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# A STUDY TO UNDERSTAND BARRIERS AND ENABLERS OF ADHERENCE TO ART AND RETENTION IN CARE AMONG HIV-POSITIVE CLIENTS IN SOUTH SUDAN

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# A STUDY TO UNDERSTAND BARRIERS AND ENABLERS OF ADHERENCE TO ART AND RETENTION IN CARE AMONG HIV-POSITIVE CLIENTS IN SOUTH SUDAN

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## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CASG	Community ART Adherence Support Group
CMMB	Catholic Medical Missions Board
FGD	Focus Group Discussions
HIV	Human Immunodeficiency Virus
IMC	International Medical Corps
IP	Implementing Partner
IPT	Isoniazid Preventive Therapy
Jhpiego	Johns Hopkins Program for International Education in Gynecology and Obstetrics
KI	Key Informant
KII	Key Informants Interviews
LTFU	Lost to Follow Up
MMD	Multi-Month Dispensing
MoH	Ministry of Health
MSI	Management Systems International
PEPFAR	President's Emergency Plan for AIDS Relief
PHCC	Primary Health Care Centre
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
RTI	Research Triangle Institute
SOP	Standard Operating Procedure
TLD	Tenofovir, Lamivudine and Dolutegravir

UNAIDS	The Joint United Nations Program on HIV and AIDS
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WFP	World Food Programme
WHO	World Health Organization

# EXECUTIVE SUMMARY

## BACKGROUND

In 2018, according to the Joint United Nations Program on HIV and AIDS (UNAIDS), South Sudan had approximately 19,000 new Human Immunodeficiency Virus (HIV) infections and approximately 9,900 Acquired Immune Deficiency Syndrome (AIDS)-related deaths. There were 190,000 people living with HIV in 2018 in South Sudan. Of these, 24% knew their status and only 16% were accessing antiretroviral therapy (ART). Among pregnant women living with HIV, 56% were accessing treatment or prophylaxis to prevent transmission of HIV to their children. An estimated 2,400 (1,200 – 3,900) children were newly infected with HIV due to mother-to-child transmission. There are limited infrastructure and systems in place to provide HIV services despite investments in HIV response. Prevention efforts are hampered by low levels of knowledge about HIV, low literacy, and harmful socio-cultural practices. The Presidential Emergency Plan for AIDS Relief (PEPFAR) South Sudan program works in collaboration with the Ministry of Health (MoH), the Global Fund, and other stakeholders including civil society organizations to effectively and efficiently improve access to quality HIV prevention, care and treatment services for South Sudan. PEPFAR supports comprehensive HIV prevention, care and treatment services in different health facilities throughout South Sudan through several implementing partners (IPs). Although the IPs have demonstrated successes in critical indicators, including putting new people on treatment, retention remains a significant challenge. Local solutions ranging from client tracking through phone calls and deploying community-based actors such as mentor mothers to do community tracing have been instituted to address poor retention, but these have yielded limited success, as have similar activities implemented by other partners.

## METHODOLOGY

This study was intended to assist PEPFAR and its partners to understand the enablers and barriers to retention among people who have good adherence and among those who dropped off treatment and were recently traced and reinstated to care.

Secondly, it also investigated why the localized solutions implemented did not achieve the results initially expected. This study identifies gaps, strengths, and opportunities that exist in strengthening interventions around enhancing adherence to care and treatment. The objectives of the assessment as defined and agreed with USAID were as follows:

1. To understand the enablers/facilitators to ART adherence/retention to care.
2. To understand the barriers to retention among clients that missed appointments, dropped off treatment or were lost to follow-up and subsequently traced and reinstated in treatment.
3. To determine strengths, gaps and opportunities that exist in strengthening interventions around enhancing adherence to care and treatment.

Data were collected through focus group discussions (FGDs), key informant interviews (KIIs), and a desk review of treatment registers, project reports, treatment guidelines and other available literature. Clients, providers, IPs and other stakeholder perspectives were collected. Their views on

past achievements, constraints and lessons learned provided insight into ART service provision. Permission to conduct this study was granted from the MoH Research and Ethics Committee following formal application by the study team. Management Systems International's (MSI) internal ethical review committee approval was granted after a review of the study design and draft protocols prior to the beginning of data collection activities.

## **FINDINGS AND CONCLUSIONS**

The findings from client interviews have been summarized into enablers/facilitators of adherence and barriers to adherence to ART.

### **ENABLERS**

The main enablers to ART adherence cited by all client categories, providers and IPs were knowledge on lifelong antiretrovirals (ARVs) as the only treatment for HIV; expanded hours of operation for picking up ARVs for clients with various needs; short travel time to health facilities; reduced need to travel to clinic; multi-month dispensing of ARVs; disclosure of status and support from family and friends; good treatment by providers; counseling and follow-ups; treatment support; viral load testing and positive feedback; privacy; and conducive facility environment. In addition, the study team made the following observations overall:

- Provider knowledge and skills as observed during the clinical observation were helpful in satisfying client needs for HIV treatment and care.
- Client tracking, through reminder calls and engagement of community support groups in tracing and tracking clients, has been helpful in supporting clients with adherence to care and treatment.
- Availability of ARVs in health facilities and in private clinics eases access to clients – especially working-class clients, youth, and key populations including VIPs – who prefer flexible refilling times, which has enabled them to remain adherent to care and treatment.

### **BARRIERS**

The main barriers to ART adherence cited by non-adherent clients were: lack of food; access to care; perceived side effects of medications; medication costs; competing for work/home responsibilities; poor treatment/lack of social support; and overcrowded health facilities. Barriers cited by IPs included: access to care; client mobility; poor HIV literacy; stigma; insecurity; competing alternative beliefs; and co-morbidities (interrelated nature) with other illnesses. In addition, the study team observed the pressures under which health workers are operating, delayed salaries which can be demoralizing, and heavy workloads. However, the fact that a vast majority of clients reported feeling listened to, given the limited time providers have for patient counseling and education on the use of ARVs, is commendable. Many barriers are interrelated, each of which can exacerbate the effect of the other. Understanding how each barrier conceptually relates to others may help to strategize programming.

## **RECOMMENDATIONS**

Based on the enablers and barriers identified through this study at the systems level, the team recommends the following **systems-level** actions:



- **Partner with agriculture/nutrition programs** as the primary barrier to adherence to ART is food insecurity.
- **Integrate livelihoods and life skills into ART programs** to support clients with income-generating activities and teach skills of living positively and influencing people living with HIV (PLHIV) to live a productive life.
- **Invest in a national campaign addressing low HIV literacy** in the community through partnerships with government, donors and other IPs.
- **Expand ART services in more private clinics** to decongest the busy clinics in public facilities, as well as utilize flexible hours for clinic operation.
- **Scale-up community outreach ARV refill strategies** to enable clients who would not access ART services due to distance and transport challenges to receive adequate refills.

Based on the enablers and barriers identified through this study at the systems level, the team recommends the following **clinic-level** actions be considered:

- Consider further **task shifting options**. To help decongest clinics, consider delegating additional provider responsibilities to lower cadre, counselors, social workers, lab technicians, lay volunteers or the patients themselves.
- Develop new **strategies for identifying and addressing stigma**.
- Create or **strengthen linkages with clients who are mobile** and their providers in the locations they are visiting.
- Conduct **refresher training/orientation of counseling staff** on staff attitudes toward clients that default on treatment, foreigners, and key populations and how negative attitudes reduce adherence and retention.
- Consider the feasibility of playing **patient education videos** in the waiting areas of clinics.
- Introduce **anonymous client response feedback mechanisms** (e.g., suggestion boxes, ombudsman) that can provide clinic management feedback on positive and negative experiences at the clinic, including negative interactions with specific providers observed or experienced.
- Consider piloting or assessing the feasibility of **community ART adherence support groups** (CASGs) and other support groups models.
- Strengthen the **defaulter tracking system**. Consider the feasibility of introducing a unique code identifier of clients or biometric systems to track clients and avoid the same client being registered in many facilities and being double-counted.

Finally, the team further recommends additional research on the following topics:

- Effectiveness for **community linkages with health facilities** in ART service delivery.
- Effectiveness of **contact tracing mechanisms** for defaulters and clients lost to follow up.
- **Private health facilities engagement** in ART service provision and its effectiveness.

# INTRODUCTION

## BACKGROUND

In 2018, according to the Joint United Nations Program on HIV and AIDS (UNAIDS), South Sudan had approximately 19,000 new Human Immunodeficiency Virus (HIV) infections and approximately 9,900 Acquired Immune Deficiency Syndrome (AIDS)-related deaths. There were 190,000 people living with HIV in South Sudan in 2018. Of these, 24% knew their status and only 16% were accessing antiretroviral therapy (ART). Among pregnant women living with HIV, 56% were accessing treatment or prophylaxis to prevent transmission of HIV to their children. An estimated 2,400 (1,200 – 3,900) children were newly infected with HIV due to mother-to-child transmission. Since 2010, new HIV infections have increased by 3%, and AIDS-related deaths have similarly increased. Among adults aged 15 to 49, the HIV prevalence rate is 2.5%. The number of new HIV infections among a susceptible population during a certain time among all people of all ages (incidence) was 1.56%.

There are limited infrastructure and systems in place to provide HIV services despite investments in HIV response. Prevention efforts are hampered by low levels of knowledge about HIV, low literacy, and harmful socio-cultural practices. The humanitarian crisis and population displacements hamper the response and make women and girls more vulnerable to HIV infection (UNAIDS Estimates 2019).

The Presidential Emergency Plan for AIDS Relief (PEPFAR) South Sudan program works in collaboration with the Ministry of Health, the Global Fund, and other stakeholders including civil society organizations to effectively and efficiently improve access to quality HIV prevention, care and treatment services for South Sudan. Scaling up case findings and putting people on medication are key PEPFAR indicators and are essential steps in achieving epidemic control. Among the programmatic challenges preventing progress on epidemic control, improving yields and retaining clients on treatment (preventing loss to follow-up) continue to be among the most challenging areas in which to make progress.

PEPFAR supports comprehensive HIV prevention, care and treatment services in different health facilities throughout South Sudan through several implementing partners (IPs), including: jhpiego, which supports eight health facilities; ICAP, which supports 14 health facilities across the country; Intrahealth International, which supports four health facilities and one outreach site for comprehensive HIV services and key population as well as community-based testing in three locations; Catholic Medical Missions Board (CMMB), which supports 10 static and eight outreach sites; and Research Triangle Institute (RTI), which supports three sites. Although the IPs have demonstrated successes in critical indicators, including putting new people on treatment, retention remains a significant challenge. Local solutions ranging from client tracking through phone calls to deploying community-based actors such as mentor mothers to do community tracing have been instituted to address poor retention, but these have yielded limited success, as have similar activities implemented by other partners.

## OVERALL PURPOSE OF THE STUDY

This study was intended to assist PEPFAR and its partners to understand the enablers and barriers to retention among people who have good adherence and among those who dropped off treatment and were recently traced and reinstated to care.

Secondly, it also investigated why the localized solutions implemented did not achieve the results initially expected. This study identifies gaps, strengths, and opportunities that exist in strengthening interventions around enhancing adherence to care and treatment.

## **STUDY OBJECTIVES**

1. To understand the enablers/facilitators to ART adherence/retention to care.
2. To understand the barriers to retention among clients that missed appointments, dropped off treatment or were lost to follow-up and subsequently traced and reinstated in treatment.
3. To determine strengths, gaps, and opportunities that exist in strengthening interventions around enhancing adherence to care and treatment.

## **SCOPE OF THE STUDY**

Overall, this study focused on establishing an understanding of the facilitators/enablers and barriers to HIV/AIDS care and treatment adherence, including those at the systems level (IP and provider levels as well as clients). It also reviewed the efficiency and effectiveness of the current defaulter tracking system established at the health facilities. It identified gaps, strengths, and opportunities that exist for strengthening systems by incorporating localized and incentivized solutions.

While this study primarily focused on understanding factors and influencers of adherence to ART and prevention of mother-to-child transmission (PMTCT) and follow-up among adult clients attending both centers, it also assessed the establishment and functionality of defaulter tracking systems at ART centers.

## **KEY STUDY AREAS COVERED**

The study explored the following areas:

- Adherence facilitators/enablers and barriers, and factors influencing loss to follow up.
- Availability and functionality of the defaulter tracking systems, how it works, success and constraints associated with it.

Gender and youth dimensions are associated with retention. Age groups and sex were considered when conducting focus group discussions.

## **TARGET POPULATION**

Views and experiences of clients, providers, and IPs were collected. The below categories of clients, providers, IPs and key stakeholders were selected for the interviews and group discussions.

### **CLIENTS**

- Missed appointments: Clients who have missed follow-up appointments, either clinical or drug pick-up appointment, by at least one month.
- Lost-to-follow-up (LTFU) among clients who were reinstated: Clients alive and on ART who had not returned to the ART center for at least one month and were, therefore, declared lost to follow up, but traced and reinstated.

- Adherent patients: Patients who had history of taking their medications consistently as prescribed and did not miss appointments (either a clinical or drug pick-up appointment) for at least 90 days.
- PMTCT clients: breastfeeding and pregnant women receiving care and treatment.

## PROVIDERS

- ART center counselors and clinical providers or ART nurses and case managers aware of patient treatment histories.

## IMPLEMENTING PARTNERS

- PEPFAR partners were considered for the KIIs; program managers were selected for the KIIs.

## METHODOLOGY

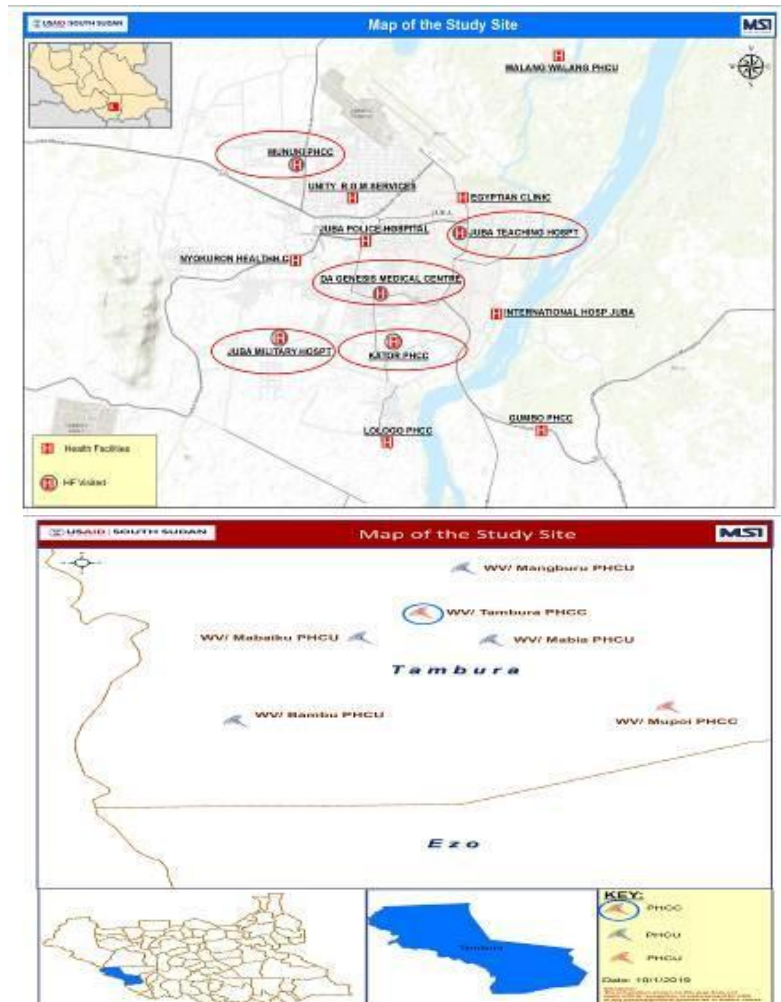
### STUDY DESIGN

Data were collected through focus group discussions (FGDs), key informant interviews (KIIs), and a desk review of treatment registers, project reports, treatment guidelines, and other literature available. Clients, providers and IP perspectives were collected; their views on past achievements, constraints, and lessons learned provided insight into ART service provision.

### STUDY SETTING

Six study sites were pre-selected based on evidence of high volumes of patients lost to follow up and PEPFAR’s footprint in Juba and Tambura. The selected sites include:

1. Juba Teaching Hospital
2. Juba Military Hospital
3. Kator Primary Health Care Center (PHCC) in Juba
4. Munuki Primary Health Care Center PHCC in Juba
5. Da Genesis Medical Centre (a private facility in Juba)
6. Tambura PHCC in Tambura, Western Equatoria.



The sites were visited prior to the start of data collection to ensure the process was well arranged, data collection dates agreed upon and ethical aspects fully taken care of. The facility staff was also part of the study team either as key informants or identifiers of clients for the interviews. The providers made registers and other documentation available for the study team for client identification and reviews.

## STUDY PARTICIPANTS

Clients were identified by the providers thorough review of the register history for August 2019 for clients in the missed appointments and LTFU categories per the one-month MoH guidance on classification for each. For adherent clients, the history for the last three months was considered. A purposive sampling technique was used to identify non-adherent clients (i.e., those that missed an appointment or were LTFU then reinstated to care) as well as adherent clients (i.e., from the PMTCT clinic and from the ART clinic). Clients were assigned to different categories for either KIIs or FGDs while ensuring gender and age were factored into the groupings. In the register, counting from August 31 backwards, clients were selected in the order of the most recent history. For example, a client who missed an appointment on August 31 was automatically selected first, followed by those who missed appointments on other dates, such as August 30, moving backwards. If required numbers of clients were not reached, the team reviewed previous months' registers.

**FOCUS GROUP DISCUSSIONS (FGDS)** FGD Group I consisted of non-adherent clients—or rather, ART clients that either missed an appointment<sup>1</sup> or that at one point had been LTFU<sup>2</sup> and were subsequently reinstated to care. FGD Group II was comprised of ART clients that were adherent at the time of the study, i.e., clients that had consistently attended scheduled clinic visits and picked up ARVs for a minimum of three months. FGD Group III was formed of pregnant or breastfeeding clients that initiated ARVs through the PMTCT program. While the original study design had sought to recruit non-adherent women receiving services from PMTCT services, none were identified during the short study timeframe, and thus, Group III clients were all considered adherent to ARV. Finally, FGD Group IV was intended to focus on adherent ART clients. One FGD was conducted with the youth group (adherent clients) in Tambura.

**KEY INFORMANT INTERVIEWS (KIIS)** KIIs were also conducted with adherent and non-adherent clients from both PMTCT and ART services. One adherent client and two non-adherent clients selected from missed appointments and LTFU but re-instated from PMTCT and ART were selected

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<sup>1</sup> **Operational definition of missed appointment for this study:** clients who have missed follow up appointments, either clinical or drug pick-up, on the appointment date and came on a different date or through reminder calls or were able to go for refills within one month but not on the actual appointment dates.

<sup>2</sup> **Operational definition of lost to follow up (LTFU) for this study:** clients alive and on antiretroviral treatment (ART) who had not returned to the ART center for at least one month, missed appointment, and after a series of attempts including reminder calls and tracing of the client in the community within a month did not come for a refill one month after the last refill date.

and interviewed individually per facility for ART. Two males and one female had been selected since females are sufficiently covered in PMTCT. In addition, ART and PMTCT nurses, midwives, case managers, as well as IPs supporting these services were interviewed to provide their perspectives of the enablers and barriers to retention, as well as defaulter tracking systems.

**TABLE 1: SUMMARY OF FOCUS GROUP DISCUSSIONS AND KEY INFORMANT INTERVIEWS CONDUCTED**

Means of Data Collection	Male		Female		Total FGDs Conducted	Total Participants Interviewed
	FGDs Conducted	Participants Interviewed	FGDs Conducted	Participants Interviewed		
FGD Group I: ART/Non-Adherent	3	16	3	27	6	43
FGD Group II: ART/Adherent	5	33	10	62	15	95
FGD Group III: PMTCT/Adherent	N/A	N/A	1	7	1	7
FGD Group IV: ART/Adherent/Youth	1	10	1	10	2	20
KII-ART/Non-Adherent		0		7		7
KII-ART/Adherent		15		9		24
KII-Providers		4		8		12
KII-Partners		12		3		15
Observations		3		2		5
<b>TOTAL</b>	<b>9</b>	<b>93</b>	<b>15</b>	<b>135</b>	<b>24</b>	<b>228</b>

### INCLUSION/EXCLUSION CRITERIA

**CLIENTS** Patients (at least 18 years old) who received ART in the study clinics for at least a month and could provide informed consent in English or Arabic were eligible for the interviews. Patients who were too sick or not capable of giving information as required were excluded from the interviews. Patients who consented initially and withdrew consent during the interview for any reason were excluded.

**PROVIDERS** All ART nurses and case managers who worked in the ART clinics for at least six months were invited to participate in the provider KIIs.

## RESEARCH/STUDY ETHICS

Permission to conduct this study was granted from the National MoH Research and Ethics Committee following a formal application by the study team. MSI's internal ethical review committee approval was granted after a review of the study design and draft protocols prior to the beginning of data collection activities. Client discussions and interviews were conducted in private rooms or places where clients felt safe and stress-free, including the ART center. The ART staff were interviewed separately from clients to ensure privacy and confidentiality. Focus group participants were required to maintain the confidentiality of the identities of other participants and the content of the discussion. All participant interviews took place face-to-face. The data collection team had planned to make provisions for telephone interviews in instances where face-to-face discussions were not possible, but this was not required.

## DATA COLLECTION

The desk review included a review of existing literature published in the areas of ART adherence, World Health Organization (WHO) guidelines, South Sudan treatment guidelines, provider perspectives, review of health facility records and meetings with IPs. Within this literature, the study team examined relevant and available secondary data and developed in-depth interview guides and instruments to collect the primary data in consultations with USAID. Data were collected using six research tools designed for the KIIs for clients, providers' adherent clients FGDs, non-adherent clients FGD, provider observation checklists and IP checklists. The study team also observed provider-client interactions for potential enablers and barriers related to retention in care.

On-site data collection was done by trained researchers. Two data collection teams were constituted. One team traveled to Tambura for data collection, while the other team collected data in five facilities in Juba. Data collection in Juba Teaching Hospital was done collectively by the two teams. Data collection took place from September 11-20, 2019. Interviews and FGDs were conducted in clients' languages of choice (i.e., local language, Azande, Arabic or English), and FGDs were recorded. Due to time constraints, interview transcripts were transcribed and summarized instead of verbatim except for quotes and translated into English for swift analysis.

## DATA ANALYSIS

Microsoft Excel was used for data entry and coding. After data were cleaned and quality assured (i.e., verified for accuracy and completeness), the team began analysis to identify key themes emerging from the responses related to facilitators and barriers to ART adherence and retention. The frequency of themes mentioned at least once by individual KIIs or FGD participants were tabulated to identify most frequently cited barriers and facilitators, a content analysis technique. Commonalities and dissimilarities between categories of respondents were also noted, as such findings provide USAID and IPs with critical data to inform future programming. Throughout analysis, codes were continuously compared amongst the team to ensure reliability amongst the coders.

## STUDY LIMITATIONS

Like any other study, this study had several limitations mostly related to the study design and data collection. Below are a few limitations to this study:

- The study timeline was quite short given the scope and amount of data to be collected. Some facilities, like the private medical center, could better be accessed over the weekend for data collection, which proved difficult for the research team. Due to the crowding at the health facilities, alongside short operating hours for the clinics, it was difficult to meet with providers to document their insights and observations, and the data collection team needed extra time to find private meeting rooms in smaller and crowded clinics.
- The non-adherent clients, especially the males, were quite difficult to mobilize to participate in the interviews. As such, more women than men participated in the interviews and results may be biased in this regard.
- The data collection team had difficulties in tracking and interviewing the LTFU clients and those clients not reinstated on treatment. Studying clients who were truly LTFU would have no doubt provided greater insights as to insurmountable barriers. As a result, all findings were similar throughout all the categories interviewed.
- Given the qualitative nature of the assessment, the study could not test for critical confounding variables that extant literature suggests affect adherence to ART and retention in care.

## FINDINGS

The findings from the clients' interviews and discussions have been summarized into enablers/facilitators of adherence and barriers to adherence to ART. Illustrative quotes to support the team's findings are also included. The enablers and barriers found were mostly similar across the different categories; therefore, doing comparison between different category of clients was proven to be not helpful. However, since barriers to adherence must be addressed, the team did some comparison and ranked the main barriers based on the frequency of responses from the interviews.

### ENABLERS/FACILITATORS OF ADHERENCE

**LIFELONG ARVS AS ONLY TREATMENT FOR HIV** When clients were asked about what motivates them to take ARVs, the majority of the adherent clients consistently mentioned that their knowledge of HIV as a chronic disease requiring lifetime treatment with ARVs enables them to remain faithful to ARVs to stay alive and healthy and to deliver HIV negative children. Others said they are motivated by the fact they would like to live long to support their children. Client knowledge about ARV as helping to reduce the virus is cited as an enabler, and most of the PMTCT clients interviewed mentioned ARVs as the only drug that can treat HIV/AIDS clients. Once the drugs are taken they prevent other infections and sickness. Most of the adherent clients mentioned that ARV prolong life, while some of the clients said having stayed in the program and having taken drugs for years has placed them in a better position to be counselors and behavior change agents. Clients also mentioned that staying on treatment has helped improve their health and now have gained weight and are looking better.

*“There are no other medicines for HIV not even traditional medicine” (Female, adherent on ART).*



*“I am one of the first persons who tested HIV positive in Tambura in 2009, however there was no ARVs here except from Nzara. So, I had to travel there to access treatment. There is no other drug apart from ARVs that can treat HIV, prayer goes along with ARVs” (Female, adherent on ART).*

*“What motivated me is the sickness itself that affect my body and am getting weak throughout. My husband died, and I was left with kids, if I did not take the medicine I will died too. then who will take care of my kids” (Female, 41-year-old client on ART)*

**EXPANDED HOURS OF OPERATION FOR PICKING UP ARVS** Clients reported that easy access to ART services from private clinics at convenient times including evenings, nights and weekends helped them to adhere to treatment since they can access the refills at any time. This particular experience was cited by female clients from the key populations who were accessing ART services at private facilities. Few of the providers in public facilities also indicated flexibility in handling clients who preferred refills after regular working hours. One provider has taken drugs to clients in social places and opened the clinic to serve VIPs over the weekend, giving clients an opportunity to refill and remain on treatment.

*“One day my pills ran out in the evening towards weekend, I was worried of missing treatment but when I came to the private clinic, I was able to get the refill that evening, so I didn’t disrupt treatment. This wouldn’t be possible in government hospital where ART clinic time is restricted” (Female adherent on ART)*

**SHORT TRAVEL TIME TO THE HEALTH FACILITY** Clients cited short distance to the clinics has enabled them to refill easily without having to spend money and time to access ARVs. The clients who stayed near health facilities said they have never missed services and are able to go for reviews and seek care for any complications without disrupting treatment. Both male and female clients adherent on treatment cited living within the vicinity of the health facilities as a facilitator to accessing ART services, leading to adherence which from the general discussions stems from continuation in treatment, access to refills or returning to health facilities for appointments as key linkages or gateways to adherence to treatment. Providers further reported that clients staying within the vicinity are mostly adherent compared to those that stay far away.

**REDUCED NEED TO TRAVEL TO CLINIC, MULTI-MONTH DISPENSING OF ARVS AND AVAILABILITY OF DRUGS** Clients said whenever they tell the providers of their travel plans or feel stable and do not need to come frequently for refills, the providers usually cooperate and are able to give them drugs for more than one month which allows them to take the drugs consistently. Providers have confirmed providing more than one-month supply of drugs for clients who are have shared their travels plans with them; however, they said this depends on the stability of the client and the viral load testing date. Clients who need a follow-up visit to the clinic for clinical review are normally advised to come back and they are provided with the monthly pills. Perception on multi-month dispensing of ARVs was that it is an important enabler to ART adherence/retention to care in that receiving medicines for two months or more rather than coming to the clinic monthly enables adherence, especially for clients who are very mobile and move from one place to another.

**DISCLOSURE AND SUPPORT FROM FAMILY AND FRIENDS** Clients who have disclosed their status said they have received better support from friends and family members and that their friends and fellow clients have supported them in collecting refills. An example was for a soldier who was deployed for patrols but is permitted to go back to the clinic for ARV refills without having to convince his boss for permission since he has disclosed his status and is known by his commander.

Clients reported receiving financial assistance for transport to the health facilities from friends and family members, and as well as receiving reminders and encouragement to take pills. Many clients have said that friends helped them most advising them not to stress themselves because of stigma and should feel free to take the medication as prescribed. This came out strongly in Tambura, a rural area where social cohesion was seen as being higher compared to the urban settings like Juba. Providers also confirmed advising clients to discuss and as appropriate to disclose their status to their partners and family to get more support.

*“I have been on ART for many years, my commanders know that I am taking ARVs, when am deployed for operations and my time to collect the drugs come, I am given permission to travel back to Juba and take my medicines. This way I have kept healthy and adherent on treatment because I disclosed my status to my commanders” (ART adherent, 31-year-old male soldier).*

*“My mother is very good, she always reminds me to take my drugs every day and even comes with me to the hospital to see the doctor when am not feeling well” (ART adherent, female client).*

*“I have been able to take my medication well because of support from my mother and my sister. They encourage me to take medicine, eat well, worry not and live a happy life. With their support I have been able to take treatment as required and I have been looking healthy” (FGD ART non-adherent, female client).*

**GOOD TREATMENT BY PROVIDERS, COUNSELING AND FOLLOW-UPS** was cited by respondents as an important enabler. Most clients said that providers are friendly with them, talking to them freely which has helped them to open up to discuss their problems, and have provided advice and encouragement to continue taking the ARVs. This has helped clients not miss appointments. Some clients said that they have been respected and their views have been valued, giving them positive outlook into taking ARVs. KIIs indicated that when interacting with providers, clients would like to be important, treated with respect, given privacy and listened to. Clients also reported that providers do not ask money from them. All this was further validated during the providers’ observation. Throughout the discussion, most clients have expressed gratitude to providers for providing service free of charge. Some clients wondered what could have happened if they were charged for services; with the current economic crisis, many people would have lost their lives since most clients may not be able to afford care and treatment.

*“The way the doctors are friendly and talk to me always, makes me not to miss my appointments” (ART adherent, female client). “The doctors are generally good with us, they encourage us to come for our drugs regularly. They do not ask for money but provide us free treatment, so I am motivated to take my medications and follow their advice” (ART non-adherent, female)*

*“When I was tested and the result for HIV was positive. I was sent to the counselor office, he was kind. He encourages me more about the importance of ARV drug and he advise me to take it on time” (ART adherent, 43-year-old female client).*

*“Despite fear of going to the facility or being known to have HIV, my peer navigator helps me to collect my medicines from the facility as well as for other colleagues and distribute to us. This way I have been able to take my medications without going physically to the ART center and without people around me knowing I am taking medications” (ART non-adherent, key population 31-year-old female).*

**PROVIDERS FOLLOW-UP** Most clients shared that being cared for by the provider through tracking phone calls, reminders to take medications, inquiring about side effects and being reminded

to come for appointments to collect refills and take medications. The clients perceived the calls as a sign that providers care, and this encourages them to adhere to medications.

**CONTINUOUS COUNSELLING BY PROVIDERS** Clients reported to be receiving counseling at each appointment about the importance of taking the drugs, the convenient time for taking the drugs, good feeding, how to avoid reinfection through use of condoms, health education, and how avoid stress and heavy workload. Most clients said this was the reason they remain on treatment to date. Providers also mentioned that some clients searched for information on the internet, and times when they come during appointment, they often demonstrate familiarity with what they have to do. One client offered to provide counseling to their fellow clients. This was further witnessed in the provider observation, that providers continue to provide counselling to clients on every visit. Provider knowledge and skills as observed during the clinical observation was helpful in satisfying client needs for HIV treatment and care.

**TREATMENT SUPPORTERS** Having treatment supporters was also reported to be a major enabler to adherence. Clients with treatment supporters reported that the supporters accompany them to the clinics, get their drugs for them in case they are unable to travel and remind them to take their drugs on time and regularly.

**PEER NAVIGATORS AND PEER EDUCATORS** Support from peer navigators/peer educators was seen by clients as improving adherence and retention to care. Being accompanied to the clinic by the peer navigators relieved anxiety, fears, and stigma that would be a barrier to treatment. This way the clients are encouraged to take medications, keep appointments and are supported to take medications.

**AVAILABILITY OF PLHIV GROUPS** This was cited as an enabler especially in rural settings. Clients come together occasionally in meetings to share experiences, knowledge, and advice and to encourage each other on aspects of positive living, which encouraged non-adherent clients to continue treatment. The mother-to-mother support groups were also active in Tambura, with activities ranging from fund- and awareness-raising to providing support to PLHIV groups in fighting stigma and discrimination among the community members.

**VIRAL LOAD TESTING AND FEEDBACK** Clients said when the viral load testing report indicates a lower viral level as a result of taking ARVs, it motivates them to continue taking ARVs consistently. It also serves as proof that the ARVs are indeed working, countering the rumors in the community that ARVs are made in China and therefore are fake and cannot work.

*“ARVs keeps our viral load low and prolongs our life” (PMTCT client).*

**PRIVACY AND FACILITY ENVIRONMENT** Clients consistently mentioned that privacy with providers during counseling gave convenience and provided a conducive environment for accessing services hence making them adhere to treatment.

### **IMPLEMENTING PARTNERS PERSPECTIVE**

Presented below are the perceived enablers to ART adherence and retention coming from IP KIs conducted with a selection of PEPFAR partners.

- Availability of drugs, positive and healthy living, nearness of the services to the community, continuous medical education/awareness reduces stigma/discrimination and teamwork among the health workers in the facility, and well-streamlined supply chain for commodities at national level enable adherence in that barriers due to disruption inflow of commodities supplies are eliminated.
- Multi-month dispensing started in June 2019. This is perceived to have aided better adherence to treatment. More staff is to be recruited or brought on board to help scale up services while the existing staff continue to serve.
- Data management system: patient registers are being updated to patient-based registers and have helped improve the information system.
- Stationary lifestyles and improved security enable access to health facilities. Access to services at health facilities without disrupting treatment as well as a stationary lifestyle can enable clients to adhere to treatment. Scaling-up of the ART centers, including private clinics, made access easy for key populations as well. Scaling-up of the services to the countryside has been a key enabler in accessing ART services and keeping on treatment, unlike in the past where clients had to travel very long distances to access services.
- Case identification and treatment, rather than the initial focus on voluntary counseling and testing (VCT) and not treatment services, have been brought closer to the community hence better acceptance. Use of peer navigators for key populations has been a gateway to first have clients tested then initiated into treatment and followed up to ensure they adhere.
- Linkage to care for those tested and found positive are escorted by their peers/navigators, hence they gain psychosocial support which enables them to adhere to treatment.
- Investment in awareness creation among clients. Provision of integrated services, not just limited to HIV only, has provided access to information for clients that consistently emphasizes the importance of remaining on treatment.
- The client flow is well regulated and not mixed up in the clinics for the different categories: index visits, refills, viral load monitoring etc. Community refills are being done in centers outside Juba which lessens burdens on clients to come for treatment at health facility. Regular Continued Medical Education (CME) is done for clinical trainers to improve knowledge and better support clients to adhere to treatment and care. It also helps reduce time spent at the clinics, improving access for clients since the clinics are often overcrowded.
- Transition from TLE to TLD already started, which may lead to better adherence due to fewer side effects. The 90-90-90 targets are on course with viral load testing scaled up with high viral suppression rates. PMTCT is moving towards elimination. A cohort of mothers on PMTCT have over 97% of babies born without HIV, which helps the client to stay on treatment.
- Privacy and convenience. The clients served in the private clinics are mainly from the working class and key populations at risk that can access the facility any time, have privacy and convenience of hours including weekends and night, closer interactions with clients due to congestion at the clinics has greatly enabled clients to remain on treatment. Privacy is a concern in some ART centers given that space is limited, and facilities are crowded with clients on ART and non-HIV patients. This makes it not conducive to return and receive services in the facilities. Up-to-date country guidelines, standard operating procedures (SOPs), reporting systems, and dedicated data clerks create an enabling environment for ART clients as well as for providers to give adequate information to clients regarding side effects and the need to adhere. The clinics are overcrowded and the space between waiting area and

counseling is very close, so any discussions could be overheard by other clients and chaperones in the corridors who tend to be attentive to what is going on in the rooms.

## **CONCLUSIONS: ENABLERS TO ART ADHERENCE**

In summary, the main enablers to ART adherence cited by all client categories and providers were knowledge on lifelong ARVs as the only treatment for HIV; expanded hours of operation for picking up ARVs; short travel time to health facility; reduced need to travel to clinic; multi-month dispensing of ARVs; disclosure of status; support from family and friends; good treatment by providers; counseling and follow-ups; treatment support; viral load testing and feedback; privacy; and facility environment. In addition, the study team made the following observations overall:

- Provider knowledge and skills as observed during the clinical observation were helpful in satisfying clients' needs for HIV treatment and care.
- Client tracking, through reminder calls and community, supports groups engagement in tracing and tracking clients have been helpful in supporting clients to adhere to care and treatment.
- Availability of ARVs in health facilities and in private clinics provides easy access to clients – especially working-class clients, youth, and key population including VIPs – who prefer flexible refilling times, and this has enabled them to remain adherent to care and treatment.

## **BARRIERS TO ADHERENCE/RETENTION TO CARE**

FGDs and KIIs used slightly different strategies to identify barriers to adherence. FGD participants were first led into a discussion about their experience with ART, with the facilitator probing on a list of issues that are commonly known difficulties ART patients have with treatment.<sup>3</sup> This question elicited responses regarding clients' physical experience while taking ARVs, including side effects, effects of HIV infection, and hunger. This was followed by a question regarding the main barriers and facilitators affecting adherence to treatment among the issues previously discussed. Barriers from KIIs, on the other hand, were derived from two questions: *What is the main challenge you face to take the ARV pills every day at the same time?* and *What motivates and demotivates you to take the ARV treatment?* Responses to these questions sometimes appeared to stray from descriptions of the respondent's own barriers, sometimes explicitly stating they were describing barriers "others" experienced. Directly asking the non-adherent clients in KIIs about the challenges they faced taking ARVs or demotivating factors for ART, surprisingly, did not provide much insight. Three out of seven clients declared having no challenges in taking ARVs for both questions, two mentioned barriers others faced, while the barriers mentioned included stigma, lack of food, transport, and side effects (nightmares and weakness). Given this, in the following sections, insight derived from KIIs will not be distinguished by adherence status.

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<sup>3</sup> The probes were: side/adverse effects, pill burden/fatigue, lack of food, lifestyle issues, adherence, depression, mental; health side effects, costs involved in meeting appointments

Overall, the categories of barriers frequently mentioned by clients in KIIs and FGDs, independent of adherence status<sup>4</sup>, were food or hunger and long distance or transport or cost of transport. These were also the two barriers cited by the PMTCT and youth FGD participants, both of which were composed of adherent clients. Additional barriers cited by non-adherent clients included perceived side effects, cost<sup>5</sup>, work/home responsibilities, discrimination/poor treatment, and lack of support or discrimination from family. The following sections discuss each of these issues separately.

## **FOOD OR HUNGER**

Lack of food or hunger were common themes throughout the interviews and discussions. Among clients, the manner in which this topic was most commonly expressed in KIIs was simply “hunger,” “no food,” and “lack of food.”

While food or hunger was cited by far more non-adherent clients compared to adherent clients, this was also the most frequently cited barrier mentioned by adherent clients, as well as all key informants, who were not influenced by peer opinions since KIIs are individually implemented. Among non-adherent clients, it was also far more frequently mentioned by male compared to female clients, and it was the second most commonly mentioned barrier among KIIs describing the physical experience of ART. Few clients mentioned receiving any support with respect to food from sources such as community members, the clients’ son-in-law and the World Food Programme (WFP). In fact, an IP key informant (KI) shared that lack of supplementary food has led to clients being lost to follow up or going to facilities where they can get food. Even for the existing WFP program, an IP KI expressed concern about the eligibility criteria for the WFP feeding program for malnourished HIV clients, as he felt the body-mass index criterion is a barrier to adherence.

*“Sometimes when there is no food, I do not take the ARV drug because it weakens me when I take it on empty stomach” (27-year old female client).*

*“People are saying ARV is strong and bad if you take it without food it will weaken your body” (53-year old female client).*

*“Hunger take milk to take drug. Now things are more expensive in Juba. I'm a widow and nobody is helping me only trying to help myself alone” (40-year old female client).*

*“The challenge is that if take the drug without food I feel very weak. I will not be able to sleep at night” (53-year old female client).*

When providers were asked about the main challenges faced in supporting their patients to adhere to ART, their responses appeared inconsistent with the prominence of the issue of hunger/lack of food for clients. Instead, the top two reasons providers mentioned were transportation/distance and lack of disclosure/fear of disclosure, both of which were mentioned by three out of six providers. It is

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<sup>4</sup> Adherent or non-adherent as described in the methodology section of this report.

<sup>5</sup> Includes any mention of cost of transportation.

possible that the pervasiveness of hunger and/or the rarity of support in this area may reduce clients' tendency to present this complaint to providers.

## **ACCESS TO CARE**

Access to health facilities was a key barrier to adherence described in client FGDs and KIIs. IP KIIs explained that some clients have to travel very long distances between clinics, with insecurity along the way and disrupted services at the health facilities, including occasional closures caused by insecurity. In Western Equatoria, some villages are over 70 km to the nearest ART center, which is not open daily. Typical ways clients described this barrier included: “*long distance to the facility,*” “*high cost of transportation,*” “*no money for transport,*” “*lack of transportation,*” and “*long distances.*”

When asked about barriers to ART adherence, non-adherent clients cited distance or issues related to transport compared to adherent clients. Distance/transport was also the top barrier for FGD participants in the PMTCT and youth groups. Among non-adherent clients, distance/transport was more frequently mentioned as a barrier among men than women. Finally, as previously mentioned, providers recognized the challenges of traveling to the clinic, as it was one of the two most cited challenges, they faced in supporting their patients to adhere to ART.

*“The main challenge is the transport because we are using boda boda to the clinic. (44-year-old female client).*

Key informants were asked how much they paid to cover travel expenses, Client responses ranged from 200 to 3000 South Sudanese pounds (\$1.5 to \$23), with a median response of \$2.3 and mode of \$1.5. The remaining clients indicated they did not pay to travel, suggesting they would have walked to the clinic.

## **PERCEIVED SIDE EFFECTS**

FGD and KII discussions about ART side effects sometimes elicited responses that included hunger and symptoms of HIV infection. Clients mentioned perceived side effects as a barrier; this barrier category was mentioned much more among non-adherent clients compared to adherent clients. Among non-adherent clients, most men cited side effects to be a barrier compared to women. On the other hand, perceived side effects were mentioned by only a minority of PMTCT and youth FGD participants.

Among the non-adherent clients, the most frequently cited perceived side effects (excluding hunger) were: dizziness, fatigue/body weakness, body pain/heat, nausea/vomiting, and abnormal menstruation (see Table 2). Providers also reported that many clients have also rejected isoniazid preventive therapy (IPT) due to concerns over an additional pill burden. Those who have accepted may have actually dropped out of care because of pill fatigue and side effects:

*“I have introduced 21 clients to the IPT regimen 2 months ago, out of the 21 clients only 2 of them have managed to return for refill” (ART provider).*

## **COST OF MONEY**

The cost of money was cited as a barrier more often among non-adherent clients compared to adherent clients. Among non-adherent clients, men were nearly twice as women to mention cost as a barrier.

Since ARVs are provided free of charge, a fact confirmed by KIs, interviewers probed to learn about the types of relevant costs. As previously mentioned, four out of five KIs reported incurring a cost to travel to the clinic. In addition, while no clients reported paying registration fees, two Juba Teaching Hospital clients mentioned they needed to pay hospital entrance fees. Additional costs KIs mentioned included costs for performing tests conducted by external labs and the cost for buying other drugs (i.e., besides ARVs).

## **WORK/HOME RESPONSIBILITIES**

Non-adherent clients mentioned more than adherent clients work and home responsibilities as a barrier. All non-adherent clients that cited work/home responsibilities as a barrier were women participating in a single FGD, and they provided few details besides “farm work.”

*“What demotivated me is that I was at a working place far in Luri county– I was cultivating there. Secondly, my daughter is insulting me: that am not a good mother at my age, where did I get the disease, makes me to stop taking my drugs. But know I am taking it because my son-in-law advised me to continue on the drugs for my health to get better” (53-year-old female client).” Male ART client*

In addition, KIs also mentioned the cost of the lost income from their various businesses (farming; production of milk, tea, and charcoal; and selling items). Finally, as can be seen from the quotes in the embedded figure, some clients mentioned work as a barrier to adherence for other clients.

## **POOR TREATMENT AND LACK OF SUPPORT**

Non-adherent clients cited more than adherent clients poor treatment or discrimination as a barrier. Again, all non-adherent clients who described isolation, discrimination, stigma, and abuse from family members and neighbors at the workplace and funerals were female.

*“They isolate us not even eating with us” They say PLHIV are useless” The community say we are dead people so no need to interact with us” People in the community say negative things about ARVs. People do not like sharing things with you and sometimes even abuse you. In some situations, when you are dating your boyfriend, they will say you are sick, and the boy should not befriend you” ART Clients*

KIs investigated this issue further. However, some clients reported being treated rudely, being shouted at or simply treated with lack of respect by providers.

**TREATMENT BY FAMILY, FRIENDS AND COMMUNITY** Clients were asked how they felt about the level of support they received from others in taking ARVs—specifically, family, friends, and other people in the community. While it was encouraging that most of KIs reported receiving support from family and from friends, others reported receiving support from no one, including two that had not disclosed to anyone. Those fortunate to receive support described advice (e.g., to continue treatment, to not drink alcohol or engage in sex) and encouragement, and in a few cases, clients reported receiving support in the form of transport money or food. A few clients reported support



from other sources, including the WFP, church (counseling and praying), other PLHIV, and facility staff.

*“My aunt gives me advice about the importance of taking ARVs but other people in the community [are] negative about people ARVs but not very common though” (ART Client).*

*“People in community know very well that ARV is a drug for HIV. Before, in the community, if people knew that you were taking ART they would abuse and devolve [sic] you. But now people are aware, and they understand the importance of ARV” (ART client).*

Two out of six provider KIs mentioned stigma as one of the main challenges they faced in supporting their patients’ adherence to ART. In particular, they commented on the prominence of stigma as a barrier for new patients and patients that had not disclosed their status. An IP KI reflected that sometimes there are different levels of stigma and discrimination that add another layer of complexity—for instance between the military and civilian population, urban versus rural, etc.

**TREATMENT BY HEALTH WORKERS** In this context, the support that clients receive at the clinic could be one of the very few sources of support for many patients. KIs also asked clients how they would rate the quality of care at the clinic compared to other clinics they were aware of, and responses were overwhelmingly positive. The two most common remarks were simply “better,” or comment regarding how staff listened. Nearly as many clients agreed that they felt staff listened to their questions and concerns and answered them. Two clients provided a mixed rating—they felt that while some staff respected and listened to them, others did not. That said, four clients felt there was no privacy during consultations because of insufficient space, or because they did not completely trust the provider. The clinic observations confirmed that clinics are often overcrowded, with limited space between the waiting area and the counseling room, so any discussions could be overheard by other clients and chaperones in the corridors who tend to be attentive to what is taking place in the rooms. In short, most health worker interactions with clients are supported and appreciated, though infrastructure constraints sometimes limit privacy and confidentiality.

This rosy picture of the health worker bedside manner was counterbalanced by one clinic observation. The study team observed a provider whose attitude towards clients that missed appointments was decidedly negative. After learning that a client had missed treatment for eight months, the provider shouted and did not give the client the opportunity to explain why they missed their appointment. Given that client-provider observations are subject to courtesy bias, we conclude that negative interactions still take place.

## **SUMMARY OF OTHER BARRIERS**

**EXISTENCE OF OTHER PARALLEL TREATMENT METHODS OF TREATMENT IN THE COMMUNITY** The emergence of other drugs from the traditional herbalists is noted as one of the factors affecting adhering to ARVs. There are clients who believe in the use of herbals for the treatment of HIV as opposed to the use of scientifically approved drugs.

*“One of us died because of following drugs which are traditional which didn’t help him. Last year but one, one of us died similarly because of using traditional herbal drugs which can’t help, and he finally died” (Female client in FGD in Juba)*

**POOR COUNSELING OF CLIENTS AT THE FACILITIES** Clients frequently cited that there is poor counseling of HIV positive clients in the country. The method facilities/service providers have adopted is “test and treat method,” which does not take seriously the importance of counseling in the treatment of HIV and that according to clients interviewed affects adherence to ART. Because of limited information, clients find themselves not adequately aware of what needs to be done and not prepared enough to take ARVs.

*“In Uganda before taking treatment, they counsel you first but here they don’t – from test to treatment which is dangerous” (Client in Juba FGD). “had no proper counselling to date, when I was given the drugs at first, I just started taking them that afternoon and the drugs had terrible effects on me and tried to take the drugs in the morning still the side effects were bad on me, so am just trying to adjust timing for my drugs on my own” (FGD - ART non-adherent client).*

**STOCKOUT OF ARV DRUGS IN THE HEALTH FACILITIES** Clients were also quoted by the interviewers saying that drug stockout at the health facilities is a paramount factor while discussing reasons for non-adherence amongst HIV positive clients, noting that when drugs get stockout, clients are left with no ARVs in the community and have to wait until drugs are brought by the service providers thus affecting adherence to ART.

*“I told the doctor; my husband is also HIV positive and very weak right now and has no appetite for food. The doctor instead told me to go and buy vitamin from the clinic. as we talk, the doctor has not given me drugs for my husband including ARV’s and yet I don’t have money for buying drugs and just don’t know why doctors are not giving me the drugs” (FGD ART non-adherent client).*

**NON-DISCLOSURE OF HIV STATUS** The clients interviewed in the FGDs said other clients do not want to disclose to their families their status for fear of stigma and or do not want to be known to be having HIV. This complicates the process of getting treatment drugs since all has to be done in a hidden manner where drugs are procured when clients feel safe to go for or take the drugs. Hence a factor that cannot be underrated while discussing reasons for non-adherence to ARVs in some of the communities in South Sudan.

*“We used to be called by the community members “SUBI, 7+1, 9-1, MIM DAL, BONA” and etc. it was so stigmatizing but at least those names are fading out slowly” (FGD female client).*

**PRAYERS FOR TREATMENT OF HIV** Clients also attribute poor adherence to ARVs to the fact that many people believe God’s healing can be perfect and resorted to praying and there are dedicated churches who pray for the HIV positive people who have the trust in spiritual healing.

*“There is also a pastor offering prayers but at some point, whenever clients go to test, they still tested positive with HIV. Now I don’t pick any different method apart from those from the hospital” (FGD female client in Juba).*

## **IMPLEMENTING PARTNER PERSPECTIVE**

Implementing partners, due to the role they play, tend to have systems-level perspective and insights that the role affords. Below are some barriers as voiced by implementing partners interviewed during the course of this assessment:

- **ACCESS** Cited by five out of nine IP KIs, IP perspectives were described under the Access section of the report. Also mentioned was a lack of integration of services where clients have to

move for different services to different facilities and sometimes clients are refused admission in a ward or have to pay money for tests within the same hospital. Clients get uncomfortable and request to access all these services within the ART.

- **CLIENT MOBILITY** was cited by four out of nine IP KIs. Clients can be mobile, because of insecurity or their profession (e.g., traders, soldiers). For instance, when soldiers are transferred, continuity of treatment can be challenging especially if the client has not disclosed at the workplace. Disclosure would allow for a request for permission to travel back for refills. Other clients are mobile because they may move to their farms during the cultivation season. This can result in self-referrals from one facility to another introducing difficulty in tracking treatment at the initial site.
- **POOR HIV LITERACY** or inadequate knowledge about HIV was mentioned as a barrier by four out of nine IP KIs. In part due to the late initiation of the South Sudan HIV program, HIV literacy is low “even among the educated population” and even more so among the less educated and rural communities. Lack of basic HIV understanding makes adherence a key challenge. One KI pointed to understanding Test and Treat as a key gap leading to treatment defaulting. IP KIs noted knowledge gaps on side effects, how long they need to take medication, what it does to the body and the need and consequences of lack of adhere to treatment. There has been a shift of funding from awareness-raising to treatment support, yet knowledge of HIV remains very low. Some clients drop out from taking ARVs they feel better or notice improvements (for example weight gain).
- **STIGMA** was cited by four out of nine IP KIs. KIs described high levels of stigma. In addition, complications arise when layered over other issues, such as workplace disclosure. “*Stigma is a big issue particularly when senior officers are being treated by junior officers who are medical.*”
- **INSECURITY** Cited by four out of nine IP KIs, insecurity was described as a factor increasing the lack of access to care.
- **STAFF** entirely on government payroll feel demotivated as their salaries can be delayed and so report late and leave work earlier, leaving most of the work to be done by staff who are salaried by IPs whose limited time and heavy workload interferes with patient counseling and education on the use of ARVs. Thus, most facilities close early, inconveniencing clients who preferred late refills, especially for the working-class clients.
- **COMPETING ALTERNATIVE BELIEFS** Cited by three out of nine IP KIs, examples provided included the perception that prayer can substitute for ART and local herbs as remedies for HIV.
- **CO-MORBIDITIES** like tuberculosis (TB), hepatitis B virus (HBV) and hepatitis C virus (HCV) divert focus on ART. Clients who take medicine or drugs for TB, HBV or HCV concentrate much on the uptake of those medicines given the severity of these co-morbidities. This can interfere with adherence to the ARV schedule as well as follow-up clinic visits, as echoed by providers during KIs that many clients on ARVs who complete TB treatment have declined to resume treatment as they feel better and therefore no need to continue ART. Those were counseled and re-instated.

## **CONCLUSIONS: BARRIERS TO ART ADHERENCE**

In summary, the main barriers to ART adherence cited by non-adherent clients were lack of food; access to care; perceived side effects; costs; work/home responsibilities; and poor treatment/lack of support. Barriers cited by IP KIs were: access to care; client mobility; poor HIV literacy; stigma;

insecurity; competing for alternative beliefs; and co-morbidities. In addition, the study team made the following observations overall:

- Study teams observed the pressures under which health workers are operating, with limited time and heavy workloads, which was also mentioned by four out of six providers. The fact that a large majority of clients reported feeling listened to, given the limited time providers have for patient counseling and education on the use of ARVs, is commendable.
- Many barriers are inter-related, each of which can exacerbate the effect of the other. Understanding how each barrier conceptually relates to the other may help to strategize programming, for instance:
  - Need to take ARVs with food/clients' perceived weakness after taking ARVs without food/weakness from hunger making it more difficult to work or go to the clinic/the trade-off between farming and going to the clinic/side effects and HIV symptoms.
  - Low HIV literacy/stigma/lack of social support/lack of disclosure/isolation/competing alternative beliefs.
- Observations from clinic visits included:
  - Overcrowding at the facilities, coupled with few staff providing ART services with one staff doing counseling, filling registers and dispensing, also constrained service delivery. The clinic opening hours in public facilities is quite short, from 9:00 to 13:00 hours, which limits the number of clients that can be served.
  - Staff on government payroll appear demotivated as their salaries can be delayed and so report late and leave work earlier, leaving most of the work to be done by staff who are salaried by IPs.

## **DEFAULTER TRACKING SYSTEMS FOR LTFU**

### **AVAILABILITY AND FUNCTIONALITY**

Providers indicated in all health facilities visited that the defaulters tracking registers are in place. Phone calls by health facility staff to clients to remind them of appointment schedules are done and reminders are sent to those who missed their appointments. A local initiative to share names of LTFU clients within facilities within Juba was also initiated for tracing clients LTFU. In one facility, peer educators, navigators and mentor-mothers are recruited and are also tasked with client tracking and follow-up in the community.

### **CHALLENGES/GAPS**

Even though defaulter tracking registers are available in all facilities, poor recording has been noted in these facilities as the registers are not regularly updated. Clients reinstated to care often remain as LTFU in the register. The number of LTFU clients has been often overstated due to poor recording and lack of centralized national identification systems. Peer educators, navigators, and mentor-mothers are recruited but poorly motivated and have no transport for tracing clients. Providers also are further faced with irregular and inadequate provisions of airtime to keep in contact with clients. They are also mostly not recruited from within the vicinity of the clinics or from the communities they need to work in; as such, they have to incur transport costs to go to the communities to work, yet they have also experienced difficulty in identifying clients. The mentor mothers are deployed in

and not among the clients themselves, making it harder for clients to engage with them in Juba. In Tambura, the mentor-mothers are among the PLHIV and have direct connection with their fellow clients and have provided better support to the clients. A key challenge has been also in non-adherent clients changing locations, phone numbers and having duplicate records in different facilities, making it hard to trace them, and the local initiative to exchange list of those LTFU with the other facilities in order to exchange information about a client who might have moved from one facility to another to better track them have not been supported. Staff know the systems but have not received any refresher training on how to track clients for over a year. All staff were unable to present a written job description though most of them were able to demonstrate what they are supposed to do with tracking systems.

*“I have checked the number of those LTFU against clients cards many times I realized the LTFU register is not updated.”*  
(ART provider).

## **OPPORTUNITIES**

Introducing a centralized online national tracking system with a unique code identifier that a client would use in any facility visited would help sort the double counting and use of the biometric registry to avoid duplicate clientele. Strengthening the local community level groups to help trace clients LTFU and encouraging and supporting local information exchange between health facilities for tracing clients as a starting point will be cost effective for health facilities especially in urban settings.

## **RECOMMENDATIONS**

### **HEALTH SYSTEM-LEVEL RECOMMENDATIONS**

- **PARTNER WITH AGRICULTURE/NUTRITION PROGRAMS.** The primary barrier to adherence to ART is food insecurity. Given that most clients grow their own food, improving the productivity of agricultural practices could yield outsized benefits for clients, given the significant dependence on subsistence agriculture for sustenance, nutrition, and income, all of which are barriers to adherence. New partnerships could focus on improving the productivity of agricultural practices. Existing partnerships such as WFP can be re-examined on whether eligibility criteria constitute a barrier and how to move forward.
- **INTEGRATE LIVELIHOODS AND LIFE SKILLS INTO THE ART PROGRAM** to support clients for income-generating activities and also teach skills of living positively and influencing PLHIV to live a productive life.
- **INVEST IN A NATIONAL CAMPAIGN ADDRESSING LOW HIV LITERACY IN THE COMMUNITY** through partnerships with government, donors and other IPs. At the community level, the focus should be on prevention and awareness creation by engaging traditional, religious and political leaders to improve knowledge, reduce misconceptions and stigma by scaling up mass media campaigns.
- **EXPAND ART SERVICES IN MORE PRIVATE CLINICS** to decongest the busy clinics in public facilities, as well as utilize flexible hours for clinic operation.  
**SCALE-UP COMMUNITY OUTREACH ARV REFILL STRATEGIES** to enable clients who would not access ART services due to distance and transport challenges to receive adequate refills.

## CLINIC-LEVEL RECOMMENDATIONS

- **CONSIDER FURTHER TASK SHIFTING OPTIONS** to help decongest clinics, consider delegating additional provider responsibilities to lower cadre, counselors, social workers, lab technicians, lay volunteers or the patient themselves. For instance, volunteers or individual/paired patients may be able to weigh the patient and document the weight separately for later transcription to medical records while waiting for appointments. If mentor mothers, community officers/mentors and peer educators are not consistently supporting ART initiation and adherence counseling or documentation for clients that miss appointments consider how to make this possible. The clinic flow may need to be re-thought in order to increase efficiency.
- **DEVELOP NEW STRATEGIES FOR IDENTIFYING AND ADDRESSING STIGMA** Skilled trained HIV counselors can help clients to disclose to partners and family when the client is ready. Such HIV counselors can be mentor mothers, community mentors, peer navigators, expert clients or volunteers.
- **CREATE OR STRENGTHEN LINKAGES WITH CLIENTS WHO ARE MOBILE** and their providers in the locations they are visiting, along with multi months dispensing and community refills done through outreach. Systematically screen all patients for their likelihood of mobility affecting ART and problem-solve together.
- **CONDUCT REFRESHER TRAINING/ORIENTATION OF COUNSELING STAFF** on the following topics:
  - Staff attitudes toward clients that default treatment, foreigners, and key populations and how negative attitudes reduce adherence and retention.
  - Capacity building of the health cadres involved in TB and TBHIV control.
  - ART guidelines. Four out of six providers felt the need for refresher training due to the fact that recommendations are always changing.
  - Counseling on topics such as:
    - ART initiation, including readiness assessment, the importance of starting only when ready to commit to lifelong treatment.
    - Adherence, including assessment of adherence, checking in with patients that have not disclosed their status to others, reduced side effects of TLD regimen compared to TLE regimen. Clients should be educated on the safety of TLD based regimens that have less side effects hence better prospects for adherence.
    - Personal and public health consequences of lack of adherence to ARVs (e.g. drug holiday).
    - How to support disclosure.
    - Potential side effects of all medication prescribed to the patient including IPT, HBV, HCV, and cotrimoxazole (advantages and disadvantages of options).
- **CONSIDER THE FEASIBILITY OF PLAYING PATIENT EDUCATION VIDEOS IN THE WAITING AREAS OF CLINICS** on a variety of relevant topics such as TB treatment, adherence to medications and risk of developing resistance, nutrition, hygiene, antenatal care, immunizations, as well as HIV prevention and HIV treatment. Alternatively, these can be group talks on rotating topics. Such talks or videos should not be limited to the HIV clinic.

- **INTRODUCE ANONYMOUS CLIENT RESPONSE FEEDBACK MECHANISMS** (e.g., suggestion box, ombudsman<sup>6</sup>) that can provide clinic management feedback on positive and negative experiences at the clinic, including negative interactions with specific providers observed or experienced.
- **CONSIDER PILOTING OR ASSESSING THE FEASIBILITY OF COMMUNITY ART ADHERENCE SUPPORT GROUPS** (CASGs) and other support groups models. The typical CASG model consists of six patients that have been adherent for a minimum number of months after initiation, who disclose among themselves and live relatively close to each other. Members rotate picking up ARVs for all six members so that each person takes the burden of collecting ARVs once every six months. Each traveling member also takes the responsibility of checking on the wellbeing of each member before retrieving ARVs. Such groups can also serve as psychosocial support for members.
- **STRENGTHEN THE DEFAULTER TRACKING SYSTEM.** There are numerous ways a defaulter tracking system can fail. Reliable systems rely on consistent and accurate register and medical record documentation and follow up procedures for missed appointments, including documentation for tracking and tracing defaulters and patients that are LTFU. Key indicators for a reliable defaulter tracking system should be able to report on are listed below. Without such data, there is no way of assessing whether the system is reliable.
  - Proportion of appointments in the appointment book that are scheduled among patients who should have an appointment in current week.
  - Proportion of clients that missed appointments in current week for which clients have received appropriate follow-up calls and/or visits within X days.
  - The proportion of clients that missed appointments in the current week that return to the clinic within X days.
  - Consider the feasibility of introducing unique code identifier of clients or biometric systems to track clients and avoid the same client being registered in many facilities and being double-counted.

## RECOMMENDATIONS FOR FURTHER RESEARCH

Interviews and FGDs, when considered against extant literature reviewed during the desk study, point to several recommendations for further research:

- Effectiveness for community linkages with health facilities in ART service delivery.
- Effectiveness of contact tracing mechanisms for defaulters and clients lost to follow up.
- Private health facilities engagement in ART service provision and its effectiveness.
- The multiplicity of factors centered on access to services, food provision, distance, and transport.

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<sup>6</sup> An ombudsman can be recruited through mentor-mothers' groups, expert clients and peer navigators, and this person can provide official feedback to clinic management.

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## **ANNEX I: LIST OF RESPONDENTS/INTERVIEWEES (IPS)**

## ANNEX 2: TIMELINES FOR THE ART ADHERENCE STUDY

PHASE	ACTIVITIES/TASKS	TIMELINES	RESPONSIBLE	STATUS	REMARKS
	Planning (Pre-field Work) (26%) LOE				
Phase I	Review of Scope of Work, inputs into Ethical Submission documents.	Aug. 30 – Sep. 6, 2019		Done	Application submitted
	Meet with Dr. Richard Lako and Ethics Committee of MOH	Sep. 3, 2019		Done	Clearance obtained
	Review of data collection tools and inputs based on comments from MOH ethical review and USAID	Sep. 4-5, 2019		Done	
	Desk review of literatures, project documents from Jhpiego, CMMB, Intrahealth International, ICAP and MOH.	Sep. 4-12, 2019		Done	
	Visit the study sites in Juba and agree on plans and dates.	Sep. 6, 2019		Done	Visited JTH, JMH, Munuki PHCC, Kator PHCC and Da Genesis Hospital
	Review of the data collection tools by USAID and MIS Home office	Sep. 9, 2019		Done	

PHASE	ACTIVITIES/TASKS	TIMELINES	RESPONSIBLE	STATUS	REMARKS
	Preliminary meetings with implementing partners: ICAP, Jhpiego and Ministry of Health HIV/AIDS department.	Sep. 9-18, 2019		Done	Met Jhpiego on 5th and ICAP on 6th Sept.
	Submission of the inception report	Sep. 10, 2019		Done	
	In-brief to USAID	Sep. 10, 2019		Done	
Field Work – (32%) LOE					
Phase 2	Training/orientation of the data collection team and Field testing in one site in Juba	Sep. 10, 2019		Done	After in brief at USAID Mission
	Data collection at Juba Military Hospital	Sep. 11-12, 2019		Done	Stephen and Amzah
	Data collection at Juba Teaching Hospital ART Centre	Sep. 19-20, 2019		Done	Stephen and Amzah
	Data collection at Munuki PHCC	Sep. 16-17, 2019		Done	Stephen and Amzah
	Data collection at Kator PHCC	Sep. 13-16, 2019		Done	Stephen and Amzah
	Data collection at Da Genesis Medical Centre	Sep. 15-16, 2019		Done	Stephen and Amzah

PHASE	ACTIVITIES/TASKS	TIMELINES	RESPONSIBLE	STATUS	REMARKS
	Data collection at Tombura Hospital (including travel time) 11-18 Sept.	Sep. 11-18, 2019		Done	Travel booking done. Lilian and Godwin to go
	Analysis & Draft Report (Post Field Work) – (26%) LOE				
Phase 3:	Integrating inputs/data collected from the field teams (Tombura) and Juba sites into one.	Sep. 18 -26, 2019		Done	
	Analysis of the data collected from FGDs, Key Informants Interviews.	Sep. 18 -26, 2019		Done	
	Analysis of reports and review of registers	Sep. 18 -26, 2019		Done	
	Preparation of first draft reports for MSI Juba and Home Office Review	Sep. 18 -26, 2019		Done	
	Incorporating inputs from the draft reviews.	Sep. 18 -26, 2019		Ongoing	
	Submission and presentation of Findings – (16%) LOE				
Phase 4:	Presentation of preliminary findings in an out brief meeting	Sep. 27, 2019		Done	

PHASE	ACTIVITIES/TASKS	TIMELINES	RESPONSIBLE	STATUS	REMARKS
	Incorporating comments from the debrief session and preparing a final draft report	Sep. 26-30, 2019		Ongoing	
	Submission of final draft report	Sep. 20, 2019			

## ANNEX 3: NUMBER OF KIIS, CLINICAL OBSERVATIONS AND FGDS PLANNED AND CONDUCTED

This table summarizes the number of interviews, FGDs and clinical observations planned and conducted. There was only one client who came for the KII but later declined to participate citing tiredness and hunger and that she left children alone at home. Otherwise, the number of people who declined to participate on the table is high; however, this does not necessarily mean that staff declined, rather there was limited time for researchers to conduct staff interviews in all facilities. The yellow shaded figures indicate the categories where participation surpassed the planned numbers. The green shaded figures indicate two FGDs held for the same category; in this case for adhering clients. For “Either” they were not contacted or could not make it to the health facility for the interview, because the study time was fixed and there was not flexibility by the study team to accommodate every client coming at their own time to attend the interviews. The issue of having a fixed time and appointment with the facilities did not allow all clients to make it to the FGD and KIIs.

CATEGORIES	KATOR PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			MUNUKI PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			DA GENESIS HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)			TAMBURA PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			MILITARY HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)			JUBA TEACHING HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)			
	P	A	D	P	A	D	P	A	D	P	A	D	P	A	D	P	A	D	
FGD-1 MALE	8	5	3	8	0	8	8	0	8	8	8	0	8	8	3	5	8	0	8
FGD-1 FEMALE	8	6	2	8	0	8	8	0	8	8	15	0	8	8	6	2	8	0	8
FGD-2 MALE	8	6	2	8	5	8	8	0	8	8	8	0	8	8	6	2	8	8	0
FGD-2 FEMALE	8	5	3	8	16	0	8	11	0	8	10	0	8	8	8	0	8	12	0
FGD-PMTCT	8	0	8	8	0	8	8	0	8	8	7	1	8	0	8	8	0	8	
KII-CLIENT	4	6	0	4	5	0	4	0	4	4	6	0	4	6	0	4	8	0	
KII-STAFF	2	1	1	2	3	0	2	0	2	2	3	0	2	2	0	2	3	0	
KII Observations were only done in two HF (Tambura PHCC and Juba Military Hospital due to time factor)																			

CATEGORIES	KATOR PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			MUNUKI PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			DA GENESIS HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)			TAMBURA PHCC (# of participants in each category; P=Planned, A=Achieved and D=Declined)			MILITARY HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)			JUBA TEACHING HOSPITAL (# of participants in each category; P=Planned, A=Achieved and D=Declined)		
KII-OBSERVAT <u>N</u>	0	0	0	0	0	0	0	0	0	2	3	0	0	0	0	2	2	0
Youth FGDs were only done in Tambura PHCC																		
FGD-Youth Male	8	0	8	8	0	8	8	0	8	8	10	0	8	0	8	8	0	8
FGD-Youth Female	8	0	8	8	0	8	8	0	8	8	10	0	8	0	8	8	0	8
Total	62	29	35	62	29	48	62	11	54	64	80	1	62	31	33	64	33	40



## ANNEX 4: TOOLS FOR THE ART ADHERENCE STUDY

### TOOL 1: PROVIDER OBSERVATION TOOL AT HEALTH FACILITY CONSULTATIONS

Person observed: \_\_\_\_\_

Category of client observed: \_\_\_\_\_

Time observation ended:

1. Doctor – Dr
2. Clinical officer - Co
3. Nurse – N
4. Pharmacist – P
5. Counsellor – Co
6. Social workers – So

**Consent:** The observer explains to the person observed and as well as the ART client the purpose of the observation and seeks informed consent from both, ensuring confidentiality prior to starting the observation.

#### Things to note for observation

- Questions 2,6,7,8,19,20,21 should be answered by all categories of persons
- Questions 1,3,4,5,9,10,11,12,13,15,16,18 should be answered by Doctors, Nurses, Pharmacists and Social workers
- Questions 14 and 17 should be answered by a Pharmacist only
- Suggest a 'one-in, one-out' approach for conducting observations - follow one patient in for observation; take time to write up notes while the next one goes in; then follow the next patient in.
- Response forms should include 'yes/no' boxes to be ticked where relevant, with space for writing down other details.

Number	Topics for checklist	Yes	No	N/A	Details
I	What is the reason for the visit? Tick one a. ART initiation for new patients b. Follow up treatment c. Re-initiation of treatment				

2	Is patient well received? (If not, describe.)				
3	Does the consultation take place in privacy? (describe consultation room and environment)				
4	Does the health worker ask about any symptoms?				
5	Is the patient invited to ask questions? (If yes, what do they ask? If yes, was the question addressed appropriately/correctly? Details.)				
6	Is the patient told what to do next (within the health facility)?				
7	Is the patient told where to go for that?				
8	Is the patient told when to come back for refill and review?				
9	Is the sequence of events in relation to treatment protocols explained to <i>new</i> patients? (Requires training for observer)				
10	Do <i>new</i> patients receive comprehensive general information about ART? (How ARVs work, How to use them, The need to continue treatment, What to do if a pill is forgotten, Possible interactions with other drugs, Which side effects can occur & what to do if they occur, (Breast) feeding requirements, When and where to get re-supply) Are new patients asked if they were previously exposed ARVs through PMTCT, Or buying themselves from medical stores?				
11	Are <i>new</i> patients and those switching regimens given information about importance of adherence to ART: (i) dose, (ii) timing, (iii) what will happen if vomit up the pill, (iv) forgets timing, (v) misses dose, (vi) travelling?				
12	For follow-up users only: is there any discussion about the patient's experience of using their medicines? (specifically, side effects and challenges and possible solutions to adherence)				

13	For follow-up users only: Does the health worker ask if the patient missed a dose? If yes, does the health worker explain what the effects are of missing a dose?				
14	For follow-up users only: Does the health worker count the patient's pills before giving him/her a new supply?				
15	Does the health worker ask the patient if they are taking any other medicines? (Anti TB, Rx for OIs, Contraceptive Pills, DM, H-T)				
16	Is the importance of adherence to ART reinforced?				
17	Does the patient receive specific tools to remind them to take their drugs? (eg pill calendar)				
18	Is the patient asked anything about their adherence strategies (include categories for adherence support partner/s, clock, mobile phone, other)?				
19	Is there any effort made to confirm whether or not the patient understands the information and instructions given?				
20	Does the clinician/nurse/counsellor listen attentively to the client? (details?)				
21	Do the health workers ever act or speak in any negative way (impatient, judgmental etc) towards patients? (If yes, describe)				
	Suggest: Does the health worker ask the patient whether he or she have any questions regarding HIV or ART or in general? Or any issues patient would like to bring up?				

**The observer thanks the provider and also the client as the observation is concluded. Gives opportunities for any questions or comments or concerns from either of them.**

## TOOL 2: KEY INFORMANTS INTERVIEWS FOR PARTNERS SUPPORTING ART SERVICES

### Introduction and background to the study:

Overview of the study, processes, objectives and ethical considerations.

Preferable for the provider to give overview and scope in general.

Name of the Interviewer: \_\_\_\_\_

Date of the Interview: \_\_\_\_\_

Name of the Partner Organization: \_\_\_\_\_

Number of Facilities supported: \_\_\_\_\_

### Services provided:

- ART (Adult and Pediatric)
- PMTCT
- Systems Strengthening/Capacity Building
- HMIS/Data Systems
- Supplies: Medicines, Laboratory
- **Scope of Support, when it started/current project timelines:**

1. How many patients are enrolled on treatment or are benefitting from the services: Pediatric, PMTCT, Adults etc.?
2. Funding: How much funding goes to support the program? Sources of funding (PEPFAR, Global Fund etc.)
3. Human Resources support: How many staff are supported in the Health Facilities under this program (give details and Cadres)
4. How is the Supply chain managed: Any challenges or key lessons from this?
5. Data, Reporting and Information Systems: Please provide details on how information systems are managed as well as reporting.
6. What are the key program successes? What do you perceive as enablers of adherence to ART?
7. What are the key constraints or challenges encountered in service delivery? What do you perceive as barriers of adherence to ART?
8. Any other remarks or information valuable to add?

## TOOL 3: FOCUS GROUP DISCUSSION GUIDE (ARV USERS)

### FGD Group 2 (Male and Female)

(Adherent patients (Youth), and PMTCT clients (pregnant and breastfeeding))

#### Things to note for discussion

Name of ARV-providing health facility: \_\_\_\_\_

Participants per FGD (6-12) (responses will be corded) as respondent 1-12

Adults (= or >18 years, men and women separately)

One moderator, one note-taker (and use of recorder)

Neutral venue outside the facility, or in the private room of the facility.

Two FGDs with men, and two with women per facility per the categories described in the SOW

#### Short introductory remarks

Introduction of researchers and participants

- Thank participants for agreeing to participate, all share a common feature - they are on ARV treatment and factors affecting adherence and would like to learn from participants.
- Explain purpose of study, purpose of this discussion, reassurance about confidentiality (read the standard confidentiality statement), agree on discussion rules.

#### Guide for discussions

1. What treatments do you know to be available for treating HIV? Apart from the regular ARVs you take, what is your opinion about these? probe (e.g. alternative treatments; traditional remedies; healing; spiritual; prayers; perceived benefit of treatment).

2. What has been your experience of being on ART? (probe about side/adverse effects, pill burden/fatigue, lack of food, lifestyle issues, adherence, expenses/opportunity costs involved in meeting appointments, those who stop taking ARVs can give reasons for stopping to take ARVs).

Among the few mentioned, what are the few main issues affecting adherence to treatment, start with the major issues.

- **Among the few mentioned, what are the main barriers and facilitators affecting adherence to treatment, start with the top major issues.**

3. How do you think you are being treated (handled) by the health care workers (probe, *in relation to adherence*: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services, under- the-counter payments, being followed by health workers)

4. What do you think about the counselling that you receive? (probe especially on importance of adherence and tips/helpful advice for adherence)

**Note; Probe more on the challenges they have faced and what techniques/approaches they have used to overcome them?**

5. What support is available for you in the community, in the family, in the workplace? (probe about discrimination, stigma)

What do people in the community say about ARVs? Are most people similar to you living with HIV and on ARV adherent? What makes you say that? What do people in the community say about people who take ARVs?

6. Many people who start ART in South Sudan do not continue their treatment. What are some reasons you think this would be? What advice might you have for health providers that want to keep these persons

on ART?

Duration of discussion (1½ to 2 hours); provide refreshments

Conclusion, thank participants and ask for any concerns, questions, remarks and clarifications as the FGD closes.

#### **TOOL 4: FOCUS GROUP DISCUSSION GUIDE (ANTI-RETROVIRAL) ARV USERS)**

##### **FGD Group I (Male and Female)**

**(Missed appointment, lost to follow up (LTFU), and Clients deferring ART)**

**Name of health facility providing ART:** \_\_\_\_\_

Participants per FGD (6-12) (responses will be corded) as respondent 1-12

Adults (= or >18 years, men and women separately)

One moderator, one note-taker (*and* use of recorder)

Neutral venue outside the facility, or in the private room of the facility.

Two FGDS with men, and two with women per facility per the categories described in the SOW.

##### **Short introductory remarks**

Introduction of researchers and participants

- Thank participants for agreeing to participate, all share a common feature - they are on ARV treatment and are here to share thinking about ARVs and challenges to take ARVs, factors affecting adherence and would like to learn from participants.
- Explain purpose of study, purpose of this discussion, reassurance about confidentiality (read the standard confidentiality statement), agree on discussion rules.

##### **Guide for discussion**

1. What treatments do you know to be available for treating HIV? Apart from the regular ARVs you take, what is your opinion about these? probe (e.g. alternative treatments; traditional remedies; healing; spiritual; prayers; perceived benefit of treatment).

2. What is your experience of Anti-Retroviral Therapy (ART)? (probe about side/adverse effects, pill burden/fatigue, lack of food, lifestyle issues, adherence, depression, mental; health side effects, costs involved in meeting appointments, those who stop taking ARVs can give reasons for stopping to take ARVs).

- **Among the few mentioned, what are the main barriers and facilitators affecting adherence to treatment, start with the top major issues.**

3. How do you think you are being treated (handled) by the health care workers (probe, *in relation to adherence*: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time and waiting room, integration with other services, under- the-counter payments, being followed by health workers)

4. What do you think about the counseling that you receive? (Probe especially on importance of adherence)

5. What support is available for you in the community, in the family, in the workplace? (Probe about discrimination, stigma)

What do people in the community say about ARVs? What do people in the community say about people who take ARVs?

6. What do you think could be done to help people to adhere more easily to their treatment/be retained on treatment?

**Duration of discussion (1 ½ to 2 hours); provide refreshments**

**Conclusion, thank the participants**

**TOOL 5: STAFF - SEMI STRUCTURE INTERVIEW QUESTIONNAIRE (ART/PMTCT STAFF)**

**Short introductory remarks**

**Introduction of researchers and participants**

- Thank participant for agreeing to participate to share thinking about ARVs and difficulties to administer ARVs, factors affecting adherence want to learn from participant.
- Explain purpose of study, purpose of this discussion, reassurance about confidentiality (read the standard confidentiality statement) before proceeding with interviews.

Name of Health facility:	
Date:	
Staff identification number:	
Interviewer:	

#	Question	Responses
<b>Tasks and training (roles and responsibilities)</b>		
1	What is your job in this clinic? Do you have a written job description?	
2	How long have you been doing this job?	
3	What specific training have you received for this job in relation to ARVs? Tell me about the training (Details)	
4	Do you think this training has been sufficient? What makes you say that? (Details)	
<b>Drugs, treatment and procedures:</b>		
5	Which treatment guidelines for ARVs do you use in this facility? (Give details as necessary, e.g. national guidelines etc.)?	
6	Have you experienced any stock out in the last months?	
8	What is the turnaround time for getting Laboratory results for tests conducted?	
9	What is the criteria you use for putting a client on ARV treatment for the first time (treatment initiation)?	
<b>Adherence issues</b>		
10	How do you think your patients do in terms of adherence to ARV? What do you think are the main facilitators and barriers to adherence?	
11	How do you think patients' keeping appointments impact on adherence?	
12	Could you estimate the percentage of your patients who you think are sufficiently adherent to ART? (Respondent gives their definition of 'sufficiently adherent'.	

<b>13</b>	We would like to get your views on the following in relation to retention (probe):	
	a. How would you compare adherence between women and men?	
	b. How would you compare adherence between older patients and younger patients?	
	c. How does a patient's educational level affect adherence?	
	d. How do you think that cost to patients influences adherence?	
	e. How do you think the distance to the health facility affects adherence?	
	f. In what way does having or not having a treatment-support partner affect adherence?	
	g. Duration of treatment?	
	h. Side effects?	
	i. Lack of food?	
	j. Knowledge about ART?	
k. Addition of IPT to pill regimen		
<b>14</b>	What are the different ways this facility supports your patients to adhere to their treatment? If yes, is it documented? Can we see it? In what ways is it used?	
<b>15</b>	What are the main challenges you face in supporting your patients to adhere to ART (especially for longer term users)? Suggest breaking it up: <ul style="list-style-type: none"> <li>• Patients who have just begun treatment Etc</li> <li>• How prepared/resourced do you feel in helping them overcome these challenges?</li> </ul>	
<b>Challenges, staff support and defaulter tracking</b>		
<b>16</b>	What are the main challenges you and your colleagues face more generally in your work? (if necessary, prompt re workload, stress, burnout)	
<b>17</b>	Have these challenges changed in any way since you started here?	
<b>18</b>	Is any special support made available to staff engaged in ARV at this facility?	
<b>19</b>	What is your experience with the defaulter tracking systems, (highlighting (effectiveness and efficiency in tracking clients; challenges, opportunities and recommendation for improvement)	
<b>20</b>	Is there anything you would like to see done differently in this facility with respect to providing ART services? If yes, what?	

**Thank participant and ask for any questions, remarks, comments or clarifications.**



**TOOL 6: CLIENT- SEMI STRUCTURED INTERVIEW QUESTIONNAIRE (ART/PMTCT CLIENTS)  
FACE TO FACE AND TELEPHONE INTERVIEW**

<b>Name of Health Facility:</b>	
<b>Date:</b>	
<b>Patient identification number</b>	
<b>Interviewer:</b>	

**Short introductory remarks**

**Introduction of researchers and participants**

- Thank participant for agreeing to participate to share thinking about ARVs and difficulties to take ARVs, factors affecting adherence want to learn from participant.
- Explain purpose of study, purpose of this discussion, reassurance about confidentiality (read the standard confidentiality statement) before proceeding with interviews.

#	Question	Responses
<b>Socio-demographic information on informant</b>		
1	a) Sex	
	b) Age	
2	Educational level (no education, primary, secondary, tertiary)	
3	Who do you live with (spouse, children, parents, house girl etc)?	
4	Employment status (unemployed, self-employed, government, NGO, private sector)	
5	Distance from facility (in time or distance)	
<b>Assessment of adherence and non-adherence</b>		
6	What motivates and demotivate you to take the ARV treatment?	
7	Do you feel that you have all necessary information you need to know about ART? Are there things about ARVS that you would like more? What are they?	
8	What do people in the community say about ARVs? What do people in the community say about people who take ARVs?	
9	How do you feel about the level of support you get from friends in taking ARVs? What about family members? Other people in the community? What kind of support do you get from them?	
10	What are the main challenges you face to take the ARV pills every day at the same time?	
	What do you think could be done to help other people to overcome challenges to taking their medication every day? What tips would you have to overcome them?	
11	What do you think could be done to improve this? (answers to question a)	

<b>Retention in care- Cost considerations</b>		
12	How much do you have to pay to cover your travel expenses when you visit the clinic?	
13	What is the cost of registering at the clinic (if any)?	
14	Do you lose any income as a result of your coming to the clinic? Please specify.	
15	Have you incurred any other costs when you go to your routine clinic visit for your physical exam and to pick up ARVs?	
16	Do you and your family have to give anything up in order to be able to pay for your ART?	
<b>Patient satisfaction with care at the center</b>		
17	How would you rate the quality of care at this clinic in comparison to other clinics you know about? Much better, BETTER, _the SAME, _ WORSE, MUCH worse, _ not sure	
18	Do you feel like the staff listens to any questions or concerns you may have?	
19	Do health workers treat you with respect?	
20	Do you have sufficient privacy during consultation and counseling?	
21	Do you find the environment of the clinic conducive?	
22	How long was your last clinic visit when you last came for review?	
23	How long did you have to wait before being attended to by a Doctor or clinician?	
24	Did you receive any written information?	

Thank participant

Do we want to add anything related to the following which may affect adherence and retention in care?

- Awareness of U-U (stated in terms client can understand)
- Effect of transition to TLD (if applicable)
- Myths or misconceptions about ARVs – are there any we want to probe?