggest barrier and the root of many people's reluctance to test their infants. Innovative programmes have been shown to reduce stigma in communities (such as mobile theatre, community dialogues etc.). We need to see many more of these initiatives across communities.

Work with existing support networks: Peer support systems play a significant part in the HIV response. These structures can be used to spread messages about infant testing. Whether it is mentor mothers, expert clients, male champions or PLHIV support groups, there are many schemes that already exist that are reaching out to parents of HIV-exposed infants and are already trusted by communities.

Train health workers: People who work with the families of HIV-exposed infants need enough time to talk to these families properly, to explain testing to them and answer their questions. Whether they are paid healthcare workers or volunteers, they need to be trained to encourage and support infant testing and to ensure mother-baby pairs are not lost to follow up. Many programmes already do this such as support schemes working with midwives like the "Bring back mother baby" campaign in Uganda and "Ndeye-Dické" in Senegal.

We need you

As an organisation that is rooted in the community, you can make a difference, whether you are advocating for others to take action or getting involved and taking action yourselves. Turn to section 3 to read more about what you can do.

Taking children by the hand in Senegal [25]

In Senegal, the National AIDS Council have joined together with RNP+ (the national network of people living with HIV) and UNICEF to launch a campaign called "Prenons un enfant par le main" (take a child by the hand). With a dedicated website, videos and leaflets they have launched a nationwide campaign to raise awareness of the need to test children for HIV.

©UNICEF

> **"Through partners and community leaders, across the country, we are playing our part and finding suitable solutions to improve the care given to children who are often neglected and not given the priority they need in policies and strategies to fight against HIV and AIDS in Senegal."**
>
> Soukèye Ndiaye,
> *President, RNP, 2019*

3.

How community-based organisations can support early infant diagnosis

Communities and the HIV response

The word ‘community’ includes a whole range of organisations and individuals: people living with HIV, their groups and networks; community-based organisations, including those run for and by key populations; local, national and international nongovernmental organisations (NGOs); AIDS service organisations and faith-based organisations. They may be focused on HIV, or on other related areas such as health, sexual and reproductive health, children, women, economic development etc. They all have a role to play in the global response to HIV and can support the provision and uptake of EID services. Without the active engagement of communities, POC technologies and other EID initiatives will not achieve their full potential.

> **“Communities have a role to really mobilise, give information and create demand.”**
>
> Jackie Okinyi,
> *Women Fighting AIDS in Kenya (WOFAK) 2019*

HIV has been affecting your communities for many years now, so you understand the problems you face and know the solutions that you want to see. When individual activists, groups and networks work together, you are able to make sure that the HIV response respects your rights and reflects your realities. You have already had many successes but there is still much more to be done. With these new POC machines there is an opportunity to significantly improve health outcomes for infants living with HIV in your communities.

3.

What can you do to bring the benefits of POC early infant diagnosis into your community?

Although POC EID machines are relatively new, many CSOs have already learnt about the new technology and are working to create demand for the tests and support implementation.

There are five key areas where civil society can make a difference:

1. advocacy
2. supporting parents and caregivers
3. engaging with the wider community
4. delivering services
5. gathering evidence

You will need to consider what role you can play depending on your organisation's aims, strengths and capacity. It is particularly important that you are driven by the communities you represent so that your work is really owned, shaped and delivered by community members.

So what can you actually do, where do you begin? In the previous section we outlined what needs to be done to support POC EID. Here we focus specifically on the areas where civil society organisations can make a difference. Below you will see some suggestions on what you could do and in section 4 we give guidance on how you can turn these ideas in to a firm plan of action for your organisation.[26]

Case Study: Adaptable Kenyan activists

The *Lean on Me Foundation* is a community-based organisation in Kenya supporting women and adolescent girls to access health, education and human rights. When a pilot project introduced POC EID machines to Kenya, *Lean on Me* saw that many mothers were reluctant to have their babies tested for HIV. So, *Lean on Me* set up a programme where peer supporters spoke to the mothers, listened to their concerns and gave psychosocial support. They organised individual and group therapies that were flexible enough to adapt to the needs of each individual woman.

As a result, women became more confident and willing to have their babies tested and levels of early infant diagnosis increased. When the POC EID pilot programmes were coming to an end, *Lean on Me* advocated for the Kenyan government and donors to commit to continuing to fund POC EID. But in 2019, they were dealt a blow when lab technicians won a court case preventing non-laboratory trained staff from being allowed to operate POC EID diagnostic machines. Now, *Lean on Me* has turned its attention to appealing against the court ruling. They have found women who will testify to the importance of POC EID and are determined to try and ensure that POC continues to bring benefits in Kenya.

Advocating for access to quality EID testing services

An obvious place to start is advocacy. Governments are a key stakeholder in the HIV response: their political commitment and financial support are needed if POC EID is to have a real impact. CSOs can lobby government to make sure that they commit to providing POC diagnostic machines and investing in the systems that are needed to deliver EID services. You can help to make sure that your government has information explaining the benefits of POC diagnosis and can share with them evidence from your community about the benefits that EID can bring.

Training CSOs in Mozambique

Following the success of pilot projects in Mozambique, the government began to introduce POC EID in different regions. Civil society organisations in Mozambique had very limited knowledge of EID, so NAIMA+, a network of NGOs working on HIV and Health, organised a workshop to train CSOs. 15 different organisations attended including representatives from women's groups, key populations and youth groups. Presentations were made on EID, POC diagnostics and HIV treatment and the participants discussed how to support people to access tests, treatment and care.

Rondinho Viligueia from REJUSIDA attended the training:

"I had never heard of POC machines, this is my first time. I think they can be really helpful in the community, provided we have funds to buy them and get trained on their use." 2019

CSOs may also use their influence with implementing organisations and donors to try to increase access to EID services, for example by calling for integrated services that enable mothers and their infants to receive all the health services they require in one place.

Don't underestimate how much you know. CSOs that work on infant testing can quickly build up a lot of expert knowledge. You can use this to help to shape policies at a national, district or facility level. For example, some community-based activists are already sharing their expertise as members of the working groups of the Country Coordinating Mechanisms (CCM) of the Global Fund.

CSOs can also keep an eye on how services are implemented. You can check that the services respect the human rights of the clients and are accessible to everyone who needs them, and you can give feedback from the service users to the service providers to help to them make improvements.

If you work together with other CSOs you can have even more impact. In some countries, CSOs have set up systems to coordinate their work on EID and allow them to speak with one strong voice in their advocacy. By coming together you also have an opportunity to share information and expertise. If there is a CSO in your country that is already working on early infant diagnosis they could help to train other organisations and share their knowledge and experience.

Supporting parents and caregivers

Early infant diagnosis can only work if parents and caregivers access HIV tests for their children and, for many reasons, some choose not to. There are many ways that CSOs like yours can support parents and help address their concerns.

From your position of trust within the community, CSOs can give parents and caregivers information about the tests and explain the treatment options that are available for infants that test positive. You are also well placed to provide psychosocial support to help support families before and after HIV testing. One way of doing this is to bring them together with others who have accessed the tests so that they can share their experiences. Your organisation may set up your own initiatives or work with some of the systems that already exist including peer supporters, community activists, outreach workers, support groups and women's groups.

CSOs also have a role to play connecting people to services beyond testing. You can help guide families to treatment services, support treatment adherence and help to prevent children from being lost to follow up. Again, you may find you can be more effective if you work with some of the structures that already exist to do this including community treatments supporters, outreach workers, mentor mothers, etc.

The lack of male involvement in seeking healthcare for themselves and their children is an ongoing problem. CSOs can work with fathers to encourage them to be actively engaged in their family's healthcare, to support their partners and to get tested for HIV themselves.

Creating communities that support infant testing

There is an important role for CSOs to play in raising awareness and support for infant testing among the wider community. You are well placed to work with community, religious and traditional leaders to increase awareness of HIV testing services, the need for early infant diagnosis and the benefits of HIV treatment. This can help to create a supportive environment around mothers and caregivers, where they feel able to access HIV tests and treatment for their children.[27]

A South African community unites against stigma

In Amathole, a small rural community in South Africa, local activists encouraged local people to join in discussions about HIV. At the end of a whole series of participatory activities, the community came together to create its own declaration to support people living with HIV. It included these words:

"… We resolve to discuss the issue in community gatherings;

We agree to disclose our HIV status with the knowledge that we will have support from our community;

We encourage all and their families to disclose HIV status when one has AIDS;

We pledge to support, and never to gossip about or humiliate in any way; those who are known to have HIV/AIDS;

We pledge to draw PWAs close and to encourage them to live positively…"

You can give community, religious and traditional leaders all the information they need to understand the importance of early infant diagnosis and treatment for children living with HIV. One of the biggest barriers preventing parents and caregivers accessing HIV tests is stigma. Although there are already many initiatives aimed at eliminating stigma and discrimination within communities, much more needs to be done. CSOs can start conversations within communities, provide accurate information and break down myths surrounding HIV. You can also identify role models and support them to speak out about their own personal experiences.[28]

> **"We need to identify community gate-keepers, talk to them, and create more awareness. Also other positive women need to sensitize fellow positive mothers on the need to test their babies."**
>
> Woman living with HIV,
> *Nigeria, 2014*

Delivering health services

In many countries, CSOs provide services themselves, including counselling, testing, delivery of ART, support for adherence, mobile consultations, search for lost clients, monitoring of ART adherence etc. For example, some CSOs keep track of clients and the dates when they are due to take their child for tests. They then contact the mother and remind her of the appointments and if necessary, help to arrange transport for her to get there. Many programmes that bring services into communi-ties instead of conventional healthcare facilities rely on help from community-based volunteers and CSOs. Some of these programmes can be particularly good at providing a one stop shop where a whole set of services are available in one place.

Integrated paediatric HIV and nutritional programmes in Malawi

Abwenzi Pa Za, an organisation based in Malawi, has developed a community-based programme that combines paediatric HIV services with nutritional programmes. Children who enter the programme because of their nutritional needs are tested for HIV, as well as children under the age of 2 whose mothers are living with HIV and malnutrition screening is offered for people accessing HIV services.

"I believe that the training of village health workers has been essential in ensuring this success. Community-based patients are more easily reached and at the same time we can address stigma."

Blessings Banda, Nutrition and HIV Coordinator

Some CSOs also have the skills to provide technical support to implementers, for example holding sensitisation sessions or trainings with health workers.[29]

Conducting community-led research

People who make up community-based CSOs are uniquely placed to inform the HIV response. You may be living with HIV yourself and you are working right in the heart of communities affected by HIV. You have your own first-hand experiences and are trusted by the people that services and programmes are trying to reach.

This makes you well placed to carry out research to understand the needs, perspectives and experiences of local people.[30] Research data can be used to shape advocacy demands and ensure those demands are evidence-based. Research can also highlight any changes that are needed to make sure that interventions are relevant and tailored to the local context.

Community feedback in Zimbabwe

Zimbabwe Young Positives (ZY+) are working alongside CHAI and AFROCAB to support point-of-care EID. They have asked the community to share their experiences of accessing EID services. They gathered all the feedback and then presented it to key stakeholders to encourage them to review and adapt the services.

©UNICEF

CSOs can help to build local ownership and engagement in specific programmes or services just by seeking local people's views on them and involving them in the research process. Annex 1 has some guidance to help you consider what research you might want to undertake.

The information gained through community research can also help to shape your own organisation's priorities and action plan.

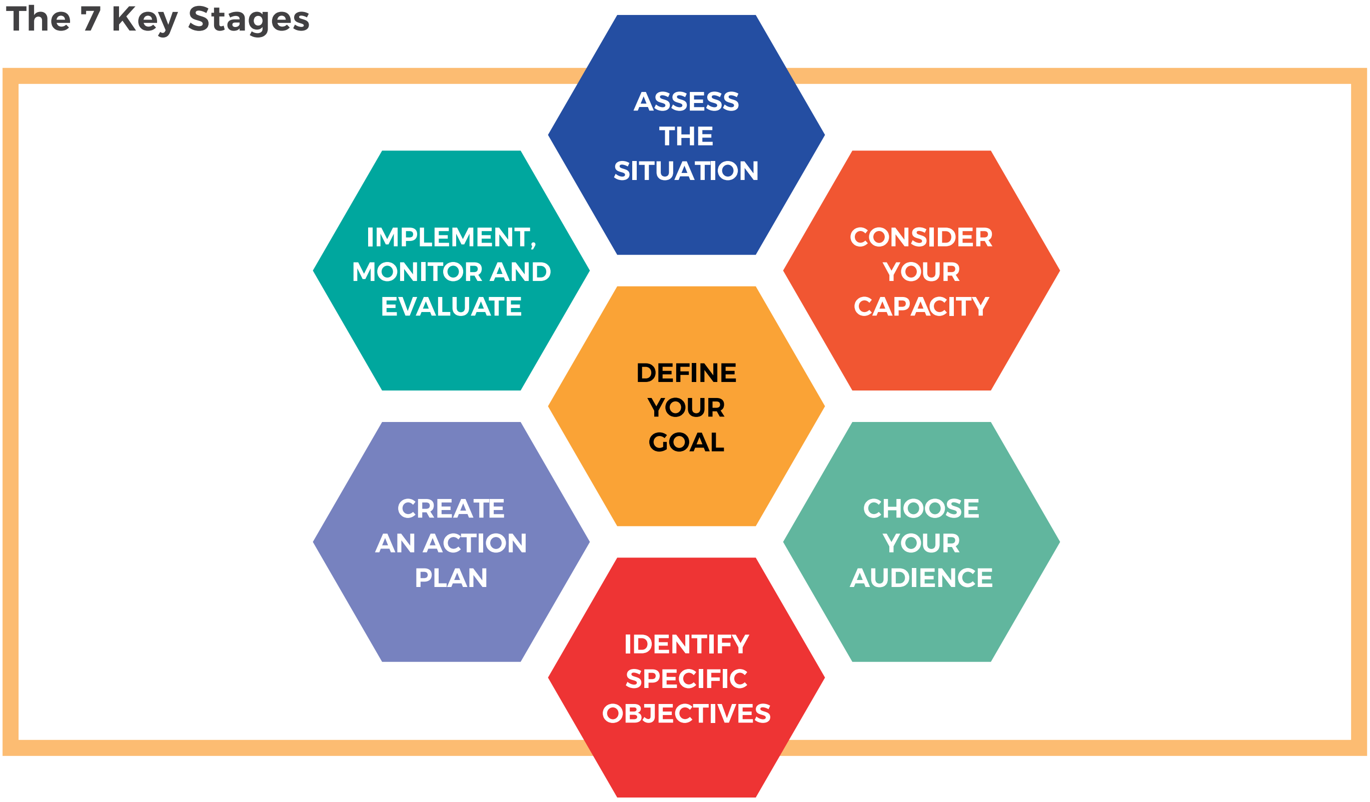
PEDIATRIE
Hospitalisation
UNE NOUVELLE TECHNOLOGIE APPELÉE «POINT-OF-CARE»
AU CAMEROUN POUR LE DIAGNOSTIC DU VIH, TUBERCULOSE, MESURE DE LA CHARGE VIRALE

4.

Guide to developing an action plan

Do you think your organisation could make a difference? Would you like to see more POC machines in health facilities near you? Could you help to support parents and families to access the tests and treatment that their children need? Then this section is important for you. Here we guide you through seven key stages that you can follow to help you to create an action plan to work on EID. You can follow the stages in the recommended order that is given here, but they are not a fixed set of instructions, each organisation will work differently. The nature of your organisation and your country setting will shape how you approach this, so feel free to use the following guide in any way that is helpful for you.

The 7 Key Stages


ASSESS THE SITUATION
IMPLEMENT, MONITOR AND EVALUATE
CONSIDER YOUR CAPACITY
DEFINE YOUR GOAL
CREATE AN ACTION PLAN
CHOOSE YOUR AUDIENCE
IDENTIFY SPECIFIC OBJECTIVES

DEFINE YOUR GOAL

Your action plan needs an overall goal that describes what you are hoping to achieve through this work - something that you can aim to change or influence through your work. Your goal could be something like this:

"To increase the understanding, demand for and uptake of early infant diagnosis (in particular point-of-care tests) so that more HIV-exposed infants can be tested and where appropriate linked to treatment and care."

ASSESS THE SITUATION

To plan how to achieve your goal, you need a good understanding of the situation in your country. There are two key parts to this: you need to assess the reality of EID and POC EID programmes in your country; and you need to understand the perspectives of your key audiences.

To assess the EID programmes in your country you could complete these three tasks:

1. Find any national or local health data, study findings and other information relating to EID and POC EID in your country.
2. Review your national HIV/AIDS strategy and PMTCT guidelines to see what programmes are planned, targets set, budgets allocated etc.
3. Speak to and review reports from key stakeholders (Ministry of Health/ National AIDS Council, UNICEF, implementing partners) to see what interventions they are working on or planning.

The table below has examples of the questions you may want to ask to help you with the second part of assessing the situation – understanding the perspectives of your key audiences. The questions will vary depending on which audience you choose to target.

Perspectives of key audiences relating to EID and POC EID	
The needs, opinions, knowledge, attitudes and behaviours of the key audiences you plan to reach	*What are the current attitudes of the parents and caregivers of HIV-exposed infants towards EID and POC EID?*
	What gaps do they have in their knowledge of POC EID?
	What level of understanding do healthworkers have of EID / POC EID?
	Are religious and traditional leaders aware of POC EID? What are their attitudes towards it?
	Are community healthworkers aware of POC EID services?
	What level of awareness do government officials have of POC EID?
The barriers and challenges faced by each audience when accessing, demanding or providing services.	*What barriers prevent mothers living with HIV from accessing testing services for their infants?*
	Are fathers involved in decisions around whether or not their infant is tested for HIV? Why or why not?
	Do both parents / the caregivers have a full understanding of what tests are recommended?
	Are levels of stigma high in the community?
	Does anything prevent healthworkers from offering testing services?
How EID / POC EID fits within their priorities as well as the language they use, their social networks and communications channels they use.	*Who are the opinion leaders on EID?*
	Who are the role models within the community?
	Which types of media do the parents and caregivers of HIV-exposed infants access?
	Where does POC EID sit on the list of priorities of the Ministry of Health?

It may take some time to properly assess the situation, particularly if you need to carry out any research or gather evidence through focus groups etc., but give it as much time as you can because it will help you to understand what you are trying to change. The results of your assessment can also be used as a benchmark later on when you come to measuring the progress and impact of your work (see Annex 9 for more information about baseline evaluations).

Whatever you decide to do you will need resources to make it happen. You may need to increase your capacity to be able to work on this issue, that could involve taking on additional staff or volunteers, or fundraising for specific work.

CONSIDER YOUR CAPACITY

When you are planning, think about all the different resources available to you, not simply money:

- **Human resources** – how much time do your staff/volunteers have to work on this issue?
- **Knowledge and skills** – do you have all the knowledge and skills you need to plan and implement the work?
- **Finances**: what funds are available for staff, materials, events, activities etc?
- **Evidence**: what data and evidence is there to support the campaign? Is it credible?
- **Reputation**: how is your organisation viewed by those you want to influence?
- **Power**: what power do you have? What actions/decisions can you take directly? What influence do you have over the actions/decisiions of others?
- **Relationships/ access**: Do you have access to stakeholders? Can you access things such as distribution networks or communication channels?

Partners and Allies

Working with partners will help you to increase the effectiveness of your work and add valuable knowledge, it also increases the resources that are available to you. It is vital that groups/networks of women living with HIV are involved in leading this work as women are the main users of EID services. This follows the GIPA principle (‘Greater Involvement of People Living with HIV/AIDS’, see box) and guarantees that their input and perspectives will guide the whole project. You may also want to join with other networks and organisations that represent people living with HIV in your country and others that have an interest in EID, such as those working on health, human rights, women or children. Choose partners that you trust and that are respected by your intended audiences.

At different stages of your planning you may find it helpful to talk to other stakeholders to get their perspectives or expertise such as health providers, development partners and donors, and marketing or communication specialists. Even if some of your work targets government departments, remember that government officials can also be your allies, so work with them wherever possible. In the same way, you should remember the importance of influencers, such as religious and traditional leaders, and think about how you can engage with them.

What is GIPA?

The GIPA principle calls for the greater involvement of people living with HIV (GIPA) in design, implementation and monitoring of HIV policies and programmes at all levels. It is commonly summed up as “nothing about us, without us”.

"Who's going to pay for all this work?"

It is an important question. You may find that you already have all the resources you need to begin work on your action plan. You may find that if you work in partnership with other organisations, you can combine your resources to have enough for this work. Or some of you may find you simply cannot begin working on EID at all without extra funding.

For those of you who need extra finances, developing a fundraising plan is essential. Think about what sources of funding there are in your country. Try and find out if your work ties in with any of their priorities, for many donors paediatric HIV treatment is one of their main concerns. Also remember that you may be able to get donations other than money e.g. the use of certain equipment, photocopying, use of a meeting space etc. See Annex 3 for a fundraising plan template.

©UNICEF

> "At different stages of your planning you may find it helpful to talk to other stakeholders to get their perspectives or expertise such as health providers, development partners and donors, and marketing or communication specialists."

CHOOSE YOUR AUDIENCE

You will have gathered lots of information when you assessed the situation in your country. When you look at that information you will probably see many different challenges that need to be addressed, but you will not be able to work on all of them. If you organise and analyse the information, it will help you narrow it down so that you can work out where you can have the most impact. Then you can choose your target audiences and specific objectives. To do this you may find it helpful to use a table like the one below (blank table is included in Annex 4). The rows are not complete, some challenges have been filled in as examples.

The challenge/ problem	Target audience	Desired behaviour	Main barrier preventing desired behaviour	Potential advantages of changing to desired behaviour
Not enough infants are being tested for HIV	*Mothers of HIV exposed infants*	*Choose to take their infant for HIV tests*	*Afraid of the stigma their child (and family) will face if found to be living with HIV*	*The infant could immediately begin treatment*
			Unaware of the treatment options that are available to infants living with HIV and the positive health outcomes	*The infant would have a much higher life expectancy*
Parents are not receiving the information they need about EID at health facilities	*Healthcare workers in MNCH facilities*	*Spend time with parents to explain the importance of EID and answer their questions*	*They are short staffed*	*Parents would be better informed*
			They do not fully appreciate the concerns of parents	*Parents would be more likely to consent to EID testing.*
High levels of stigma and discrimination exist within the community	*Influencers*	*Speak openly about the importance of infant testing and against all forms of stigma*	*People do not fully understand HIV, how it is transmitted and how it is treated*	*Parents would feel more comfortable getting their children tested for HIV*
EID testing services are only offered in a few places	*Government*	*Introduce a range of strategies to improve access to EID testing*	*Funding is limited*	*Parents would find it easier to access HIV testing services for their children.*
			They have other political priorities	
			They do not fully appreciate the benefits of EID	*Health outcomes would improve for HIV exposed infants*
Etc.	*Etc.*	*Etc.*	*Etc.*	*Etc.*

Once you have organised and analysed your data you will need to ask yourself, 'whose behaviour can we try to change?'. You may choose more than one target audience. For example, you may decide that your first target is parents / caregivers and you will encourage them to access EID/POC EID tests. Your second target audience could be government and you will push them to commit to financing EID/POC EID for a set number of years.

For each of your target audiences there may also be other groups or individuals that influence them, these are your secondary audiences. For example, parents/caregivers may be influenced by other family members, community leaders, healthworkers or peer supporters. Governments, on the other hand, may be influenced by implementing organisations, donors or public opinion. Once you have begun working on this issue and feel that you are making progress you might decide to try and develop a new action plan that targets these secondary audiences too.

4.

IDENTIFY SPECIFIC OBJECTIVES

As well as an overall goal you need to have specific objectives. These are the short-term outcomes that you hope to achieve that will bring you nearer to your overall long-term aim. For example, if your overall aim is to increase the number of infants living with HIV that are on treatment, you might have three short term objectives: to conduct a six month HIV testing awareness raising campaign with parents; to ensure there is a commitment to sustained political and financial support for POC testing from the government in its next AIDS strategic plan; to train a group of peer workers to support families to access HIV tests, treatment and care.

Your objectives will depend on your situation analysis and target audiences. Think about the timescale for your work and make sure your objectives are achievable and realistic with the resources that you have. When you are deciding on your objectives it is important to make them as precise as possible.

Here are examples:

- To increase by 10% the number of infants being tested using POC EID machines in your country within 2 years.
- To conduct a sensitisation training session with nurses in 4 different health facilities over the next year, to ensure they fully understand the needs of parents accessing POC EID tests.
- To hold a training session for CSOs and civil society groups in the next six months to educate them on the benefits of POC EID.

If you find it helpful you can build on the same table used above to help you choose specific objectives that will reach your key audiences (see template in Annex 5).

An example has been added into the table below:

The challenge/ problem	**Target audience**	**Desired behaviour**	**Main barrier preventing desired behaviour**	**Potential advantages of changing to desired behaviour**	**Specific objectives**
EID testing services are only offered in a few locations	*Government*	*Introduce a range of strategies to improve access to EID testing*	*Funding is limited*	*Parents would find it easier to access HIV testing services for their children.*	*Ensure the Ministry of Health receives data showing the cost effectiveness of POC EID before their next budget allocation deadline.*
			They have other political priorities	*Health outcomes would improve for HIV exposed infants*	
			They do not fully appreciate the benefits of EID		

CREATE AN ACTION PLAN

You should now have a clear understanding of the situation in your country, who you want to target, what you hope to achieve and what resources you have available to you. The next step is deciding on specific activities and creating a detailed action plan. The outcome of each of the specific activities should be closely linked to your objectives. There are many different activities that you could consider. Choose carefully remembering the time and resources needed and your ability to reach your chosen target audience(s).

Here are examples:

Audience: Other CSOs

- Set up a coalition of CSOs to coordinate advocacy on EID
- Hold a training workshop for other CSOs

Audience: Service providers

- Hold sensitisation meetings with health-care workers
- Provide training for peer supporters

Audience: Decision makers

- Provide them with technical information and facts to support infant testing
- Use evidence and analysis from community-led data collection to advocate with decision makers
- Hold policy dialogues with key stakeholders
- Outline problems for policymakers (e.g. present them with a report)
- Hold face to face advocacy meetings
- Mobilise people within the community to contact policymakers (using petitions, social media, emails etc.)

Audience: Parents/caregivers

- Produce targeted testing and treatment literacy materials (leaflets, posters, flyers etc.)
- Spread key messages widely using posters, billboards, adverts (on buses, at community meeting places, health facilities etc.)
- Hold educational briefings and events (e.g. talks at women's groups)
- Create content for radio spot or TV broadcast or start a buzz on social media using facebook, twitter etc.
- Link in with existing support networks (spread messages via peer supporters, mentor mothers etc.)
- Talk to mothers about testing when they access other services (e.g. speak to them in antenatal clinics/groups)

Audience: Community

- Organise special events to share key messages e.g. mobile theatre or cinema
- Hold meetings with traditional and religious leaders
- Conduct community dialogues – bring the community together to inform them about infant testing and answer their concerns and questions.
- Identify key influencers who are supportive of infant testing and develop them to be testing "champions" who can help share information.
- Make presentations at existing events or in places where community members gather (eg. workplaces, markets, presentations, social gatherings)

Ideally you should plan a range of activities that all have messages that support your aim. It is important that you develop key messages that you want to get across to your audience. You will have more impact if all the work that you do reinforces the same key messages so spend some time talking to the groups that you are working with to develop agreed messages that you can all use.

The communication channel that you use to spread those messages will depend on what would work best with your audience. It can be anything from a briefing paper, to a social media post, a radio spot or a leaflet.

To help you choose which is the best communication channel to use think about these questions:

- Can it deliver your message to the right audience?
- Will they remember the information?
- Will it motivate them to talk to others about your messages?
- Will it change their behaviour or the behaviour of the wider community?

Annex 6 is about channels of communication and includes examples of the kinds of questions you need to ask yourself.

You should also plan your activities to make the most of any opportunities that you know about. For example, there might be structures that already exist that you can connect with to make your work easier or more effective. This could be anything from a peer support network to a government consultation process. Remember, that the people working in your partnership may have access to other audiences where they can help to spread your campaign messages, for example they may be involved in committees, networks or decision-making bodies. Also be aware of any planned events or processes that may make it easier for you to carry out your activities. For example, there may be a process that you can get involved in such as consultations held by your National AIDS Council of there may be an event planned where you can highlight your campaign, like World AIDS Day.

Don't attempt to get involved in every opportunity, instead weigh up your options and try to be as effective as possible. Here the table has been adapted again to include activities, one row has been filled in as an example. The Action Plan template (Annex 7 has a blank table like this that you can use to work out your own action plan. Annex 8 is a template for a calendar of activities that you can use alongside the Action Plan template to organise a timetable for your work.

Audiences	**Objectives**	**Entry points / Opportunities**	**Communications channels**	**Activities**
Mothers of HIV exposed infants	*To increase by 10% the number of infants being tested using POC EID technologies in your country within 2 years.*	*Antenatal support groups*	*Mentor mothers*	***Conduct a training session for mentor mothers, to explain how POC EID technology works and the benefits it can bring.***

IMPLEMENT, MONITOR AND EVALUATE

Once all these stages are complete, you will be ready to begin implementing your action plan. Throughout your work you should keep track of the activities that you have completed to make sure that you are sticking to your plan.

You will also need a monitoring and evaluation plan. This should be developed at the same time as your action plan, so that you can monitor your work as you go along. If you have come up with clear, detailed objectives, then you should be able to identify some indicators that will show if you are making progress towards your goal. If you monitor your activities regularly you can check if you are on track. For example, are your messages consistent, the roles of partners clear and being followed, are activities taking place on time and within budget? Your findings will show whether you need to adapt your action plan.

The monitoring doesn’t need to be complicated: it can be a combination of routine tracking of activities and some specific monitoring. For example, if you conduct a meeting or training session, you can ask participants to give their feedback at the end. You could also gather together members of one of your target audiences for a focus group discussion where they can share their views and experiences.

Once you have completed your activities you could carry out an evaluation of your work. There are many different ways of doing this depending on your resources – do you have a budget for evaluation, do you have people who can conduct the data collection and analysis? The more detailed you are able to be the more useful the evaluation will be for shaping your future work.

Annex 9 has further guidance on monitoring and evaluation.

Action plan summary

We hope this section has given you enough information and guidance for you to be able to make your own action plan to work on early infant diagnosis. If it all seems a bit overwhelming at first, the key stages in the action plan are here to help you. Work your way through the stages and remember that every country is different and each organisation in the country will have different strengths and weaknesses. You can adapt the guidance that we have given you and make an action plan that works for you.

Remember:

- Define your goal
- Assess the situation
- Consider your capacity
- Choose your audience
- Identify your specific objectives
- Create your action plan
- Implement your plan
- Monitor and evaluate your work

5.

Time to get to work

It's an exciting time! With new point-of-care technology we have a real opportunity to increase access to early infant diagnosis tests. With these tests, we can ensure that babies and young children who are found to be living with HIV can be connected to treatment and care and given the chance to go on and live long healthy lives. We need as many machines as possible to be placed in health facilities, parents and caregivers need to know about the tests and they must be given all the support that they need to be able to access them.

We hope that this strategic framework will help you to play a part in this vital work. As well as using the framework, you may find it helps to talk to other CSOs in your country or in the wider region to learn from their experiences, or you can contact us. Section 7 also has a list of other resources that you may find helpful. It may not be easy, especially if your organisation has never worked in this area before, but you can make a difference!

6.

About us

GNP+ is the global network for and by people living with HIV. We work to improve the quality of life of all people living with HIV. We advocate for, and support fair and equal access to treatment, care and support services for people living with HIV around the world. We work with communities of people living with HIV, regardless of whether they are geographic, or identity-based, to challenge governments and global leaders to improve access to and quality of essential HIV prevention, treatment, care and support services.

GNP+ advocates for the highest quality of treatment to be available and accessible for all people living with HIV, when and where they want it and when and where they need it. As part of this work, GNP+ has worked to ensure that the perspectives and concerns of women living with HIV and their communities are meaningfully considered in the design and implementation of programmes to prevent vertical transmission and diagnose infants living with HIV. [31]

UNICEF's HIV and AIDS programme is dedicated to preventing HIV among women, children, and adolescents who have been left behind and treating those living with HIV. Our HIV programme response has three core goals: eliminate mother-to-child transmission of HIV; eliminate the treatment gap in children and adolescents; and prevent HIV in adolescents.

Through technical support, education, advocacy and a range of other efforts, UNICEF seeks to ensure that all babies, children, adolescents and their mothers can access life-saving HIV prevention, treatment, care and support. UNICEF engages country-level partners around the world to make HIV prevention, testing, and treatment as widely available as possible, including in remote areas, in fragile states and among marginalized populations. UNICEF works through its country offices and regional offices as well as at an international level and through the UN organisations. UNICEF is also one of the co-sponsors of UNAIDS.

Together GNP+ and UNICEF are committed to working to support the scale up of timely diagnosis and treatment of paediatric HIV. [32]

7.

Useful resources

Start Free, Stay Free, AIDS Free, 2019 Report
https://www.unaids.org/sites/default/files/media_asset/20190722_UNAIDS_SFSFAF_2019_en.pdf

UNICEF HIV website, with dedicated section on POC EID, including many resources.
https://www.childrenandaids.org/point-of-care

Video of the Malawi experience
https://www.childrenandaids.org/pilot_early_infant_diagnosis_malawi

Postnatal clubs toolkit, Doctors without Borders SA
https://doctorswithoutborderssa.exposure.co/pnc-toolkit

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

Tackle exclusion: End AIDS in children, The Coalition for Children Affected by AIDS
https://childrenandhiv.org/wp-content/uploads/2018/07/AdvocacyFlyerAIDS2018_FINAL.pdf

HIV-positive infants in Cameroon are accessing treatment faster: results of point-of-care early infant HIV diagnosis supported by the Elizabeth Glaser Paediatric AIDS foundation
https://www.pedaids.org/wp-content/uploads/2019/09/2019POCEIDCameroon.pdf

Video of AIDSfonds “Kids to Care” programme that works with communities to find and support children living with HIV.
https://www.aidsfonds.org/community/children

AIDS free toolkit, WHO
https://www.who.int/hiv/pub/paediatric/aids-free-toolkit/en/

Prenons un enfant par la main (Take a child by the hand), Senegalese website dedicated to accelerating care for children living with HIV
http://prenonsunenfantparlamain.com/

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

The Kigali Declaration: Wake Up! Our Children are Dying!
https://healthgap.org/children-with-hiv-are-dying/

8.

Acknowledgements

Project coordinators:
Saima Jiwan, Omar Syarif, Upjeet Chandan, Alexandre Costa and Maria Souza

Writer:
Laura Davies

Designer:
Anthea Duce

The Demand Creation and Civil Society Engagement for Point-of-Care Early Infant Diagnosis Advisory Group: Katie Lamp, Helene Damata Badini, Solange Baptise, Geoffrey Chipungu, Johary Randimbivololona, Buki Ayinde and Laurie Gulaid.

Lawrence Khonyongwa and Eric Mcheka from The Malawi Network of People Living with HIV (MANET+)

Saliou Gueye and Soukeye Ndiaye from the National Network of Associations of People Living with HIV in Senegal (RNP+)

Maureeen Murenga, Matias Langa and Dorothy Namutamba

We are grateful to Unitaid and UNICEF for their financial support.

Published by:
Global Network of People Living with HIV (GNP+) and UNICEF

Suggested citation:
GNP+, UNICEF. 2020. NO TIME TO WAIT! Actions to support point-of-care early infant diagnosis: a strategic framework for community-based organisations.

9.

Annexes

Annex 1 – Guidance on conducting research

There are many different ways you can carry out research and gather together data or evidence to support your work. These are some options you may want to consider

- **Personal testimonies** – find out how people feel in detail by speaking to them directly. This can be done individually through interviews, or through small group discussions (often called focus groups).
- **Surveys / questionnaires** – this is a useful way of getting information from a large number of people, but it is usually less detailed. You can ask people to answer a set group of questions. For example, are you living with HIV? Have you had your children tested for HIV? If so, did you get the test result?
- **Visiting relevant sites** – for example you may find it useful to visit the clinics that offer testing to find out more about the process and how well it works.
- **Other sources of information** - you may be able to find statistics or information that is helpful in planning your work or supporting your arguments by looking at documents that other people have produced. This could be anything from a government report to newspaper articles or respected and trusted websites.

If you decide to gather personal stories from individuals, these questions may help your planning:

Who do you want to talk to?

For example, mothers, parents/caregivers, members of the wider community, healthcare workers.
Do you want them to be people who are living with HIV?
What about government officials?

How many people do you aim to speak to?

This will depend partly on who they are for example you may wish to speak to 50 mothers living with HIV, but only 5 government officials working on HIV.

How will you find the people you want to talk to?

Do you already know the people you want to speak to? Do you have contacts who can put you in touch with the right people? Do you need to hold some kind of meeting (like a focus group) to bring people together? Will you need to provide refreshments, pay people for their travel expenses or give them a payment for their time?

Try and remember that you want to get an idea of how people feel about this issue, so you need to try and make sure that you are speaking to a balanced group of people and that you hear a wide range of views.

Who will do the interviews?

If possible, use people that are trusted and respected by the people being interviewed. Will they need specific training?

Are you allowed to carry out your research?

In some cases you might find that you need to apply for permission to do the research.

Annex 2 – Situation Analysis questionnaire

Checklist to support your assessment of the situation in your country

	Tick here when complete
Data collection	
Do you have information / evidence about how EID services are being delivered across the country?	
Have you found and information / data / evidence about how EID services are provided in your local area?	
Do you have data / information about the national policy on EID and POC EID?	
Have you got a copy of your national HIV/AIDS strategy?	
Have you got a copy of your national PMTCT guidelines?	
Have you seen any reports from the Ministry of Health or National AIDS council outlining their planned interventions on EID?	
Have you spoken to government officials to discover more about their approach to EID?	
Have you contacted implementing partners in your country to see what they are doing to support EID?	
Perspectives of key audiences (the questions you consider will depend on which key audience you are looking at)	
Do you know if they are aware of EID / POC EID?	
Have you discovered their attitudes towards EID and POC EID?	
Do you know what gaps they have in their knowledge / understanding of EID / POC EID?	
Have you discovered how much priority the Ministry of Health gives to EID / POC EID?	
Have you discovered what barriers may be preventing parents / caregivers from accessing EID tests?	
Do you know if health facilities are offering EID testing services in line with government policy?	
Can you identify who the opinion leaders are on EID? Are there role models within the community?	
Do you know which types of media the parents / caregivers of HIV-exposed infants access?	

Annex 3 – Fundraising plan template

X	Complete this column
What do you need funds for? This could be: • Your entire programme of work on EID / POC EID • A specific activity (e.g. a piece of research, a community meeting, the production of a leaflet or other publication, a bicycle for a peer outreach worker etc.)	**The funding is for:**
Who could provide the funds? • A person or organisation that already gives money to support your work • A new funder find out who the possible funders are, - talk to other CSOs to see if they can suggest anyone - if you have links with implementing partners, ask them if they have any resources available - do you have contacts within the government that you could ask for advice?	**Name of potential funder:**
What are the chances they will provide you with funding? Try and find out if they have set priorities and see if your work ties in with them – e.g. they may be an implementing organisation with a specific focus on children. You could talk to them informally first and ask if they would consider a funding application from you. They may be able to give you some guidance on how to go about the process.	**Reasons why they may be prepared to give funding:**
Put together a proposal Make sure that it is as specific as possible. Say what you plan to do with the money in detail, explain the timescale of the work and give specific deliverables that you will commit to. For example, you could say you will use the money to organise 2 community meetings, each will involve between 30-50 people and they will be held within the next 6 months.	**Overall budget:** **Timescale:** **Deliverables:**
The budget Try to be as realistic as possible. Think about all the costs involved – it could be anything from room hire, to printing costs, expenses for people travelling to meetings or paying for staff time to complete the work.	**Budget breakdown:**

Other ways of reducing your costs
Remember that you can ask for donations of practical things that will help you rather than money. For example, an organisation may be able to let you use some of their office space or their photo-copier. This will reduce your costs and the need to fundraise.

Annex 4 – Challenges assessment template

The challenge / problem	Target audience	Desired behaviour	Main barrier preventing desired behaviour	Potential advantages of changing to desired behaviour

Annex 5 – Objectives template

The challenge/ problem	Target audience	Desired behaviour	Main barrier preventing desired behaviour	Potential advantages of changing to desired behaviour	Specific objectives

Annex 6 – Choosing channels of communication[33]

1. The intended population you want to reach:

- a. Does your intended population have access to the channel?
- b. Will the channel reach your intended population?
- c. Does the channel allow for feedback from the population?
- d. Are the channels perceived as trusted sources of information about your issue?

2. The message(s) you want to deliver:

- a. Is the channel appropriate for the type of message you want to deliver (e.g. visual, oral, simple, complex)?

3. The channel reach:

- a. Does the channel cover enough area to expose your intended population to the messages?

4. Timeliness of the channel:

- a. Does the channel allow the intended population to receive the messages whenever they want (e.g. via text message or a website) or on a set schedule (e.g. a radio advertisement)?

5. Cost of using the channel:

- a. Do you have the resources to utilize certain channels?
- b. What is the cost-effectiveness of the channel(s) being considered?

6. Synergies with other programme activities:

- a. Does the channel reinforce messages for other programme activities?
- b. Does the channel encourage the population to engage in dialogue?
- c. Do the messages motivate the population to seek/demand rights and services?

Annex 7 – Action plan template

The challenge / problem	Target audience	Desired behaviour	Barrier(s) preventing desired behaviour	Advantages of changing to desired behaviour	Objectives	Entry points Opportunities	Communications channels	Activities

Annex 8 – Calendar of activities

Activity	**Date**	**Partners**	**Additional Information**
Example:Community information day	10 / 11 / 20	Mildmay	More community days to be scheduled in if this day is successful.

Annex 9 – Monitoring and evaluation guidance

M & E words explained:

	Definition	Examples
Monitoring	Ongoing collection, analysis and reporting of programme data – focused on programme implementation	
Evaluation	Occasional in-depth analysis of programme performance to answer specific questions – focused on programme effectiveness	
Output	Things that can be counted immediately after the activity	Number of leaflets distributed
		Number of people attending a meeting
		Number of people hearing a radio broadcast
Outcome	Short- medium- and long-term effects seen after the activity is over and the outputs have been produced.	Increased awareness of importance of EID among parents after attending a support group
		Reduction in stigma after community dialogues
		Government commitment to fund EID programmes following an advocacy meeting
Impact	Long-term result of the activities relating to uptake in testing and better health outcomes for infants living with HIV	Higher proportion of HIV-exposed infants being tested for HIV within 6 weeks of birth
		Reduction in deaths among infants living with HIV

Monitoring: To measure how well your action plan is being implemented.
For each activity you can monitor the outputs and outcomes. You need a way of measuring them for each of the activities – these are called indicators. The indicators are the things that you will use to measure if a thing has happened. Here are examples of indicators that you could use:

Activity	Output indicator	Outcome indicator
Create a coalition of CSOs working on EID to advocate for increased political commitment	Number of organisations participating in the coalition.	Annual work plan developed and shared with members.
	Number of coalition meetings held during the year.	All key populations represented within the coalition.
		Coordinated advocacy messages are heard at the national level.
Develop and print leaflets and posters on EID for parents/caregivers	Number of leaflets and posters printed	Percentage of clients who can recall at least two key messages during exit interviews from clinics where leaflets and posters are available versus clinics without the materials.
	Number of leaflets and posters distributed	
Sensitise traditional / religious leaders to the challenges of HIV stigma and the benefits of EID	Number of materials developed	Number of speeches given by religious leaders with positive messages about HIV
	Number of sensitisation meetings held	
	Number of leaders sensitised to HIV sigma and EID	Percentage of local populations expressing accepting attitudes towards people living with HIV

Once you have identified the indicators you then need to decide where you will get the data for that indicator (a focus group, interviews, surveys etc.), when you will gather the data and who will do it.

Evaluation:
There are many different types of evaluation that can be done to assess the design and effectiveness of a programme. Depending on the type of evaluation that you do it will need to be conducted at a different time in the process. You can carry out more than one of these types of evaluation as they can all be useful in different ways.

Baseline:
This is done at the beginning of a project. It looks closely at what the main problem is how it could possibly be solved. The kind of questions it might try to answer are: Are uptake of testing rates better in some areas than others? Are there certain types of clients who do not access EID tests for their infants? These are some of the types of questions that you might ask during your situation analysis and they can help to shape what work you choose to do.

Formative:
This type of evaluation can help you to choose what type of activities are most likely to be successful. This will answer questions like, what is the right way to reach people? Will the audience understand this campaign message? It is carried out as a kind of trial or pre-test to see if the activities are likely to work.

Process:
This takes place sometime after the activities have begun and will enable you to see how well the activities are going, which ones need to be adapted and why, are there any circumstances that have changed that need to be addressed? It is similar to routine monitoring but is more in-depth, not looking at what has happened, instead why or how it happened, what is working and what is not.

Outcome:
This would happen at the end to see how well your work achieved its planned results. In particular, answering questions like, how did our work influence knowledge, attitudes, behaviour?

Impact:
This is a more scientific and time-consuming evaluation that tries to measure the extent to which an outcome can be attributed to a specific activity. To do this properly, you would usually need to look at the behaviour of two groups and compare them, one group would be involved in the activity and the other would not.

This information has been given as an introduction to monitoring and evaluation. It is up to you to decide how much and which types of monitoring and evaluation you do. Much of the information here was taken from a "*Guide to Monitoring and Evaluation of Advocacy, Communication and Social Mobilization to Support TB Prevention and care*". If you would like more guidance you may find the full document useful, it can be found at:

https://path.azureedge.net/media/documents/TB_acsm_me_guide.pdf

10.

References

[1] UNAIDS data 2019. https://aidsinfo.unaids.org/

[2] UNAIDS, *Start Free Stay Free AIDS Free*. 2019. https://www.unaids.org/en/resources/documents/2019/20190722_UNAIDS_SFSFAF_2019

[3] UNAIDS data 2019. https://aidsinfo.unaids.org/

[4] Ibid.

[5] Ibid.

[6] https://childrenandaids.org/

[7] UNAIDS, *Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*. 2011. https://www.unaids.org/en/resources/documents/2011/20110609_JC2137_Global-Plan-Elimination-HIV-Children_en.pdf

[8] https://free.unaids.org/

[9] UNAIDS, *Start Free Stay Free AIDS Free*. 2019. https://www.unaids.org/en/resources/documents/2019/20190722_UNAIDS_SFSFAF_2019

[10] Newell, Marie-Louise, et al., *Mortality of Infected and Uninfected Infants Born to HIV-Infected Mothers in Africa: A pooled analysis'*, The Lancet, vol. 364, no. 9441, 2004, pp. 1236–1243. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(04)17140-7/fulltext

[11] UNAIDS, *Update: Only half of HIV-exposed babies are tested for HIV*. 25 March 2019. https://www.unaids.org/en/resources/presscentre/featurestories/2019/march/20190325_gow_babies

[12] For World Health Organization guidelines on diagnosis of paediatric HIV see *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection - Recommendations for a public health approach*. Chapter 2, 2016. https://www.who.int/hiv/pub/arv/chapter2.pdf?ua=1
and *Update on Antiretroviral Regimens for Treating and Preventing HIV Infection and Update on Early Infant Diagnosis of HIV*, July 2018. https://apps.who.int/iris/bitstream/handle/10665/273129/WHO-CDS-HIV-18.19-eng.pdf?sequence=1&isAllowed=y

[13] UNAIDS data 2019. https://aidsinfo.unaids.org/

[14] Data for any country can be found at https://aidsinfo.unaids.org/

[15] International Community of Women Living with HIV (ICW) and the Global Network of People Living with HV (GNP+), *Early Infant Diagnosis – Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia and Nigeria*. 2015. https://www.gnpplus.net/assets/wbb_file_updown/4894/ICW%20GNP+Early%20Infant%20Diagnosis-%20Perspectives%20of%20Women%20Living%20with%20HIV.pdf

[16] Based on EGPAF POC EID implementation data from 8 countries and a weighted average of 8 studies. See UNICEF, *Strengthening point-of-care early infant diagnosis towards the elimination of paediatric AIDS*. 2018. https://www.childrenandaids.org/sites/default/files/2018-11/Strengthening%20Point-of-Care%20Early%20Infant%20Diagnosis%20ENG%20Oct%202018.pdf

[17] World Health Organization, *WHO Recommendations on the Diagnosis of HIV Infection in Infants and Children*. 2010. https://www.who.int/hiv/pub/paediatric/diagnosis/en/

[18] 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.

[19] Bianchi F, Cohn J, Sacks E, Bailey R, Lemaire JF, Machekano R, et al. *Evaluation of a routine point-of-care intervention for early infant diagnosis of HIV: an observational study in eight African countries*. Lancet HIV. 6(6):e373–81, 2019. https://www.pedaids.org/resource/evaluation-of-a-routine-point-of-care-intervention-for-early-infant-diagnosis-of-hiv/

[20] Jani I et al. *Effect of point-of-care testing on antiretroviral-therapy initiation rates in infants. Conference on Retroviruses and Opportunistic Infections* (CROI 2017), Seattle, abstract 26, 2017. https://www.childrenandaids.org/node/993

[21] The project is funded and delivered by African Society for Laboratory Medicine (ASLM), Clinton Health Access Initiative (CHAI), Elizabeth Glaser Paediatric AIDS Foundation (EGPAF), UNICEF and Unitaid.

[22] This project is 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)

[23] MHCC Zimbabwe, ASLM, CHAI, UNICEF and Unitaid, *Integrated testing for TB and HIV using GeneXpert devices expands access to near-point-of-care testing*. August 2019

[24] For more information see - https://www.pedaids.org/community-engagement/

[25] For more information see – https://www.prenonsunenfantparlamain.com

[26] To find out more about the Lean on Me Foundation see https://www.facebook.com/leanonmek/

[27] Parker and Birdsall, *HIV/AIDS, Stigma and Faith-based Organisations: A Review*. 2005.

[28] ICW and GNP+, *Early Infant Diagnosis – Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia and Nigeria*. 2015.
https://www.gnpplus.net/assets/wbb_file_updown/4894/ICW%20GNP+Early%20Infant%20Diagnosis-%20Perspectives%20of%20Women%20Living%20with%20HIV.pdf

[29] The Coalition for Children Affected by AIDS. *Now more than ever! A need to reach the youngest children affected by HIV and AIDS*. 2014.
https://static1.squarespace.com/static/5519047ce4b0d9aaa8c82e69/t/5551b955e4b0e3bbbdd6d590/1431419221512/Now+More+than+Ever+brochure+-+web+version_0.pdf

[30] For example, see ICW and GNP+ *Early Infant Diagnosis – Understanding the perceptions…*, 2015
https://www.gnpplus.net/assets/wbb_file_updown/4894/ICW%20GNP+Early%20Infant%20Diagnosis-%20Perspectives%20of%20Women%20Living%20with%20HIV.pdf

[31] Ibid.
In addition, see ICW and GNP+, *Understanding the perspectives and /or experiences of women living with HIV regarding Option B+ in Uganda and Malawi*. 2013
https://www.gnpplus.net/assets/wbb_file_updown/2793/Option-B+%20Understanding%20perspectives%20experiences%20of%20women%20living%20with%20HIV.pdf
ICW and GNP+, *Walking in our shoes – Perspectives of pregnant and breastfeeding women living with HIV on access to and retention in care in Malawi, Uganda and Zambia*. 2018
https://www.gnpplus.net/assets/GNP_ICW_Walking_in_our_shoes_Report.pdf

[32] See the statement issued by the Pontifical Academy of Sciences following the *High-Level Dialogue to Assess Progress on and Intensify Commitment to Scaling Up Diagnosis and Treatment of Paediatric HIV.* Vatican City, 6-7 December 2018.

[33] This information is taken from UNICEF's, *Global Communication Strategy Development Guide for MNCHN Programme*. 2015. https://www.unicef.org/cbsc/index_65738.html

NO
TIME
TO
WAIT!

GNP+
GLOBAL NETWORK
OF PEOPLE LIVING
WITH HIV

unicef
for every child

Unitaid
Innovation in Global Health