Bringing People Living with HIV Back to Care

In August 2020, six months into the COVID-19 pandemic, the Ending AIDS in West Africa (#EAWA) project in Togo and Burkina Faso noticed that the number of people living with HIV (PLHIV) experiencing interruption in treatment (IIT) was increasing. The Back to Care campaign was launched in response, mitigating the impact of COVID-19 and reducing the rate of PLHIV interrupting treatment by more than 60 percent.

The campaign, held from August to October 2020, has been important for achieving epidemic control because it directly addressed the core issue of loss of individuals from the HIV diagnostic and treatment cascade. Many PLHIV on antiretroviral therapy (ART) miss appointments and fail to return to care. With careful tracking and tracing, interventions could be targeted to help retain them in care, and records could demonstrate if individuals had transferred to another care site, abandoned treatment, or had died.

The campaign was made possible by additional support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to significantly improve HIV/AIDS clinical cascades in the two countries during 2020 and 2021. Togo and Burkina Faso received the funds as an outcome of the PEPFAR West Africa Regional Operational Plan (ROP) 2019 process, in recognition of having the greatest progress nationally on the HIV clinical cascade.

The #EAWA project, implemented by FHI 360, oversees three components of PEPFAR's strategy: service delivery, strengthening the viral load laboratory system, and monitoring and evaluation. Direct service delivery is focused on the highest burden sites for PLHIV and key populations, particularly Centre, Hauts Bassins, and Centre Ouest regions in Burkina Faso; and Lomé Commune, Maritime, and Plateaux regions in Togo.

The Back to Care campaign process and results yielded valuable insights into avoiding and reducing IIT that may be replicable in other countries.

BACK TO CARE CAMPAIGN

The campaign was a response to the growing number of IITs in Togo and Burkina Faso. PLHIV who do not return for treatment for 28 days are listed as IIT. The objectives were to:

- Find and track individuals diagnosed with HIV who did not start ART
- Find PLHIV who interrupted ART
- Bring clients IIT back into HIV care
- Reduce those experiencing IIT to an acceptable level of 5% or less at HIV care centers

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Bringing clients back to care is vital to HIV prevention because scientific evidence has shown that ART not only preserves the health, quality of life, and life expectancy of PLHIV but also ensures achievement of an undetectable viral load. Thus, continuing ART for life as prescribed means that PLHIV have no effective risk of sexually transmitting HIV to a sexual partner. “Undetectable = Untransmittable” (U=U) has transformed HIV prevention. New HIV infections can now be sharply reduced by ensuring that each person living with HIV is aware of infection, receives the necessary treatment, and achieves sustained viral suppression. This accelerates ending HIV transmission and attaining UNAIDS targets.

Partnering HIV service delivery site managers reported that campaign targets were met or exceeded in both countries. That sparked enthusiasm among some managers who would now like to achieve 0 percent IIT. Most care providers praised FHI 360’s campaign strategy and credited it for much of their success.

Campaign search results were encouraging in both quantitative and qualitative terms. For example, in Togo, the rate of IIT in the ART cohort fell from 16 percent to 5 percent for all the sites by campaign end. Many clients were brought back to treatment, improving the trend of PLHIV receiving ART at the end of September 2020.

SUCCESSFUL RESULTS
A search for IIT was conducted in 25 partner sites in Togo and 17 sites in Burkina Faso from August 17 to October 9, 2020. Of 19,661 clients found, more than 60 percent were returned to care. Information was recorded in the E-tracker system implemented by #EAWA in 2019.

Togo
In Togo, 55 percent of the 9,299 PLHIV clients listed as IIT were successfully brought back to care. Of those, 727 were without tracking information, 6,139 had tracking information, 1,778 were updated in the E-tracker, and 655 were dead (Figure 1).

Burkina Faso
In Burkina Faso, 66.5 percent of the 10,362 PLHIV clients listed as IIT were successfully brought back to care. Of those, 749 were without tracking information, 3,914 had tracking information, 4,896 were updated in the E-tracker, and 241 were dead (Figure 2).

PROGRAMMATIC INNOVATIONS
Mixed methodology was used. The quantitative approach used data extracted from the E-tracker individualized management database while the qualitative approach used primary data from interviews carried out in a selected sample of sites.

Both the program and monitoring and evaluation (M&E) departments of #EAWA were involved in the campaign design. M&E played a catalytic role in sounding the alert and pulling relevant data from the E-tracker. However, at the site level, care providers had mixed feelings because they were not sufficiently involved in the design.

A reporting framework was drawn up to take stock of campaign results for each care site on a weekly basis, focusing on two types of activities: (1) preventing new individuals from experiencing IIT and (2) searching for those already designated as IIT.

Innovations were made to strengthen case management at #EAWA care sites and improve monitoring of contractual activities by FHI 360. The main quantitative mechanism was based on client registration in #EAWA’s unique E-tracker electronic database. It enables monitoring of a client’s status in real time, e.g., whether active or inactive.
From the E-tracker, clients are identified according to their appointment date. Those whose appointments are very soon are called on the telephone to remind them of their next visit. If clients do not show up 28 days after the last visit, they are declared IIT. In general, PLHIV are monitored by mediators who act as intermediaries between clients and care sites.

If clients cannot honor their appointments, mediators are responsible for delivering ART refills to their home, place of work, or a preferred location. Qualitative interviews revealed that the search for those IIT was not systematic at the sites although it should have been done weekly.

Difficulties arose in collecting qualitative data because three types of clients had to be interviewed: IIT found and re-engaged in care, those who transferred out, and those who dropped out of treatment. Care sites and collection agents tried to contact transfer-outs and dropouts but with limited success. Some PLHIV initially agreed to be interviewed but did not respond to appointments while others refused to participate and said they should no longer be called.

In August 2020, it was found that instead of the active queue increasing with the entry of new clients, it was decreasing due to interruption of ART. Without taking action, investments and efforts made so far would have been undone.

**MAIN CAMPAIGN FEATURES**

A central early feature was a daily follow-up meeting organized by the project team to assess search progress in real time at each site and to handle difficulties encountered because of differences among sites and their client bases.

Clients who promised to return were listed for follow-up and those who changed sites were classified as transfer-outs. Some clients were considered lost to follow-up because their information was not updated in E-tracker. Information for others was updated in the E-tracker, and corrections were made for those who had died but continued to appear as IIT. Clients who were found and resumed treatment were categorized as “lost to follow-up found.”

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**Figure 1. Results of PLHIV “lost to follow-up found”: Togo, August 17–October 9, 2020**

<table>
<thead>
<tr>
<th>Description</th>
<th>No. of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>clients</td>
<td>9,299</td>
</tr>
<tr>
<td>clients without tracking information</td>
<td>727</td>
</tr>
<tr>
<td>clients with tracking information</td>
<td>6,539</td>
</tr>
<tr>
<td>clients contacted via telephone</td>
<td>4,965</td>
</tr>
<tr>
<td>clients reached</td>
<td>4,601</td>
</tr>
<tr>
<td>clients not reached</td>
<td>364</td>
</tr>
<tr>
<td>clients contacted via physical address</td>
<td>555</td>
</tr>
<tr>
<td>clients not reached</td>
<td>83</td>
</tr>
<tr>
<td>clients reached</td>
<td>472</td>
</tr>
<tr>
<td>clients reached</td>
<td>1,358</td>
</tr>
<tr>
<td>clients stopped treatment</td>
<td>243</td>
</tr>
<tr>
<td>clients transferred out</td>
<td>1,200</td>
</tr>
<tr>
<td>clients restarted on ART</td>
<td>174</td>
</tr>
<tr>
<td>clients stopped treatment</td>
<td>00</td>
</tr>
<tr>
<td>clients transferred out</td>
<td>298</td>
</tr>
<tr>
<td>proportion of IIT back to care</td>
<td>55%</td>
</tr>
</tbody>
</table>

**Figure 2. Results of PLHIV “lost to follow-up found”: Burkina Faso, August 17–October 9, 2020**

<table>
<thead>
<tr>
<th>Description</th>
<th>No. of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>clients</td>
<td>10,362</td>
</tr>
<tr>
<td>clients without tracking information</td>
<td>1,311</td>
</tr>
<tr>
<td>clients with tracking information</td>
<td>3,914</td>
</tr>
<tr>
<td>clients contacted via telephone</td>
<td>3,033</td>
</tr>
<tr>
<td>clients reached</td>
<td>2,672</td>
</tr>
<tr>
<td>clients not reached</td>
<td>361</td>
</tr>
<tr>
<td>clients contacted via physical address</td>
<td>520</td>
</tr>
<tr>
<td>clients not reached</td>
<td>46</td>
</tr>
<tr>
<td>clients reached</td>
<td>474</td>
</tr>
<tr>
<td>clients reached</td>
<td>1,643</td>
</tr>
<tr>
<td>clients stopped treatment</td>
<td>71</td>
</tr>
<tr>
<td>clients transferred out</td>
<td>958</td>
</tr>
<tr>
<td>clients restarted on ART</td>
<td>360</td>
</tr>
<tr>
<td>clients stopped treatment</td>
<td>00</td>
</tr>
<tr>
<td>clients transferred out</td>
<td>114</td>
</tr>
<tr>
<td>proportion of IIT back to care</td>
<td>66.5%</td>
</tr>
</tbody>
</table>
An important gain was greatly improved information about clients and their retention in care. Before #EAWA was implemented in Togo and Burkina Faso, there was no mechanism for systematic monitoring of clients on ART. Clients attended the care center of their choice, where they would take treatment and leave. Providers were not greatly concerned if the client did not return, and no search action was initiated automatically.

Another significant improvement was shortening the waiting time before noting a client as IIT. Earlier, an individual IIT was not notified until three months after missing the last appointment in the EDT used for dispensing ART. The waiting time was reduced to 28 days after a missed appointment. Both practices coexist in care sites now, partly because providers do not always have enough awareness about the importance of early follow-up for ART clients. This is an ongoing capacity-building task.

Reasons for becoming lost to follow-up, re-engaging in care, transferring out to other locations, or abandoning treatment were found. The main reason given for stopping treatment was financial (see box).

Some care providers noted that the number of people experiencing IIT is higher among women than men because most women do not want their spouses to know their HIV status, so they stop going to obtain their ART refills.

Change of place of residence was the main reason given by clients for voluntarily leaving their initial treatment site to continue at another location. Some transferred to reduce travel costs by choosing a site closer to their homes.

**CAMPAIGN LESSONS FOR THE FUTURE**

Interesting and useful views emerged from the perceptions of stakeholders—providers, beneficiaries, and FHI 360 coaches—on the ingredients of a successful Back to Care campaign. They emphasized a range of actions from acquiring experience in searching for PLHIV to implementation of new care and retention strategies to minimize the risk of IIT at the different sites. A majority credited success to the campaign’s careful planning and design, and providers said having implementing teams always available was the reason for the campaign’s smooth functioning.

Sharing lessons from Togo and Burkina Faso (Table 1) is important for reinforcing #EAWA capacities to optimize the impact of PEPFAR funds and more effectively achieve UNAIDS 2025 targets. Notably, Back to Care is integral to the intensification of HIV case-finding strategies, linking clients to care and retention on ART, and suppressing viral load to reach U=U. Its success significantly improves HIV clinical cascades.

**Preparation**

- A back-to-care campaign must be well designed and consider all aspects of intended objectives.
- Keys to success are determination to achieve campaign goals and strong mobilization of participants.
- The strategy should be participatory involving all the key players.
- Campaign tools should enable each FHI 360 partner site to have reliable information on its ART cohort.

Without the support of FHI 360, I don't think we could have achieved these results since we didn’t have the techniques and the software to do this job. We had support from experts who really influenced the results.”

– A service provider

### Box 2. Reasons for Interrupted Treatment

- Inability to finance travel to a health care site to pick up ART refills
- Fear of stigma and discrimination
- Weariness with treatment for life
- COVID-19 public health restrictions
- No ART stock at health care center
- Adverse side effects of ART
- Declaration of another disease like cancer and more medicine to take
- Prefer to change to traditional medicine
- Prefer to ask God to cure them
- Transferred out and forgot to tell the health care provider
- Person may have died
Implementation

- Ensure implementing teams are always available.
- Provide appropriate motivation and capacity building to obtain individual commitment to finding IIT and bringing them back to care.
- Give attention to detail, especially:
  - Establishing campaign strategy
  - Setting up implementation teams, assigning tasks, and committing to tracking IIT
  - Dispensing ART refills and sharing advice
  - Underlining the benefits of lifelong treatment and the disadvantages of stopping
  - Being flexible and skillful in implementation at various care sites
- Increase and improve support groups to discourage clients from interrupting ART.
- Promote self-care responsibility and provide testimonials of those who experienced IIT and re-engaged with care.

Care Providers

- Pay early attention to the system of alerts and appointments, e.g., by calling clients before their appointment date and those who missed an appointment to find out more.
- Adapt ART dispensing from three to six months and provide community care to help clients in financial difficulty.
- Avoid a rush of people in care settings, especially during the COVID-19 pandemic.
- Make home visits to clients who do not have telephone numbers and regularly update contact details, including changes of residence and geographical area.
- Identify the client’s real-life problems and try to limit the influence on their HIV care.
- Emphasize individual discussions with clients to discourage ART interruption and increase awareness of adverse effects to achieve return to care.

Cautions

During the campaign’s design phase, take notice of the differences among care sites by consulting with managers. All site managers should have the same understanding of back-to-care objectives but implementation on the ground may differ because of a site’s diversity of clients and its care capacities.

Special attention is required on the functionality of the E-tracker. Care providers may need more support in using this vital and useful tool and dealing with glitches and connection issues.

Have a plan to handle issues related to pressure and stress, which could cause frustration and affect the cohesion of campaign participants and the care site’s execution schedule.
In the campaign design, consider team overload and possible execution gaps. Problems could occur in cases where providers are unable to locate people designated as IIT because of geographical issues.

Before implementation, ensure participants are aware of the tools at their disposal for finding those categorized as IIT. When needed, capacity building should be conducted so everyone understands what the tools are and how to use them.

Contact details for clients should include a clear geographical location of their residence. Thought should also be given to developing more intimacy between care providers and clients.

Care sites should make a continuous effort to raise awareness about the importance of not interrupting ART, and provide economic support to PLHIV with limited finances to improve their retention in care.

Daily updates of client appointment lists should be provided to caregivers, and they should continue to do home follow-ups, including delivery of ART refills.

CONCLUSIONS

Care providers recognized the importance of the systematic mechanism for tracking clients on ART. Implementation of the E-tracker platform revolutionized data management and monitoring of clients at various partner sites.

Each partner site has a functioning alert system to remind clients of their appointments. During the Back to Care campaign, providers recognized how the system helped to refine execution of the strategy defined by #EAWA for tracing IIT individuals.

Specific measures could be taken to reduce the number of people listed as IIT. With regularly updated records of ART clients, defaulters could be contacted before they became IIT, and the system could be searched for those who may have stopped ART and potentially brought back to treatment.

An important finding was that keeping PLHIV on ART under #EAWA’s test-and-start protocol may be too rapid for some clients. They needed time to come to terms with learning they were HIV positive and to make a genuine lifelong commitment to treatment. Otherwise, they may interrupt ART and be too reluctant to return.

Overall, the campaign has restored discipline and improved processes to avoid losing clients to follow-up and, if lost, counseling them to restart. This accomplishment is in line with the fundamental #EAWA objectives of case finding through new screening strategies, putting PLHIV immediately on ART, and supporting them to stay in care to achieve viral load suppression.

For more information about the #EAWA project, please email eawainfo@fhi360.org.

This document is made possible by the generous support of the American people through the United States Agency for International Development (USAID) and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). The contents are the responsibility of FHI 360 and do not necessarily reflect the views of USAID, PEPFAR, or the United States Government.