UGANDA

# IRAKA LY'ABANTU

CIVIL SOCIETY GUIDEBOOK TO COMMUNITY-LED MONITORING FOR HIV/TB SERVICE DELIVERY

# Acknowledgements

This advocacy guidebook has been written and developed by a consortium of PEPFAR Watch member-organizations in Uganda, consisting of the Coalition for Health Promotion and Social Development (HEPS-Uganda), International Community of Women Living with HIV East Africa (ICWEA), and Sexual Minorities Uganda (SMUG), with technical guidance from Health GAP. The development of this guidebook has been spearheaded by the Consortium's Steering Committee members: Kenneth Mwehonge, Richard Lusimbo, Lillian Mworeko, Beatrice Ajonye, Asia Russell.

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# Acronyms and Abbreviations

| | |
|---|---|
| ACTS | Access to care, treatment and support |
| ART | Antiretroviral treatment |
| CBO | Community-based organizations |
| CDC | United States Centers for Disease Control |
| COP | PEPFAR Country Operational Plan |
| CSO | Civil society organizations |
| CLM | Community Led Monitoring |
| HEPS | Coalition for Health Promotion and Social Development |
| ICWEA | International Community of Women Living with HIV East Africa |
| IP | Implementing Partner |
| KPs | Key populations |
| KPPs | Key and priority populations |
| LGBTI | Lesbian, Gay, Bisexual, Transgender, Intersex |
| MCH | Maternal and Child Health |
| MSM | Men who have sex with men |
| NGO | Non-governmental organization |
| PEPFAR | United States President's Emergency Plan for AIDS Relief |
| PLHIV | Persons living with HIV |
| RHITES | Regional Health Integration to Enhance Services |
| RHSP | Rakai Health Sciences Program |
| SMUG | Sexual Minorities Uganda |
| SRHR | Sexual and reproductive health and rights |
| TB | Tuberculosis |
| UPHIA | Uganda Population-based HIV Impact Assessment |
| USAID | United States Agency for International Development |
| VAW | Violence against women |

# 1. BACKGROUND

## 1.1 Introduction

Local monitoring of HIV service sites that are supported by the United States President's Emergency Plan for AIDS Relief (PEPFAR) has often painted a bleak picture of dysfunction and wasted resources. PEPFAR's own data also indicates that there has been poor performance by its Implementing Partners (IPs) given the amount of money being invested. PEPFAR and its IPs need to be held accountable for effective service delivery.

Inadequate scale-up of antiretroviral treatment (ART) and poor performance of the program have been of particular concern, especially the high number of clients lost to follow-up. According to PEPFAR data in 2019, 759,506 people were enrolled on treatment but the total number of people still on treatment across the country by the end of the year had only increased by 353,605. This means that 405,901 people had been lost along the treatment cascade, were not adhering, or had died during the course of the year.

In response to this poor performance, in February 2019, PEPFAR and its agencies announced a new rapid plan to improve service delivery. Through this emergency approach, progress has been made and PEPFAR and its IPs have managed to meet their targets in re-engaging people in care and testing new people living with HIV (PLHIV).

The Iraka Ly'Abantu Community-Led Monitoring Project is an initiative of a consortium of HIV community organizations advocating for improved quality of HIV and TB services in Uganda. It specifically focuses on monitoring of services supported by the PEPFAR) in Uganda and builds upon prior successful work on HIV program accountability

This guidebook has been prepared to guide civil society actors and communities, including organizations of people living with HIV (PLHIV), young people and key populations (KPs), in monitoring the quality of the HIV and TB services at PEPFAR-supported sites in Uganda. It provides step-by-step instructions on how to conduct community-led monitoring at the clinic and community levels.

It contains basic information about HIV in Uganda and the role of the PEPFAR program; how to gather and capture data, analyze it, and use the findings to come up with solutions to engage duty bearers and advocate for change for the benefit of communities.

## 1.2 Project objective

The Iraka Ly'Abantu Project aims to monitor and evaluate PEPFAR program quality improvement efforts from the perspective of the client/community in order to contribute to service quality and program accountability, and to empower service clients to make decisions regarding their health through sustainable participatory monitoring and evaluation of services for their own health and wellbeing.

## 1.3 Target audience

This advocacy guidebook has been designed to guide PLHIV, young people, KPs, activists and HIV and TB service monitors through the service monitoring cycle of data collection, analysis, solution identification, and stakeholder engagement/advocacy for better services.

## 1.4 Role of communities in Uganda's HIV response

Communities have played a critical role in Uganda's response to HIV/AIDS since the first case was identified at a fish landing site in Rakai District in 1985. This role has evolved with the epidemic, making an invaluable contribution to reduction in infections, expansion of care and treatment, and reduction in stigma and discrimination. This effort started in 1987 with the founding of The AIDS Support Organization (TASO) by a group of medical workers and activists after witnessing how badly AIDS patients were being treated in the wards of Mulago Hospital. TASO focused on providing counseling, psychosocial support and medical services to people infected and affected by HIV.

As Uganda's epidemic has evolved to become severe, mature, and generalized[1] communities have helped bring attention to vulnerable population groups that continue to be disproportionately affected. According to the Uganda Population-based HIV Impact Assessment survey (UPHIA) 2016-2017 estimated that 72.5% of adults 15-64 knew their status; of those who knew their status, 90.4% were receiving life-saving ART and 83.7% of those on treatment were virally suppressed.[2] Official government data has shown an increase in the number of men newly initiated on treatment from 60,000 in 2016 to 80,000 in 2017, while that of women newly initiated on treatment increased from 107,000 to 138,000 over the same period.[3] HIV prevalence has declined from 8.3% among adults aged 15-49 years in 2011 to a projected 5.8% in 2019, while UNAIDS data show that 85% of PLHIV were on ART in 2019.

This progress has masked pockets of severely affected populations, and activism by communities has helped shift policy and programmatic attention to these key populations, arguing that this is the only way the country can achieve epidemic control and realize the goal of ending AIDS by 2030. An estimated national prevalence of 6.2% among the adult population aged 15-49 years in 2018, translates into a total burden of HIV of 1,299,391, while the number of new infections was approximately 52,813 in 2017.[4] Prevalence remains higher among females (7.6%) than males (4.7%). Key and priority populations who are at higher risk of HIV infection and who face social and legal challenges continue to be highly vulnerable, not only to infection, but for a variety of reasons, to drop our care and treatment.

Different studies have found higher-than-average HIV prevalence rates among key populations: Men who have sex with men and people who inject drugs are 24 times more likely to acquire HIV than adults in the general population; while sex workers are 10 times more likely.[5] Transgender women are 49 times more likely to be living with HIV than other adult females.[6] Prevalence is up to 15-40% in fishing communities, 31.3 % among female sex workers, 18% in the partners of female sex workers, 12.7% in men who have sex with men (MSM), and 18.2% among men in uniformed services.[7] A study conducted in 40 districts in 2018 established that comprehensive HIV knowledge among key populations was as low as 35.6%.[8]

1 Uganda AIDS Commission, 2019. Synthesis, Consolidation and Building Consensus on Key and Priority Population Size Estimation Numbers in Uganda. Final report
2 Ministry of Health. (2019). Uganda Population-based HIV Impact Assessment 2016-2017: Final Report
3 UNAIDS, 2018. Test and treat showing results in Uganda and Zambia. Feature story, 5 April 2018. https://www.unaids.org/en/resources/presscentre/featurestories/2018/april/test-and-treat-showing-results-in-uganda-and-zambia
4 MoH Spectrum Estimates, 2017
5 UNAIDS (2016). Prevention Gap Report
6 Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz, TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and metaanalysis. Lancet Infect Dis. 2013;113(3):214–222)
7 PEPFAR 2018; Opio, Muyonga, & Mulumba, 2013; Seeley, Nakiyingi-Miiro, et al., 2012; Asiki et al., 2011
8 Priorities for Local AIDS Control Efforts (PLACE) study

The 2014 Uganda Modes of Transmission study estimated that 11% of new infections in the previous 12 months were attributed to female sex workers, their clients, and their clients' partners. A 2017 study among men who have sex with men in Kampala reported high-risk behaviors to be common, including 36% of respondents reporting regular unprotected anal sex; 38% selling sex; 54% having multiple steady partners; 64% having multiple casual partners; and 32% injecting drugs.[9]

In addition to these 'key' populations, 'priority' populations – populations which by virtue of demographic factors (age, gender, ethnicity, income level, education attainment or grade level, marital status) or behavioral factors or health care coverage status or geography – are at increased risk of HIV. In Uganda, priority populations include fisher folk, uniformed services and truck drivers and women who have sex with women (WSW). Women with disabilities and adolescent girls and young women (AGYW) are not officially recognized among key and priority populations but face equally high or even higher vulnerabilities to HIV.

These key and priority populations face many challenges in accessing prevention, care and treatment services due to stigma, harassment, discrimination, criminalization and other legal barriers. Historically, they have not received adequate priority in the policy and programmatic response to HIV. As a result, they continue to drive the HIV epidemic in Uganda. The second national PLHIV 2019 stigma index study further established that 22% of sex workers have ever felt afraid to seek health services because they were worried someone may learn that they were a sex worker. Therefore, stigma greatly affected access to services by the key populations, yet they are the ones who need the services most.

The UPHIA indicates that of all persons living with HIV in the country in 2017, 74% knew their HIV-positive status, 67% were on treatment and 60% were virally suppressed.

Currently, Uganda's main challenge in the HIV response is how to support and ensure that all PLHIV are enrolled on treatment and most importantly, stay on treatment. Doing this in the context of a dysfunctional healthcare system still remains a challenge. Fact-finding missions and facility monitoring exercises conducted by the CSOs and HIV networks have revealed several gaps. These include commodity stock outs, clogged systems, overwhelming workload for service providers, limited or no capacity in working with key populations, congestion at health facilities, limited privacy, malfunctioning infrastructure and equipment, poor record keeping, low morale, non-functional follow-up systems and poor supervision.

HIV advocates and activists in Uganda have constantly urged the government of Uganda to expeditiously improve the healthcare system that still undermines service delivery in the HIV and TB response. The government of Uganda has been urged to roll out innovative models of care in order to support improvement of services in health facilities.

9 Hladik W., Sande E, Berry M, Ganafa S, Kiyingi H, Kusiima J, and Hakim A, (2017). Men Who Have Sex with Men in Kampala, Uganda: Results from a Bio-Behavioral Respondent Driven Sampling Survey. *AIDS Behaviour*, 21(5):1478-1490. https://www.ncbi.nlm.nih.gov/pubmed/27600752

## 1.5 The Community-Led Monitoring Model

Community-Led Monitoring (CLM) is a systematic collection of data at the site of service delivery by community members that is compiled, analyzed and then used by civil society and community groups to generate solutions to problems found in service delivery during data collection. There is need for district and lower local governments to have had proper accountability for the public health services that they provide.

While lack of accountability itself is a major barrier to improving the quality of care, people who should be most motivated to demand accountability are not being empowered to do so. CLM empowers PLHIV to monitor service delivery at PEPFAR-supported HIV sites, identify challenges, generate evidence-based recommendations to relevant duty bearers. CLM data collection eventually leads to the generation of evidence based-solutions that can bring about meaningful changes to a community and enhance the capacity of community members to continue to engage in future evidence-based monitoring and advocacy.

Thus, empowering communities to monitor the quality of service provision and highlight performance problems is an indispensable strategy for improving PEPFAR performance and enabling Uganda to meet the UNAID 95-95-95 targets.

## 1.6 The CLM consortium

In Uganda, CLM is being implemented by a consortium of three civil society organizations described below;

1) **Coalition for Health Promotion and Social Development (HEPS-Uganda).**

HEPS Uganda is a national non-governmental organization (NGO) advocating for the right to health, with a special focus on access to affordable essential medicines for the poor and vulnerable people. It is a membership organization, composed of health consumers, health advocates, health practitioners, civil society organizations (CSOs) and community-based organizations (CBOs).

HEPS-Uganda has a national secretariat in Kampala and 11 field offices at regional level through which community-level interventions in a total of 20 districts are implemented. The four regional offices are located in Lira for northern region; Pallisa and Kamuli for eastern region; Mbarara for western region; and in Kiboga for Central region.

HEPS-Uganda operates in the districts of Kamuli, Pallisa, Bugiri, Jinja, Mukono and Budaka in the eastern region; Lira, Alebtong, Otuke, Gulu and Apac in the northern region; Kamwenge, Kiruhura, Ntungamo, Isingiro, Ibanda and Mbarara in the western region; and in Kampala, Kiboga, Kyankwanzi and Nakaseke in the central region. At the national level, HEPS-Uganda works through the Uganda Coalition for Access to Essential Medicines (UCAEM), a coalition of more than 50 partner CSOs which we host and coordinate, and several other national coalitions to which we belong.

2) **International Community of Women Living with HIV East Africa (ICWEA)**

The International Community of Women living with HIV/AIDS (ICW) is the only international network run for and by women living with HIV. It was founded in response to the desperate lack of support, information and services available to HIV positive women worldwide and their need to influence and provide input for policy development. ICWEA promotes all voices and advocates for changes that improve the lives of all people living with and affected by HIV.

ICWEA advocates in three thematic areas: 1) Violence Against Women (VAW) being a cross-cutting issue; 2) Access to Care, Treatment and Support including prevention (ACTS) and TB/HIV co-infection; 3) Sexual and Reproductive Health and Rights (SRHR) including Maternal & Child Health (MCH), Meaningful Involvement of Women living with HIV at all levels in policy & decision making (MIPA/MIWA). ICWEA aims to build a political and collective civil society voice from local to regional and international levels holding to account governments and institutions at all levels and ensure commitments are translated into actions.

**3) Sexual Minorities Uganda (SMUG)**

Sexual Minorities Uganda (SMUG) is an established non-profit, non-governmental umbrella organization formed in 2004 to address the need to protect and support Lesbian, Gay, Bisexual, Transgender, Intersex (LGBTI) individuals in Uganda. Today, SMUG advocates for policy reform, while simultaneously monitoring and aiding to coordinate the efforts of 18 LGBTI organizations in Uganda. These organizations provide a plethora of services to the LGBTI community such as medical attention, counselling, guidance, as well as support for the economic empowerment of LGBTI individuals. SMUG works closely with local, regional and international human rights organizations and activists with one goal: to end discrimination and injustice towards LGBTI persons in Uganda and ensure that all Ugandans are equally respected and valued no matter their sexual orientation, or gender identity or expression.

The mission of SMUG is to monitor, coordinate, and support member organizations to achieve their objectives aimed at the Liberation of LGBTI people. SMUG equips and empowers LGBTI organization leaders and community members with laws and policies necessary to inform advocacy at various levels.

## 1.7 Our principles

1) Recognize, respect and embrace diversity.
2) Actively fight for the rights of people living with HIV, women, queer people, transgender people, young people, sex workers, people who use drugs, migrants, and other marginalized populations.
3) Actively fight against any acts of racism, patriarchy, homophobia, transphobia or any other stigma and discrimination.

# 2. PEPFAR'S CONTRIBUTION TO UGANDA'S HIV RESPONSE

## 2.1 PEPFAR's investments in the HIV response

The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is the largest funding mechanism for the HIV response globally, providing support in more than 50 countries around the world. The most funding focused in Sub-Saharan Africa, Haiti, Asia, the Caribbean, and Latin America. In Uganda, PEPFAR contributes approximately 65% to the HIV response.

Over the past 16 years, PEPFAR has supported lifesaving antiretroviral treatment (ART) for an estimated 15,668,656 million people, including about 689,455 children, helping secure their health and welfare of their families. PEPFAR has also provided critical care and support for 6,310,134 million orphans, vulnerable children, and their caregivers; 22,822,833 million men and boys to receive voluntary medical male circumcision (VMMC) as of 2019.

PEPFAR's investments have secured health for individuals and families, and strengthened the systems that drive effective, efficient, and sustainable health care. In FY 2019 alone, the agency supported the training of up to 10,034 health care workers to deliver and improve HIV care and other health services, making a critical contribution to building health systems for partner countries to confront other current and future health challenges.[6]

## 2.2 PEPFAR Operating Agencies

TPEPFAR serves as the umbrella and coordinator for all U.S. government agencies providing funding for the AIDS response. Investments are made through the U.S. Centers for Disease Control (CDC), USAID, Health Resources and Services Administration (HRSA), the Departments of Defense (DOD), Commerce and Labor, and the Peace Corps. These agencies are the ones that write the contracts and manage the programs, hence HIV programs funded by CDC or USAID are part of PEPFAR's investments.

## 2.3 What is the Country Operational Plan?

In each country, PEPFAR's investments are guided by an annual Country Operational Plan (COP). The PEPFAR COP outlines how HIV investments from the U.S. Government will be allocated across programmatic priorities and targets in the beneficiary country for the specific year.

The COP consists of a detailed budget and target report, and a narrative account of PEPFAR's plans, known as a Strategic Direction Summary (SDS). The SDS outlines the main goals and targets PEPFAR aims to achieve in a given country; the priority populations and geographic areas; the strategies and interventions PEPFAR and its implementers plan to use; as well as the monitoring strategy. The SDS also details the focus areas of the different operating agencies, and an overview of the state of the epidemic and response in the country.

In line with the U.S. Government financial year, the PEPFAR COP year commences on 1st October 1 and ends on September 30. It is split into four quarters – that match the Consortium's monitoring quarters. PEPFAR publish data corresponding to each quarter that civil society partners and other stakeholders can review and assess against preset performance targets.[10]

10 All the COPs and other key PEPFAR documents are available here: https://www.state.gov/where-we-work-pepfar/

## 2.4 PEPFAR implementing mechanisms and performance in Uganda

PEPFAR has 16 implementing mechanisms in Uganda, consisting of implementing partners who are supported through the Operating Agencies to provide HIV services. The 'implementing mechanisms' or partners are mostly large, non-governmental organizations (NGOs) as well as government agencies in the implementing country. The implementing mechanisms are then responsible for running HIV programs and sometimes provide funding to other organizations as sub-contractors including smaller, local organizations to implement programs. The country has been parceled out to the different mechanisms by geographical area.

In Uganda, the implementing mechanisms currently consist of:

1) Baylor Uganda
2) Makerere University Infectious Diseases Institute (IDI)
3) Elizabeth Glazer Pediatric AIDS Foundation (EGPAF)
4) RHITES East
5) RHITES East Central
6) RHITES Acholi
7) RHITES Lango
8) RHITES Southwest
9) Mildmay Uganda
10) Makerere University Walter Reed Project (MUWRP)
11) Rakai Health Sciences Program (RHSP)
12) TASO
13) Uganda People's Defense Forces (UPDF)

# 3. THE ROLE AND PARTICIPATION OF THE CIVIL SOCIETY IN THE PEPFAR COP

## 3.1 The "People's COP/Voice Uganda"

The "People's COP" is a strategy used to influence the development of the PEPFAR COP. Using data collected from clinics and other health facilities, a comprehensive document is developed that outlines community's recommendations to PEPFAR. A series of events have pushed the voices of PLHIV, young women, KPs and health workers into the PEPFAR discussions that too often focus on numbers and targets, and less on the health and lives of clients.

In 2019, the "People's COP" recommended that CLM be funded by PEPFAR and thus the formation of the civil society implementing consortium. In 2020, the data collected in the project informed the recommendations to PEPFAR against evidence collected from the ground. Several recommendations from previous years but had not yet been implemented were outlined

## 3.2 Purpose and importance of community-led monitoring

For years the COP process was a closed confidential U.S.-government-only set of discussions that excluded affected communities. In 2013, Health GAP and a coalition of activists in the U.S. and East and Southern Africa fought hard to ensure meaningful civil society involvement in the processes. This was premised on feedback from people most affected by HIV which outweighed input and reporting from bureaucrats. Currently, members of civil society are able to take part in COP planning and monitoring in most countries through quarterly meetings organized by PEPFAR country teams.

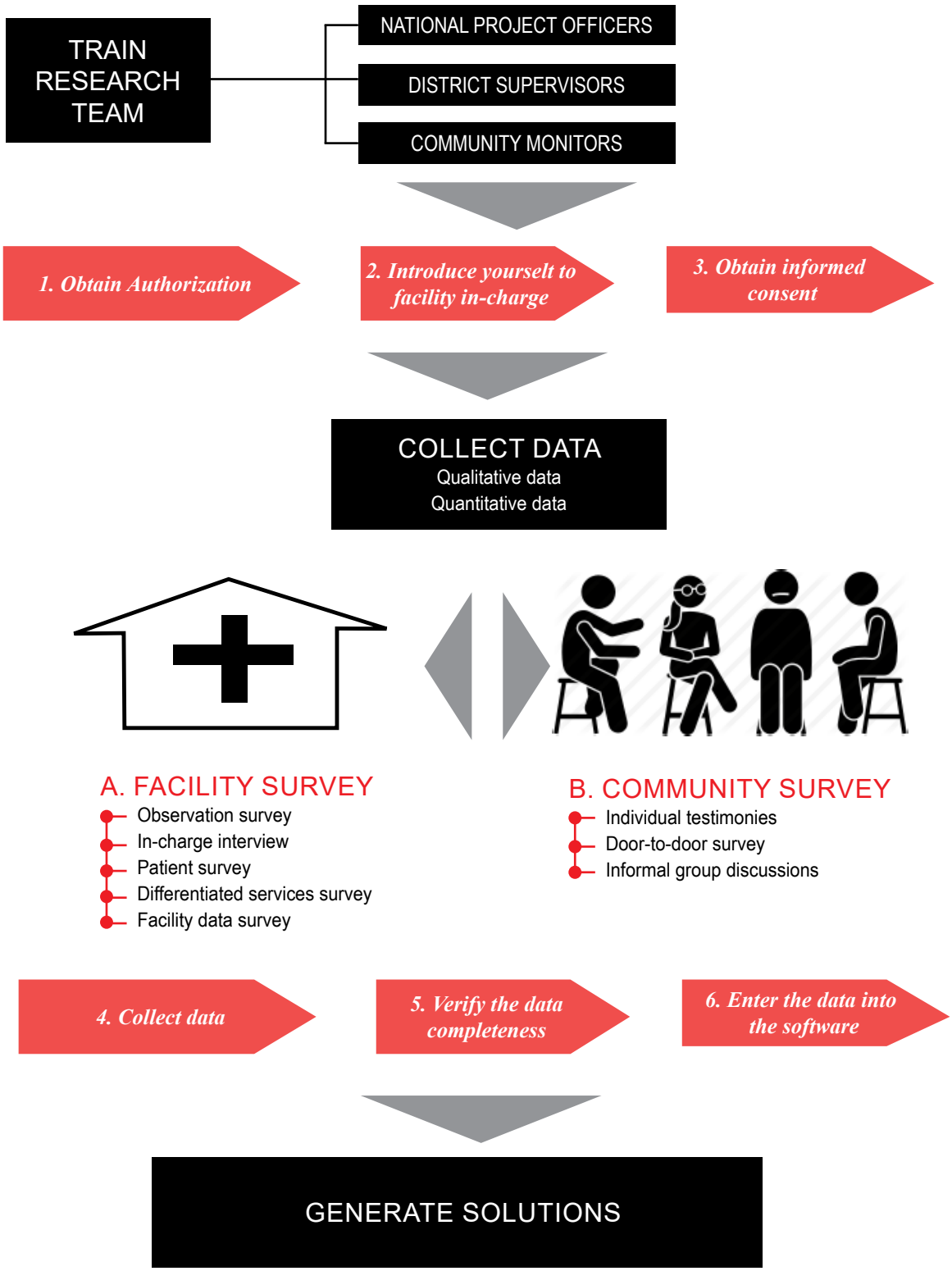
It is worth noting however, that a seat at the table does not necessarily translate into meaningful input into PEPFAR program planning and processed. Only where activists have proactively and consistently used these opportunities to hold PEPFAR accountable, and therefore pushing the program to deliver on the transparency and access pledged has 'engagement' resulted into impact.

Community-led monitoring provides an opportunity to service beneficiaries to hold service providers, PEPFAR implementing partners, program managers and policy makers accountable for the quality of HIV services they provide. This feedback enables service beneficiaries and duty bearers to jointly address barriers to the quality of care. Hence, this model motivates and empowers service beneficiaries to demand accountability from duty bearers and other stakeholders - in this case PEPFAR. In addition, it is an opportunity for supervisors at national and local government levels to receive vital feedback from service users to effectively fulfill their duty.

## 3.3 What is community-led monitoring?

Community-Led Monitoring (CLM) is the systematic collection of data at the site of service delivery by communities (persons living with HIV and key populations) who compile, analyze and then use the findings to generate solutions to the problems they have identified.

## 4. A STEP-BY-STEP APPROACH TO CLM



The monitoring team should collect both qualitative and quantitative data through the use of a standardized but contextualized set of monitoring tools[11] to gather evidence in clinics and in the community. Hence, data gathered at the facility and from the community should capture the experiences and perspectives of PLHIV who are currently accessing healthcare services from PEPFAR-supported HIV service sites, as well as from those *not* currently accessing services, with a view of gaining critical information on what is working well and what is not.

Facility-based monitoring captures observations as well as the perspectives of both healthcare users and healthcare providers. On the other hand, the community-based monitoring component gathers information directly from community members using door-to-door engagement and informal focus groups.

## 4.1 Gathering evidence from health facilities

*Seek authorization:* The monitoring should ideally cover all HIV service sites and community-based healthcare centers across the country. There should be a Memorandum of Understanding with PEPFAR and the Ministry of Health, which should be communicated to HIV service sites through a circular, cover letter or other formal communication, to facilitate this process. The monitoring team should further hold meetings or undertake other formal engagement with all district health offices (DHOs) in order to explain the project and ensure easy access to facilities in each district reached. Data collectors should be equipped with evidence of these authorizations or understandings as they are dispatched to the field and given appropriate guidance on how they introduce themselves to the service sites and communities.

*Data collection procedures:*

Data should be collected through observations, interviews and group discussions, all of which should be guided by contextualized tools for different survey site-categories and communities. These tools should contain the key questions or issue check-list that are relevant for different respondent categories.

Data shall be captured in two ways: Using a paper survey, filled by hand, and uploading the data into an online application provided on a tablet computer. Paper surveys shall be filled out by hand.

Field surveys should be conducted by the community-based monitors supported by the national and district level research teams. Each community monitor should be provided with a tablet computer, fully equipped with the requisite software application, and they should be guided to upload the data gathered at the end of each monitoring day or at the earliest opportunity thereafter. Even information collected on paper must be uploaded into the computer application. This should happen on the same day where possible, or at the earliest opportunity.

11 Samples of monitoring tools have been provided in the Annexure section

## *Data collection teams*

The monitoring shall be undertaken by the civil society and community-level monitors from the PLHIV and KP communities. Each ***Community Monitor*** will be assigned a set of clinics in a district or subcounty that they will collect data from. Community Monitors are supported by ***District Supervisors*** who oversee and verify their work. At a national level, ***Project Officers*** oversee the functioning of the entire data collection effort.

Community monitors should never collect data individually. They should work in small teams or in a pair so that a team member can verify the data collected. It also makes data collection easier and means there is another person to reflect with on the challenges found.

## *Data verification*

The Iraka Ly'Abantu tools are constituted to minimize the risk of submitting incomplete data. Each form's logic has been structured in a way that a data collector cannot skip questions and, in turn, submit partial forms. Other survey elements have been added to collect the most accurate answers from clients and Facility In-Charges. Take note of responses like: "none of the above", "don't know" and "prefer not to answer" to avoid forcing answers when there is an apparent lack of knowledge or the respondent simply prefers not to answer. Data collection supervisors assist Community Monitors in every stage of the data collection process to ensure information is correctly entered into the software in the tablet-based forms.

## *Data storage*

It is critical that data is captured accurately, effectively and stored safely, and that people's private information is not disclosed without their consent. The research leaders/project officers are required to provide all paper tools to the Community Monitors after each activity. After the Community Monitor captures the paper tools in the password protected online system, these tools should be given to the supervisor at the next opportunity and then stored safely by the project member organizations.

## *Obtaining informed consent*

Informed consent refers to giving people all the information they need to decide if they want to answer your questions or not ***before*** you interview them. This means that they will need to know:

(a) Who you are and why you want to talk to them,
(b) What information you want and what you will do with it,
(c) That participation is completely voluntary and they can skip or refuse to answer any questions, and
(d) That we will never share their name or personal information unless they give us permission to do so.

Data collectors must obtain informed consent from people they interview.

### *Cultivate a friendly relationship with the facility in-charge:*

It is important that the Facility In-Charge understands the details of the project and the importance of working together. The project team needs to build a good working relationship with the clinic. To do this, data collectors will need to introduce themselves properly before they start any interview or conversation.

(a) Before the data collector goes to the clinic, they should familiarize themselves with this guidebook which should have all the information they need to discuss the purpose and details of the project.
(b) Data collectors should contact the clinic to set up a meeting with the Facility In-Charge to introduce the project.
(c) In the meeting, data collectors should describe the background of the project, the quarterly monitoring cycle, and the specific surveys they will undertake. They should explain that there is permission from the relevant authorities and show the Facility In-Charge evidence of the permission. They should also explain that the exercise feeds back findings and potential solutions on a quarterly basis at a time to be arranged and convenient for the Facility In-Charge.
(d) If data collectors have any challenges accessing the clinic, they should contact the supervisor or data collection manager.

### *Facility monitoring tools*

The facility-based tools are divided into different surveys, to be collected through either observations, or talking to healthcare providers or healthcare users. It is critical that data collectors are very familiar with the tools (in the annex section) and understand each of the questions before going to the field.

**(a) Observational survey:** Through the observational survey, we get a sense of the functionality of the clinic based on the number of people waiting, the size, space, condition and cleanliness of the facility, and whether required procedures and information is visibly on display.

**(b) Patient survey:** Through the patient survey, we learn about the patient perspective in terms of the length of waiting times, the safety of queueing in the early hours, if there are enough staff at the facility and whether they are friendly and professional, if anyone has left the clinic empty handed recently, and whether there are adequate TB infection control measures in place. After the general questions, there is the following question in the patient survey: **"The next set of questions are for people living with HIV specifically. If that applies to you, can I continue with these questions?"** *If yes, move onto the PLHIV section.*

For those patients who are also willing to answer questions for PLHIV, we continue on to find out about the functionality and availability of differentiated service delivery options like adherence clubs and external pick up points, whether clinic staff "welcome back" people who have missed appointments or treat them poorly, the accessibility of psycho-social support options, and the level of understanding of the importance of viral load testing.

**(c) Facility In-Charge survey:** Through the Facility In-Charge survey, we gather information from the perspective of a healthcare provider about the size and adequacy of the staff, the role of the PEPFAR implementing partner, infrastructural and space challenges, the frequency of stockouts/ shortages of medicines, potential barriers to quality HIV linkage and retention, accessibility of TB services, and programs that target key populations, youth and men.

**(d) Differentiated service delivery survey:** Through the adherence club survey we delve into the details of adherence clubs to understand if they are actually functional, including uncovering the number of clubs, ratio of facilitators and nurses to PLHIV decanted, and topics covered.

**(e) Facility data capture survey:** Through the data capture survey, we find out key statistics relating to the numbers of clients accessing ART, PrEP and TB treatment, numbers of clients lost to follow up, and numbers of people decanted to differentiated service delivery models.

## *Versions of the surveys:*

Each survey outlined above has two versions - a longer and a shorter version.

**Version 1**: A longer version that includes all the questions to be taken every 6 months. The 6-month surveys include questions about less frequently changing information that does not need to be asked on every visit *e.g. about the size of the infrastructure and the staff establishment.* The longer Facility In-Charge survey can take between 30 - 45 minutes.

**Version 2**: A shorter version that includes a subset of questions to be taken in the alternating 3 months. The alternate surveys are much shorter and far quicker to carry out. They include information that can change regularly *e.g. about medicine stockouts, cleanliness and staff attitude.* The shorter Facility In-Charge survey can take between 10 - 15 minutes.

Whenever you start monitoring during the year you should always start with the 6-month longer version of the tools and then alternate going forward. This is important so that the data dashboard has a full set of information to present.

## *Which patients should you interview at the clinic?*

The monitoring team should aim to collect at least 15 patient surveys that result in data from PLHIV ad KPs being collected. You should speak to patients in all areas of the clinic including the waiting area and the queues. Not everyone you find in the clinic will be living with HIV with HIV, and some PLHIV may not want to disclose their status to you by agreeing to answer the HIV section. This means you may interview several patients who say no, when you ask **"The next set of questions are for people living with HIV specifically. If that applies to you, can I continue with these questions?"** *If yes, move onto the PLHIV section.* The team of monitors should keep collecting patient surveys until you reach a critical number of respondents. If the clinic is very small and there are not enough patients to interview, continue until you run out of people and explain in the Reflection Form.

## 4.2 Gathering evidence in the community

In order to deep dive into the challenges people experience, at certain sites we will also gather evidence in the community. Through this we will capture the experiences and insights of both of those accessing public healthcare services in specific facilities and of those who are *not* currently interacting with any facility, both of whom have critical information about what is and is not working. In the "community-based" monitoring component, we will gather information directly from community members using **door to door engagement** and **informal focus groups** interviews/discussions that will focus on specific themes and groups. The community monitoring tools allow us to gather evidence that we do not find in the facility monitoring tools. Information gathered in the community often provides deeper insights as community members can speak more freely outside of the facility, and away from the watchful eyes of healthcare providers.

### *Community-based monitoring tools*

There are three types of community-based tools (available in the Tools section in full):

1) **Individual testimonies:** This tool should be used if someone you are talking to has a specific personal story about the impact of bad healthcare services. Only fill out the individual testimony tool after you know this to be true. Individual testimonies should not have taken place too long ago - as a rule only capture testimonies that have taken place in the last year.

2) **Door to door survey:** This survey is similar to healthcare user surveys captured at the facility; however, they include more qualitative data collection. We will learn about the patient perspective in terms of the length of waiting times, the safety of waiting outside the facility in early hours, staff shortages and staff attitudes, stockouts and shortages of medicines and health technologies, the functionality and availability of differentiated service delivery options like adherence clubs and external pick up points, whether clinic staff "welcome back" people who have missed appointments or treat them poorly, the accessibility of psycho-social support options, and the level of understanding of the importance of viral load testing. Importantly, during this data collection method, we will be able to engage directly with some people who do not access healthcare services and get a clearer understanding as to why.

3) **Focus group questions**: These questions outline broad categories of topics to be discussed but are not exhaustive and will allow for open ended responses and evolving conversations. The topics are aligned to key audiences including: public healthcare users, people living with HIV, people with TB, adherence club members, adolescent girls and young women, young people, men, sex workers, men who have sex with men, transgender people and people who use drugs. The focus group questions allow us to collect information that cannot be collected through clinic surveys. There is much more qualitative data that will tell us in more detail what the challenges are and potential solutions.

## *Individual testimonies*

Individual testimonies detail a specific person's story about the impact of bad healthcare services on them. This could be a specific story about any kind of poor-quality service e.g. their experience of being treated poorly by clinic staff or how they experienced a stockout of their HIV treatment. This survey can be carried out during door to door, at the facility or at community events if a community member has a specific story or testimony they want to give.

Individual testimonies are very important - they provide insights and details not provided through facility monitoring. They allow us to raise the voices of community members struggling to access healthcare services and involve them closely in trying to fix the challenges. Working together with community members strengthens our engagement with duty bearers and further efforts to advocate for change. Decision makers cannot ignore that the problems highlighted in the data collection are negatively affecting people's lives.

Individual testimonies are integral to organize impactful public hearings and other types of advocacy. Explain to people you interview to capture a testimony the ways in which they can raise their story.

Make sure that the data collector explain that we will only raise people's stories with the consent of the individual involved - and this can either be publicly or anonymously. The individual testimony tool provides space for individuals to sign to confirm if they want to raise their story publicly (with their name on) or anonymously (without their name or face being exposed). Those who provide a testimony can change their mind at any time. You must get the consent form signed after capturing the story and give them the information slip to allow them to get in touch if they change their mind.

The testimony should have happened recently - within the last year. Try to find out when a problem occurred before noting down the story. It is difficult for us to advocate for challenges that happened a long time ago. When talking to the individual, find out as much detail as possible using "what, when, who, where, why, how" questions as outlined below. If there is something that seems unclear, or you do not understand, ask more questions to get the full story. Imagine you were reading the story in the newspaper; would it make sense to you? You can capture the story in any language you want to.

Use the individual testimony tool to collect stories. Make sure to print lots of forms to distribute to branch members before a door to door, focus group or facility monitoring in order to ensure you can collect any stories that may be raised. People may want to give their testimony privately, so wait until the end of a focus group, for instance, to take the full story when you can talk to them alone.

After you capture the form, work with the Supervisor or Survey Manger. It can then be uploaded to the app as a photo and as the written-up version of the text. It is very important to keep the original paper copy safe and to submit it to your District Supervisor at the next monthly reporting session. It will then be given to a Senior Project Officer and stored in a locked space in the head office.

In order to raise people's stories, we will need to get back in touch with the individual, and may need to ask more questions. Even if a person wants to remain anonymous, try to get their contact details which will only be for us to use internally.

## *"Door to door" engagement*

"Door to door" engagement is when we work as a team to literally go from "door to door" in the community, speaking to people about what challenges they are facing in terms of healthcare and access to HIV and TB services. It helps us to find out more about what the services are like. Often people feel more open to talk about these issues in their own homes, away from the facility setting.

Getting your introduction right influences what information you will gather during the "door to door". For example, if you arrive at a house and ask if the person has experienced any challenges such as stockouts, likely the person will only tell you if they have faced a stockout, and not think anything else is relevant. The door to door survey helps us to introduce ourselves in such a way that we can gather evidence of any challenges. It is important that all the data collectors understand the monitoring tools.

Before doing a "door to door: you should ensure that you conduct an ***in-service training*** for the branch you are working with. This should include information on the project, what evidence you are hoping to collect during the activity, and how to use the tools including getting consent. There are two monitoring tools to use for data collection during "door to door" engagement: The door to door survey and the individual testimony tool. The in-service training should be held a few days before the "door to door". You should also use the training to plan together where in the community you are going to target. Try to make the training practical - including practicing introducing yourself and practicing using the tools. It is essential to cover the following in the training:

1) An overview on the Implementing Consortium
2) The aims of this activity - what evidence are you trying to collect and why
3) How to introduce yourself
4) How to use the individual testimony tool (including getting consent)
5) How to use the "door to door" survey
6) How to note down all the issues you hear during the activity including quotes.

## *Informal focus groups*

A focus group is a method of engaging specific groups of people in a planned or thematic discussion. In Consortium we want to engage the following groups of people:

- People living with HIV
- People newly diagnosed with HIV
- People using adherence clubs, CDDP, or fast lane
- People struggling to adherence to HIV treatment
- People with TB
- Young people
- Adolescent girls and young women
- Men
- Sex workers
- Men who have sex with men (MSM)
- Transgender people
- People who use drugs

*Moving from problems to solutions*

The next stage is to generate solutions to the problems you have outlined. Here are some key questions to guide your thinking:

*What are the most important actions that could be taken to improve this facility, according to patients and staff?*
*What can be fixed in the short term? Medium term? Long term?*
*What is the role of the community in helping to resolve issues?*
*Who are the key individuals who can best address the problems? Are they at the facility level? District or national level?*

While a problem may be detected at the facility-level, sometimes the solution could be at the facility level, or at the district, provincial or national level? Do we need PEPFAR to fix it? In other words, some problems are more systemic, which is why this project includes advocacy and engagement at the district, provincial, national and international (global donors) levels as well (we'll speak more about navigating this later).

Generating solutions can take many forms. You can think of them in three main groups:
Monitoring team generated solutions (including you, your team, the branch you are working with): Community generated solutions; and solutions beyond the immediate clinic.

## 4.3 Coming up with your own solutions

Most often you will start by generating some of your own solutions. This works well for clear problems where you know what the cause is and where it can be solved within the clinic. There are a number of ways to do this:

* Talk to the PLHIV Sector branch or member about each of the major problems found and what they think could be the solution to each.

* Talk to patients or community leader's one-on-one about the problems and see what they suggest.

* Talk to clinic staff while you're there about what they think the solutions are. Maybe go back to the clinic another day to sit down with the staff you or the patients at the clinic think could be most helpful.

* Ask staff at the clinics where things seem to be going well for ideas to help your other clinics.

* Describe the problem to other Community Monitors - see if they have ideas about how that's being addressed where they are.

* Reach out to the Senior Project Officers to get their ideas.

* Ask implementing partners who are funded to support the clinics for their ideas and insights.

### *Review meetings (solution generation)*

Use the second part of your review meeting to discuss the suggestions and possible solutions you gather and develop them into a list that can be used when you meet with duty bearers.

### *Working with the community to identify solutions*

Solutions may not always be easily identified at the individual or facility level—it is then often most appropriate to turn to the community to help generate solutions. A **community dialogue** is a strategy that can be used to generate solutions that are community-based and owned. A community dialogue is a large meeting of community members that meets together to agree on the problems to tackle, identify solutions to address the problems, come up with a plan on how the solutions will be implemented, including what challenges may arise along the way.

You can hold a community dialogue where you invite people who you think have experienced the problem (is it a problem about the general clinic? PLHIV? Women? LGBT people?) or who might have good ideas (leaders in the community, local partner groups). This is a good tool when the solutions are not obvious or when you've tried the obvious solutions and they aren't working.

Community dialogues are also often useful for identifying people who want to offer individual testimonies which can be a very powerful advocacy tool.

### *Solutions beyond the immediate clinic*

Often the issue cannot be tackled in the community alone and has to be solved by the district, province, or national government or by donors such as PEPFAR. *For example, a district wide stockout of a medicine, or an implementing partner NGO pulling out of all sites*. With these kinds of problems, Community Monitors and District Supervisors should speak to the Consortium representatives to identify some solutions.

### *Potential solutions to some common problems*

Here are some possible solutions to some common problems that you may draw from when coming up with your own solutions. These solutions come from government World Health Organization (WHO) and PEPFAR policies and best practice guidelines – as well as from community-led solution generation to date. Depending on the problem, the possible solutions are aimed at different duty bearers who have the power to fix them including the clinic staff, district, or national health teams, or even PEPFAR or their implementing partners. These are not the only possible solutions – you may need to add other solutioned generated through the branch or community, or you may need to amend these based on the context at your clinic.

## Annex: Data Collection Tools

**Data capture survey**

| |
|---|
| 1. How many people access ARVs at this clinic?<br>Please give the breakdown according to:<br>I. Facility Based Groups?<br>II. CDDP/CLADDs?<br>III. Fast Track Drug Refills? |
| 2. How many children (under 15) access ARVs at the facility? |
| 3. How many unconfirmed lost to follow up HIV cases were there in the last month? |
| 4. How many confirmed lost to follow up HIV cases have there been in the last month? |
| 5. How many mothers did not return for early infant diagnosis results in the last 6 months? (It is ok to estimate) |
| 6. Does this facility offer PrEP?<br>1. Yes<br>2. No<br>3. Don't know |
| 7. About how many PrEP patients have been enrolled in the last 3 months? |
| 8. Of the PrEP patients enrolled in the past 3 months, about how many are still retained? |
| 9. How many people living with HIV were traced and brought back into care by community health workers in the last 3 months? |
| 10. How many people have been assigned to receive ART refills through CDDP/CLADDs in the last month? |
| 11. How many people have been assigned to receive ART refills through Fast Track Drug Refills in the last month? |
| 12. How many people have been assigned to receive ART refills through Facility Based Groups in the last month? |
| 13. How many people with drug sensitive TB accessed medicines at the facility last month? |
| 14. How many people with drug resistant TB accessed medicines at the facility last month? |

## Facility Based Support Group facilitator survey COVID-19

Hi my name is ____, I'm working with PLHIV to help monitor patient care in health facilities across Uganda. have a few questions that normally take about 30 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

1. Were support groups able to operate regularly since end of March 2020? (Please pick one)

I. Yes, They operated normally, with a regular schedule, enough staff, and enough clients

II. No, Clients didn't come for support groups

III. No, Staff didn't come for support groups

IV. No, neither staff nor clients came for support groups

2. Were there any interruptions to your work caused by COVID-19?

I. Yes

II. No

III. Don't Want to Answer

3. If yes, please specify (select all that apply):

I. There is no access to water and soap

II. There is no access to hand sanitizer

III. The facility is not screening people for COVID-19 symptoms

IV. Clinical staff in the facility do not have enough PPE (masks, sanitiser)

V. Non-clinical staff in the facility do not have enough PPE (masks, sanitiser)

VI. CHWs/CCGs do not have enough PPE (masks, sanitiser)

## Facility Based Support Group facilitator survey ORDINARY

Hi my name is ____, I'm working with PLHIV to help monitor patient care in health facilities across Uganda. have a few questions that normally take about 30 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

1. How many support groups are based at the facility?

2. How many support clubs are there based in the community?

3. How often do the clubs meet?
   1. Every 2 months
   2. Every 3 months
   3. Every 6 months
   4. Other (please specify)

4. What topics were covered in the adherence clubs in the last 2 months? DO NOT read options, check boxes for all topics they mention and check «none» if they do not mention any of the options listed below.
   1. Side effects of medicines
   2. Why patients should adhere
   3. Different medicine options, such as new drugs (ex. Dolutegravir)
   4. Other, please specify
   5. None of the above

5. How many support group facilitators are there?

6. How many nurses are assigned to support the groups?

Thank participant for their time and ask if they have any questions.

## Facility manager survey

**Facility manager survey COVID-19**

**INFORMED CONSENT:** Hi my name is ____, I'm working with people with HIV to help monitor patient care in health facilities across Uganda. I have a few questions that normally take about 30 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

**1. Are any of the services which you usually offer not available because of the COVID-19 crisis?**

Yes
No
Don't know
Don't want to answer

**1b. *[If yes]* Which of the following services are you NOT offering because of the COVID-19 crisis? *[Select all that apply]***

Condoms
Lubricants
HIV psychosocial counselling
HIV testing
PrEP
PEP
HIV treatment
HIV Support Groups
Viral load testing
TB testing
Contraceptives
STI screening, testing & treatment
Gender based violence support or referral
Counselling before switching regimens of people living with HIV
HIV Early Infant Diagnosis
Community outreach services
None of the above
Other _____

**2. In the past four months, have you had any of the following issues at your clinic because of the COVID-19 crisis? *[Select all that apply]***

The clinic is currently completely closed
The clinic has been completely closed
We have more restricted hours of operation than usual
We are experiencing more stockouts or shortages of medicines that usual
We are experiencing more shortages of personal protective equipment for staff than usual
We have higher patient wait times that usual
We are operating with fewer staff than usual
We can serve less patients than usual
We can only serve patients at the gate—patients do not enter the facility
Other _____
None of the above

**2b. If the clinic is closed, why?**

**2c. If the clinic is closed, when will it re-open?**

**2d. If the clinic is closed, are people being given information as to where they can access alternative services?**

Yes
No
Don't know
Don't want to answer

## Facility manager survey ORDINARY

**INFORMED CONSENT:** Hi my name is ____, I'm working with people with HIV to help monitor patient care in health facilities across Uganda. I have a few questions that normally take about 30 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

1. Which PEPFAR Implementing Partner works here and/or provides coaching or technical assistance? Please select all that apply

1. IntraHealth/RHITES E
2. URC/RHITES EC
3. TASO
4. Mildmay
5. IDI
6. Baylor
7. Rakai Health Sciences Program
8. RHITES ACHOLI
9. RHITES LANGO
10. EGPAF/RHITES SW
11. WALTER REED/MURWP
12. OTHER (PLEASE SPECIFY)

2. What does the PEPFAR implementing partner do at this facility? Select all that apply

0. Provide direct medical services
1. Mentoring/Coaching
2. HIV testing
3. Facility Based Support Group
4. Capture data
5. Other
6. Don't know what the implementing partner does

3. Please specify what other services the PEPFAR implementing partner provides at this facility

4. What is the catchment area of the patient population that this facility serves?

5. How many clinical doctors do you have working in the facility total?

6. How many professional nurses do you have working in the facility in total?

7. How many enrolled nurses do you have working in the facility in total?

8a). How many pharmacists do you have working in the facility in total?

8b) How many pharmacist assistants do you have working in the facility in total?

9. How many lab technicians do you have working in the facility in total?

10. Do you think there are enough clinical and non-clinical staff at the facility?

0. Yes
1. No
2. Don't know

11. Please tick which cadre is understaffed (Don't read the whole list)
0. Doctor
1. Clinical officers
2. Professional nurse
3. Enrolled nurse
4. Enrolled nurse assistant
5. Pharmacist
6. Assistant pharmacist
7. Lab technician
8. Lay counselors
9. Linkage officers
10. Adherence club facilitators
11. Data capturer
12. Security guard
13. Cleaner
14. General assistant
15. Other (please specify)

12a. Today, how many doctorsdo you have present in the facility?

12b. Today, how many clinical officers do you have present in the facility?

13. Today, how many professional nurses do you have present in the facility?

14. Today, how many enrolled nurses do you have present in the facility?

15. Today, how many pharmacists or pharmacist assistants do you have present in the facility?

16. Today, how many lab technicians do you have present in the facility?

17. Do you have any vacancies in the following cadres? How many?
0. Doctor
1. Clinical officer
2. Professional nurse
3. Enrolled nurse
4. Enrolled nurse assistant
5. Pharmacist
6. Assistant pharmacist
7. Lab technician
8. Lay counselors
9. Linkage officers
10. Adherence club facilitators
11. Data capturer
12. Security guard
13. Cleaner

18. When is the last time a doctor/ clinical doctor was at the facility seeing patients?
0. Present
1. This week
2. Last week
3. 2-4 weeks
4. Over 4 weeks
5. Never
6. Other
7. Please specify how long it has been since a doctor was at the facility

19. Are there community healthcare workers at this facility? (Community healthcare workers / VHTs/ CLFs?
0. Yes
1. No
2. Don't know

20. Are there support services for people living with disabilities? If yes, what services are these?
1. Sign Interpreters
2. Physical supporters
3. Other specify

21. How many CHWs are attached to this facility?

22. Who supervises the community health care workers? (Tick all that apply)
0. Clinic staff
1. PEPFAR Implementing partner
2. Other
3. Don't know
4. Please specify who supervises the CHW?

23. How many supervisors of community health workers are there?

24. Do the community health workers have transport facilitation to work in the field?
0. Yes
1. No
2. Don't know

25. Are CHWs paid? (this refers to money, not other forms of support)
1. Yes
2. No
3. Don't know

25 (b). If yes; how often are they paid?
1. Every month
2. On an unpredictable basis
3. Don't know

25 (c). If they are paid monthly, how much are they paid? (it's ok to estimate)

26. Do you consider the transport reliable?
0. Yes
1. No
2. Don't know

27. Is there enough space in the facility to meet patient's needs? This refers to total space, space to see patients, waiting rooms etc.
0. Yes enough space
1. No, we require something additional
2. Don't know

27 (b). If the space is there, what is the condition?

28. What do you need more space for? Please select that apply
0. Patients waiting space
1. Rooms for medical care
2. Private HIV counseling or testing
3. Laboratory space
4. Files
5. Data capturers
6. Adherence clubs
7. Pharmacy
8. Storage
9. Other, please specify

29. When can clients access HIV counseling or psycho-social support at your facility?
0. Before an HIV test
1. After an HIV positive result (post-test)
2. All people living with HIV at any time
3. Not offered
4. Don't know

30. Do you do index testing of HIV positive client's sexual partners and children at this facility?
0. Yes
1. No
2. Don't know

31. As part of index testing do you ask clients if they have experienced any violence from their sexual partners?
0. Yes
1. Sometimes
2. No
3. Don't know

32. If a client has experienced violence from one or more of their sexual partners what do you do with the contact information of their sexual partners?
0. Do not contact partners of client for HIV testing
1. Only contact partners of the client who have no history of violence for HIV testing
2. Contact all partners for HIV testing
3. Don't know
4. Other

33. Please describe what you do during index testing if a client tells you they have a violent partner

34. If a client has experienced violence from a sexual partner, do you offer them any additional services or referrals for services?
0. Yes, we provide support at the facility (i.e. counseling, PEP services etc.)
1. Yes we refer clients for services at another location
2. Do not have violence services here or to refer clients
3. Don't know
4. Other
5. Please specify what other services you offer for clients who experience violence

35. If a patient tests positive for HIV are they initiated on treatment the same day?
0. Always (unless contraindicated)
1. Most of the time
2. Sometimes
3. Rarely
4. Never
5. Don't know

36. If not, how long after testing positive do people begin treatment?

37. If a patient tests positive for HIV when will their next follow-up visit be scheduled?
0. Within 7 days
1. Within 14 days
2. Within 1 month
3. Within 3 months
4. Over 3 months
5. Don't know

38. Can you describe the protocol when someone misses a clinic visit to collect ARVs? Check boxes that apply and provide a detailed explanation of the process if outside of this.
0. Send client a SMS reminder
1. Call the client to remind them
2. Schedule a visit from a community healthcare worker or tracer
3. Other
4. Nothing

39.Provide a detailed explanation of the process if outside of this.

40. Is there a fast track drug refill for stable patients to collect ARVs at the facility?
0. Yes
1. No
2. Don't know

41. Are there CDDP pickup points inside or nearby the facility?
0. Yes, at the facility
1. Yes, in the community near the facility
2. No
3. Don't know

42. Are there FDDP pickup points inside this facility?
0. Yes, at the facility
1. Yes, in the community near the facility
2. No
3. Don't know

43. Do you have services specific to men? If yes, please select from the provided list
0. Voluntary male medical circumcision (at facility or referral)
1. Access to condoms & lubricant
2. Outreach services for men (outside facility setting)
3. Testing for men who come with their partners for ANC
4. None of the above
5. Don't know

44. Please specify where you conduct outreach services for men
0. Near bars/public places where members of the community gather to relax
1. Trading centers
2. Taxi parks
3. Other (please specify)

45. Do you have services specific to youth? If yes, please select from the provided list.
0. Youth outreach services
1. Youth friendly HIV testing
2. Support for young HIV positive mothers and their children
Access to PrEP
3. Access to contraception
4. Information packages for adolescent sexual and reproductive health services
5. Youth friendly STI testing & treatment
6 Facility based support groups for HIV positive youth
7. Youth champions
8. None of the above
9. Don't know

46. Please specify where you conduct youth outreach services (i.e. in schools)
0. Schools
1. Youth centers
3. Community events
4. Other

47. Does your facility have specific services for any of the following populations? Select all that apply
0. Sex workers
1. Men who have sex with men
2. People who inject drugs
3. Transgender people
4. Don't know

48. What services do you provide specifically for sex workers?
0. Sex worker outreach services
1. Sex worker friendly HIV testing and counseling
2. Access to PrEP
3. Access to contraception
4. Information packages for sexual and reproductive health services
5. Sex worker friendly STI testing & treatment
6. Access to condoms and lubricants
6. None of the above

49. What services do you have specifically for men who have sex with men (MSM)?
0. MSM outreach services
1. MSM friendly HIV testing and counseling
2. Access to PrEP
3. Information packages for MSM sexual and reproductive health services
4. MSM friendly STI testing & treatment
5. Access to condoms and lubricants
5. None of the above

50. What services do you have specifically for people who inject drugs (PWID)?
0. Counseling and risk reduction information
1. Wound and abscess care
2. Unused needles, syringes, or other injecting equipment
3. Overdose management
4. Hepatitis C testing and treatment
5. None of the above

51. What services do you have specific to transgender people?
0. Transgender outreach services
1. Transgender friendly HIV testing and counseling
2. Access to PrEP
3. Information packages for transgender sexual and reproductive health services
4. Transgender friendly STI testing & treatment
5. Hormone therapy
6. Access to condoms and lubricants
6. None of the above

52. How often, if at all, do you provide viral load tests?
0. Every 6 months after initiation
1. Once a year after initiation
2. When someone with HIV is sick
3. We do not offer viral load testing
4. Other (please specify)
5. Don't know

53. How soon after getting a viral load test do the clients get their results back?
0. Within 7 days
1. Within 14 days
2. Within 1 month
3. Within 3 months
4. Over 3 months
5. Don't know

54. What is the protocol when a patient has a detectable viral load? Please select all that apply
0. Provide adherence counseling
1. Provide psychosocial counseling
2. Genotype testing to check resistance
3. Switch to second line
4. Other
5. Don't know

55. In your facility, when do people get a CD4 test? Please select all that apply
0. When a client first tests positive for HIV
1. When a client gets sick
2. We don't have CD4 testing at this facility
3. Other
4. Don't know

56. What is the average time that is taken to get patients their CD4 results?
0. Same day
1. Within a week
2. Within a month
3. Within 3 months
4. 3-6 months
5. Over 6 months
6. Don't know

57. Is there TB LAM testing at this facility?
0. Yes
1. No
2. Don't know

58. Have staff been trained in the past 12 months on TB LAM testing?
0. Yes
1. No
2. Don't know

59. Do you think TB LAM is being adequately used to screen people for TB?
0. Yes
1. No
2. Don't know

60. Is there GeneXpert testing at this facility?
0. Yes, onsite
1. Yes, offsite
2. No
3. Don't know

61. What is the average time that is taken to get patients their GeneXpert results?
0. Same day
1. Within a week
2. Within a month
3. Within 3 months
4. 3-6 months
5. Over 6 months
6. Don't know

62. Who gets TB preventive therapy at this clinic? (Either IPT or 3HP) Select all that apply
0. People living with HIV who do not have TB
1. Children living with people who have TB (household contacts)
2. Adults living with people who have TB (household contacts)
3. Other (please specify)

63. Do you provide MDR TB treatment at your facility?
0. Yes
1. No
2. Don't know

64. How long do early infant HIV diagnosis results (PCR test) take to be returned to patients?
0. Less than a week
1. Within 2 weeks
2. Within a month
3. Within 3 months
4. 3-6 months
5. Over 6 months
6. Don't know

65. Is PrEP offered at this facility?
0. Yes
1. No
2. Don't know

66. What patients are offered PrEP? Select all that apply
0. Adolescent girls/young women
1. All women
2. Men who have sex with men
3. Sex workers
4. People who inject drugs
5. Anyone who is sexually active
6. Discordant couples
7. Other (please describe)
8. Don't know

67. Does the facility offer forensic services when someone has been sexually abused?
0. Yes, on site
1. Yes, by referral
2. No
3. Don't know

68. What contraceptive options are available at the facility? Tick all that apply
0. Condoms (male/external)
1. Female/internal condoms
2. Birth control pill
3. Injection
4. Implant
5. IUD
6. Other please specify
6. Don't know

69. Do you have staff trained and available on site for implant insertion & removal?
0. Yes
1. No
2. Don't know

70. Do you have staff trained and available on site for IUD insertion & removal?
0. Yes
1. No
2. Don't know

71. In the last two months have there been stock outs or shortages of any of the following : (Read each option) This is not a reflection on the facility, but will used to help try to reduce stock out and shortages.
0. HIV medicine
1. PrEP
2. TB medicine
3. Contraceptives
4. Pregnancy Test
5. Vaccines
6. Bandages (or other dry stock)
7. Other medicines or diagnostic tests (please specify e.g; mama kits)
8. None of the above

72. If you know, please specify the HIV medication that experienced a shortage
0. 1st line fixed dose combination (FDC). Also known as Atripla
1. Dumiva (abacavir 600MG, lamivudine 300MG)
2. Lamivudine (3TC)
3. Emtricitabine (FTC)
4. Abacavir (ABC)
5. Zidovudine (AZT)
6. Lopinavir/ritonavir (LPV/r)
7. Atazanavir/ritonavir ATV/r
8. Dolutegravir (DTG)
9. Nevirapine (NVP) tablets
10. Nevirapine syrup
11. Pediatric Dolutegravir
12. Pediatric Lopinavir/ritonavir pellets or granules
13. Other (please specify):

73. Please specify which contraception experienced a shortage
0. Condoms (male/external)
1. Female/internal condoms
2. Birth control pill
3. Injection
4. Implant
5. IUD (intrauterine device)

74. In the past 2 months did any patient leave your facility without the medicine they needed due to a stock out or shortage?
0. Yes
1. No, but we gave them a short supply
2. No, because we gave them an alternative
3. Don't know
4. Other, please specify

75. Are you providing dolutegravir based regimens for people living with HIV yet?
0. Yes
1. No
2. Don't know

76. Have your staff been trained on TLD (1st line HIV treatment: tenofovir-lamivudine-dolutegravir) transition?
0. Yes
1. No

77. Please describe your facility's policy on contraception provision and TLD (1st line HIV treatment: tenofovir-lamivudine-dolutegravir) among women of reproductive age

78. Are people given a choice between a dolutegravir or efavirenz based HIV regimen when initiating treatment?
0. Yes
1. No
2. Don't know

79. Do you think the linkage officers are effectively finding people who are lost to follow up?
0. Yes
1. No
2. Don't know

80. What are the major challenges for linkage officers to finding people who are lost to follow up? Please select all that apply.
0. Not enough phones
1. Not enough linkage officers
2. Patients give wrong phone numbers or addresses
3. Other (please specify)

81. What are the major challenges to bringing patients back into care? Please select all that apply.
0.
1. No CHWs
2. Not enough CHWs
3. CHWs not adequately paid
4. CHWs not adequately trained
5. CHWs not adequately equipped to carry out their work (with airtime, transport costs, phone, etc)
6. No transport for patients
7. Patients give wrong number or addresses
8. Safety issues
9. Other (please specify)
10. No challenges

82. In your opinion, what would make this facility better?

Now I have a few questions about the ART support clubs at this facility. Are you the best person to talk to about this? Or is there someone else here today (such as the Facility Based Support Group facilitator) that I might be able to talk to?

0. I am the best person to talk to
1. The Facility manager will answer questions
2. Someone else will answer questions
3. This facility does not have facility based support groups

# Observation tool - COVID-19

| **1. Is the clinic currently open during the COVID-19 crisis?** |
|---|
| No, the clinic is currently completely closed—without information about where to access alternative services |
| No, the clinic is currently completely closed—with clear information about where to access alternative services |
| Yes, but it is going to close very soon |
| Yes, but they will not allow us to monitor |
| Yes the clinic is open but the clinic is only serving patients outside—patients do not enter the facility |
| Yes the clinic is open, and patients can enter the facility |
| Don't know |
| Other, please specify |
| **2. Is the clinic faced with any of the following issues because of the COVID-19 crisis?** *[Select all that apply]* |
| There is no physical distancing inside the clinic grounds |
| There is no physical distancing outside the gates of the clinic |
| There is no access to water and soap |
| There is no access to hand sanitizer |
| Health workers are not wearing masks |
| Health workers are not wearing masks properly |
| Chronic patients are not entering the facility — they wait for medicines outside the gates |
| The facility is not screening people for COVID-19 symptoms |
| Clinical staff in the facility do not have enough PPE (masks, sanitiser) |
| Non-clinical staff in the facility do not have enough PPE (masks, sanitiser) |
| CHWs/CCGs do not have enough PPE (masks, sanitiser) |
| Other _____<br>None of the above |
| **3. Is it safe to continue with the observation survey?** |
| Yes, I will continue with the survey |
| No, I will end this survey |

## Clinic Monitor: Observation Ordinary

1) What is the date you are conducting this observation?

2) What is the time that you are conducting this observation?

3) About how many patients are waiting to be seen? (Try to collect this from the ART, PMTCT & TB clinics only at around 10am)

4) Is there a health worker (who may not be a pharmacist) actively giving out medicine to patients?
Yes No

5) Are there enough seats for all the people waiting?
Yes No

6) What is the condition of the ART clinic/PMTCT clinic/TB clinic building?
1. Good condition
2. Moderate condition
3. Bad condition

6b) In relation to your response above, what is in good/ bad/ moderate condition.

7) What is the condition of the following?
1. Furniture
2. Windows or doors
3. Roof or Walls
4. Other (please specify)

8) Please take photos of the building conditions

9) Are the windows in the facility open?
Yes No

10) Are there toilets at this facility?
Yes No

11) What is the condition of the toilet?
1. Good condition
2. Moderate condition
3. Bad condition

12) Please specify if the following ARE available in the toilets at the facility (Select all that apply)
1. Soap
2. Water for handwashing
3. Toilet paper
4. Light
5. Other comments about condition of the toilet: (Please specify)

13) Are there UV lights on in the TB clinic?
Yes No

14) Are there visible TB posters telling people to cover their mouths when coughing or sneezing?
1. Yes
2. Yes, but not sufficient (i.e. posters are too small)
3. No

15) Do you see a health promoter or marshal helping patients to get to where they need to go?
1. Yes
2. No

16) Other observations?

17) Is there a provision(s) for people living with disabilities to access the building/ facility?
1. Yes
2. No

# Patient Form

Hi my name is ____, I'm working with people living with HIV to help monitor patient care in clinics across Uganda.

I have a few questions that normally take about 10 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

1a). Please select the participants gender to the best of your ability

1. Female
2. Male
3. Transgender
4. Don't know

1b) Do you have a disability?

Yes
No

1c) If yes, what type of disability do you have?

1. Physical disability
2. Mental disability
3. Other (specify)

2. How old are you (in complete years)?

3. What time does the facility open on weekdays (Monday - Friday)?

1. The facility is open 24 hours a day
2. 6am
3. 7am
4. 8am
5. 9am
6. Other (please specify)
7. Don't know

4. What time does the facility open on Saturday?

1. 6am
2. 7am
3. 8am
4. 9am
5. 10am
6. 11am
7. Other
8. Don't know

5. What time do you normally arrive at the facility?

6. What time do you normally leave the facility?

7. About what time does the earliest person start queuing at the facility in the morning? It is ok to estimate

8. Do you arrive before the facility is open?

1. Yes
2. No

9. What time does the facility usually stop seeing patients? It is ok to estimate

10. When you come to the facility are there enough staff to meet the needs of patients?

1. Always
2. Sometimes
3. Never
4. Don't know

11. In the last two months, have you or anyone you know ever left the facility without being seen by staff?
Yes
No (skip to question 13)

12. If yes, why did you leave without being seen by staff?
Wait was too long
Staff were absent/not available
I was asked to pay for services
Staff were rude/unprofessional
Other (please specify):

13. Are the facility staff friendly and professional?
1. Yes
2. Sometimes
3. No
4. Don't know

14. Do you consider the queue at this facility to be long?
1. Yes
2. No (skip to question 15)
3. Don't know

15.Why are the queues at this facility long? Please select all that apply

1.There is not enough staff
2.Staff take long breaks (for tea, lunch etc.)
3.There are too many patients to serve
4.Other

16. In the last two months have you or anyone you know left the facility without the medicines, vaccines, or tests you needed because of a stock out or short supply?
1. Yes (Go to question 17-18
2. No (Skip to question 19)
3. Don't know (Skip to question 19)

17. Which medicines, vaccines, or tests had a stock out or shortage? Please select all that apply
1. HIV medicine
2. PrEP
3. TB medicine
4. Contraceptives
5. Pregnancy Test
6. Vaccines
7. Bandages (or other dry stock)
8. Other medicines (please specify)
9. None of the above

18. If you know, please specify the HIV medication that experienced a shortage
1. 1st line fixed dose combination (FDC). Also known as Atripla
2. Dumiva (abacavir 600MG, lamivudine 300MG)
3. Lamivudine (3TC)
4. Emtricitabine (FTC)
5. Abacavir (ABC)
6. Zidovudine (AZT)
7. Lopinavir/ritonavir (LPV/r)
8. Atazanavir/ritonavir ATV/r
9. Dolutegravir (DTG)
10. Nevirapine (NVP)
11. Nevirapine syrup
12. Pediatric Dolutegravir
13. Pediatric Lopinavir/ritonavir pellets or granules
14. Other (please specify):

19.If you know, please specify which contraception experienced a shortage

1. Condoms (male/external)
2. Female/internal condoms
3. Birth control pill
4. Injection
5. Implant
6. IUD (Intrauterine device)

20.On a scale of 1-5 how safe do you feel while you wait for the clinic to open? If 1 is UNSAFE and 5 is SAFE

1. 1
2. 2
3. 3
4. 4
5. 5
6. Don't know

21.On a scale of 1-5 how clean is this facility? If 1 is DIRTY and 5 is CLEAN:

1. 1
2. 2
3. 3
4. 4
5. 5
6. Don't know

22.Are people in the facility waiting area asked if they have TB symptoms (like coughing, night sweats, fever, recent weight loss) by a facility staff member?

1. Yes
2. Only sometimes
3. No
4. Don't know

23. Are people who are coughing in the waiting room separated from those who are not?

1. Yes
2. Only sometimes
3. No
4. Don't know

24.Are people who are coughing or have TB given a tissue or mask?

1. Yes
2. Only sometimes
3. No
4. Don't know

25.In your opinion, what would make this facility better?

Thank you so much for your time. The next set of questions are for people living with HIV specifically. If that applies to you, can I continue with these questions? If no, thank the participant again for their time and ask if they have any questions. If yes, move onto the PLHIV survey.

## PLHIV Form - COVID-19

**INFORMED CONSENT:** Hi my name is ____, I'm working with people with HIV to help monitor patient care in health facilities across Uganda. I have a few questions that normally take about 30 minutes to answer. You can also skip any questions you would like to or stop the conversation at any time. Would you be willing to answer a few questions about the services at this facility?

**1. In the past four months, have you avoided or delayed coming into the clinic because of the COVID-19 crisis?**

| | |
|---|---|
| Yes | Don't know |
| No | Don't want to answer |

**2. In the past four months, have you had any of the following issues getting healthcare because of the COVID-19 crisis?** *[Select all that apply]*

I couldn't get transportation to the clinic when I needed it
The fear of arrest/police violence prevented me
The fear of becoming sick with COVID-19 prevented me
Lack of food meant I couldn't swallow my medicine
The clinic wasn't open when I needed it
The clinic didn't have the medicine that I needed
The queue at the clinic was longer than usual
There were less staff working than usual
The clinic was not providing the service I needed
There is no physical distancing at the clinic putting me at risk of getting COVID-19
There is no access to soap and water at the clinic
There is no access to hand sanitiser at the clinic
Other _____
None of the above

**2b. If the clinic is not providing the service you need, *w*hich of the following services are you not getting because of the COVID-19 crisis?**

Condoms
Lubircant
Lubricants
HIV counselling
Counselling when you switched to TLD
HIV testing
PrEP
PEP
HIV treatment
Refills of medicines
Adherence clubs
Viral load testing
TB testing
Contraceptives
STI screening, testing & treatment
Gender based violence support and/or referral
Other _____
None of the above

**Questions for PLHIV**

1. Where do you collect your ARVs?
   0. At the facility
   1. A facility-based support group
   2. Through a place in your community where you can pick up your ARVs or where another PLHIV picks up ARVs for you group (also known as a Community Based Drug Distribution Point or CDDP/Community Client Led ART Delivery or CCLAD)
   3. Fast Track Drug Refill
   4. Other (Please specify where you collect your ARVs)

2. At your last ARV refill how long were you given HIV medicine for?
   0. 1 week
   1. 2 weeks
   2. 3 weeks
   3. 1 month
   4. 2 months
   5. 3 months
   6. 6 months
   7. Don't know

3. The last time you missed a visit to collect your ARVs, what were the reasons? (Check all that apply)
   0. No money for transport
   1. Fell sick
   2. Side effects from medicines
   3. Forgot my appointment
   4. Shifted to a new home
   5. Too busy
   4. Don't know/ never missed a visit
   5. Other (please specify):

4. If you miss a facility visit to collect your ARVs, which of the following happens? (Please select all that apply)
   0. Get an SMS
   1. Get a phone call
   2. A health worker comes to your house
   3. You are not contacted by the clinic
   4. Don't know/ never missed a visit
   5. Other (please specify)

5. If you miss a facility visit to collect ARVs, then you return next time to collect them, which of the following happens: (Please select all that apply)
   0. The staff are welcoming and friendly even though you missed last visit
   1. The staff reprimand you for missing a visit
   2. The staff counsel you on adherence
   3. The staff ask why you missed visits
   4. The staff send you to the back of the queue
   5. Don't know/ never missed a visit
   6. Other (Please specify what other things happen when you return to pick up your ARVs)

6. Are you aware of a support group at the facility or in the community where you can meet with other people living with HIV and pick up your medicines?
   0. Yes
   1. No
   2. Don't know

7. Does the support group provide information about HIV and why it is important to take your medicines as prescribed?
   0. Yes
   1. No
   2. Don't know

8. What information does support group provide? Select all that apply
   0. Side effects of medicines
   1. Why patients should adhere
   2. Different medicine options such as new drugs (ex. Dolutegravir)
   3. Other information (Please specify what other information you were provided)

9. Do you get support from people living with HIV in your support group?
   0. Yes
   1. No
   2. Don't know

10) What support do you get? Please specify:

11(a): If you could collect your ARVs closer to home, would you like to?
   0. Yes
   1. No
   2. Don't know

11 (b) Where would you prefer to collect your ARVs?

11 (c) How long have you been on antiretroviral treatment (ART)?

12. Do you know your viral load (this is how much HIV virus is in your blood)?
   0. Yes
   1. No
   2. Don't know

13. Have you had a viral load test in the past year? This is a blood test to see how much HIV virus is circulating in your blood
   0. Yes
   1. No
   2. Don't know

14. Did a health care provider explain what the results of this test means to you?
   0. Yes
   1. No
   2. Don't know

15(a). Do you agree with the following statement: Undetectable viral load means the treatment is working well
   0. Yes
   1. No
   2. Don't know

15(b) Do you agree with the following statement: Undetectable viral load means a person is not infectious.
   0. Yes
   1. No
   2. Don't know

16a: Has a healthcare worker ever asked you for the names and contact information of your sexual partners so that they can test them for HIV?
   0. Yes
   1. No
   2. Don't know

16b: Were you told the reason for asking the names?
   Yes
   No
   Don't know

16c. Please describe what happened:
   I gave the names
   I didn't give the names and nothing happened
   I didn't give the names and was reprimanded
   I gave names and violence happened as a result
   Other: (Please specify)

17. Did the healthcare worker tell you that you could say no or refuse to give the names of your sexual partners or children for HIV testing?
    0. Yes
    1. No
    2. Don't know

18. Do you think that this facility keeps information about the HIV status & treatment confidential and private?
    0. Yes
    1. No
    2. Don't know

19. Is psycho-social counseling available for people living with HIV here?
    0. Yes
    1. No
    2. Don't know

## Reflection form for Clinic Monitors

1.What date does this reflection refer to? DD/MM/YYYY

2.What time did your data collection START on that day?

3.What time did your data collection END on that day?

4.Please take 5 minutes and reflect on what the most important things were that happened during data collection on that day. Write down the key things you learned and common things you heard.

- *What are the most important things that happened during data collection?*

- *What are the key things that you learnt?*

- *What are the common things that you heard?*

- *What were the key challenges?*

- *Were there any successes where the clinic is functioning well?*

- *What questions do you have?*

- *What ideas do you have to improve clinic monitoring?*

- *If you were unable to collect 10 PLHIV surveys, explain why*

- *Add the cell/Telephone number of the facility manager*


ACTSIDI


HEPS
FOR HEALTH RIGHTS


HEALTH HUMAN RIGHTS
ACTION GROUP FOR
HIV AIDS


MAMA'S CLUB UGANDA


International Community
of Women Living with HIV
Eastern Africa


Ice breakers Uganda


FARUG


InPact


AWAC
Alliance of Women
Advocating for Change


UHRN


The Positive Men's Union
(POMU)


Uganda Young Positives
Together we shall make it


TRANZ NETWORK
UGANDA
My Identity, My Pride


(SALT)


HEALTH GAP
GLOBAL ACCESS PROJECT


SEXUAL MINORITIES UGANDA (SMUG)
Justice & Equality


UKPC
UGANDA KEY POPULATIONS CONSORTIUM


UNYPA
UGANDA NETWORK OF YOUNG PEOPLE LIVING WITH HIV/AIDS


UNESO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