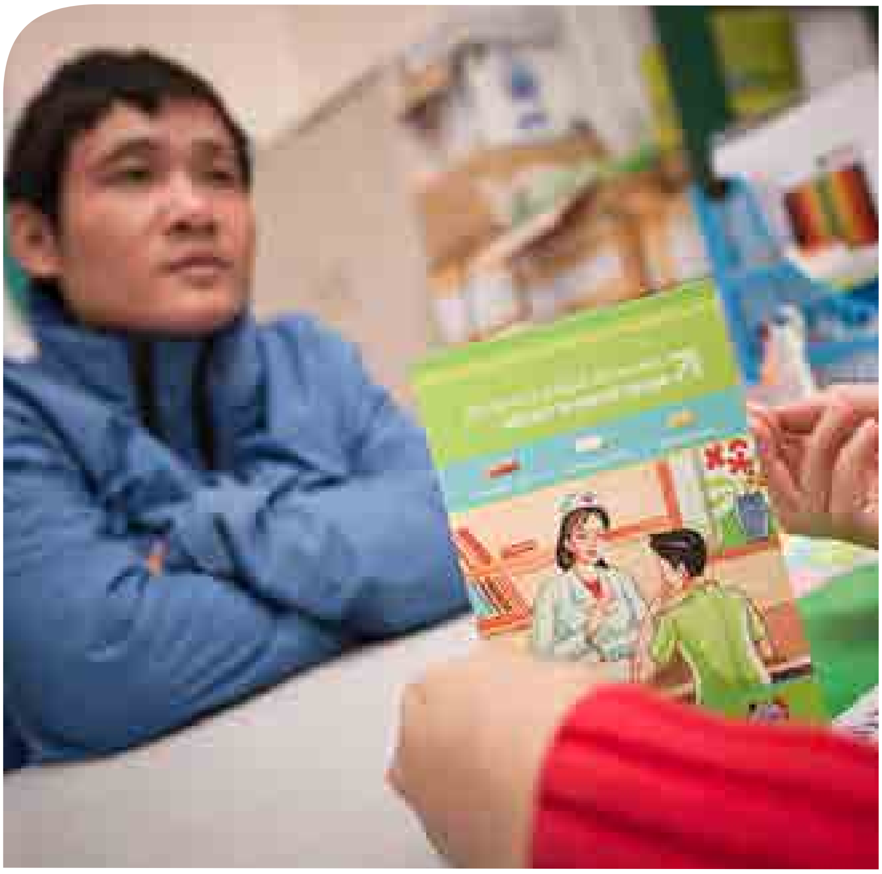

ENROLMENT AND RETENTION IN HIV CARE AND TREATMENT SERVICES IN VIETNAM

Facilitators and Barriers for People Living with HIV

August, 2012

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Acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CHBC	Community and home-based care
C&T	Care and treatment services
FSW	Female sex worker
HIV	Human immunodeficiency virus
HTC	HIV testing and counseling
I	Interviewer
IDU	Injecting drug use
IRB	Institutional review board
LTFU	Lost to follow-up
MMT	Methadone maintenance therapy
MOH	Ministry of health
MSM	Men who have sex with men
NGO	Nongovernmental organization
OI	Opportunistic infection
OPC	Outpatient clinic
P	Participant
PAC	Provincial AIDS Committee
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV/AIDS
UNGASS	United Nations General Assembly Special Session
USAID	United States Agency for International Development
VAAC	Vietnam Administration for AIDS Control
VND	Vietnamese dong
WHO	World Health Organization

Executive summary

This report summarizes a qualitative study of the factors that help ("facilitators") or hinder ("barriers") access to and continuation in HIV care and treatment services for people living with HIV (PLHIV) in Vietnam. This study was conducted in Can Tho and Hai Phong provinces between March and April 2011 by FHI 360 and the Institute of Social and Medical Studies, in partnership with the Vietnam Administration for HIV/AIDS Control (VAAC).

Background and aims

Despite great efforts to increase and retain clients in HIV care and treatment services, about half of all PLHIV in Vietnam are "out of care.".[1] Only 54 percent of those who are in need of antiretroviral therapy (ART) receive it.[1] These data highlight the following issues: (1) a large proportion of PLHIV who know their status are not enrolling in care; and (2) PLHIV who do enroll in pre-ART care are dropping out of care at higher rates than those who are on ART.

This study sought to understand why PLHIV do not access HIV care and treatment services and why PLHIV abandon these services. By identifying the facilitators and barriers, we hope to inform the design of new strategies and tailor existing strategies to improve access and retention in care and treatment services for PLHIV in Vietnam.

Methods

This qualitative descriptive study was conducted in Hai Phong and Can Tho provinces in Vietnam from March 20, 2011 to April 29, 2011. We conducted in-depth interviews (IDIs) with 145 participants from the following groups:

1. **PLHIV (n=76)**
    - PLHIV who had never accessed any HIV care and treatment services (Group A) (n= 15)
    - PLHIV who were previously enrolled in HIV care and treatment services, but have been lost to follow-up for six or more months (Group B) (n= 29)
    - PLHIV who were enrolled in and continuing with HIV care and treatment services (Group C) (n= 32)

2. **Caregivers and family members of PLHIV who had been interviewed in this study (n=22)**

3. **Key informants: program managers, staff members at HIV care and treatment facilities, and those working in the community (n=47)**

Participants were asked to identify the barriers and facilitators that PLHIV faced during enrolment and during continuation of HIV care and treatment services. Participants were also asked to recommend improvements to these services. Interviews were audio-recorded and then transcribed in Vietnamese. Transcripts were analyzed in Vietnamese using qualitative, thematic analysis methods with the aid of Atlas.ti software (version 5.10).

Key findings

A. Socio-demographic characteristics of the PLHIV study participants

- Equal numbers of men and women (N=76) participated in the study; 83 percent were less than 40 years old.
- About 78 percent reported that they had completed primary school.
- About 88 percent of the participants had a monthly household income of less than six million Vietnamese dong (US$287).
- Half of the participants were married or living with a partner.
- About 66 percent of the PLHIV had injected drugs in the past; 40 percent of PLHIV had injected drugs in the past 12 months.
- Half of the participants had a sexual partner who injected drugs.
- About 16 percent of participants had exchanged sex for money or gifts; 11 percent of the participants did so in the past 12 months.

B. Common barriers and facilitators at HIV care and treatment services

	Barriers	Facilitators
Enrolment at HIV care and treatment services	• Perceived stigma and discrimination • Misperception that HIV care and treatment services are only for those who are sick • Poor knowledge of HIV care and treatment services • No time to seek care because of work commitments • A need to travel far for care • Frustration with registration procedures for care • No effective referral linkage between counseling and testing site to the outpatient clinics • Staff members do not follow up with HIV-positive clients from counseling and testing sites to see whether the clients have sought care	Not applicable
Retention in pre-ART care	• Misperception that HIV care and treatment services are only for those who feel ill • Frustration with distance to the outpatient clinic (OPC) • Lack of privacy and confidentiality by healthcare providers at the OPC • Lack of follow-up with patients who missed appointments	• Strong family support • Previous positive experiences with healthcare providers at the OPC • Strong support from peer educators and HIV support groups to visit the OPC and receive pre-ART services
Retention in ART care	• Side effects of antiretroviral (ARV) drugs • Perceived stigma of being on ARV drugs • Difficulties accessing OPCs during clinic operating hours because of work • Missing scheduled appointments to pick up ARV drugs because of the distance to OPC • Poor service quality • Discriminatory attitudes of OPC staff members toward clients • Depression/anxiety and lack of family support	• Strong support from peer educators and HIV support groups • Strong family support • Free access to ART and drugs for opportunistic infections

Recommendations

The following recommendations are based on the study's findings.

Recommendations for policy

Mid-term recommendations:

1. Change policy to allow rapid-testing algorithms for provider-initiated counseling and testing (PITC) and HIV testing and counseling (HTC) services. The expansion of rapid testing should markedly increase access to HIV diagnostic services, reduce delays for treatment access and reduce loss to follow-up.
2. Ensure health-service privacy and confidentiality by developing and enforcing minimum guidelines for health facility infrastructure and staff so that privacy and confidentiality of PLHIV can be assured.
3. Review HIV OPC registration procedures to include the provision of emergency care and treatment services to those without identification cards.
4. Extend opening hours and mobile services to ensure the provision for HIV care and treatment services outside of working hours.

Long-term recommendations:

5. Reduce stigma and discrimination: Conduct research and implement evidence-based programs in communities and facilities.
6. Revise ART prescribing policy to include the provision of ART once every three months.

Recommendations for HIV care and treatment services

Immediate recommendations:

1. Provide materials and training for healthcare workers, peer educators and community outreach workers to help facilitate access and early enrolment. The topics should include the advantages of accessing an HIV service, the importance of starting ART before becoming sick (at a CD4 count of 350) and the benefits of pre-ART care.
2. Information on HIV services should be readily available at all levels of the health care system. Basic information includes: (i) the location of HIV-related services, (ii) the nature of the services, (iii) who provides the services, (iv) who is eligible for the services, (v) the registration procedures, and (vi) how to access the HIV OPC.
3. HTC and peer outreach services must have the resources to refer HIV-positive people to the OPC as soon as possible. Pilot projects that use peers for referral and follow-up could be tracked and monitored.
4. Provide adherence support for special-needs patients, including ART patients who are on the methadone maintenance treatment (MMT) program and ART patients who have an opioid dependence and are not accessing the MMT program. ARV-adherence counseling should include an explanation of (i) side effects, (ii) the management of side effects and (iii) when patients should return to the OPC for management.

Mid-term recommendations:

5. Develop linked referral systems and procedures between: (i) the commune health center and the district and provincial hospitals that provide HIV OPCs, (ii) the HTC services and the HIV OPCs, (iii) peer outreach workers and the OPCs, (iv) the HIV OPCs to rehabilitation centers for drug users (06 centers) and sex workers (05 centers); and (v) HIV OPCs and MMT services.
6. HIV OPCs and community-based care teams and peers need a systematic way to track and locate patients who are lost to follow-up. These patients should have the opportunity to re-enroll in services.
7. Peer educators and community home-based care (CHBC) staff should be empowered to offer a standard package of accompanied referrals, contract training, positive-health counseling and adherence support.

I. Introduction

An estimated 254,000 people are living with HIV/AIDS (PLHIV) in Vietnam. About 169,172 of these people were identified through HIV testing and counseling (HTC) according to the Vietnam Authority of HIV/AIDS control report in 2009. Approximately half of all PLHIV in Vietnam are estimated to be "out of care" — they do not receive any HIV care, treatment or support services. Antiretroviral therapy (ART) is received by only 54 percent of those who need it.[1]

Recent data from the Vietnam Authority of HIV/AIDS (VAAC) highlight several concerns about enrolment and retention in HIV care services. An analysis of HIV care enrolment in one province found that of 4,000 new HIV cases, only 1,500 new patients registered at HIV outpatient clinics (OPC); 62 percent of newly diagnosed PLHIV were not accessing care services.[2] Those who eventually enter HIV care often enroll with advanced disease. Results from a national ART cohort study suggest that PLHIV do come late to care; the mean CD4 count at the initiation of ART was 91cells/microliter — significantly lower than the average among developing countries.[3, 4] Furthermore, the twelve-month retention rate for ART was only 81.2 percent (Do 2010).[3]

These data reveal three major problems: 1) a large proportion of PLHIV (who know their status) are not enrolling in care; 2) PLHIV who do enroll in pre-ART care, withdraw from care at higher rates than those who are on ART; and 3) despite great efforts to improve ART adherence support, the annual ART attrition rate in Vietnam is 18.8 percent.

Pre-ART care: challenges in care enrolment and retention

Pre-ART care is essential to ensure that PLHIV remain as healthy as possible until they are eligible for ART. Pre-ART care includes: (1) routine CD4 counts, (2) prophylaxis, screening and treatment for tuberculosis and other opportunistic infections, (3) the promotion of self-care knowledge and skills (including optimal nutrition, hygiene and HIV/STI prevention), (4) sexual and reproductive health, and (5) access to psychosocial support and mental health services.[4]

However, the attrition rates in pre-ART care are much higher than those for ART.[5] In Ethiopia, 25 percent of pre-ART patients were lost to follow-up compared to 13 percent of patients on ART.[6] The pre-ART patients most likely to withdraw were those with less-advanced disease, those who lived in rural areas, and the newly enrolled. An attrition rate of 54 percent was associated with less-advanced disease, male sex and young age in South African pre-ART care.[5]

Given the low rates of pre-ART enrolment and retention in Vietnam, the Ministry of Health (MOH) has determined that a clinic- and community-based pre-ART package of care is essential. A better understanding of barriers and facilitators is a critical part of developing a pre-ART package that responds to these issues.

Challenges with patient retention and ART adherence

Despite the global increase in accessibility to ART, PLHIV continue to present late to care, which results in higher mortality and morbidity.[7] This is especially true in developing countries, where the median CD4 count at the point of enrollment is well under 200 cells/microliter and the 12-month mortality rate for those on ART ranges from 8 percent to 26 percent.[4]

Interruptions in HIV treatment reduce the immunological benefit of ART and increase AIDS-related mortality and morbidity.[8, 9] High rates of attrition from ART have been documented in a number of countries, especially those in sub-Saharan Africa. However, a recent review of ART retention in Asia found that 65 percent to 88 percent remained on treatment over a 12-month period.[10]

A number of studies have documented challenges to ART adherence. A meta-analysis of 569 studies reported an average non-adherence rate of about 25 percent.[11] Adherence to ART can be challenging because treatment is lifelong. A number of other factors are also associated with poor adherence, including low mobility, depression, drug and alcohol use, mental health problems, symptoms and side effects, stigma, and transport costs to the clinic.

The ART attrition rate is higher when community-based support is not provided as part of a continuum of prevention and care services. The 21-month mortality rate is only 3.5 percent when ART is linked to community-based care services, but as high as 15.5 percent without those linkages.[12] Similar effects were seen on CD4 counts and loss to follow-up (LTFU).

Because patients in pre-ART care face a unique set of challenges, this study compared the issues associated with access and retention in pre-ART and ART care and treatment services.

Qualitative studies on patient uptake and retention in HIV care

There are few qualitative studies on the barriers and facilitators associated with HIV care, especially regarding pre-ART care. Those studies that have been conducted in developing countries focus primarily on sub-Saharan Africa. A meta-ethnography of studies conducted in sub-Saharan Africa found several barriers to ART, including a mistrust of Western medicine; poor quality and poor access to services (e.g., long waiting lines, a lack of confidentiality and privacy, and drug stock-outs); treatment-related costs that compete with short-term and long-term livelihood needs; and a fear of stigma and discrimination.[13]

This report describes the findings of a qualitative investigation of access and retention in pre-ART care and ART services in Vietnam. Our goal was to uncover the individual, structural and social factors that acts as barriers and facilitators for PLHIV who access HIV care and treatment services. The results of this study should help with the design of new and existing strategies to improve access and retention for these services in Vietnam.

II. Study objectives

1. Identify facilitators and barriers for access to HIV care and treatment services among three groups of PLHIV (who are aware of their HIV status):

    - **Group A:** PLHIV who are HIV-positive, but have not accessed pre-ART or ART services at a local MOH or a PEPFAR-funded OPC
    - **Group B:** PLHIV who were previously enrolled in pre-ART and ART services but do not currently receive these services — they are lost to follow up (LTFU)
    - **Group C:** PLHIV who are currently enrolled and receiving pre-ART and ART services

2. Develop recommendations for future interventions to reduce barriers that prevent PLHIV from accessing and using HIV care and treatment services.

III. Methods

1. Study design

We conducted a qualitative, descriptive study involving in-depth interviews (IDIs) with PLHIV, family members/care-givers of PLHIV and key informants. Key informants included program managers, facility-based staff members, community-based staff members and community stakeholders. This approach provided multiple perspectives on the barriers and facilitators associated with HIV care and treatment services. Each in-depth interview lasted approximately 1 to 1.5 hours.

2. Sample and recruitment

We conducted 145 in-depth interviews (IDIs) with the groups of participants described above. The sample size of each group was based on substantiated numbers needed to reach theoretical saturation and variability for a non-probabilistic purposive sampling approach.[14]

2.1 In-depth interviews with PLHIV

We conducted 76 interviews with PLHIV (Table 1).

Table 1: Sample sizes for interviews with PLHIV

Type of interview participant	Group A		Group B				Group C				Total
PLHIV	Male	Female	Male		Female		Male		Female		76
			Pre-ART	ART	Pre-ART	ART	Pre-ART	ART	Pre-ART	ART	
	8	7	7	8	7	7	8	8	8	8	

PLHIV were purposefully selected from the following three groups:

(1) **Group A:** PLHIV who were diagnosed as HIV-positive, but had not accessed HIV care and treatment services within three months of the diagnosis.

Eligibility criteria for PLHIV-group A:

- Women or men, ages 18 years and older
- Living in Hai Phong province or Can Tho province
- Self-identified as HIV positive and having received an HIV-positive diagnosis at least 3 months prior to study recruitment.
- Never enrolled in an HIV OPC or fixed facility that provided care and treatment services

Group A participants were reached primarily through HIV-prevention peer educators, leaders and peers of PLHIV support groups, health care workers from OPCs, community- and home-based care teams.

(2) **Group B:** PLHIV who were previously enrolled in an HIV out-patient clinic (OPC), who in the past received monthly pre-ART or ART care but were no longer receiving care and treatment services and were classified as LTFU. Pre-ART individuals were defined as LTFU if they did not return to the OPC they were enrolled in within six months. ART individuals were defined as LTFU if they did not return to the HIV OPC they were enrolled in within three months.

Eligibility criteria for PLHIV-group B:

- Women or men, ages 18 years and older
- Live in (or have received HIV services at an OPC in) Hai Phong province or Can Tho province
- HIV-positive persons who have been enrolled in HIV care and treatment services but have been lost to follow-up.
- Individuals who are pre-ART are defined as lost to follow up if they have not returned to any HIV OPC within six months of their last visit. Individuals on ART are defined as lost to follow-up if they have not returned to a HIV OPC within three months of their last visit. So, if a client transferred to another HIV OPC, he or she is not lost to follow-up and is not eligible for inclusion in group B.

Group B participants were recruited by peer-outreach workers, PLHIV support groups and their networks, and peers who were using injecting drugs. Study participants also served as a source to reach potential participants for group B.

(3) **Group C:** PLHIV who have enrolled in HIV care and treatment services and were currently receiving HIV care and treatment services.

Eligibility criteria for PLHIV-group C:

- Women or men, ages 18 years and older
- Live in (or have received HIV care and treatment services at an OPC) in Hai Phong province or Can Tho province
- PLHIV, both on ART and pre-ART, who have enrolled in HIV OPC and are currently retained and receiving services.

Group C participants were reached through HIV OPC pre-ART and ART OPC registers.

We purposely recruited male and female PLHIV, sub-divided into those who are currently receiving pre-ART or ART care. Staff members from HIV OPCs were approached to help with the recruitment of clients.

2.2 In-depth interviews with key informants

Interviews were conducted with key informants who were program managers and facility-based staff members such as PAC staff, OPC staff, MMT staff, community health-based care (CHBC) staff members, PLHIV support-group members, and peer educators. We conducted 47 interviews (Table 2).

Table 2: Sample sizes for interviews with key informants

Type of interview participant	Total
Program managers and facility-based health care workers: • 10 from different OPCs • 4 from provincial preventive medicines centers • 3 from HTC • 4 from MMT clinics • 4 from prevention programs (for people who inject drugs, MSM, and FSWs) • 1 from a PAC	26
Community stakeholders and health care workers in the community • 8 commune health care staff • 13 peer educators and home-based care team members	21
Total	**47**

Eligibility criteria for key informants:

- Women or men, ages 18 years and older
- Program managers and facility-based health workers, including:
  - Program managers (from Provincial AIDS Center (PAC) or Provincial Health Services (PHS))
  - Adherence counselors and physicians (from HIV care and treatment OPCs)
  - HTC counselors from HTC sites
  - Doctors and counselors from MMT clinics or drop-in centers for drug users.

- Community-based health workers, commune health staff and community-based organizations/peer support groups:
  - Community and home-based care team members
  - Commune health staff members who are in charge of communicable diseases (including HIV) from a high-prevalence commune
  - PLHIV support-group leadership
  - Prevention peer educators and outreach workers
  - Peer support-group members in MMT clinics

Key informants were identified through discussions with staff members at the following organizations and groups: Vietnam Administration for HIV/AIDS Control (VAAC), PEPFAR HIV Care and Treatment program, Provincial AIDS Committee (PAC), HIV testing and counseling (HTC) sites, HIV care and treatment OPCs, PLHIV support groups, community and home-based care (CHBC) networks, methadone maintenance therapy (MMT) clinics and prevention outreach programs.

2.3 In-depth interviews with family members and caregivers of PLHIV

We also interviewed 22 people who were family members or caregivers of PLHIV (Table 3).

Table 3: Sample sizes for interviews with family and caregivers of PLHIV

Type of interview participant	Group A	Group B	Group C	Total
Family and caregivers of PLHIV	6	8	8	22

Eligibility criteria for family members and caregivers of PLHIV:

- PLHIV have consented to have caregivers approached for inclusion in the study
- Women or men, ages 18 years and older
- Family members and caregivers (parents, spouses, siblings, friends, children), ages 18 years and older

2.4 Recruitment procedures

Step 1: Recruiters received a list of potential participants (as outlined above). Recruiters contacted and screened potential participants, using the eligibility criteria mentioned above. Recruiters briefly introduced the study objectives and invited potential participants to meet the interviewers.

Step 2: Potential participants who agreed to meet the interviewers were introduced by the recruiters. Interviewers checked the eligibility criteria and invited the potential participants to take part in the study. We then obtained the participant's informed consent.

Step 3: Interviews were conducted when the participants gave their consent, at a time and location agreed to by the participants.

Family members and caregivers of PLHIV were recruited with the following procedure. PLHIV in groups A, B and C who were enrolled in the study were asked whether we could invite their family members or caregivers to participate in the study. If the participants agreed, their family members or caregivers were then contacted by recruiters according to the procedures described above.

3. Study sites

The study was conducted in Hai Phong and Can Tho provinces, which represents provinces in Southern and Northern Vietnam. The study site selection was discussed jointly with VAAC and USAID/PEPFAR. The two provinces were selected using the following rationale:

(i) Both provinces have HTC clinics, HIV Care and Treatment OPCs, PLHIV support groups, CHBC networks, MMT clinics and prevention outreach programs.
(ii) Both provinces have many HIV care and treatment programs for PLHIV and clinics for MMT where participants could be recruited.
(iii) Neither province had many patients from other provinces seeking HIV care and treatment services (who would be difficult to trace in case they were LTFU)
(iv) Both provinces have reasonable commitments and capacity at the PACs, reasonable geographic scale for study logistics, and both are administratively accessible.
(v) Both provinces have prevention and care/treatment programs, which are supported by a variety of PEPFAR and non-PEPFAR partners.
(vi) Both provinces have a reasonable number of HIV care and treatment services, but the uptake of these services is lower than expected.

Two study sites were chosen in each province: an urban district and a peri-urban district. The descriptions of each of the two provinces as well as the urban and peri-urban districts chosen are as follows:

Hai Phong is a coastal city, about 90 kilometers (km) east of Hanoi. It is the third largest city in Vietnam, and the country's second largest industrial center. Hai Phong has an area of 1,507.57 km^2 and an estimated population of 1,857,641 by the end of 2010.[15] According to the Hai Phong PAC, 9,560 people were infected with HIV by October 2010; about half were AIDS patients and 5,077 had died. Injection drug use accounted for more than 43 percent of the HIV infections.

Since the 2005 implementation of the ARV treatment program in Hai Phong 13 OPC sites had provided ARV treatment for 3,834 PLHIV by the end of 2010. Hai Phong has 15 districts (7 urban districts and 8 peri-urban/rural/island districts). Two districts (Le Chan and Thuy Nguyen) were selected for the recruitment of study participants in Hai Phong province. Le Chan district is a densely populated urban center, whereas Thuy Nguyen is a peri-urban district, about 30 km from the center of the city.

Can Tho is considered the most important center for economics, culture, science and technology in the Mekong Delta region. With an estimated population of 1,200,276 in 2010[15], Can Tho is the biggest city in the Mekong Delta River. It has an area of 1.389,59 km^2 and is located on the south bank of the Hau river, which is about 169 km away from Ho Chi Minh City.

According to the Can Tho Provincial HIV/AIDS Center, 4,426 people had been infected with HIV in Can Tho by June 2011. Approximately 1,811 were AIDS patients and 1,262 had died. Since the 2006 implementation of the ARV treatment program in Can Tho, six OPC sites had provided ARV treatment for 1,280 PLHIV by the end of 2010. Can Tho has 9 districts (5 urban districts and 4 rural districts). Two districts (Ninh Kieu and Thot Not) were selected for this study. Ninh Kieu, an urban district at the center of the city, has the highest number of PLHIV (about 43 percent) in the city. Thot Not is a peri-urban district, about 45 km from the center of the city.

4. Data collection

4.1 Data collectors and training

The data-collection team consisted of eight interviewers from the Institute of Social and Medical Studies. With strong backgrounds in public health and social services, the data collectors had experience conducting in-depth interviews and facilitating focus-group discussions. They also had conducted research with other marginalized groups, people who used injecting drugs, female sex workers (FSWs), and men who have sex with men (MSM).

The data-collection team received a four-day training on in-depth interview techniques, basic knowledge about HIV care and treatment, ethical issues, study protocol and procedures. The team was also familiarized with IDI guides for each participant groups.

During the training, the data collectors conducted mock interviews with each other, then practiced using the IDI guides with PLHIV who were invited to the training for pilot interviews. The PLHIV were informed that these were practice sessions designed to train the interviewers and test the IDI questions.

4.2 Two rounds of data collection

We conducted two rounds of data collection: The first round involved 37 IDIs in both provinces; the second round, involving 108 IDIs, was conducted two to three weeks later in both provinces.

Table 4: Two rounds of data collection

Type of participant	IDIs conducted in round 1	IDIs conducted in round 2	Total IDIs conducted/ total IDIs as planned
PLHIV Group A	2	13	15 / 16
PLHIV Group B	9	20	29 / 32
PLHIV Group C	12	20	32 / 32
Key Informant	8	39	47 / 48
Caregiver	6	16	22/ 24
Total	**37**	**108**	**145/ 154**

The two rounds of data collection allowed the research team to work on preliminary coding of the transcripts after the first round. We were able to improve the IDI guides as needed. Our experience in the first round also helped us to identify any concerns and retrain the interviewers.

5. Data management and analysis

Audio recordings were transcribed verbatim into Vietnamese. The first few transcripts from each interviewer were reviewed in detail by trained and experienced staff members who provided feedback on interviewing techniques (e.g., adequacy of probing, appropriate linking of topics). This feedback provided additional training to interviewers and improved the quality of the data collection.

Electronic files (e.g., transcripts) were password protected and stored on a secure, password-protected computer; hardcopies of the data were stored in a locked file cabinet or drawer. Hardcopies of the demographic questionnaire, transcripts, and other notes taken during each interview were kept in a corresponding envelope, which was stored in a locked file cabinet.

Transcripts were analyzed using a qualitative thematic analysis method. The Vietnamese transcripts were read and re-read by the data analysts to become familiar with the interview, correct any error, identify recurrent themes and areas for future probing, and to make adjustments to the interview guides.

A preliminary codebook was developed, based on the objectives of this study, the interview topic domains and the emergent themes. All data analysts were trained on the codebook and the coding process. New codes were added to the codebook during the ongoing analysis. The codebook was used to apply codes to passages of text in the transcripts.

The data analysis team identified and discussed the major themes identified and the sub-themes that emerged, and how the data could be presented. The data and key findings from each code were summarized. Finally, all data were brought together to uncover relationships between key themes and to develop an organizational structure for data presentation to respond to the objectives of the study. We used Atlas.ti (version 5.2) as a qualitative research software program.

IV. Ethical considerations

Research ethics approval was received from FHI 360's Protection of Human Subjects Committee (PHSC) and the Ha Noi School of Public Health institutional review board (IRB).

All staff members successfully completed FHI 360's *Research Ethics Training Curriculum*. We obtained oral informed consent from all interviewed participants. At the end of each interview, the PLHIV study participants were provided with information about HIV care and treatment services and the contact information for the facilities. Participants also received information about support groups and other HIV care and treatment services available in the local area.

Interviews were conducted in a private place to make it difficult for other people to listen to what was being said during the interview, at a location agreed upon by the participant.
We collected basic demographic information, such as age, education, marital status and occupation with the aid of a demographic questionnaire. The participants' names were not collected, but all participants were assigned an ID number.

The names and contact information of key informants were collected with their permission. This information was only used for possible follow-up, including additional research questions, requesting recommendations for the study, or to provide a copy of this report (if it is approved for distribution).

V. Findings

In findings section of this report, we first present key socio-demographic characteristics of different participant groups. This will be followed by the following three sections: (i) barriers to ever accessing HIV care and treatment services; (ii) barriers and facilitators to retention in pre-ART care; (iii) barriers and facilitators to retention in ART treatment services.

1. Socio-demographic characteristics of study participants

1.1 Socio-demographic characteristics of PLHIV study participants

A total of 76 PLHIV participated in this study, with equal numbers of men and women. About 83 percent were less than 40 years old. About 78 percent had completed primary school. About 8 percent of the participants had a monthly household income of less than 6 million Vietnamese dong (equivalent to US$287.00). Half of the participants were married or living with a partner. About 66 percent of the PLHIV had used injecting drugs in the past; 40 percent had done so in the past 12 months. Half of the participants had a sexual partner who used injecting drugs. About 16 percent had exchanged sex for money or gifts in the past; 11 percent did so in the past 12 months.

Table 5: Socio-demographic characteristics of the PLHIV study participants (1)

Characteristics	Group A (n=15)	Group B (n=29)	Group C (n=32)	Total (%) (n=76)
Gender				
Male	8	15	16	39 (51%)
Female	7	14	16	37 (49%)
Age				
18 – 29	8	10	9	27 (36%)
30 – 39	4	16	16	36 (47%)
≥ 40	3	3	7	13 (17%)
Marital Status				
Single	6	8	2	16 (21%)
Unmarried but living with partner	2	3	3	8 (11%)
Married	5	8	18	31 (41%)
Divorced/separated	1	4	5	10 (14%)
Widowed	1	6	4	11 (14%)
Ethnicity				
Kinh	14	26	30	70 (92%)
Other	1	3	2	6 (8%)
Resident/Migrant				
Resident	14	25	31	70 (92%)
Migrant	1	4	1	6 (8%)
Religion				
No religion	14	22	16	52 (68%)
Buddhism	1	4	9	14 (18%)
“Hoa Hao”	0	1	5	6 (8%)
Christian/Catholics	0	2	2	4 (5%)
Education				
Did not go to school (illiterate)	2	1	3	6 (8%)
Primary school or under	4	3	5	12 (16%)
Secondary school (grade 5-9)	6	14	17	37 (49%)
High school (grade 10-12)	3	8	5	16 (22%)
University, college, post-graduate	0	3	2	5 (7%)
Occupation				
Farmer	1	1	4	6 (8%)
Government officer	0	1	1	2 (3%)
Entertainment staff	0	1	0	1 (1%)
Shop keeper	1	0	0	1 (1%)
Own business	0	6	12	18 (24%)
Other*	13	20	15	48 (63%)

Table 5: Socio-demographic characteristics of the PLHIV study participants (2)

Characteristics	Group A (n=15)	Group B (n=29)	Group C (n=32)	Total (%) (n=76)
Household monthly income (VND)				
< 2 million	6	5	11	22 (29%)
2 - 4 million	4	15	12	31 (41%)
4 - 6 million	4	4	4	12 (16%)
> 6 million	1	5	3	9 (12%)
ARV status				
Pre - ART	N/A	14	16	30 (40%)
ART	N/A	15	16	31 (41%)
Have ever				
Injected drugs	14	22	15	51 (67%)
Sold sex	4	5	3	12 (16%)
In the past 12 months, have ever				
Injected drugs	10	14	7	31 (41%)
Sold sex	2	5	1	8 (11%)
Have sex partner injecting drugs	**9**	**16**	**11**	**36 (47%)**

*Note: *Other occupations included hired laborers, maids, housewives, "xe om" drivers, and unemployed.*

1.2 Socio-demographic characteristics of family members andcaregivers of PLHIV

In addition to 76 PLHIV, 22 caregivers were interviewed. More than a third were male (Table 6). About 61 percent of the caregivers were 25 to 50 years old, the rest were older (range: 53 – 70 years old). The majority of the caregivers were married.

Table 6: Socio-demographic characteristics of the family members/caregivers of PLHIV (1)

Characteristics	Care givers % (n=22)
Gender	
Male	8 (36%)
Female	14 (64%)
Age	
25 - 50	13 (61%)
≥ 50	9 (39%)
Marital status	
Unmarried but living with partner	1 (5%)
Married	17 (77%)
Divorced/separated/widowed	4 (18%)
Ethnicity	
Kinh	100%

Table 6: Socio-demographic characteristics of the family members/caregivers of PLHIV (2)

Characteristics	Care givers % (n=22)
Resident/migrant	
Resident	21 (95%)
Migrant	1 (5%)
Occupation	
Farmer	4 (18%)
Student	4 (18%)
Other*	14 (64%)
Education	
Did not go to school (illiterate)	2 (9%)
Primary school or under	3 (14%)
Secondary school (grade 5-9)	7 (32%)
High school (grade 10-12)	9 (40%)
University, college, post-graduate	1 (5%)

** Other occupations include: construction worker, housewife, retiree, cook, truck driver, and laborer.*

2. Barriers to accessing HIV care and treatment services

Barriers to accessing HIV care and treatment (C&T) services were identified from 15 interviews with the PLHIV group A participants (seven males and eight females), from 6 interviews with their caregivers/family members, and 47 interviews with key informants.

Group A PLHIV participants were primarily users of injecting drugs, the partners of people who use injecting drugs, and female sex workers. Half of the PLHIV group A participants had known their HIV status in the past year, whereas the rest had known their status for at least three years (some for eight to ten years). About two thirds of the PLHIV participants reported that they had been advised to attend C&T services by a peer educator or an outreach worker. However, none had ever accessed HIV care and treatment services.

2.1 Findings from PLHIV and their caregivers or family members

Interviews with the PLHIV group A participants revealed many factors associated with their delay in seeking HIV care and treatment services. The three most common barriers included: (i) perceived stigma; (ii) misperception that HIV care and treatment services are only for those who feel sick; and (iii) a lack of knowledge of HIV care and treatment services. Some participants also mentioned economic barriers and policy-related barriers.

Stigma and discrimination

Perceived stigma

Perceived stigma was the most important barrier to accessing HIV care and treatment services among PLHIV. All participants in group A had a fear of being stigmatized and discriminated against should their family members or others learn that the participant was HIV positive. A large proportion of participants in group A used injecting drugs or were the spouses of people who used injecting drugs. These participants were particularly fearful about stigma and discrimination because they faced the double stigma associated with HIV and drug use.

About half of the study participants (8/15) said that they were afraid to seek HIV care and treatment services because others would know their HIV status and discriminate against them.

These quotes provide some examples:

> *Interviewer (I): Yes, you find that medicine (ARV) is good, why do you not register for treatment?*
> *Participant (P): I am afraid of being seen by some people that I know there, they would tell others in the village."* (Male, living with HIV, group A participant, Can Tho)
>
> *I am afraid of being seen by other people, they would say 'what kind of disease she has and why she comes here every month to get medicines' One time, when I just stepped out of the clinic, a stranger inside asked 'What kind of medicine is it?' It would be good if they don't tell anyone, but when I am not their close friend, they would tell others.* (Female, living with HIV, group A participant, Can Tho)
>
> *For that reason, many people may be scared to go there. Because, they are afraid of being seen by other people when they go there for treatment of syphilis, then others will ask what disease or why they go there, etc.* (Female, living with HIV, group A participant, Hai Phong)
>
> *I: If there is another site for treatment not [name of OPC] site, will you register for treatment?*
> *P: I am not ready, still afraid.*
> *I: There are other sites far from here, for example in Cai Rang district or in Thot Not or Binh Thuy, will you register for treatment?*
> *P: I do not dare to go anywhere as I am afraid of being seen by people that I know.* (Male, living with HIV, group A participant, Can Tho)

Interviews with caregivers/family members of PLHIV group A also revealed that self-stigma and perceived discrimination by health care staff members discouraged PLHIV to access HIV care and treatment services.

> *I: Now, there are many cases who have the disease [HIV/AIDS] but not go to OPC for registration and treatment, could you tell me the main reasons for that?*
> *P: In my opinion, partly because they themselves feel stigma, and they are afraid of being left out…. It means that they are afraid of discrimination, and they do not know how they will be treated when they get there. They also wonder whether the care there is good or not. Generally, I am afraid too.* (Caregiver of person living with HIV from group A, Hai Phong)

Several PLHIV hide their HIV status because they fear losing their jobs.

> *I: Why do you not tell other people [that you are HIV positive]?*
> *P: I am afraid that it will affect my work.*
> *I: How does it affect?*
> *P: I am afraid of losing my job, being unemployed.* (Female, living with HIV, group A participant, Hai Phong)
>
> *I: Are there other reasons that you do not go for treatment?*
> *P: I am afraid of not being able to continue my work, people will say I have the disease [HIV], then they will not allow me to work* (Male, living with HIV, group A participant, Can Tho)

Experiencing discrimination and breach of confidentiality by health care providers

While all participants in group A shared perceived stigma related to their HIV infection, some PLHIV reported that they actually experienced stigma and discrimination from health care providers. Unfriendly attitudes from some health service providers discouraged them from visiting the OPCs.

> *I: What did Mr. X [a health care staff member] counsel you when you went there?*
> *P: He asked me about the disease. Mr. X seemed to just have worked there for a short time so his manner was not good. I stood up and went home.*
> *I: Could you tell me why his manner was not good?*
> *P: He asked me why I had the disease, I did not know. He asked if I injected drugs. I said that I had injected drugs once or twice, then I quit. He seemed to look down on me. I was angry so I left.* (Male, living with HIV, group A participant, Can Tho)

Breach of confidentiality is another issue that some PLHIV experienced. Information about PLHIV is strictly confidential and health staff members are responsible for ensuring the confidentiality of their patients. However, not all health staff members strictly follow this requirement.

PLHIV lose trust in health care providers when they experience a breach of confidentially and also suffer from stigmatization. A man, living with HIV(group A participant in Can Tho) shared the following:

> *P: The general health clinic sent us to the commune health station. At that time, the doctor X [name of doctor] working there is my neighbor. He knew I had it [HIV]) but he did not keep it to himself. Instead, he told others in the village.*
> *I: How did you feel when doctor X told it to other people?*
> *P: Angry, I felt annoyed. He is a doctor, he should keep it to himself but he told other people.*
> *I: How did people treat you?*
> *P: They did not want to sit, talk and drink with me anymore.*

Perception that HIV care and treatment services are only for those who are sick

Participants said that because they were feeling healthy, they did not feel that they needed to seek HIV care and treatment services. This belief was another common reason for the delay in seeking care.

Eight out of 15 interviewed PLHIV group A participants stated that they felt healthy so they did not need any HIV care and treatment services. The majority believed that they only needed care and treatment services when they became weak.

> *I was told that having this kind of disease [HIV] I should go to the clinic where I would get free treatment. But at that time, I was still healthy so I did not go there.* (Female, living with HIV, group A participant, Hai Phong)
> *When I feel I am getting weak I will register for treatment, it is not too late then.* (Female, living with HIV, group A participant, Hai Phong)

> *I: It means that they sent you to other clinics to continue care, is it right?*
> *P: Yes, but I did not go there. I think things are simple. Now I am still healthy, still working normally. While I work, I do not think about the disease [HIV].* (Male, living with HIV, group A participant, Hai Phong)

> *Many times I think my health is not getting worse, frankly speaking, so I do not think I have to go for check-ups. Do you understand? Because I am still healthy, I feel normal inside.* (Male, living with HIV, group A participant, Hai Phong)

> *I: You said your friend used to stay in bed but now he can walk and live normally, it means that his health is better, so why don't you register?*
> *P: I feel I am still healthy, nothing to fear.* (Male, living with HIV, group A participant, Can Tho)

Caregivers and family members consistently noted that the perceptions of PLHIV in group A regarding their healthy status was a barrier to HIV care and treatment. When PLHIV felt healthy, they did not feel the need to seek care and treatment services; they also felt that they did not need to adhere to the drug treatment regimen.

> *I: I would like to ask about him [PLHIV]; he knows about care and treatment service but why does he not go to those services?*
> *P: I do not know. Generally, he said he was still healthy. He does not want to let people know about his status so he does not go there. He is afraid that he cannot follow the strict medicine dosage and regimen like what I am doing. He is not sure to follow those regimens like I do. And he said it would be bad if he quit halfway through. He said he would consider it later. That is why he does not go.* (Caregiver of a person living with HIV from group A, Hai Phong)

> *I think if they were counseled at the HTC, they would agree to go to OPC. However, on the way from HTC to OPC they might have other thoughts and changed their mind. They might think their CD4 counts were still high so they didn't need treatment yet.* (Key informant, Can Tho)

Poor knowledge of HIV care and treatment services

The majority of PLHIV in group A did not know which services are provided at OPCs or where they are located. They often said that no one had informed them about care and treatment services.

> *I: Has he been referred to HIV care and treatment services since he received HIV positive testing result?*
> *P: No. He and his wife used to seek [C&T services] but the site was moved to another place. They have found it now but they do not go there.*
> *I: How is the situation now?*
> *P: The same…..No one has referred them yet. Only if someone instructed them so they would know how to get there.*
> *I: Have you ever heard about the OPC?*
> *P: Not yet. Truly, not yet.* (Caregiver of person living with HIV from group A, Hai Phong)

> *No one told me. Until yesterday I met a friend and she told me. Then, I come here [OPC].*
> (Female, living with HIV, group A participant, Can Tho)

Some caregivers also mentioned that PLHIV did not know where to go for care and treatment services.

> *No. Many people do not know where to go, like I used to. In Hai Phong I did not know at first either. I heard that Nghe An has [OPC] but I didn't know where it is. That is why, many people are afraid of asking about it.* (Female, living with HIV, group A participant, Hai Phong)

Many PLHIV in group A had no information about ARV drugs and were not actively trying to learn about them.

> *I: Have you ever heard about ARV in detail?*
> *P: Not yet. As I am a driver, I am on the road all the time, I hardly hear about it. Sometimes, I watch television, that's all.*
> *I: Have you ever been told about the benefits of ARV by outreach workers, counselors or health workers?*
> *P: Not yet...I only asked about the registration procedures so that I would have information. It will save me time when I want to register in the near future. I did not ask about the medicines.*
> (Male, living with HIV, group A participant, Hai Phong)

Misconceptions about the purpose of ARV drugs were also barriers to obtaining treatment.

> *P: I am afraid that taking medicine [ARV drugs] will kill me.*
> *I: Ah, why are you so afraid?*
> *P: Because, I have been told that the sooner I take the medicine, the sooner I will die.*
> *I: Who told you that?*
> *P: Some of my friends told me.*
> *I: Did they also take medicine or how so?*
> *P: All of them did. One of my friends said even when you take the medicine, you would still die. He has lived with HIV for a long time. I have been told that taking the medicine reduces my blood [volume of blood in the body]. As I am afraid of my blood being reduced, I do not dare to take the medicine.* (Male, living with HIV, group A participant, Can Tho)

Other barriers

Although care and treatment services are provided free of charge in OPCs, several study participants stated that they did not have time to seek care and treatment since they had other priorities in life.

> *I want to arrange everything [my work and family] before I think of focusing on treatment.*
> (Female, living with HIV, group A participant, Hai Phong)

The majority of the male PLHIV were drug users, who worked so they could buy drugs rather than go for treatment.

> *People that I know are drug users. In my opinion, they have to work for money to buy drugs. No one wants to spend their working hours to go for [HIV] treatment although the treatment is free of charge.* (Female, living with HIV, group A participant, Hai Phong)

Frustration with the registration process at treatment centers is another barrier mentioned by five out of 15 of the PLHIV in group A. The documents required for registration caused difficulty for them, since many of them inject drugs. Documents required include an identity (ID) card, residential/household book, and appointment paper. Without these documents, they were barred from registering at OPCs.

> *I did not have any ID card but I had the appointment paper. However, I lost it (appointment paper) when I went there (OPC), I told them my name but they did not see it. They checked for a couple of times but still could not find it. Therefore, even when I had another appointment later on, I did not go back there as I felt frustrated.* (Female, living with HIV, group A participant, Hai Phong)

Caregivers also highlighted frustrations with the registration process and the need to present all the required documents.

> *He [PLHIV] wanted to know about his CD4 count result. But one time . . . when he did not have any ID card with him . . . they [health care staff] made it difficult for him and said he couldn't get his result and sent him home. Even later on when he had his ID card, they still said the same thing. He became really frustrated and sad. He still does not know his [CD4] status.* (Caregiver of person living with HIV from group A, Hai Phong)

> *Not having a residential book is a really big issue and very frustrating. When he [PLHIV] was in the detention/rehabilitation [06] center, his name was removed from the residential book. He is only able to re-register at the commune. Now, even when he has his name on the residential book and an ID card, it is still difficult for him to register at the OPC.* (Caregiver of person living with HIV from group A, Hai Phong)

2.2 Findings from key informants

Key informants were asked about common barriers that prevented PLHIV from accessing care and treatment services. The key informants included healthcare providers at OPCs and HTCs as well as community outreach workers. The following two barriers were the most commonly reported.

First, distances from HTC sites to OPCs can affect the referral and registration of patients.

> *Some people live in a district where there is HTC but no OPC – and they have to travel to another district about 40km away to register. Traveling is difficult for them.* (Key informant, Can Tho)

Second, some key informants mentioned that there is no referral linkage between HTC sites and OPCs. Also, there are no procedures for follow-up with patients who have been referred from the HTC to the OPC.

> *HTC sites do not have staff to take patients to the OPC, so they cannot follow up and see if patients register for care and treatment services or not. Without being followed-up, many patients self-stigmatize and stay away from services and we lose track of them.* (Key informant, Hai Phong)

The connection between OPC staff and peer educators (PEs) and outreach workers (ORWs) is very limited. The poor attitude of some health care staff members toward PEs was frustrating for the PEs. This may hinder referrals of PLHIV from the community to OPCs by PEs and ORWs.

> *…When peer educators bring patients to the clinic, the staff [nurses] in the clinic do not behave in nice manner. They don't say such things like 'thank you,' 'next time please bring your clients to us,' etc. They lack behaviors to appreciate the work of the peer educator. Very few staff have such nice behaviors.* (Key informant, Hai Phong)

3. Barriers to and facilitators of retention in pre-ART care

In this section we describe the barriers faced by PLHIV who were LTFU after enrolment in an OPC and routine pre-ART care. We also describe facilitators that encouraged these people to return for monthly pre-ART care.

These findings are based on interviews with the following three groups: PLHIV on pre-ART care who were LTFU (Group B participants; n=14); PLHIV who were enrolled and receiving pre-ART care (Group C participants; n=16); and key informants (n=47).

3.1 Barriers to retention in pre-ART services from the perspective of PLHIV

Men and women in this study reported various barriers that prevented them from attending pre-ART care and treatment. The three most commonly reported barriers included: (i) the belief that HIV care and treatment services are for those who were feeling ill; (ii) frustration with travel distance and time; and (iii) a lack of privacy and confidentiality at health facilities.

Some other less common barriers included (i) the lack of follow-up by OPC staff members with patients who had missed their appointments; and (ii) patients could not return to the OPC because he or she had been arrested and detained at the 06 center (rehabilitation center for drug users). These barriers are described below.

Perception that HIV care and treatment services are only for those who feel ill

The most frequent reason for not returning back to the OPC cited by the majority of participants and health care providers was the client's perception that HIV treatment is for the "sick." When patients felt healthy (because of their high CD4 counts), they did not find any benefit to visiting the OPC for further check-ups.

> *It was simply because my CD4 count was more than 500 so I didn't need to go back there [OPC]. Later on, if I start to feel weak, I will go back and get my CD4 count tested again and ask the doctor if I need to be on ARV or not. If I need to take ARV, I would do it; if not, I prefer not to take it. My husband said that if you are very weak you need to be on ART, if you feel normal, you don't have to. Taking ART also has some side effects and toxicities.* (Female, living with HIV, group B participant, Hai Phong)

For these participants, going to the OPC is associated with receiving ARV drugs. They perceived that the only benefit of going to the OPC is to receive ARVs, which were not necessary if their CD4 counts were still too high for eligibility.

> *I went to the OPC in order to receive medicine [ART]. I wondered why they did not give me ART when other people got it. Then I asked Mr. X. [a health care staff member], he said that my CD4 count was still high so I did not need to take ART.* (Female, living with HIV, group B participant, Hai Phong)

> *I thought my CD4 count was too high, so even if I went there [the OPC], they would not give me medicines.* (Male, living with HIV, group B participant, Can Tho)

This perception was common in patients according to a key informant from Hai Phong:

> *There are people who need care and support from health care staff at the clinic during certain times. However, when they overcome their problems - they don't feel that they need any more care, and so they do not go back.* (Key informant, Hai Phong)

Frustration with travel distance and time

Several participants said the distance to the OPC was one of the obstacles faced by PLHIV; people needed permission to take time off from work. As one participant stated:

> *In addition, the OPC is far so I need to take a day off to get there. It is difficult to get approval to have a whole day off from work. That's why I feel reluctant to go to the OPC. It is so time consuming.* (Female, living with HIV, group B participant, Hai Phong)

Lack of privacy and confidentiality

Some study participants were concerned about a lack of privacy and confidentiality at the health facilities. The small size of the clinics allow conversations in the counseling or exam rooms to be heard outside those rooms. Some participants also reported that they did not want to be stigmatized because they entered an OPC. For many patients, especially PLHIV, the fear of revealing their status was so high that they were reluctant to go to these facilities for treatment.

> *The examination room is too small, and far too small compared to the number of patients who go there for a check-up. Why are such services not located in more private places? There is a café outside the clinic and people sitting drinking coffee can hear all the conversations going on inside the OPC. They know exactly who has HIV. Why does the clinic have such poor privacy and confidentiality protection? They do not say anything, but they all know it. Anyone who comes to that clinic would think the same.* (Male, living with HIV, group B participant, Can Tho)

> *I saw some people from my commune who had come to the OPC for medicine and I am afraid of being seen by them.* (Female, living with HIV, group B participant, Hai Phong)

Lack of follow-up with patients

Lack of follow-up with patients who missed their appointments reduced patient retention. The PLHIV gave their personal contact information to health care providers and expected that they would be reminded of their appointments. However, in many cases, this did not happen.

> *Actually people here are not active or motivated to follow-up their patients. I gave them both my husband's and my phone numbers, and my address so that they had a few options to reach me. But I have never heard anything from them. If they called us and asked us to come for counseling, for example, I would have come. Unfortunately, in reality, no one has ever called me or followed up with me.* (Female, living with HIV, group B participant, Hai Phong)

Many PLHIV did not know what to expect for pre-ART care from the OPCs and what services were offered. They did not understand what to do at the OPC, so they waited for health care providers to tell them what services could be provided. Some PLHIV also blamed health care workers for not contacting them to offer follow-up services at the OPC.

3.2 Barriers to retention in pre-ART care — findings from key informants

The key informants agreed with some of the barriers mentioned by PLHIV (described above), but they also mentioned that PLHIV who were LTFU during pre-ART were usually males, typically users of drugs. As a health care provider from Hai Phong noted:

> *More males dropped out than females. Male HIV patients were mainly drug users. They could steal something and were arrested. If they did not steal anything, they had to work very hard to earn money for drugs. In both cases, they were not able to go back to OPC for check-ups.*

It was a challenge to follow-up with OPC patients who were in the Pre-ART phase. During this phase, patients are often in good health because of a high CD4 count; they were not required to visit the OPC for a monthly check-up or to receive ARV drugs. Pre-ART patients often worked far from home and did not go back for their scheduled appointments. Also, because of the long interval between appointments (every three months), OPC staff members did not keep track of who was being treated. The OPC staff members followed-up with patients by calling them if they did not show up at the clinic after 6 months.

> *In general, when registering for patients who are addicted, we always ask them to come back here any time if they have any problems with their health. However, it is hard for us to know if they are retained in are or not. We only know if they are retained or have dropped out of treatment if they are on ARV. When taking the drug treatment [ARV], they have to come here monthly, so we know if they have dropped the treatment. If we don't see them coming for drugs, we know that they have dropped the treatment. When they are waiting to be eligible for [ARV] treatment, we are not able to know because they are in good health, and still go to work normally.* (Key informant, Hai Phong)

3.3 Facilitators for retention in pre-ART care

According to PLHIV (mainly from group C participants in pre-ART care), major facilitators that kept them coming back to the OPC included strong family support, previous positive experiences at the OPC with the health staff, and strong encouragement from peer educators.

Family support is crucial to a patient's decision of taking care of themselves, enrolling and continuing in pre-ART care. Many study participants mentioned that family support had helped them to live their lives with the hope for a better future. One participant said:

> *My mom encouraged me; she said that even though I have the disease there is medicine to keep people like us alive longer…* (Male, living with HIV, group C participant, Can Tho)

Family members encouraged PLHIV to go for check-ups and stay healthy.

> *My family encouraged me a lot. They took me to Sai Gon for a check-up because at that time there was no care and treatment service in Can Tho.* (Male, living with HIV, group C participant, Can Tho)

> *My mother encouraged me to go there [the OPC] to get ART. If I do not have money, she will give it to me.* (Male, living with HIV, group C participant, Hai Phong)

A good experience with health care workers (or providers) and peer educators also encouraged PLHIV to return to the health facility (OPC).

> *All staff there [OPC] from juniors to seniors are kind, caring and enthusiastic. When they give me ART, they were very kind, I don't know how others report their experiences at the OPC but for me I have always had a very good experience"* (Female, living with HIV, group C participant, Hai Phong)

Receiving support from peer educators is one of the main factors that help patients stay in the program. Many PLHIV reported that peer educators and PLHIV support group members provided counseling and encouraged them to go to the OPC. Some even reported that the peer educators/ PLHIV support group members took them to the OPC for registration. Peer educators are not only a source of moral support, they also serves as role models for PLHIV.

> *When I knew I was HIV positive, it is was very difficult for me and I couldn't stand up for myself or feel motivated to do anything. Mr. X [name of peer educator] in [name of PLHIV support group] and Ms. Y [name of peer educator] had encouraged me a lot. They [Mr. X and Ms. Y] are also infected with HIV. I can feel that they had such positive attitudes toward living with HIV, receiving support including treatment and being open and looking after others. Since then I have been more open and reach out to other people.* (Female, living with HIV, group C participant, Hai Phong)

PLHIV are often more sensitive and vulnerable because of their HIV status. They need the support of family, friends, and health workers if they are to maintain regular visits to the clinic.

> *I: In your opinion, what should be done to retain people who have registered for treatment?*
> *P: I think it depends on each individual. I myself find that doctors there are very good, friendly and caring.*
> *I: You said it depends on each individual. Is this also related to the attitude of the health workers?*
> *P: No, I have gone to the OPC several times, and the staffs are always very kind.* (Female, living with HIV, group C participant, Hai Phong)

For many study participants, short waiting times, having access to free services, living near the OPC and receiving travel support are additional motivations for them to come back to the OPC.

Waiting time at the clinic is also an important factor. Many participants said that they stopped visiting the OPC because of the long waiting time.

> *I: Do you have to wait for long to see the doctor or other health staff at the OPC?*
> *P: Not at all, it is always quite quick. Sometimes it is crowded, but there are several doctors. The longest wait was about 15 minutes."* (Female, living with HIV, group C participant, Hai Phong)
> *I: When you get to the OPC do you have to wait for long?*
> *P: Not usually. Sometimes when there are many patients I have to wait, but if it is not too crowded they usually see me straight away. If it is crowded, I have to wait for about 15 minutes. I often get priority because I am older than the others.* (Female, living with HIV, group C participant, Hai Phong)

Another motivation for PLHIV to return to the OPC is when they receive travel support:

> *For people living far from there, I have seen that they receive financial assistance for their travel. One time I happened to see that a person from Hung Yen received an amount of 50,000 VND to travel from home to the OPC.* (Female, living with HIV, group C participant, Hai Phong)

We found that many PLHIV were not aware of the benefits provided by the clinics. They needed counseling on what the services were and how they would benefit. Peer educators played critical roles in getting these messages to PLHIV.

> *I plan to go to the OPC soon because the peer educator advised us many times. What he said was very interesting and helpful. I will go to the clinic soon.* (Female, living with HIV, group C participant, Hai Phong)

Interviews with program peer educators and health providers also confirmed that family support helped PLHIV to overcome self-stigma and other obstacles that prevented them from receiving care and treatment. Peer educators and HIV support groups have been important factors in the retention of PLHIV in OPCs. The peer educators identified, encouraged and supported PLHIV so that they would visit and maintain treatment at the OPCs. The importance of peer educators was also recognized by PLHIV and confirmed by health care providers.

4. Barriers to and facilitators of retention in ART care

Findings on barriers and facilitators came from in-depth interviews with PLHIV who had been lost to follow-up for the past six monthsfrom ART care (Group B participantswho were previously in ART care) (n=15), PLHIV who were continuing with their routine visits for ART care (Group C participants in ART care) (n=16) and key informants (n=47).

4.1 Barriers to retention in ART care

Although HIV care and treatment services are free for PLHIV, many obstacles prevent PLHIV – even those who are already on ARV drugs – from continuing to receive proper treatment and follow-up. The PLHIV in our study mentioned the following main obstacles:

- Side effects of ARV drugs
- Perceived stigma regarding being on ARV drugs
- Difficulty picking ARV drugs up from OPCs at scheduled times due to distance from workplace or home
- Misinformation about ARV drugs
- Lack of counseling on adherence to ARV drugs
- Difficulty accessing OPCs during clinic hours
- Distance to OPCs
- Negative and discriminatory attitudes of OPC staff
- Depression/anxiety and lack of family support

We will detail the barriers to HIV care and treatment services below and have separated the findings from three groups of PLHIV as there were some differences across groups. These three groups of PLHIV are:

1) PLHIV who were not using injecting drugs
2) PLHIV who were using injecting drugs
3) Female PLHIV

Findings from PLHIV who were not using injecting drugs

Thirteen interviews with PLHIV who were not using injecting drugs (five men and eight women) suggested that side effects were the most frequent reason for stopping ART.

> *When taking ARV drugs, I felt so uncomfortable. I could hardly sleep. It made me hot inside. My lips were so dry and I got some blisters in my mouth and had constipation.* (Male, living with HIV, group B participant, Can Tho)
> *I got a rash all over my body. I was so scared and I called Dr. X to ask about it. He told me it was due to side effects of the ARV drugs and advised me to buy some medicines [i.e., anti-allergic ones] from the pharmacy to take. I took it and rash got better – but still felt very hot inside my body, and had a terrible headache.* (Female, living with HIV, group C participant, Can Tho)

PLHIV who had already experienced negative side effects of ARV drugs feared taking more, especially if they had had nightmares after taking the drugs.

> *In 2007, I got sick and had to be hospitalized. When I got better, they [doctors] prescribed me ARV drugs. However, when I took them, I felt nausea, vomited and often had nightmare. I was even not able to sleep. I was so scared and stopped taking drugs. I have stopped taking them for about one year.* (Female, living with HIV, group B participant, Hai Phong)

In addition to side effects, stigma associated with taking ARV drugs was an obstacle for PLHIV. Some participants mentioned that they were so afraid of being stigmatized that they had to hide their HIV status in order to keep their jobs and to continue earning a living.

> *I hide (taking medicines) very well, I am scared that if they know I am HIV infected they will no longer ask me to give them rides.* (Male motorbike driver (xe om), living with HIV, group C participant, Hai Phong)

Findings showed that PLHIV who are revealed as HIV-positive or as being on ART can become victims of social stigma and discrimination, as can their family members and associates. This can cause them to become isolated and to lose trust in life and society.

> *There is a lot of stigma… a man who I introduced to the clinic to get ARV has a child who goes to school - no friends play with him, even though the child is HIV negative – they ignore him because his father is an IDU and has HIV. Each month he went to the commune health clinic to get medicine, he went there for treatment and they gave him medicines. Everyone knew he was taking medicines for opportunistic infections and that also meant they knew he had HIV, which made him need such treatment. People in the commune health clinic knew [he had HIV], the commune leaders knew, then all residents in the ward knew, then the schools knew. It has happened as such.* (Male, living with HIV, group C participant, Hai Phong)

Although ART is free for PLHIV, necessary supplements and complementary drugs are not free. In many cases, full treatment is a big financial challenge for PLHIV.

> *At that time I was very weak. I had fever continuously. I had to take many different drugs, not just only this one [ARV]. I took ARV drugs, TB drugs, vitamins and other drugs too. Some medications required intravenous transfusion. Those were very expensive. It cost 1.1 million dong a bottle. You could die if you couldn't afford all these extra medications.* (Male, living with HIV, group B participant, Hai Phong)

Communications related to service costs provided at the OPC were not always clear to PLHIV. Many study participants understood and expected that required tests and HIV treatment would be free once they registered at an OPC.. They were disappointed when they found out that only ARV drugs – and not all costs associated with being on ART – were free. They even had to pay for tests of CD4 counts, which would have been free if the OPCs had sent their blood samples to another site.

Findings from PLHIV who were using injecting drugs

Nineteen interviews with PLHIV who were using injecting drugs (12 men and 7 women) revealed additional barriers to retention in ART care.

First, many PLHIV on ART care who were dependent on opioids found it difficult to remember to take their ARV drugs on time and as they do not tell their families that they are on ARVs, they cannot count on their family to provide support to remind them to take their ARVs on time.

> *It is difficult. When I first started [ART], I often forgot. For example, I took my ARV drugs in the morning, but in the afternoon I had to work to earn money for heroin so I forgot to take it. I was meant to take my ARV drugs at 8 am and 8 pm. However, I had to work at 8 pm so I took medicine at 10 pm instead.* (Male, living with HIV, group C participant, Hai Phong)

> *Drug users have to spend time working to earn money for drugs so they forget to take ARVs... Drug users don't tell their family that they need to take medicines, or ask for help to remember to take their ARVs. Forgetting is very common.* (Male, living with HIV, group C participant, Hai Phong)

Serious interactions between ARV drugs and methadone were another barrier to retention in ART care. Several male participants reported side effects when taking ARV drugs with methadone and chose to discontinue with ARV drugs instead of methadone.

> *The first day I took both ARV and methadone, I felt normal. The second day I took both drugs, I felt something strange happening in my body, it was very uncomfortable. When I took ARV only, I experienced no side effects but when I took the two together, it was unbearable - I felt tired and my body was hot. After two weeks, I was not able to bear it so I stopped ARV. I decided to give up ARV rather than methadone because I was afraid that if I gave up methadone, I would relapse. Following that day I felt much better, so then I stopped taking ARV for a second day. Nothing happened but feeling good again so I gave up ARV completely.* (Male, living with HIV, group B participant, Can Tho)

> *I gave up ARV because I took methadone at the same time. When I took methadone and ART together, it made me feel very hot inside my body. I lost weight. My body was very dry, my lips were cracked, and I got diarrhea too. So I decided to stop taking ARV.* (Male, living with HIV, group B participant, Hai Phong)

Because drug users are often concerned about the availability of money to buy more drugs, many preferred to stop taking ARV drugs rather than stop taking methadone when they experienced interactions between the two.

> *I: Why did you decide to stop taking ART, not methadone?*
> *P: Because from a financial point of view, if I take ART and stop methadone, I have to pay for my heroin. Since both methadone and ART are free of charge, I chose to stop ART and continue methadone so that I can save money instead of paying for drugs (illegal drugs)."* (Male, living with HIV, group B participant, Can Tho)

Findings from female PLHIV

Female PLHIV faced different barriers to HIV care and treatment. Relevant findings were gathered from interviews with 15 female PLHIV (seven in group B and eight in group C). Barriers that women faced included difficulties with access to OPCs, negative and discriminatory attitudes of OPC staff, lack of counseling on drug adherence, and side effects,

Difficulties with access to OPCs

The hours that OPCs were open and the distance to OPCs were main barriers to women's access to the clinics. Study participants reported that they worked during the day and had difficulty accessing the OPC during clinic hours, especially if they worked far from the OPC (sometimes in a different province). This made it difficult to regularly obtain refills for their ARV drugs.

> *When I came back home from work, the clinic was already closed, and it did not open yet when I came in the early morning. It was also closed early at noon and opened late in the afternoon. Thus I was often late for my work to get my drugs. It is definitely closed on Sunday. I wish it opened half day on Saturday or a little bit longer during week day so that I can come [to get drugs].* (Female, living with HIV, group B participant, Hai Phong)
>
> *I knew that when I stopped ARV drugs, my body would get weaker and my CD4 count would go down. However, because my house is far away from the clinic [OPC], and I don't have a motorbike, I couldn't get to the clinic to get help during working hours.* (Female, living with HIV, group B participant, Hai Phong)

Negative and discriminatory attitudes of OPC staff

As many PLHIV had to overcome multiple barriers to get to an OPC, they expected support and a positive experience from OPC staff. The attitudes of the OPC staff also affected a patient's decision on whether to continue services. Also, negative attitudes and behaviors such as reprimanding patients when they admitted that they forgot to take ARV drugs regularly or making them scared would cause them to stop going back to the OPC.

> *I: When you went to [name of an OPC], what did you feel? How was the staff there?*
> *P: So so, they were not enthusiastic.*
> *I: Was there anything that you felt that you were not satisfied about that OPC?*
> *P: One time when I got there. I stepped in to give my paperwork to a young staff. There was an older woman, she was working there. When she saw me she said out loud: 'Ah, this woman is a sex worker! I was totally shocked and ashamed in front of other patients who were taking ARVs right there. She could have said behind my back, but no, she said it to my face!* (Female, living with HIV, group B participant, Hai Phong)

Lack of counseling on drug adherence

Insufficient information, lack of counseling on ARV drug adherence, and misinformation about ART prevented women from taking ARV drugs.

> *I went to counseling place [in OPC]. I asked [about drug adherence] and a staff there answered me. However, I think she was not professional, her answers were not clear to me. She answered me curtly and quickly. It seemed she was not trained so she could not give counseling.* (Female, living with HIV, group B participant, Can Tho)

Side effects

Half of the female PLHIV on ART who were interviewed, reported that they had stopped taking their ARV drugs, and thus stopped going to the OPC, because they had experienced serious side effects.

> *I have been on ARV since 2005. I used 1A therapy. I realized that the muscles on my arms and legs shrank, and my chest enlarged. I was worried about what I would end up looking like if I continued taking ARV drugs. I was very scared... My muscles continued shrinking, my chest enlarging so I had to stop treatment.* (Female, living with HIV, group B participant, Hai Phong)

> *P: I heard a doctor counseling that those drugs [ARV] could delay HIV multiplication, and help us live longer. The doctor also talked about side effects of the drugs.*
> *I: Have you tried?*
> *P: At that time I only took medicines for opportunistic infections. After that I heard my friends said that many patients taking drugs [ARV] experienced muscle shrinkage. I was so scared so I dropped and did not go back [to OPC].* (Female, living with HIV, group C participant, Hai Phong)

Findings from key informants

Key informants (mainly peer educators and health care providers) mentioned obstacles to retention that were similar to those mentioned by PLHIV.

Side effects of ARV drugs, especially after a period of poor adherence, was the top barrier mentioned.

> *He [PLHIV] was scared because he was taking ARV drugs and then he stopped. He thought that if he restarted the ART that it may not be effective, or may even harm his body. He was very scared about restarting ART – that's what he shared with me.* (Key informant, Hai Phong)

According to peer educators, PLHIV may not have received sufficient information about ARV drugs, as the PLHIV were not properly adhering to their drug regimens. Peer educators also said that PLHIV stopped taking ARV drugs if they did not see any difference in their health after taking the drugs or if they forgot several doses.

Sometimes, PLHIV were required to temporarily stop taking ARV drugs because they had tuberculosis (TB) as a co-infection. (The TB had to be treated first.) However, after their TB treatment was completed, these PLHIV did not go back on ARV drugs.

According to health care staff, some PLHIV who had jobs became so frustrated that they would need to take ARV drugs every day for the rest of their lives that they stopped taking them. Others moved away from their hometowns or got jobs in different provinces, so it was very hard for them to go back to the OPC for ART.

Negative attitudes of health care staff and corruption were other barriers to continued treatment in some clinics. One key informant revealed that some PLHIV had to pay money to health care staff if they wanted to receive early treatment.

> *They (health care staff) have negative attitudes toward PLHIV – for example, they do not get close to or touch patients. They scold or yell at them. This would make patients angry, depressed and frustrated. PLHIV would not want to come back to clinics.* (Key informant, Hai Phong)

> *Another reason is corruption. It has happened in some clinics, if you had money you would get treatment early, if you had no money you had to wait for a long time.* (Key informant, Hai Phong)

Finally, the current HIV care and treatment system lacked linkages or referral feedback among commune health centers, HTC centers and OPCs.

> *The district clinic often asked us to refer patients to their clinic for ARV treatment, often the new cases. Recently we also sent patients to their clinic but we did not know if the patient had been treated. They never informed us.* (Key informant, Can Tho)

OPC staff had trouble tracking patients who did not return for drug refills. Also, it was not easy for commune health centers to support OPCs, as they did not know if the patients they referred to the OPCs actually registered at the clinics. The staff at these commune health centers were not informed whether patients were pre-ART or on ART, so they could not remind them to go back to the OPCs.

4.2 Facilitators of retention in ART care

Despite the barriers to retention, PLHIV who remained in ART care identified several facilitators that helped them continue taking their drugs. These facilitators included peer support, family support and free drugs.

PLHIV received significant support from PLHIV support groups and peer educators. Support groups and peers have a key role in encouraging and motivating PLHIV on ART. They can counsel patients and can encourage or remind them to return to the OPC for health checks and refills of ARV drugs.

> *When the patients stop coming for ARV care, the peer educator or community and home-based care teams come to their houses to encourage or advise them to go back to OPC for treatment. For example, [name of peer educator] came to my house and encouraged, and counseled me on the benefits of taking ARV and how it would harm my health if I stopped taking it, so that I understood and decided to go back for treatment.* (Male, living with HIV, group B participant, Can Tho)

PLHIV also received strong support from their families. Family members have a critical role in reminding patients to take their ARV drugs on time and encouraging them to continue taking them despite obstacles.

> *Thanks to my wife [who is also HIV positive]. She took the medicines [ART] and her health got better. She encouraged me 'even when you are addicted you should try to go there to get treatment otherwise you will die soon,' so I went there. At the time I was very weak and my wife had to carry me there [OPC]. Since then I have followed my wife to go there for treatment.* (Male, living with HIV, group C participant, Hai Phong)

> *Regarding finance, we are OK as we are still working. However, in terms of spiritual aspect, generally speaking, without my wife and my child, it is very likely that I would stop [treatment]… Without my wife, probably I would die.* (Male, living with HIV, group C participant, Hai Phong)

Most PLHIV in the study were of lower socioeconomic status. Access to free ART and drugs for opportunistic infections was an important factor that enabled PLHIV to afford HIV care and treatment services.

> *I think receiving free treatment and drugs was very helpful for us because as you know, we are PLHIV, we don't make much money. At the beginning I had to buy drugs because they were not free. I had asked the PE[peer educator] to help buying it for me. It cost me more than three million dong per month – it was very costly. I had to buy them for four or five months then I received drugs for free.* (Male, living with HIV, group B participant, Can Tho)

VI. Recommendations

All study participants were asked for recommendations to help PLHIV better access HIV care and treatment services and continue their clinic visits. Their recommendations are highlighted below, organized according to participant group. Recommendations from the research team are listed afterward.

1. Recommendations to improve access to HIV care and treatment services (Findings from PLHIV group A participants)

Recommendations in this section were gathered from 15 interviews with PLHIV who had never accessed HIV care and treatment services (group A participants). Table 7 summarizes the recommendations, including the percentage of participants who responded that the specific recommendation would help them access services.

Table 7: Summary of recommendations to improve access to HIV care and treatment services, as suggested by PLHIV who had never accessed these services (n=15)

Recommendation	Response rate* (n=15)
Have staff or volunteers follow up with PLHIV.	80%
Have home-based care staff or other health workers distribute ARV drugs to the homes of PLHIV.	60%
Provide mobile HIV care and treatment services.	40%
Extend clinic hours.	33%
Make ART and other HIV care and treatment services available at the commune level.	33%
Provide transport stipends to cover transport costs.	27%
Provide more training to OPC staff so they can better support patients.	27%
Provide ARV drugs to patients every 3 to 6 months instead of once a month.	27%
Make more staff available at OPCs.	13%
Train home-based care workers to provide support and to visit patients at home to advocate for positive health and support drug adherence.	7%

** Study participants were asked from a list of recommendations which recommendations would assist them with gaining access to HIV care and treatment services. Multiple responses were permitted.*

The top recommendation was to have staff or volunteers follow up with PLHIV (80 percent). This would help determine if the PLHIV had enrolled in HIV care and treatment services, link PLHIV to appropriate services, or remind PLHIV of their clinic visits. The second most frequent recommendation was to have home-based care staff or other health care providers deliver ARV drugs to the homes of PLHIV (60 percent).

> *I: What do you think about having health care staff or volunteers to follow up with PLHIV?*
> *P: I think it will be good.*
> *I: Why that?*
> *P: Because they can call us... If we forget to go to clinic for checkup they can call and remind us. I think it would be too good, and very enthusiastic.* (Male, living with HIV, group A participant, Hai Phong)

> *I: What do you think about having home-based care staff bringing drugs to patients' houses?*
> *P: I think it will be even better.*
> *I: Why that?*
> *P: When we need medicines and if there is someone to bring medicines to us, I think it would be too good.*
> *I: Is there anything inconvenient to patients' family?*
> *P: In my opinion, there is nothing inconvenient. They come to give drugs, to help, not to bother.*
> (Male, living with HIV, group A participant, Can Tho)

Although many group A participants agreed with having home-based care staff deliver ARV drugs to the homes of PLHIV, some group A participants who had not yet disclosed their HIV status did not agree. This was because they did not want their family and neighbors to know that they were HIV infected.

About one-third of group A participants supported the following strategies: providing mobile HIV care and treatment services, providing travel support, extending clinic hours, and having ART and other HIV care and treatment services available at the commune level.

> *I think it is good (having mobile HIV care and treatment service) because it would help many other patients like me, when I am too weak to go [to OPC], if there was such mobile service, itwould help and I would feel safe and comfortable.* (Female, living with HIV, group A participant, Hai Phong)

2. Recommendations to improve access and retention in HIV care and treatment services (Findings from PLHIV group B participants)

Recommendations in this section were gathered from 29 interviews with PLHIV who had previously received HIV care and treatment services but who had been lost to follow-up for the past six or more months (group B participants). Table 8 summarizes the recommendations, including the percentage of participants who responded that the specific recommendation would help increase access and retention in HIV care and treatment services.

Table 8: Summary of recommendations to improve access and retention in HIV care and treatment services, as suggested by PLHIV who had received ART but were lost to follow-up (n=29)

Recommendation	Response rate* (n=29)
1. Provide mobile HIV care and treatment services.	66%
2. Have staff or volunteers follow up with patients who are lost to follow-up.	55%
3. Provide transport stipends to cover transport costs.	52%
4. Provide more training for OPC staff so that they can better support patients.	45%
5. Train home-based care workers to provide support and to visit patients at home to advocate for positive health and support adherence.	41%
6. Provide ARV drugs to patients every 3 to 6 months instead of once a month.	38%
7. Have home-based care staff or other health workers distribute ARV drugs to the homes of PLHIV.	34%
8. Extend clinic hours.	31%
9. Make ART and other HIV care and treatment services available at the commune level.	31%
10. Make more staff available at OPCs.	17%

** Study participants were asked from a list of recommendations which recommendations would assist them with improving access to HIV care and treatment services. Multiple responses were permitted.*

The top three strategies for improving access and retention were to (i) provide mobile HIV care and treatment services so that PLHIV have better access to these services (66 percent), (ii) have health care staff or volunteers follow up with PLHIV registered at the OPC (55 percent) and (iii) provide patients with stipends to cover the cost of transport to the OPC (52 percent).

> *I: What do you think about mobile HIV care and treatment services?*
> *P: It could be good for those who do not have means of transportation or their houses are far way. Mobile services will be more accessible for them. As the services are brought closer to them, it will encourage PLHIV.* (Female, living with HIV, group B participant, Hai Phong)

> *I: When you did not come back to the OPC for checkup, did anybody from the OPC call you to remind you of the checkup?*
> *P: Yes, they called me one or two times.*
> *I: What do you think about the OPC maintaining this practice?*
> *P: It should be maintained... because sometimes patients travel elsewhere or they forgot, if the OPC calls to remind them, they might ask their family members or authorize someone to go to the OPC to pick up drugs for them.* (Female, living with HIV, group B participant, Hai Phong)

> *I: Do you think that there should be support for transportation costs of PLHIV?*
> *P: Yes, because they have such a disease, their income is just enough for food, they have no money to go back and forth for the treatment. Poor them!* (Male, living with HIV, group B participant, Can Tho)

3. Recommendations to improve access and retention in HIV care and treatment services (Findings from PLHIV group C participants)

Recommendations in this section were gathered from 32 interviews with PLHIV who were currently receiving HIV care and treatment services (group C participants). Table 9 summarizes the recommendations, including the percentage of participants who responded that the specific recommendation would help increase access and retention in HIV care and treatment services.

Table 9: Summary of recommendations to improve access and retention in HIV care and treatment services, as suggested by PLHIV who were currently on ART (n=32)

Recommendation	Response rate* (n=32)
1. Provide transport stipends to cover transport costs.	53%
2. Provide mobile HIV care and treatment services.	50%
3. Have staff or volunteers follow up with patients who are lost to follow-up.	38%
4. Provide more training for OPC staff so they can better support patients.	25%
5. Extend clinic hours.	25%
6. Make ART and other HIV care and treatment services available at the commune level.	25%
7. Have home-based care staff or other health workers distribute ARV drugs at the homes of PLHIV.	19%
8. Make more staff available at OPCs.	16%
9. Provide ARV drugs to patients every 3 to 6 months instead of once a month.	13%
10. Train home-based case workers to provide support and to visit patients at home to advocate for positive health and support drug adherence.	13%

** Study participants were asked from a list of recommendations which recommendations would assist them with improving access to HIV care and treatment services. Multiple responses were permitted.*

Most PLHIV group C participants had the same top three strategies for improving access and retention as the PLHIV group B participants had: (i) provide transport stipends (53 percent), (ii) provide mobile HIV care and treatment services so that PLHIV have better access to these services (50 percent) and (iii) have health care staff or volunteers follow up with PLHIV who are registered at the OPC (38 percent).

> *P: We want to have support such as monthly travel support so that PLHIV can come to the OPC to get drugs.*
> *I: How much support per month do you think?*
> *P: Just support for the gas. For example, for those who live far away, they can be provided with some more money than those who stay closer to clinic. The support is just to help cover gas cost for them.* (Female, living with HIV, group C participant, Hai Phong)
>
> *I think it should be it [to give PLHIV some money to cover transportation fee]. My family's economic status is better than several others. However, sometimes I still did not have money. I felt sorry for my friend, who was very sick and poor, on the days that he had to pick up medicine, he did not have money so he had to borrow money from others to travel to the clinic.* (Female, living with HIV, group C participant, Can Tho)
>
> *I: What do you think about having mobile care and treatment service? Can a mobile team go to communes?*
> *P: I think it would be very good. There are many patients taking drugs [ARV] but they do not understand much. If health care staff go to their family to explain, their family would understand and better support patients. I think it would be good. Take me as an example, I am taking drugs, but my mother does not know about the drugs. She only knows that I have to take medicine twice a day, but she does not know of its side effects.* (Female, living with HIV, group C participant, Can Tho)
>
> *I: Do you think if we should encourage this [health care staff or volunteers follow up with patients]?*
> *P: Yes, I do. For example, if they change my schedule to pick up drugs today, they should call and inform me. It is also good for patients as it reminds patients to pick up drugs so they would not miss doses. I know there were several people who were scheduled to get drugs but they did not show up as scheduled. They came some days later.* (Female, living with HIV, group C participant, Hai Phong)

4. Recommendations to improve access and retention in HIV care and treatment services (Findings from caregivers and family members of PLHIV)

Recommendations in this section were gathered from 22 interviews with caregivers and family members of PLHIV in the study. Table 10 summarizes the recommendations, including the percentage of caregivers and family members who responded that the specific recommendation would help increase access and retention in HIV care and treatment services.

Table 10: Summary of recommendations to improve access and retention in HIV care and treatment services, as suggested by caregivers and family members of PLHIV (n=22)

Recommendation	Response rate* (n=22)
1. Have staff or volunteers follow up with patients who are lost to follow-up.	64%
2. Provide transport stipends to cover transport costs.	55%
3. Provide mobile HIV care and treatment services.	45%
4. Provide more training for OPC staff so they can better support patients.	41%
5. Train home-based case workers to provide support and to visit patients at home to advocate for positive health and support drug adherence.	36%
6. Extend clinic hours.	32%
7. Have home-based care staff or other health workers distribute ARV drugs to the homes of PLHIV.	27%
8. Make ART and other HIV care and treatment services available at the commune level.	27%
9. Provide ARV drugs to patients every 3 to 6 months instead of once a month.	27%
10. Make more staff available at OPCs.	14%

** Study participants were asked from a list of recommendations which recommendations would assist them with improving access to HIV care and treatment services. Multiple responses were permitted.*

Caregivers and family members of PLHIV recommended the same top three strategies as PLHIV group B and group C participants did: (i) have health care staff or volunteers follow up with PLHIV who are registered at OPCs (64 percent), (ii) provide transport stipends (55 percent) and (iii) provide mobile HIV care and treatment services so that PLHIV have better access to these services (45 percent).

> *I: What do you think about having some staff following up with patients to see who came back for checkup, who did not. The staff would then call patients and/or visit patients at home?*
> *P: I think it would be good. There should be someone following up with patients. If patients do not return for check up, they can encourage them to come for checkup and pick up drugs.*
> *I: Would there be any inconvenience?*
> *P: I don't think so.* (Caregiver, Hai Phong)
>
> *It would be very good [having travel support for patients], for example they have to travel to pick up drugs. If they work they can have money, if not they have to get money from their parents or family. If they have motorcycle, they still have to pay for the gas. If no motorcycle, they have to take "xe om"[motorbike taxi] and have to pay. It is not easy for them so travel support would be very good.* (Caregiver, Can Tho)
>
> *I: What do you think about mobile HIV care and treatment services?*
> *P: If they can provide that, it would be great. I am just afraid that they cannot do it. If they cannot provide good mobile services then patients would not appreciate it, and later health care providers would feel frustrated.* (Caregiver, Hai Phong)

5. Recommendations to improve enrolment and retention in HIV care and treatment services (Findings from key informants)

Key informants were asked for recommendations to increase enrolment of PLHIV into HIV care and treatment services and recommendations to retain them in these services. Interviews were conducted with 47 key informants. Table 11 summarizes the recommendations for increasing enrolment, and Table 12 summarizes strategies for increasing retention in HIV care and treatment services.

Table 11: Recommendations to increase enrolment of PLHIV into HIV care and treatment services, as suggested by key informants (n=47)

Recommendation	Response rate (n=47)
For people who use injecting drugs	
Increase communication about ART enrolment procedures and adherence.	6%
Have peer educators approach people who use injecting drugs and encourage them to visit the OPC.	4%
Link OPCs to MMT clinics to identify PLHIV and help them enroll at OPCs.	4%
Link OPCs to 05/06 centers (rehabilitation centers for sex workers and drug users respectively) to identify PLHIV and help them enroll at OPCs.	2%
Link OPCs to self-help groups.	2%
For men who have sex with men	
Develop mass media communications about ARV care and treatment and tailor them to the MSM population.	4%
Provide financial support for peer leaders to encourage members' participation.	2%
Improve face-to-face individual counseling or counseling via telephone on ARV care and treatment.	2%
For female sex workers	
Increase communication with and encouragement from peer educators.	9%
For general PLHIV	
Increase communications on ARV care and treatment.	11%
Increase communication with and encouragement from peer educators.	6%
Require health care workers to have positive and non-discriminatory attitudes toward PLHIV.	4%
Establish OPCs in main hospitals.	2%
Improve patient counseling skills.	2%
Assist with job placement and setting up businesses.	2%
Patient monitoring and management strategies	
Monitor patients.	32%
Provide case management	21%

Table 12: Recommendations to increase retention of PLHIV in HIV care and treatment services, as suggested by key informants (n=47)

Recommendation	Response rate (n=47)
Combine home-based care with OPCs to provide services.	28%
Provide mobile HIV care and treatment services.	28%
Provide case management	23%
Extend clinic hours.	19%
Provide ARV drugs at commune health centers.	17%
Increase the number of OPC staff.	13%
Train OPC health workers (home-based care teams) to provide patients with better services.	11%
Encourage family members of PLHIV to support enrolment and retention in HIV care and treatment services.	11%
Provide transportation support for patients.	11%
Train home-based care teams to support treatment adherence.	9%
Provide ARV drugs to patients every 3 to 6 months instead of once a month.	4%
Get support from self-help groups.	2%

Nearly one-third of the key informants agreed that patient monitoring and case management strategies are needed to improve enrolment. Case managers would help follow patients, identify their needs and link them with service providers in the community. They would meet regularly with patients at the patients' homes to assess their progress and adjust their care as needed. Case managers would also work closely with medical staff to monitor client health, and they could support trained community volunteers in providing home-based care.

> *I: According to you, is there any solution or recommendation to reduce patients lost follow up?*
> *P: It would be easy if it is informed to a case manager. Case manager can check whether patient takes drugs or not, and if patient is still in the community or moves to another place.*
> (Key informant, Can Tho)

Some health care providers suggested strengthening the linkages between OPCs and outreach workers or community staff to improve enrolment. Others emphasized the importance of peers in encouraging PLHIV to attend the OPC.

> *I: In your opinion, what should the OPC do to attract more PLHIV to register for care and treatment services?*
> *P: I think there should be stronger linkages between the OPC and outreach workers and community staff. Outreach workers and community staff can introduce and refer patients to the OPC. There should be channels to provide patients with information about the services in the OPC. Outreach workers and commune health staff are one of those channels. If they do not refer patients to the OPC, patients may not know about it as well as not be aware of registration procedures. It will be difficult for them. That's why there should be closer linkages.* (Key informant, Hai Phong)
>
> *First, patients need someone to share and talk with them like dear friends. That person would persuade them to go to the OPC. They should be assured of the confidential and private services at the OPC. They should be given information about the location, address of the OPC. If they need*

> *help, that person can take them to the OPC. For example, if they do not want to go to an OPC close to their house, they can go to another OPC in another location.* (Key informant, Hai Phong)

According to health care providers, linkages between OPCs and outreach workers or self-help groups (clubs) would not only help to enroll more patients but also help to retain them in care and treatment services.

> *First, we need to connect with each other to have more information about patients, for example where they live, what are their current situations. After that, OPC and clubs should regularly communicate with each other. For example, a patient comes to our OPC for counseling and treatment, our counselors should ask if he has enrolled in any club (for PLHIV). If not, we should introduce him to join a club. When he goes to the club, he would be instructed about drug adherence, and provided with psychological counseling. It would be helpful for them. However, I think OPC and those clubs should communicate, exchange information regularly about those patients, of course with the consent from patients. I believe with this connection/linkage, it will be more effective (to retain them in care and treatment).* (Key informant, Hai Phong)

> *To improve the service in the OPC, we can provide some travel support to patients who come to take ARV drugs. This would help to cover for the gas. Or there should be some nutrition support for patients.* (Key informant, Hai Phong)

6. Recommendations by the research team

Based on the study participants' recommendations for improving access and retention in HIV care and treatment services, the research team and the FHI 360 program team developed the following recommendations for policy and for HIV care and treatment services.

6.1 Recommendations for policy

Mid-term recommendations:

1. Change policy to allow rapid-testing algorithms for provider-initiated counseling and testing (PITC) and HIV testing and counseling (HTC) services. The expansion of rapid testing should markedly increase access to HIV diagnostic services, reduce delays for treatment access and reduce loss to follow-up.
2. Ensure health-service privacy and confidentiality for PLHIV by developing and enforcing minimum guidelines for health facility infrastructure and staff so that privacy and confidentiality of PLHIV can be assured.
3. Review HIV OPC registration procedures to include the provision of emergency care and treatment services to those without identification cards.
4. Extend opening hours and mobile services to ensure the provision for HIV care and treatment services outside of working hours.

Long-term recommendations:

5. Reduce stigma and discrimination: Conduct research and implement evidence-based programs in communities and facilities.
6. Revise ART prescribing policy to include the provision of ART once every three months.

6.2 Recommendations for HIV care and treatment services

Immediate recommendations:

8. Provide materials and training for healthcare workers, peer educators and community outreach workers to help facilitate access and early enrolment. The topics should include the advantages of accessing an HIV service, the importance of starting ART before becoming sick (at a CD4 count of 350) and the benefits of pre-ART care.
9. Information on HIV services should be readily available at all levels of the health care system. Basic information includes: (i) the location of HIV-related services, (ii) the nature of the services, (iii) who provides the services, (iv) who is eligible for the services, (v) the registration procedures, and (vi) how to access the HIV OPC.
10. HTC and peer outreach services must have the resources to refer HIV-positive people to the OPC as soon as possible. Pilot projects involving the systematic use of peers to facilitate and assist with the referral and follow up of those just diagnosed until they are enrolled in the OPC should be tested.
11. Provide adherence support for special-needs patients, including ART patients who are on the methadone maintenance treatment (MMT) program and ART patients who have an opioid dependence and are not accessing the MMT program. ARV-adherence counseling should include an explanation of (i) side effects, (ii) the management of side effects and (iii) when patients should return to the OPC for management.

Mid-term recommendations:

12. Develop linked referral systems and procedures between: (i) the commune health center and the district and provincial hospitals that provide HIV OPCs, (ii) the HTC services and the HIV OPCs, (iii) peer outreach workers and the OPCs, (iv) the HIV OPCs to rehabilitation centers for drug users (06 centers) and sex workers (05 centers); and (v) HIV OPCs and MMT services.
13. HIV OPCs and community-based care teams and peers need a systematic way to track and locate patients who are lost to follow-up. These patients should have the opportunity to re-enroll in services.
14. Peer educators and community home-based care (CHBC) staff should be empowered to offer a standard package of accompanied referrals, contract training, positive-health counseling and adherence support.

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