

PLHIV and Health Service Access

A Participatory Research



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Akronim

AIDS	Aquired Immuno-deficiency Syndrome
APCASO	Asia Pacific Council of AIDS Service Organization
APN+	Asia Pacific Network for people living with HIV/AIDS
ARV	Antiretroviral
CD4	Class Difference 4
CST	Care, Support & Treatment
Exit interview	Interview right after clients received services
FDG	Focus Discussion Group
GAKIN	Social Security for Poor Family
GIPA	Greater Involvement of people living with or affected by HIV & AIDS)
HAART	Highly Active Anti Retroviral Therapy
HIV	Human Immuno-deficiency Virus
IDU	Injecting Drug User
JPS	Social Security Network
MAP	Monitoring AIDS Pandemic
NAC	National AIDS Commission
Napza	Narkotika dan zat adiktif
NGO	Non Governmental Organization
PAR	Participatory Action Research
PKBI	Perkumpulan Keluarga Berencana Indonesia (Family Planned Association)
PLHIV	People Living with HIV
PMTCT	Prevention Mother To Child Transmisson
RSCM	Rumah Sakit Cipto Mangunkusumo (Cipto Mangunkusumo Hospital)
RSKO	Rumah Sakit Ketergantungan Obat (Drug Addiction Hospital)
SKTM	Surat Keterangan Tanda Miskin (A letter to inform that the person lives in a poor condition)
STI	Sexually Transmitted Infection
TBC	Tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary Coueseling and Testing
VL	Viral Load

Foreword

Secretary National AIDS Commission



The National AIDS Commission (NAC) welcomes the publication of this report and recognizes its role as an important reference towards improving healthcare services for people living with HIV and AIDS (PLHIV). Improving healthcare services as part of the efforts to improve PLHIV's quality of life is clearly one of the main objectives of the national response to AIDS.

Aside from being a reference, the National AIDS Commission considers this participative research as an experience valuable for the greater involvement of PLHIVs, as set about in the Greater Involvement of People Living with and affected by AIDS (GIPA) principle.

In the National AIDS Commission's agenda, the involvement of people living with HIV is of utmost importance in the response to the AIDS epidemic. Presidential Regulation No. 75/2006 clearly stressed for the participation of a national PLHIV organization to be a member of NAC, so that PLHIV's involvement in policy making for the response to AIDS in Indonesia could be optimized.

We understand that there are many obstacles still to be faced, and that ideal participation models for PLHIVs have yet to be found, but this participative research, bringing together PLHIVs, healthcare service providers and academics, is a breakthrough in this effort.

The National AIDS Commission supports cooperations that aim to increase effectivity and quality of the AIDS response. We hope that leadership from the civil community, and from PLHIV organizations in particular, would be effective in changing the course of the epidemic in Indonesia.

We thank everyone who have supported this effort, and particularly those who have worked hard in providing data and review for this research.

A handwritten signature in black ink, appearing to read 'Nafsiah Mboi', written in a cursive style.

Dr. Nafsiah Mboi, SpA, MPH
Secretary National AIDS Commission

Foreword



Ever since the Paris AIDS Summit in 1994, where 42 countries declared the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), the Joint United Nations Program on HIV/AIDS (UNAIDS) has promoted the GIPA principle and supported organizations in their work to monitor and promote the greater involvement and active participation of people living with HIV.

UNAIDS recognizes that people living with HIV (PLHIV) and PLHIV organizations are key driving forces in the AIDS response, where their participation gives personal power and immediacy to AIDS efforts that drives and inspires others into action.

Personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic, and their participation is critical to ethical and effective national responses to the epidemic.

For these reasons this report on *People Living with HIV (PLHIV) and Health Service Access: A Participatory Research* makes an important contribution in the effort to make healthcare services more accessible and friendlier for PLHIVs.

People living with HIV understand each other's situation better than anyone and are often best placed to counsel and advise, and to represent the needs of people with HIV in decision- and policy- making forums.

It was with this in mind that the research was conducted, beginning with recruitment of 12 PLHIVs and 11 NGO researchers from across Java. The team surveyed healthcare facilities, interviewed other people living with HIV, and organized focus group discussions to get a comprehensive view of how PLHIVs are being treated in public healthcare facilities.

While it should not be regarded as an overall general picture of the quality of PLHIV-related services across the country, the collective experiences presented here provide a glimpse of what needs to be done to make care, support and treatment services more accessible to those living with HIV, as well as those being affected by HIV.

A handwritten signature in black ink, appearing to read 'Jane Wilson'.

Jane Wilson, PhD.
UNAIDS Country Coordinator
Jakarta

Executive Summary

HIV/AIDS infection in Indonesia has been officially recognized since 1987. UNAIDS/WHO (2005) estimated that there were between 53,000 and 180,000 persons living with HIV/AIDS in the country. Currently, infection among Injecting drug users (IDUs) constitutes 48% of all reported cases (MOH, 2005). In some provinces, IDUs contribute to more than 60-90% of all reported cases. Most infections occurred among the young and productive members of the society.

Considering all of the consequences, the government has made a serious commitment to improve surveillance as well as Care, Support, and Treatment (CST). By the end of 2005, ART was provided for 10,000 out of 15,000 PLHIVs who needed this treatment through 3 by 5 programme. In addition, preventive measures were scaled-up, especially access to clean needles, substitution therapy, Voluntary Counselling and testing (VCT), medical care, and support groups. This study is an attempt to reflect on the experiences of PLHIVs in accessing those services as well as an attempt to involve and improve PLHIV in participatory research.

Twelve people living with HIV (PLHIVs) were recruited along with 11 NGO researchers. They were trained in participatory research and survey methods and assigned to collect data among their peers and service providers in their respective residences in Jakarta, West Java (Bandung Sukabumi, Tasikmalaya), Central Java (Semarang and Salatiga), East Java (Surabaya, Malang) and DI Yogyakarta. Two hundred and seventy (270) PLHIVs 172 (64%) males, 77 (29%) females, and 21 (8%) transgender participated in the survey and 94 out of 270 participated in exit interviews. Fourteen focus group discussions (FGDs) were conducted, 109 service providers were interviewed, and 11 facilities were observed. The mean age for male respondents was 28, for females 31. and for transgender 25 years old.

The survey indicated that the most common co-infection which currently effect respondents was Hepatitis C, especially among male respondents who were largely IDUs. Two other common infections for all respondents were STI and TB. When asked about significant others who provided support for them, sexual partners and friends were their closest allies except for male respondents who felt that their parents did supported them. In line with that, respondents indicated that sexual partners and close friends were the ones who knew their HIV+ status. More male respondents mentioned parents who knew their serostatus than other respondents. Information gathered through FGD confirmed that PLHIV were often reluctant to tell their parents and siblings due to feelings of guilt and shame. They were afraid that they would upset their family members resulting in further isolation and exclusion from the family. When asked whether they knew the sero status of their sexual

partners, the majority of respondents, except females, indicated that they did not know their serostatus.

Most available services were mentioned by respondents, but VCT, Medical Care, antiretroviral (ARV), CD4 counts, and support group were the most frequently known services. Important services such as PMTCT, oral substitution, and Hepatitis C treatment were less known to the respondents. Respondents also indicated that the last time they accessed those services was less than a month before the survey. When asked with whom did they access these services, the most common response was by him/herself followed by accompanied by friends. In fact, FGD and exit interview revealed that many of them were accompanied by an NGO staff.

Why do they have to be accompanied by others? Over half of the respondents indicated fear and shame as their major constraints. FGD revealed that PLHIV were concerned that during their treatment or medication they might be spotted by relatives or friends whom they did not like to share their problems. Other than that, they were afraid that they might be treated inappropriately by the service providers due to their status and illnesses. The other constraints in accessing those services were distance and transportation costs and complicated administrative procedures.

One hundred and sixty four (61% of respondents) had received ARV treatment. In fact many of them have received ARV over a year ago and most of them accessed ARV in a hospital although many of them received ARV from outreach workers or case managers, buying it from pharmacies¹, clinic in an NGO, and physicians' private practice. Altogether 161 respondents (98%) said that they were currently still receiving this treatment.

When asked about constraints in accessing ARV, respondents indicated that they often need the money to fulfill their drug dependency by buying drugs rather than spending the money for transportation and other expenditures. They also complained about the complexity of the procedures, especially when they had to go to several locations for related services, such as VCT and HIV testing or ARV and CD4 counts and Viral Load diagnosis. Some of them were concerned with the benefits of the treatment, sustained availability of drugs, and side effects.

Respondents were asked to provide us with constructive ideas to improve services. The most common suggestions were to improve accessibility by setting up more locations which provide services, to provide more subsidies to lower costs, and to integrate services as a one stop service center. They were especially concerned with the costs of laboratory procedures in CD4 count and Viral Load diagnosis, and the costs of Opportunistic Infection treatment and care in hospital. Clients in prisons and female PLHIVs were especially concerned with lack of supports for their special needs. In addition, they also suggested that service providers also get appropriate

¹By exchanging coupons provided by donor agencies.

education to help them understand better about HIV/AIDS and addiction and their appropriate standard operating procedures for treatment and care. Respondents believed that such education would help them deal with their clients. Since NGOs have been instrumental in helping them meet their essential needs, they suggested having more NGOs involved.

Exit interviews were able to reveal that most services were delivered appropriately and professionally according to existing standard. Some clients, however, found that the procedures were too complicated, service providers were not patient and polite, standard operating procedures (SOP) was not transparent, and locations too far or difficult to find.

From the service providers' point of view, we learned that most of them cherished their professions, especially being able to help other people who were marginalized, grateful for the opportunities to enrich knowledge and skills, and being a part of an important government program. Some of them, however, expressed their complaints for lack of institutional and government support, overloaded and lack of compensation or incentives, having to deal with very complex problems and (often) non-cooperative clients, and not being able to see the future of their professional careers.

In the recommendations, we suggest that as PLHIV we should be able to reflect our own needs, worries, and to what extent the community and government should assist us. As far as government assistance is concerned, we identified a lot of rooms for improvements. One of them is to scale up accessibility of CST services to increase coverage of programs. In addition to that is to meet the challenge of integration of services and to improve the standard quality of services. We also suggest that government should be able to deal with the limitation of program delivery through the Block Grant financing so that services become universally accessible without residential barriers. In the recommendation, we also like to see more community involvement, including PLHIV, to improve both access and quality of services. Public education through the media should be intensified and sustained to ensure that all segments of society are aware of the problems and are empowered to provide timely and necessary assistance.

1 The Problems of HIV/AIDS in Indonesia

A. HIV/AIDS as an epidemic of the young generation

HIV infection in Indonesia has been officially recognized since nineteen years ago. During the period, the trends (see Fig.1) keeps going up. Although the reported cases were under 6000. It is estimated that there are 53,000 – 180,000 persons living with HIV in the country (UNAIDS/WHO, 2005). Most of them are male (82%), and the last six years, reports were dominated by infection among IDUs.

Similar to the trends found in other Asian countries (China, Thailand, Vietnam, etc), HIV/ AIDS occurred among young generation. Fig.2 below indicates that almost 80% of the cases reported are from those aged below 40 years – moreover, 60% of the PLHIV are aged below 30.

Figure 1:
Total number of cases in the last 19 years (As of 31 Desember 2005)

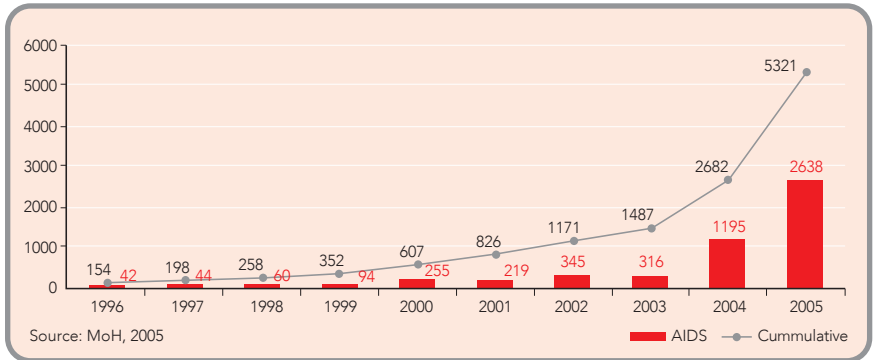
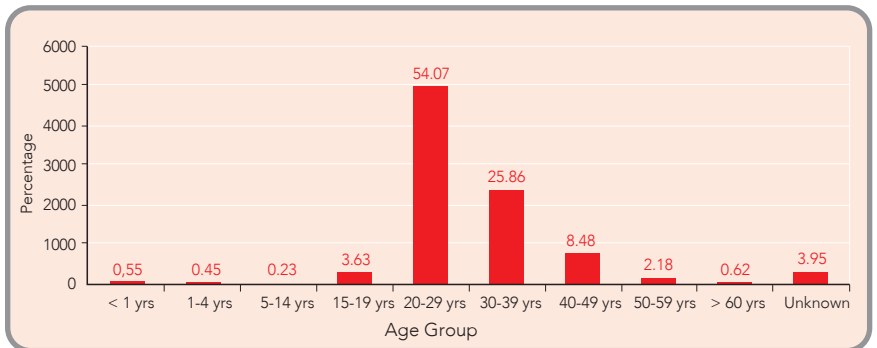


Figure 2:
Number of cases by age group



²2002 MoH estimate is 90.000-130.000 HIV infection (Day, 2005).

The fact that the epidemic affects young generation is disturbing as they belong to productive and highly educated group. Due to their characteristics, they are very important for their country. (MAP, 2004; KPA, 2003). If PLHIV health needs are neglected, their quality of life will be deteriorating drastically in line with their worsening health condition. It means that when the infection get more serious, PLHIV will be vulnerable to many diseases and cannot share their contribution to his family and community effectively.

After 19 years of living with HIV/AIDS, many of PLHIV in Indonesia have already died, or are suffering from opportunistic infections that may threat their life. It is estimated that at present, approximately 15,000 PLHIV need ARV and the government has launched a programme to provide ARV for 10,000 PLHIV by the end of 2005. Such a modest target seems to be in line with WHO's 3 by 5 programme. (WHO,2004).

B. Need for Care, Support and Treatment (CST)

Improvement and advance in HIV/AIDS medication and treatment, as well as the treatment of its opportunistic diseases have improved life expectancy and the quality of life for PLHIV. Brazil, for example, has invested a large amount of money in its health systems in order to save the young generation affected by HIV/AIDS. Brazilian Constitution of 1988 has demonstrated its commitment to its people by developing *Free Universal Health Care*. With the policy, Brazilian PLHIV could access Zidovudine under the state subsidy in 1991, and since 1996, PLHIV are entitled to receive a package of HAART (Highly Active Anti Retroviral Therapy). By the end of 2003, approximately 123,000 PLHIV in the country have received HAART. This decision has absorbed 2.3% of the health budget, but within 5 years, the policy has cut the overall health cost by 80%. This decrease has benefitted health sector and given a concrete positive impact on the quality of the people's life. (Mesquita, 2004). Indonesia is entering the critical period in the development of the HIV/AIDS epidemic, as Brazil's did in the 1997/1998 when the epidemic is no longer concentrated among vulnerable / special groups only but as indicated in the *Monitoring Aids Pandemic* report MAP, 2004 the epidemic if rampant in a special group, like IDU group, will definitely spread out to the community at large through their sexual partners or other contacts. Indonesia is currently known for its low prevalence, but since the end of the last millennium, the

world has turned its attention to the country due to the fact that the infection among IDU has been increasing (UNAIDS, 2004; KPA, 2003). In order to anticipate changes in how HIV spread, i.e. from sexual transmission to combination between sexual transmission and injecting drug use and prevent them from spreading out to the general population, National Strategy 1994 was revised. This revision, (KPA 2004) includes the intervention strategy that does not only involve the policy to minimize risk but also the establishment/ endorsement of the role of KPA and social organization. In addition, the role of PLHIV should be recognized and endorsed and more specific commitment should be made in order to develop *Care, Support, and Treatment (CST)* service.

C. The Role of PLHIV (People living with HIV)

PLHIV participation/ involvement is a critical issue that has been reiterated by activists and international organizations. PLHIV are not the object of intervention but the subject. As the subject of intervention, the potential roles of PLHIV in sharing their significant experiences in all aspects of intervention must be recognized, appreciated, and utilized as much as possible. (APN+ & APCASO, n.d.y). In many countries, the role of PLHIV in developing medical and technical knowledge in understanding HIV and PLHIV contribution in providing support to their fellow PLHIV and PLHIV roles in controlling HIV/AIDS in their community has been part of the best practices.

PLHIV contribution in supporting peer PLHIV in Indonesia has been long known and according to APN+ (2004), it is regarded as best practice of GIPA in the field (*Greater Involvement of People with or affected by HIV/AIDS*). However, many PLHIV have not yet been involved in intervention efforts – especially in research, monitoring and evaluation. PLHIV involvement in such issues shall give significant contribution as there are many research and development programmes conducted by experts and bureaucrats that may not be able to understand the life of PLHIV. PLHIV involvement will help bureaucrats and programme planner to *fine-tune* the implementation of PLHIV research results in order to develop a programme that is sensitive to PLHIV needs.

chapter **2** Methodology

2.1 Research Objectives

This research is conducted in order to achieve the following three objectives which will serve the long term goals of developing better programmes and improving the capacity of PLHIV to contribute to the development of such programmes.

The objectives are:

1. To develop competency among activists in conducting empirical research targeted at PLHIV.
2. To reflect PLHIV's experience in using CST (*Care, Support and Treatment*) services.
3. To explore various issues that support or impede the provision of CST services for PLHIV.

2.2 Research Method

A. Field Research

Twelve PLHIV along with 12 NGO researchers from West Java, Jakarta, Central Java, Yogyakarta and East Java were recruited by UNAIDS and were trained on Participatory Action Research (Djohani & Moeliono, 1996; Shah, Zambesi & Simasiku, 1999; Greenwood & Levin, 1998) in Bogor for 5 days (50 hours). The training dealt with key concepts of PAR methodologies, PAR instruments, and other trainings for the implementation or the use of the PAR instruments. During the training the participants had the opportunity to practice focused group discussions (FGDs), exit interviews and observations involving the respondents who were the subjects of this research. The development of the research instruments as well as the report writing process were all done with full participation of the PLHIVs.

The objective of the PAR methodology is to obtain meaning beyond statistical figures in the survey. It also allows the PLHIVs to reflect on their roles in this research, which in turn would also be a tool for empowerment.

B. Subject of the research and data collection

The subjects of the research were PLHIVs and service providers. The PLHIVs were contacted through their peers or by NGOs in their home addresses, workplaces, or when they made use of a service (exit interview). The data was collected through various methods, such as structured interview (interview with PLHIVs, with service providers and exit interview), observation on a number of service facilities for PLHIVs, and Focus Group Discussions. Table 1 below shows types of data collected in each region.

Using various methods of data collection has enabled the researchers to triangulate the data which was useful in controlling the quality validity and reliability of the data.

PROVINCE	PLHIV Survey	Exit Interview	Provider Interview	FGD	Observation
Jakarta	81	31	22	5	8
West Java	87	-	30	3	-
Central Java	23	9	21	1	-
Yogyakarta	12	26	17	1	-
East Java	67	18	19	4	3
Total	270	94	109	14	11

Table 1:
Data collection

Quantitative data was processed descriptively using cross tabulation. The interpretation was done on the basis of the frequency of answers for each variable. Content analysis was carried out for qualitative data. It should be noted that the qualitative data was collected in various manners and so was the data recording. The FGD data was recorded and processed based on verbatim transcription. Most exit interview data was also done in the same manner, even though some records were based on the researchers' notes. Data from interviews with service providers was analyzed based on the researchers' notes. The observation data was also analyzed based on the notes, written records, pictures or photos. Using these various data collection method enhanced the reliability of the information gathered.

C. Data Analysis

As one of the purposes of the research was to improve the capacity of PLHIV to carry out empirical research and to use the data for advocacy, all analysis processes were carried out with the participation of PLHIV who were doing the research. In the dissemination process of the research, all researchers were also actively involved.

2.3 Limitations and Challenges

This research is an effort to get PLHIVs involved in appraising the services designed for PLHIV. However, the idea of participation seems to encounter some limitations and challenges. Firstly, not all PLHIV were ready and open enough to talk about their experience in assessing the service. Secondly, a few PLHIV were not yet ready to give constructive suggestions in order to improve the service – despite some useful comments. Thirdly, as the PLHIV were recruited through their peers and NGOs, they could not be said to be representatives of the PLHIV population in general. Furthermore, a large number of PLHIV participating did not know the exact number of PLHIV population in the region.

chapter **3** Research Findings

A. Survey of PLHIVs A.1. Respondent characteristics

As many as 270 respondents were contacted and interviewed, The majority (64%) were male, 29% were female, and the rest (8%) were transgender. The table shows that most respondents were from West Java, followed by Jakarta and East Java. Apart from Jakarta, transgender respondents are to be found in other locations. The average age for male was 28, for females 31 and for transgender. 25. However, the age range shows that there are PLHIVs aged above 40 in each gender category. There were 3 respondents (1 male and 2 females) aged below 20. The rest were all aged above 20.

A.2. The health status of PLHIVs

Picture 3 below shows the current health status of PLHIVs in terms of co-infection.. There are a number of co-infections affecting the PLHIVs. Most respondents admitted that they were infected by Hepatitis C – most probably because of injecting drug use. The number of female respondents suffering from Hepatitis, TB and Herpes and sexually transmitted diseases was almost equal. On the other hand, there were 7 respondents who admitted to have skin diseases, 7 respondents had stomach disorder, 5 respondents reported feeling stressed), 3 respondents said that they were afraid to die, and others said that they felt depressed and temperamental.

LOCATION	Number			Mean Age			Range Age		
	M	F	TG	M	F	TG	M	F	TG
Jakarta	59	22	0	28.37	28.55	0	20-59	23-41	0
West Java	55	31	1	25.71	24.52	26	17-34	18-31	26-26
Central Java	11	11	1	28.73	30.27	21	22-45	24-43	21-21
East Java	38	12	17	29.66	30.83	35.75	21-49	22-40	25-51
Yogyakarta	9	1	2	29.89	43	43	26-35	43	43
Total/mean /range	172	77	21	28.472	31.434	25.15	17-59	18-43	21-51

Table 2:
Number of respondents

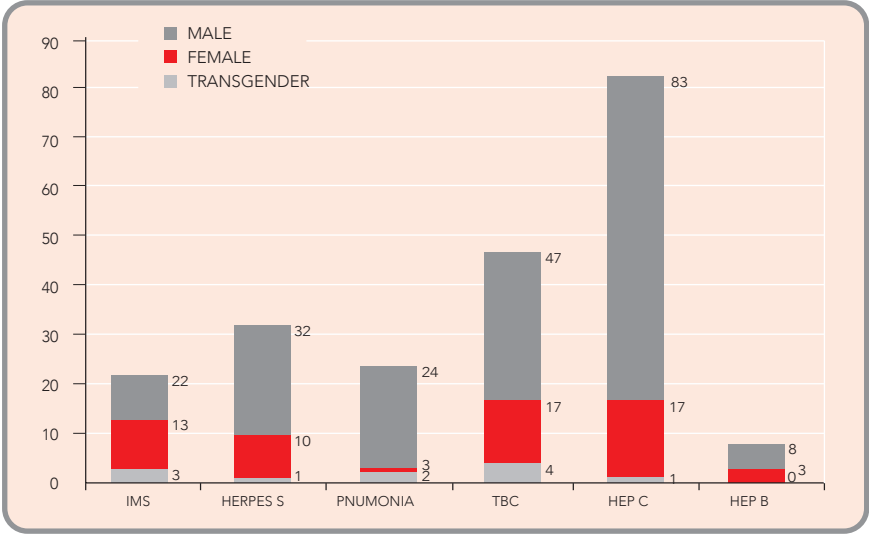


Figure 3: Health status of respondents

A.3. People who respondents feel close to

Figure 4 below clearly shows that for female respondents parents are the ones they feel close to, followed by other family members and their sexual partners.

Transgender respondents, report that they feel close to their peers and members of their support group. They rarely mention parents or other family members as their closest allies. It is easy to understand because most male respondents are probably young injecting drug users (IDUs). Female respondents and transgender often face double stigmatization, including from their own

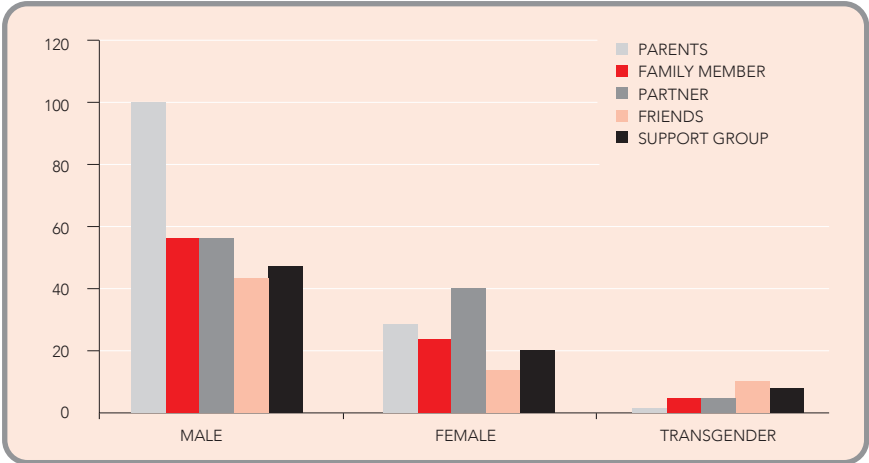


Figure 4: People closest to respondents

family members in that peers and members of support group become very important. The variation is consistent across the provinces.

Male respondents are the only respondents who said that parents were their closest allies. Female respondents felt that their sexual partners were their closest allies, while for the transgender their closest allies were their peers.

A.4. Family members who know the respondents' HIV+ status

In the survey we asked whether respondents' parents knew about their HIV+ status. This is important because one of the potential supports – mentally, spiritually and financially, is likely to come from parents. The results are as follows.

Sex	Region		Parents Know
MALE	Region	Jakarta	49(0.83)
		West Java	50(0.91)
		Central Java	6(0.55)
		East Java	31(0.82)
		Yogyakarta	8(0.89)
	Total		144(0.84)
FEMALE	Region	Jakarta	18(0.82)
		West Java	18(0.58)
		Central Java	5(0.45)
		East Java	5(0.42)
		Yogyakarta	1(1.0)
	Total		47(0.61)
TRANSGENDER	Region	West Java	0
		Central Java	1(1.0)
		East Java	5(0.42)
		Yogyakarta	0
	Total		

Table 3:
Knowledge of
parents about
respondents'
HIV+ status

Table 3 above gives information which is consistent with answers given to the next question which is that more male respondents than female and transgender who said that their parents knew about their HIV+ status.

When asked about whether any family member knew about their serostatus, more male respondents mentioned parents who knew their serostatus than other respondents (Table 4). In addition to that, it is shown that other family members were ignorant about their serostatus, except for transgender respondents who felt

that other family members were more knowledgeable about HIV/AIDS than parents.

Answers to above questions have some implications to program design, including the support.

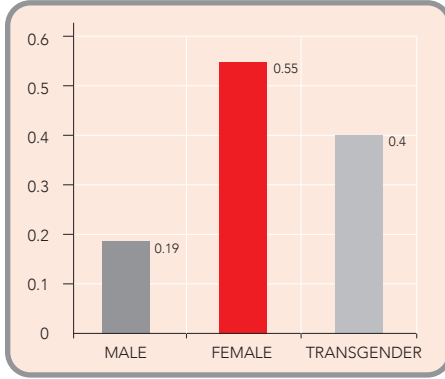
A.5. Serostatus of sexual partners

In the survey, it is important to know the serostatus of the respondents' sexual partners. (Figure 5 below shows that more than half of female respondents and almost half of transgender respondents mentioned that their sexual partners were HIV-positive. Most female and transgender respondents indicated that they were infected through sexual activities with their partners. Male respondents who answered that their sexual partners were HIV-positive probably? Reflected the number of respondents who knew about the serostatus of their partners. The rest did not know the serostatus of their partners.

Sex	Region		Family members who know respondents' HIV status
MALE	Region	Jakarta	43(0.73)
		West Java	45(0.82)
		Central Java	8(0.73)
		East Java	25(0.66)
		Yogyakarta	5(0.56)
		Total	
FEMALE	Region	Jakarta	15(0.68)
		West Java	17(0.55)
		Central Java	5(0.45)
		East Java	6(0.50)
		Yogyakarta	1(1.0)
		Total	
TRANSGENDER	Region	West Java	0
		Central Java	1(1.0)
		East Java	7(0.41)
		Yogyakarta	0
		Total	

Table 4: Family members who know about respondents' HIV+ status

Figure 5:
Partners with HIV+ status



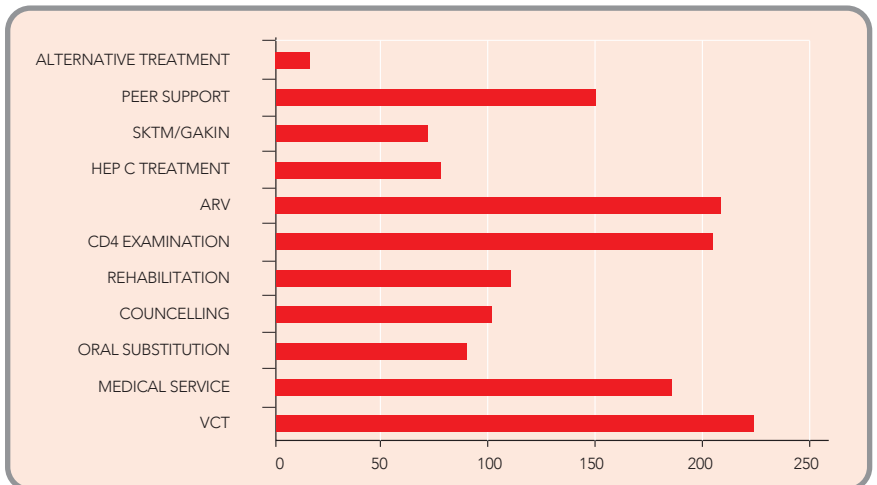
A.6. Services known and used by PLHIVs and constraints in their use

With regard to services available to PLHIVs, respondents were asked what they knew about services available to them. Picture 6 below indicates that only a few respondents knew about alternative treatment, oral substitution, and GAKIN (Keluarga Miskin/Poor Family)/

SKTM (Surat Keterangan Tidak Mampu/Letter of poor) services. Perhaps, these were not available in their respective area. Peer support groups were relatively unpopular compared to VCT service, CD4, ARV provision showing that a number of new services introduced to the public were well known. Of all the known services respondents reported that the most popular were VCT, medical examination, CD4 examination, ARV, and peer support. The answers given by respondents also indicate variation to gender and province.

There were few female and transgender respondents who said that they had ever participated in rehabilitation programs and used counselling services. It can be explained because not all PLHIVs were drug addicts. More than 30% respondents in Jakarta had ‘ever’ used oral substitution services but the number is less in other regions because of limited access and availability of the service.

Figure 6:
Services known



Of all services used, which one was free of charge? Judging from the declining number of responses for services requiring payment, it can be said that not all respondents accessed services subsidized by the government or the ones given by NGOs free of charge. However, VCT, ARV, CD4 examination, addiction counseling, medical care and treatment and oral substitution were used by most respondents free of charge.

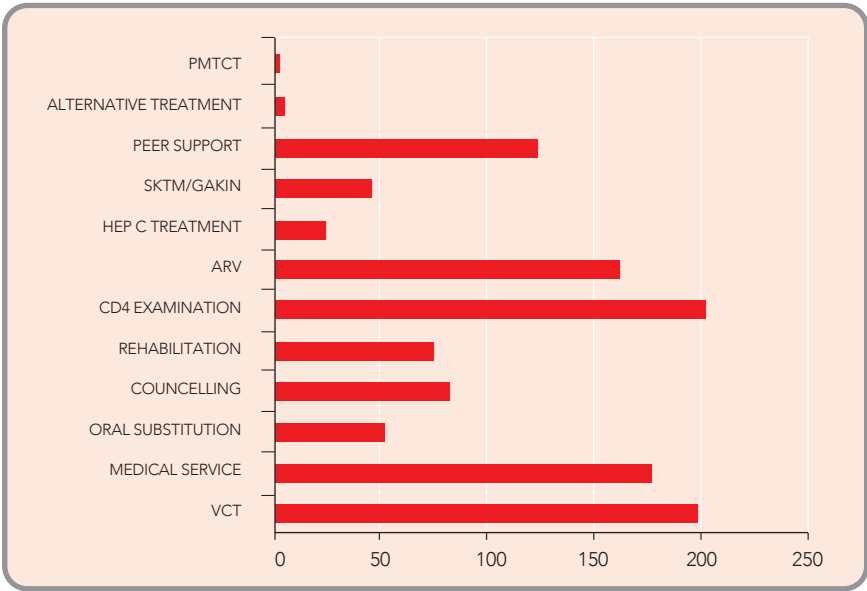


Figure 7: Services accessed

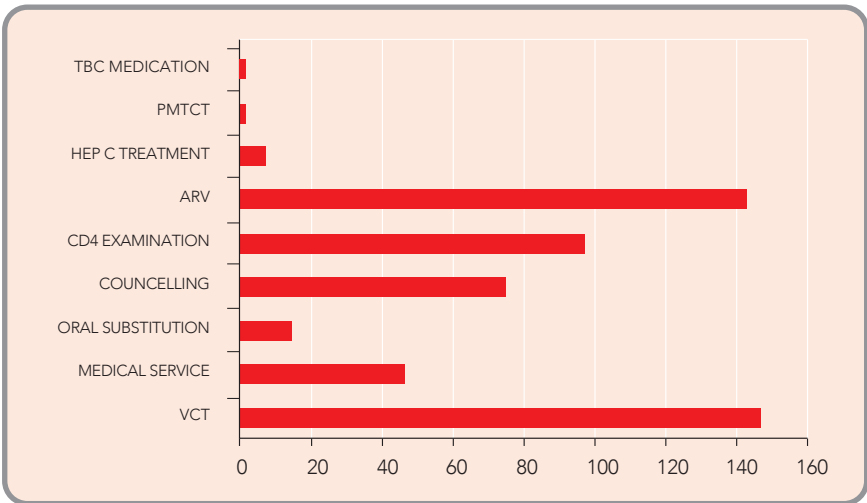


Figure 8: Free of charge services

When was the last service accessed? From the answer below, it seems that the respondents accessed most services more than a week before they were involved in this research.

In accessing the services, did the respondents go alone or accompanied by others? The answers given can be used to see whether the respondents have support to help them access the services (especially ARV).

Figure 9:
The last service accessed

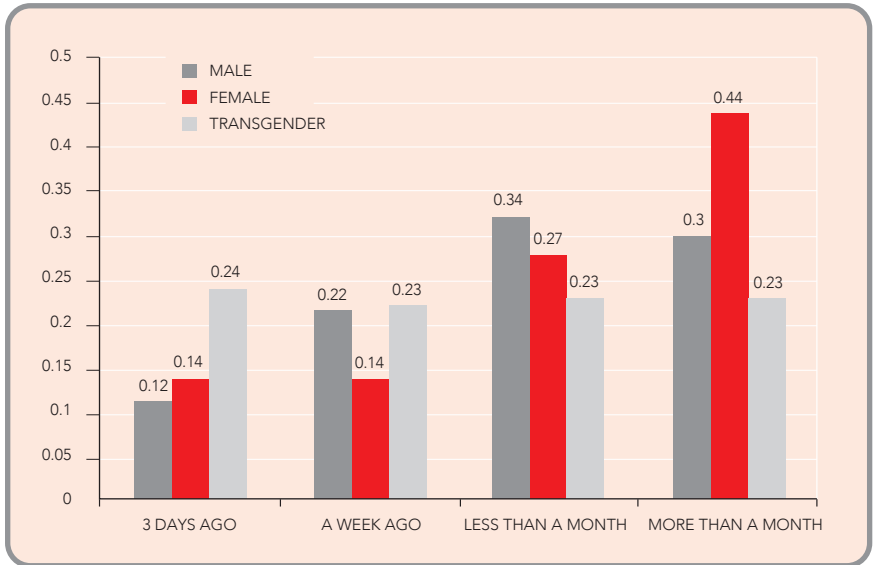


Figure 10:
Companion

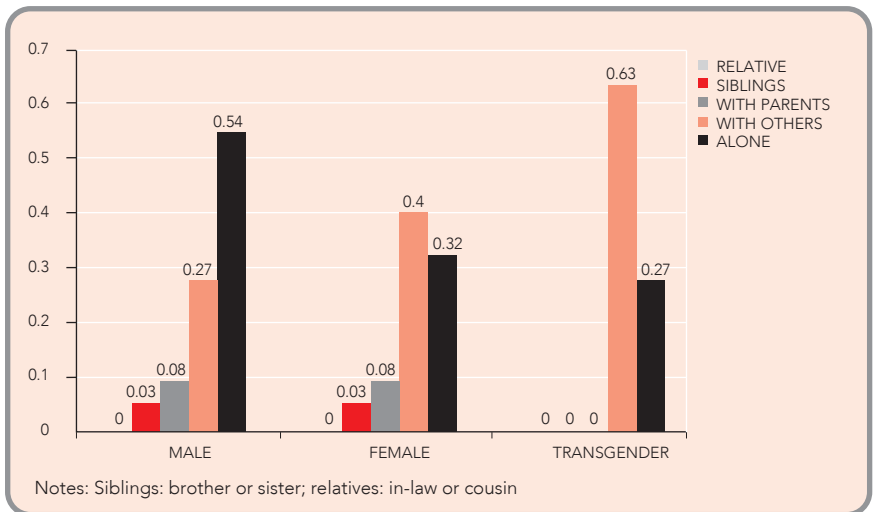


Figure 10 above shows that family members, including parents, did not necessarily accompany respondents to services, are not the close allies of the respondents, even though some male respondents indicated that they were close to their parents.

We speculated that there may be some constraints in accessing services. Fear and shame might be the ones the PLHIVs would feel. From the respondents' responses, we found out that female respondents felt ashamed to access the service. The feeling of shame also experiences by transgender whose number was slightly higher than male respondents. The respondents were not asked specifically about shame and fear when asked about this matter.

Apart from personal constraints, what are the other factors that obstruct the access to services? Figure 12 shows that the other constraints were distance, cost, quality of service, as well as the chance of being spotted by a family members or an acquaintances. Family constraints were mostly mentioned by male and female respondents, and not by the transgendered ones, whereas those who report that ARV is not useful were mostly men. Fear for being spotted were mostly felt by female respondents, who also reported the complicated procedure to receive services and the unfriendliness of the service providers. The transgendered respondents had no complains about service providers. Most respondents complained about cost and distance, with the latter being reported by most transgendered respondents.

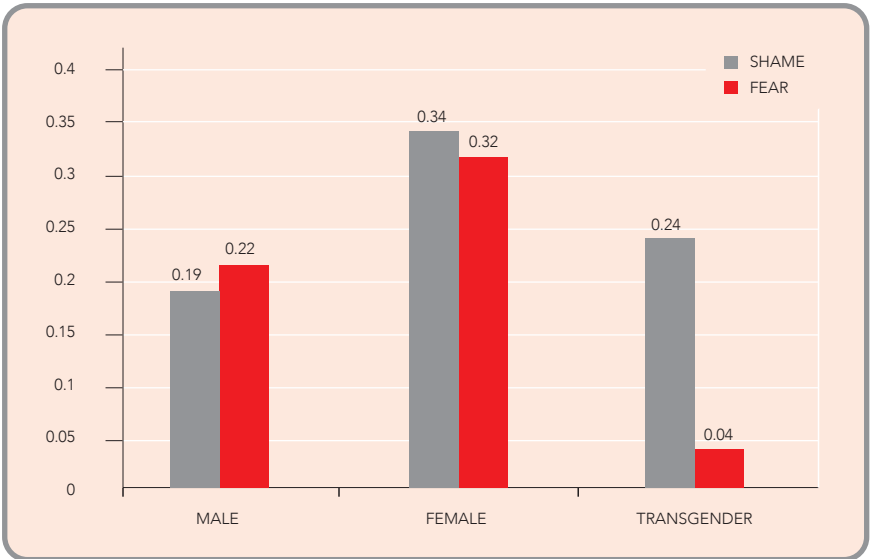
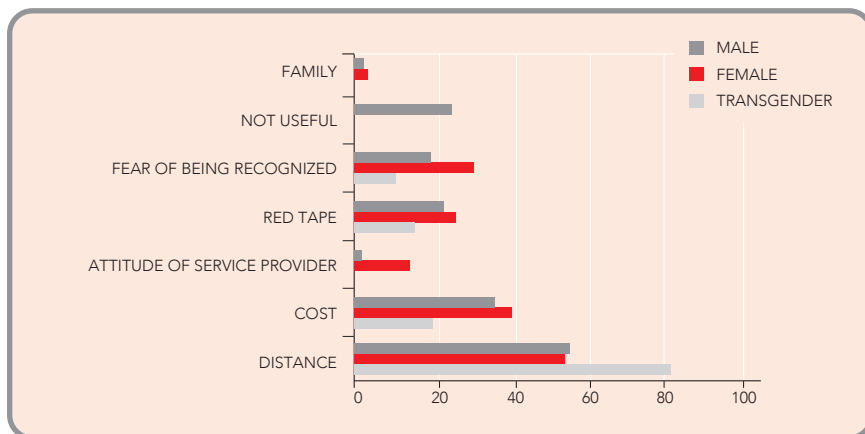


Figure 11:
Personal
Constraints

Figure 12:
Other obstacles in
accessing ARV (%)



A.7. Access to the ARV service

As many as 164 mostly male respondents (64% of the total) mentioned that they had access to the ARV service. More than half of them accessed the service in the last year and one-third had accessed for more than one year. However, it is male respondents who accessed the service in the last year.

Figure 13 shows that ARV service is mostly accessed in clinics, hospitals, drug stores, or at NGOs providing medical care in line with the protocol developed by the Ministry of Health and WHO.

When asked whether they were still currently receiving ARV, as many as 161 respondents (98%) mentioned that they still actively received the service. Almost all male respondents (except 1) mentioned that they still received ARV. Only two female respondents no longer received the service. It is interesting to note that no transgender respondent received ARV delivered by health officials or NGOs.

In discussions with the PLHIVs during the training, and survey we found that ARV delivery was not always smooth and continuous. Sometimes the treatment stopped for certain reasons. Therefore, we asked the respondents about the reasons for stopping ARV treatment. The answers from those who had ever used ARV on and off were as follows:

Table 5:
Access to
ARV services

Respondents	< 1 month	<3 months	< 6 months	<1 year	>1 year	Total
Male	11 (0.10)	12 (0.11)	18 (0.17)	19 (0.18)	48 (0.44)	108 (0.63)
Female	4 (0.09)	13 (0.30)	9 (0.20)	6 (0.14)	12 (0.27)	44 (0.57)
Transgender	3 (0.25)	4 (0.30)	1 (0.08)	3 (0.25)	1 (0.08)	12 (0.57)
Total	18 (0.11)	29 (0.18)	28 (0.17)	28 (0.17)	61 (0.37)	164 (0.61)

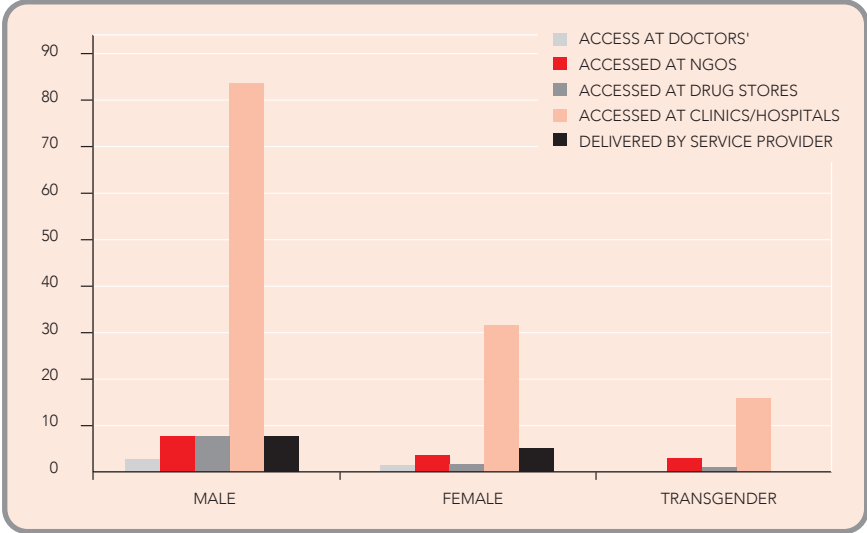


Figure 13:
Locations of access to ARV

The most common reason for stopping and starting was that the respondents needed money and therefore sold the medicine or used the money provided for transport for other purposes. Another reason was that they felt well or considered the medicine as not useful. Distance from the treatment facility,

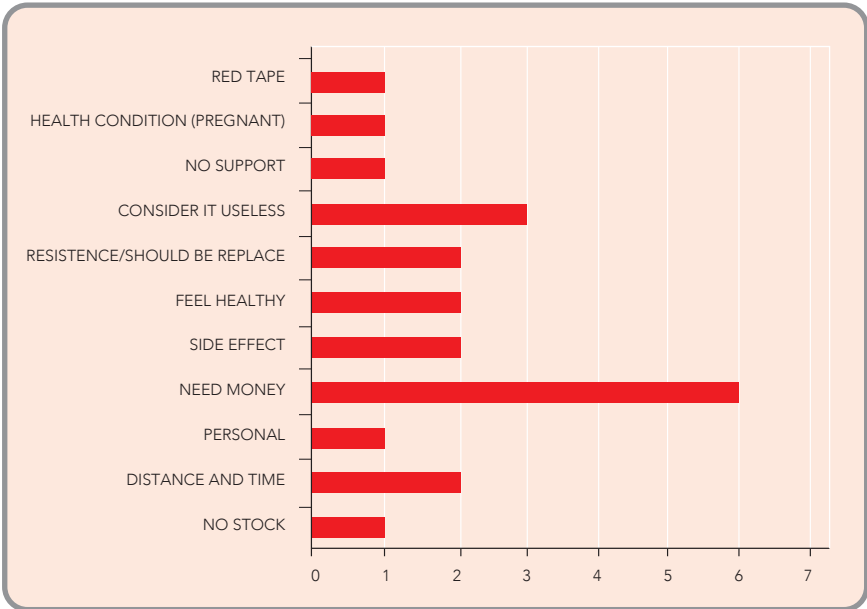


Figure 14:
Reasons for stopping using ARV

the time needed to get there and unpleasant side effect were also reasons why respondents stopped using ARV.

For PLHIV who no longer used ARV at all, the reasons were as above.

A.8. Respondents' constructive suggestion

At the end of the interview, the respondents were asked to give constructive suggestions to improve the quality of life of PLHIVs. Below are the suggestions regarding access to treatment, in terms of price, integrated services and quality of service, procedures for accessing treatment, attitude of officials, and the need for monitoring and evaluation for the good of the clients.

All respondents' suggestions from research locations are summarized in Table 6 below.

- SOP for standard service to be the same across cities.
- Reduce the price for examinations, such VCT, CD4, viral load, sperm cleaning, IMS examination, PMTCT service, the provision of condoms and sterile needles.
- Make the service procedure easy
- Guarantee of ARV stock
- Scale up service facilities - more accessible locations
- Complete and effective education and education for public
- Improve the quality of service provider to eliminate discrimination
- Ensure that prescription is made for more than one withdrawal. Sometimes the doctor is not available when the medicine is about to withdraw.
- Confirm whether a further HIV test should be done (oftentimes this is not confirmed)
- Access to consultations and services for female PLHIVs who have children should be made easier .
- Peer support to be available in each region.
- Improve the quality of NGOs to give services to PLHIVs.
- Ensure more volunteers in the field
- Provide comfortable waiting rooms and examination rooms
- Ensure an adequate stock of medicine
- Improve the monitoring of those on ART
- CST service to be integrated: one stop clinic which includes VCT, CD4, IMS, oral substitution, psychiatric and psychological services
- Evaluation on client satisfaction to be conducted in each hospital

Table 6:
Summary of
respondents'
constructive
suggestions

B. Interview With Service Providers

B.1. Informant characteristics

One hundred and nine (109) service providers, male and female in a number of hospitals, clinics, community health centers, and NGOs, were interviewed. The interviews were done with open-ended questions. The informants educational background ranged from high school to post-graduate level, and their ages from 26-46 years. The professional trainings that the respondents had ‘ever’ participated in are as follow:

B.2. Service providers’ attitude to their job

We asked how the respondents see their daily activities in dealing with PLHIVs. Most respondents regarded their job as important and satisfactory. However, we heard some complaints from the PLHIVs. Table 8 below summarizes PLHIVs’ opinions on the service providers taken from all locations. Challenges they found in doing their job, the chance to help others, and the expected outcome were the positive aspects of the job. The lack of technical support, financial problem, complication of work and negative result, as well as uncooperative PLHIVs were the ones that service providers often complained about.

■ Care Support and Treatment
■ IMS
■ Basic HIV/AIDS
■ ARV
■ VCT
■ Palliative care
■ Indigenous Leadership Outreach Model
■ Case management
■ Training on substitution therapy and addiction
■ Complementary therapy
■ Basic counseling
■ Peer Support Group

Table 7:
Trainings for service providers

B.3. Attitude to PLHIVs

Giving services to PLHIVs has its own challenge due to stigmatization. The summary below shows that there are a number of positive things expressed by service providers, especially when PLHIVs are cooperative and show high spirit. The complexity of PLHIV problems and their lack of cooperation with service providers are part of their complaints.

⁴Tidak semua pewawancara mencatat jenis kelamin dari responden

SATISFACTION	COMPLAINT
Good incentive for the job.	Financial support, facilities, human resources (lack of experts in dealing with HIV/AIDS).
Experience in helping others and the chance to apply useful knowledge.	Unclear job description.
Love the job as a nurse feel satisfied after the job done well.	Afraid of being infected.
Can optimize my ability to help, especially those who are marginalized.	Time consuming, complicated and hard. Too many patients to take care of.
Can give psychological support to marginalized PLHIVs. It is good to see PLHIVs smile even though they are sad and hopeless.	Not yet satisfied because there are too many problems to deal with.
Available laboratory facilities.	Lack of cooperation from PLHIVs.
Experience the unexpected.	Lack of information and ability to deal with PLHIVs.
Good result. Feel happy when the therapy is helping patients get healthier, survive and live better lives.	Disappointed when the patient dies.
Challenging and gives pride. Can learn from experience and gain knowledge.	Team work not solid. This makes the service not good.

Table 8:
Attitude to work

B.4. Cost of service

We also asked questions about the cost of service. Below are the result. Even though cost varies, we present it in lowest and highest range.

SATISFACTORY ASPECTS	COMPLAINTS
PLHIVs are just like other patients.	PLHIVs are not disciplined.
PLHIVs have information and know about HIV/AIDS.	PLHIVs have more complex problems.
Patients are cooperative: obey the rules and take medicine regularly.	PLHIVs are distrustful. They should be strictly observed in a friendly manner.
Patients are in high spirit and active.	Concern about the young generation who do not think of their future.
The parents and relatives of the client are cooperative and give their full support when the treatment goes smoothly.	
PLHIVs should be given a chance to be self-reliant.	

Tabel 9:
Komentar
Terhadap ODHA

NO	TYPE OF SERVICE	COST
1	CD4 count	Rp 125.000
2	vitamin, supplement	
3	methadone, IO	
4	Consultation & examination (basic examination, blood test, urine, HIV test)	Rp 20.000-500.000
5	Registration	Rp 3.000- 15.000
6	Oral substitution	
7	Viral load	Rp 850.000-1.350.000
8	Rehabilitation	Rp 3.500.000
9	SGOT / SGPT	Rp 43.000
10	IMS	Rp 25.000
11	VCT	Rp 20.000-25.000
12	TB medicine	Rp 35.000
NO	TYPES OF FREE-OF-CHARGE SERVICE	
1	ARV	
2	VCT	
3	Counseling (pre & post), addiction consultation and health	
4	CD4, IO	
5	HIV test, lever function (IHPCP)	
6	TB medicine (combipact)	

Table 10:
Cost of service
(5 regions)

Exit interviews were carried out in Jakarta, East Java, Central Java and Yogyakarta, involving 94 clients and 15 service facilities in hospitals, clinics and NGOs. The report from Central Java could not be analyzed due to technical problem of recording. The interview was carried out after a client got a service in a health facility, and s/he was then asked about his/her experience in accessing the service in the facility. S/He was also asked to give suggestions on how to improve the quality of service. Each interview took about 10 minutes.

Clients come to service facilities to have medical examination, pick up ARV (PMO), get methadone, CD4 count, blood test, obtain condoms and have TB examination. The result of the interviews are presented in Tables 11, 12 and 13 (Appendices). In general, the results are as follows.

C. Exit Interview

C.1. Appraised by clients

Clients appreciated it if the service was not complicated, easy to meet the doctor or counselor, cheap or free, friendly, and accompanied by adequate and easy-to-understand information. In addition, PLHIVs said that they would like to have easy-to-reach locations so that they do not have to travel a lot in order to receive related activities, such as VCT and blood tests, or ARV and CD4 examinations. They also appreciated the availability of comprehensive laboratory and supporting equipment, comfortable rooms, and privacy.. During the interview we also found out that the presence of companion was regarded as a bonus to quality services but it nothing to do with the service itself...

C.2. What the clients complained about

In general, PLHIVs had positive experience with the service, even though some of them felt that the procedure was complicated, with a long waiting time (more than 1 hour). The long waiting time was associated with limited number of doctors while the number of clients was large. Besides, there were clients who felt that they did not get friendly service and that the procedure was too complicated. Clients who were subsidized by the government in the form of JPS-BK (Jaring Pengaman Sosial – Bidang Kesehatan/ Social Security Network – Health Sector) felt discriminated against in comparison to those who paid cash. Clients who needed viral load examination felt that the facilities were limited and expensive. There were clients who felt that the service providers were not ready to receive them or to listen to their problems. As for the substitution therapy, some clients saw that there were other clients who still had drugs with them and used them at the clinic . As service facilities were only available in certain institutions, clients who lived far away complained about the time they had to spend to get there and the expensive travel cost.

C.3. Constructive suggestions

Most clients suggested that the facilities should be improved to make them more accessible. The clients also would like to see easier procedure, more than one doctor, cheaper and friendly service (especially for CD4 and viral load examinations). The PLHIVs also expected an integrated one-roof service. As far as building is concerned, they would like to have private bigger rooms. For the fear of being spotted, some clients get their medicine in other separate counters. For the substitution service, some clients asked for stricter security as there were clients who took drugs with them.

D.1. Introduction

The FGD findings in several places and communities show some situations similar to those experienced by most PLHIVs, especially physical and psychological conditions, access to medicines and ARV therapy, health service in general and what the PLHIVs expected.

However, we also found specific problems and needs in certain communities, such as prison inmates, women groups, transgender, etc.

D.2. PLHIVs's personal problems

From the FGD results in several cities, it was apparent that PLHIVs not only had problems with access to health services, but also faced other social problems. The problems can be classified into 3 levels, namely personal/individual problems, family/peer problems, and problems related to society, policy, and social services.

At the micro level, PLHIVs faced physical, psychological and emotional problems.

- Physically, PLHIVs were confronted with vulnerability and the chance of being infected (opportunistic infection) and the side effect of various medicines. A number of PLHIVs mentioned that they experienced allergic and bad side effect of the medicine consumed.
- Some PLHIVs said that they were refused to get medical services due to their serostatus (dentists, medical examination, etc) because the official refused to serve them (with various excuses)
- As the people who faced certain problems with the society (family, work environment, medical service, etc), PLHIVs also had psychological and emotional problems. Some PLHIVs could not face the fact that they were PLHIVs and felt worried, ashamed, afraid, disappointed and angry with their HIV+ status. Being sad and angry was the common expression in dealing with their daily situation. When felt discriminated at hospitals, PLHIVs tend to be sensitive and angry.
- Psychological problems such as fear and worried occurred when they were being examined, undergoing therapy, knowing the result of the test, or imagining the effect of the therapy. When they knew other PLHIVs experience allergic and side effect of the therapy, they became constantly worried: *"I am always in constant fear of the side effect of the therapy when I know my friends started the therapy."* (FGD-Bandung).

At the meso level, PLHIVs cannot be free from the influence of their family and peers.

- Most PLHIVs complained about the lack of support or even the non-existence of support from their own family while they knew that the support was very important. Some PLHIVs did not have the courage to tell their family because they feared the family could not take it and it would make matter worse. The consequence was that the PLHIVs failed to get support they were supposed to get as the family failed to understand their needs.
- The lack of support from the family was mainly due to lack of information and knowledge about HIV/AIDS. Some PLHIVs who had informed their family about their status got support from the family. This was because the family had enough information.
- At hospitals (and also prisons) the absence of family member accompanying the patient was an obstacle to get adequate service and medicine.
- Even though it was relatively easy to communicate with peers, PLHIVs were not always comfortable to tell about their status for the fear of being rejected. In addition, the peers who potentially could give support, might have negative effect on their emotion and mentality, for example, when PLHIVs experience side effect of medicine, or in critical situation, or even death.

Most PLHIVs faced problems at macro level. Stigma and discrimination were the main issues expressed by PLHIVs at all FGDs.

- Discrimination was felt by PLHIVs in their environment and workplace. But discrimination was mostly experienced with health officials at various health centers. Almost all PLHIVs who had ever accessed service, either for test, counseling or therapy, had “felt” or “experienced” being discriminated.

In 2005, I had bad toothache. I was afraid to tell the dentist about my status. So I chose RSCM. When I was there, they asked a lot of questions. “Have you ever used drugs?” Use needles? Have Hep C? They stopped there. “Okay, then”, the doctor said. “You wait outside. You will be called to have an X-ray”. I was waiting for a long time. The nurse came out. I asked her whether I could have an X-ray now. She said she could not do it here. She gave me a letter.

FGD- EXCEED COMMUNITY

- Some PLHIVs expressed their concern about the government attention to continuous services for PLHIVs. PLHIVs wanted to know how far the government could guarantee the sustainability of ARV and other medication

"personal experience, because I started to have TB therapy, I registered. When they found out I was from a certain institution, they asked me about my status, especially about PLHIV. When the last nurse came, she said they were about to close."

FGD-BANDUNG

"I saw two friends of mine ran out of medicines and finally died, perhaps because there were not enough officials, I had to call the hospital myself to remind them my friends had run out of medicines. They ignored me until my friends died. I was so sad..."

FGD- SUKABUMI POSITIF COMMUNITY

that should be consumed by increasing number of PLHIVs. How could the government maintain the subsidy for medical care and treatment for PLHIVs, and to guarantee good services even though they were through JPS, ASKES (Asuransi Kesehatan/Health Insurance), GAKIN-BK, etc.

- Non-existence of consistent support for Health Office, BNP, KPAK, Bupati and walikota for HIV problems (even though advocacy had been done).

"The medicine is for the rest of our lives. Will the government be ready to supply the medicine forever?"

FGD- D.I.YOGYAKARTA

- Policy concerning JPS, Askes, Gakin, etc, was felt not to be in favor of the patients because of complicated procedures.

D.3. Medical Service

Almost all FGDs expressed their concern about complexity of problems regarding health service for PLHIVs, such as problems of complicated procedure to access therapy, high cost of test and medicine, and cost to access service, violation of standard procedure by health officials, limited variation of medicine, side effect, resistance to medicine, discrimination and limited information about HIV/AIDS (including health officials).

a. Supply of medicine

- Limited stock and scarcity of medicine. In some places, medicines are rare, especially in clinics, community health centers, and even in hospitals far from big cities where FGDs were conducted (Jakarta, Bandung, Semarang, Surabaya, Yogyakarta). Lack of medicine should not hinder the therapy which should be continuous.
- Limited variation of medicine for ARV therapy was experienced by PLHIVs who had undergone therapy and was allergic that they needed replacement. It was not easy for PLHIVs to get replacement as the alternative medicines were available at the place where they used to get the medicine.

Limited variation of medicine was also felt for opportunistic infection or medicine to cure side effect and allergy.

- Non-existence of health officials. Even though it did not happen all the time, the health official or doctor was not available when he was needed. One reason was that it was a holiday so there was no doctor to give special medicine for ARV, or because the 'special' doctor who was responsible to give the medicine was on duty in another place. It was a problem that could obstruct continuous process of medicine taking.

"I used to have ARV therapy but had to stop for about two years because of the side effect. I had sore eyes, so I stopped the next morning. I couldn't do any activities because I felt dizzy. I no longer take the therapy".

FGD-EXCEED COMMUNITY

b. Access and JPS

- Access to therapy and medicine is one of the recurrent problems in FGD. What is meant by access is the procedure and the distance that should be followed to get the service. There was a complain that not all hospitals or health centers provide therapy and medicine so that the clients had to go to a hospital which was sometimes too far away and it cost money. It was experienced by clients living in Sukabumi, Tasikmalaya or other cities far from Surabaya.

"I had to go to Bandung and Jakarta back and forth to get the medicine. It cost me a lot of money. I hope there would be one in Tasik."

FGD - KELOMPOK DUKUNGAN TASIK+

"It is quite far away to get ARV, as Jatinangor, for example, is far, far away for the district centre. It is better to access it in the place close by."

FGD-BANDUNG

"When I had an HIV test in Sukabumi, I was referred to Bandung, but after I received the result... in Sukabumi they couldn't decide whether it was negative or positive. I had to take the test again in Jakarta, but the doctor wasn't sure about the result".

FGD- SUKABUMI POSITIF COMMUNITY

- Access is also related to complicated procedure. In some places we found a complicated procedure to get the service, especially when a client was unaccompanied.

I was about to get medicine at a drugstore, I was ping-ponged, though the doctor had written a prescription. The attendant said it was a wrong medicine. I went back to the doctor, but he's gone..

It took me along time to get JPS. At the clinic, who came first was served last.

FGD AT RS DR.SUTOMO SURABAYA (1)

- To get Askes insurance is also related to the process to get JPS or complicated bureaucracy. It was complained by PLHIVs who were not rich but needed the service. Different hospitals have different rules about getting Askes. Some hospitals give 2 x 24 hour to get Askes but some give the service only after Askes has been processed.
- PLHIVs also complained about the non-existence of private insurance to cover AIDS problem.

“It was very bureaucratic. We have to go to RW (head of sub-sub district) first, then to kelurahan (sub-district). And there are other procedure that we have to go through at hospital.”

FGD AT RS DR.SUTOMO SURABAYA (2)

c. Expenses

- Most PLHIVs complained about high cost to get test and medicine. Even though they get ARV therapy free of charge because it is subsidized by the government in some cities, PLHIVs still have to pay high cost for preliminary tests, or when the medicine is not suitable that they have to get substitution which is not subsidized by the government. They also have to pay high cost when allergy or side effect occur from ARV therapy. The substitution is usually not for free.
- Beside medicine, PLHIVs also complained about the fee to get access to the service. It applies to those who live far from the hospital. For PLHIVs who are not rich, travel cost is another problem they have to deal with.
- The high cost also has to be paid by patients who need medical care, and because of their low economy status they have to get health insurance which also cost a lot of money (for transportation, administration fee, etc.)
- Different cost or non-existence of standard price has made PLHIVs feel confused about the tariff for examination or for consultation with the doctor.

“It cost me at least about Rp. 300.000 to Rp. 400.000 every month to go to Bandung. It even bigger if I have to go to Jakarta.”

FGD - KELOMPOK DUKUNGAN TASIK+

d. Medical care and service

Medical care at hospital also poses certain problem to PLHIVs. When they have to be admitted at the hospital, the unaccompanied PLHIVs will have a problem with the procedure because they do not have any information about the process. In addition, the unaccompanied PLHIVs will not get optimal service because the hospital expect the family to deal with what the patient needs (including medicine). Even the PLHIVs who have had experience in accessing the service still have problems when they in medical care. Some complained that they did not get the service because of their serostatus. Some had to move from one official to another, did not get proper service, were

discriminated and did not proper attention from the official or the nurse. The care for PLHIVs is still not good and fail to meet the standard in some places.

- Discrimination occurs not only because of the patient's sero status, but also because they have to get insurances such as JPS, Askes, Gakin, etc. Some FGDs reveal discriminatory services between “the poor” (those who use JPS) and “the not poor”, while most PLHIVs are poor.
- Violation of standard procedure (SOP) and Universal Precautions (UP) by health officials. FGDs revealed some cases where medical officials did not follow the right procedure in dealing with HIV (not using gloves, not washing their hands, etc.) FGDs also revealed cases of SOP violations and ethical violation by medical officials, such as not conducting counseling before the test, not explaining the side effects of the medicine or therapy. Confidentiality was well kept by the officials in the laboratory or those in the counseling room.

“I went to a doctor in the morning and had to wait until noon, because he was busy with patients. I was the last to serve even though I was the first to register”.

FGD- SUKABUMI POSITIF COMMUNITY

“I feel they are experimenting on us. The doctors keep changing every three month”.

FGD-AT RS DR.SUTOMO SURABAYA (2)

“If we have JPS, we have to wait for the medicine for 3 hours. If you pay, it will be faster”.

FGD-AT RS DR.SUTOMO SURABAYA (2)

“I got the letter of reference from Health Office and they said it should be opened, but I came to get the letter, it was already opened by the laboratory doctor”.

FGD- SUKABUMI POSITIF COMMUNITY

“I knew it didn't happen at Rumah Damai but in the laboratory. At the time an PLHIV was giving a presentation (I'm not sure what), but a friend was there. He wasn't a friend from Rumah Damai, but he knew the names of those from Rumah Damai. They showed the names of those who had tested in our place, and my name was there ... ha ha ha”.

FGD- RUMAH DAMAI - SEMARANG

"Usually, the officers did not know about the rules, UP, they have to wash their hands first, that is for their own good, so when they take our blood they have to put on gloves. In my opinion, it is because they don't have enough information and education for paramedics. We cannot say it stigma, but it is because they are ignorant about that".

FGD- D.I.YOGYAKARTA

"When I had CD4 test, that's it ... it's this nurse and that nurse. "Wait a moment: ... yes ... there came another one".

FGD- D.I.YOGYAKARTA

- Limited information, knowledge and skill on the part of medical officers, including some doctors dealing with HIV/AIDS. It was revealed when PLHIVs got different information and treatment from different officers.

"I had a check-up with this doctor, my CD4 was still 350, but I was feeling bad, weak, sometimes I was sick for two days in a weeks, so I went to see this doctor, he was I had to take ARV. when I went back to this doctor, it should not be done now because my CD4 had not yet reached 200. I was so confused."

FGD-BANDUNG

"When we are ill, sometimes even doctor himself is not sure about my illness. Just like me, for example, I have got pain in my foot but doctor only provides vitamins, vitamin B, without examining me. And then he asked me about my complaint, and if he found my SGOT and SGPT went up, the doctor only gives me Curcuma", and then he asked me again .. and finally, he may recommend me taking test...."

FGD-SUKABUMI POSITIF COMMUNITY

"I found out that I was positive, I went to see a most famous doctor in Kediri, He didn't know what to do with my test result, then I had some information about HIV in a newspaper, it was estimated that the number of PLHIVs in Kediri was 50."

FGD-AT RS DR.SUTOMO SURABAYA

"They told me to take ARV for 2 weeks, the effect was to my nerve, they asked me to stop, the doctor didn't give any explanation".

FGD-AT RS DR.SUTOMO SURABAYA

- Fear and wrong treatment by medical officers also mean limited information about HIV/AIDS.
- Discontinuous treatments and treatments done by different officers/ doctors/counselors are also source of complain. The treatment cannot be done thoroughly the officers dealing with PLHIVs keep changing.

e. Supporting factors

- In some places, there are free-of-charge CD4 services and at some hospitals the access to ARV is quite easy and the service is good. Some health centers at sub-districts even have modest laboratory that can be used to examine the PLHIVs' health.
- In some places, the community is active and give their support that makes it an important factor to support the PLHIVs.
- At some hospitals/cities there are some dedicated doctors who deal with PLHIVs. They give some explanations at the start of the therapy, including information about side effects. After being given explanations, the PLHIVs are given a chance to think before they make any decision.
- There will be 10 kinds of medicine for IO, which "they said" will be free, including for TB.
- Examination rooms and counseling service are better at some hospitals in Yogyakarta. The procedure for examination is no longer too complicated. The service is getting better in spite of some problems. For the unaccompanied PLHIVs, they can go directly to hospital (Sarjito) to see the doctor or case manager who are always standby at the hospital.

D.4. Expectation and suggestions

Based on the problems faced by the PLHIVs, there are some needs to deal with the problems. The expectation and needs of the PLHIVs can be differentiated according to the problems they face, such as:

a. Availability of medicine and service improvement

- It is hoped that access to medicine be made easier so that PLHIVs will not have any problem in getting and maintaining the therapy. There should be a reference for HIV/AIDS treatment in each district. There should be more variants of medicine for therapy and side effect so that the PLHIVs who are resistant or experience side effect will have alternatives to continue the therapy.
- Test implementation related to therapy and treatment should be made easier in terms of procedure and cost so that the public can afford it.
- There should be more health facilities in the suburbs and small towns so that the PLHIVs will not have any difficulty in accessing the therapy and do not have to spend some money for transportation. With the doctor's prescription, they can access ARV in any referential health centre. ARV can be accessed at community health centers (puskesmas)

- There should be more wards at reference hospitals, especially third class wards. (some hospitals have limited third class wards, so PLHIVs are offered first, second or even VIP classes). It is also hoped that private hospitals provide third class wards for PLHIVs).
- There should be 24-hour drug stores for the peers to get medicine, even during the holidays, so the therapy can be continuous.

b. Confidentiality and service ethics

- The patients should be kept confidential. The local authority should not abuse their power to get detailed data on PLHIVs when they ask for JPS. (the officers should be told how to keep it a secret). The same applies to health centers (hospitals, clinics, laboratories, etc).

c. Information and capacity improvement of health officers and the general public

- Information and support for PLHIVs’ family get full attention because the support has proved to be an important factor needed by the PLHIVs.
- Trainings to improve capacity (information, knowledge, skill, UP, etc) for the related parties (buddies, health officers, companion to take medicine, family, etc) including the health centre officers at sub-districts dealing with PLHIVs.
- As preventive measure, drugs and HIV should be in the curriculum at elementary and secondary schools.
- There should be continuous campaign and information dissemination because discrimination and misunderstanding are still to be found.

“We are afraid to get JPS in our region because we have to tell the truth about our illness, and when they find that we are HIV-positive, they will put it in the local newspaper”.

FGD-D.I.YOGYAKARTA

d. PLHIV empowerment and improvement of the government’s role

- It is hoped that the government and related parties make easy procedure and lower cost for PLHIVs and poor families. JPS-GAKIN should be accessible at each hospital.
- The government should guarantee the continuity of ARV subsidy (for the rest of their lives).
- The PLHIVs’ involvement should be improved by applying GIPA principles.
- Economy empowerment for PLHIVs through vocational trainings.

- Insurance for outreach officers with high vulnerability.
- Important parties to be advocated: to family to give financial support, Health Office, The Ministry of Manpower, donor related to treatment, The Ministry of Social Affairs, and general public for anti-stigma campaign and discrimination.

D.5. Specific findings

Specific things related to problems, needs, and expectation

- Most female PLHIVs are worried about the survival of their children. They are worried that their children would be discriminated because they come from the family with HIV/AIDS, and they worried about the expenses for their children.
 - o Hope: Clear information about PMTCT (where to access and how).
 - o Job opportunities for PLHIV left by the husband and have to earn their own living.
 - o There will be doctors to look after the children with HIV/AIDS.
- PLHIVs in prisons have their own situation which needs specific treatment. Situation, rules, and routine activities in prisons often get in the way of the on-going process of therapy. The availability of medicines there cannot always be guaranteed. Without the help from the family, the PLHIVs cannot access ARV and other medicines needed. They have to pay to access ARV (which should be for free) or to get other medicines which are not available in the prison. What this community expects is advocacy in order to pay more attention to PLHIVs and to improve the capacity of prison officers with regard to HIV/AIDS problem.

“We are sometimes confronted with the system here, such as the doctor who comes at one o'clock when he is supposed to come at 10. They get us out of the cell at 3. I don't know. What if we run out of medicine while we are being locked up.?”

(FGD - LP NARKOTIKA CIPINANG)

- o Expectation
 - Improvement capacity for prison officers (interview).
 - Available stock of ARV in prisons.
 - Provision of simple laboratory equipment (to check SGPY – SGOT, Hb, HbsAG).

E. Observation Data

Observation was done at 11 hospitals and institutions giving services to PLHIVs in Jakarta and East Java. The observer was equipped with paper and pencil to draw the map of the room, and to take photos if necessary. For privacy, the photos are not included in this report. Observation was aimed to look into the following aspects.

E.1 Accessibility

Observation on whether it is easy or not for the clients to find and to reach the facilities has led to the following results.

- Even though the service room in a number of NGOs and hospitals are easy to find, at some hospitals the room is located on the corner where it is difficult to find. It is probably for privacy reason.
- The facility to give ARV is separated from medicine delivery for other clients.
- Payment and medicine delivery are at different locations.
- The laboratory is too far away, but it can be understood as the facility is limited.

E.2 Comfort

Observation on the comfort of waiting (location, ventilation, seats, room arrangement) resulted in the following notes:

- Some examination rooms are open so that the privacy cannot be guaranteed.
- The waiting room is not comfortable, too small with bad ventilation that makes it hot, especially the one fitted into a clinic.
- In the facility where oral substitution is to be fetched, the security is not adequate.
- In some facilities, the clients are not separated from other patients which make them feel uncomfortable for the fear of being spotted.

It cannot be denied that most facilities are quite adequate as they have waiting rooms facing an open space, comfortable seat in the lobby, air-conditioned consultation room, complete laboratory equipment and neat and clean room.

E.3 Location of Service

As the locations of service for PLHIVs are limited, observation done at a number of public hospitals suggest that the locations are quite good – easy to reach by public transportation. In addition, they are known to the public and easy to find.

A. Capacity and participation of the people living with HIV/AIDS

The primary objective of this research was to improve the capacity of people living with HIV/AIDS to conduct simple participatory research to help improve the service quality. This objective has not yet been fully achieved, due to some hindrances observed in this research:

1. Group leaders are not yet ready to assume the responsibility. In addition to the management of workload, the group leader is also asked to be responsible for managing financial administration. People living with HIV/AIDS who are still in unstable condition and lack of attention during the recruitment process have caused the research progress to far behind the schedule as the group leader relapsed and it disturbed the work group and impeded the research organization.
2. Due to lack of time and limited resources, reflection regarding the results of research in the respective region has not been conducted yet. As a result, it is only a small part of the people living with HIV/AIDS who are involved in this research have the opportunity to analyze the data with the consultants.
3. Difficulties in finding field data were caused by: (a) lack of openness among local community of people living with HIV/AIDS, (b) bureaucratic matters, and (c) lack of time and resources for providing assistance from Jakarta.

All the problems above are actually a challenge that could be anticipated in the future. In the end of analyses, it was agreed that this result shall be used as the basis for reflection in the region and Jakarta.

B. People Living with HIV/AIDS and Their Needs

This research confirms that people living with HIV/AIDS indeed need individual and institutional supports in order to survive and be able to participate in the community as other productive and responsible persons do. It seems that people living with HIV/AIDS have a lot of problems, either internal or external ones.

B.1. People living with HIV/AIDS and themselves

It is unquestionable that people living with HIV/AIDS needs moral, financial and emotional supports, and wide range of services in the community. But, in

accessing such supports, people living with HIV/ AIDS are confronted with some problems. Various information from different resources, which is collected by using some different methods in this research indicates that people living with HIV/AIDS needs supports from their closest friends, parents, sexual partners, and so on. However, they frequently feel anxious, afraid, or ashamed. In this research, it is clear that parents may not be the source of support they can enjoy although they are mentioned as an important part of their life. People living with HIV/ AIDS who are sexually infected such as transgender and female respondents and those who are injecting drugs users were often stigmatized by its community or their own family. That is why they often do not inform their relatives or parents regarding the infection status they have.

Stigmatization that lead to social isolation gives additional consequences to the people living with HIV/AIDS, which make worsen the relationship between health service provider and NGOs with them as they become over-sensitive. It is undeniable that such tense relation, among others, was caused by prejudices and fear that also affect health professionals – and it must be death appropriately. However, it must be realized that service industry, including health service, hospitality is still in the state of scarcity. People living with HIV/ AIDS, therefore, share the same experience as most hospital or clinic clients have in general, except in that they are treated due to their HIV status that is related to their problems as people living with HIV/AIDS as IDU or other characteristics. It is also quite often that people living with HIV/AIDS are associated with commercial sex and certain sexual behavior that were seen as a moral deviation.

People living with HIV/AIDS sometimes experience poor/inappropriate treatment – not because of their sero status, but due to the nature of the service itself that is subsidized by government. As a (subsidized) government service, it can be accessed free or charge or they are cheap. Indonesia is notoriously known as having poor track-record in providing services to client or patient of this group as such activities is usually considered as part of the government programmes targeted to the poor. In relation to the situation above, it can be predicted that the people living with HIV/AIDS seems to share the same experiences as those who access health service using JPS – BK. As JPS –BK is designed for disadvantaged/ poor population, not many private institutions would accept this program, and even government institution such a service must be limited. If the experience of the people living with HIV/AIDS are not far different from other poor community, another problem may rise: that the poor – including most people living with HIV/ AIDS – will need such health

service when their health condition has been serious. In such condition, discrimination and stigmatization is indeed very painful. Therefore, it is not surprising that health service provider has impression that people living with HIV/ AIDS are not cooperative and reclusive (closed).

This research also indicates clearly that people living with HIV/AIDS still longing for government initiative to invest more in the form of subsidy that enables them to have free or low cost medical treatment and examination, CD4 check, Viral Load examination, Hepatitis B and C medication, ARV therapy, oral substitution, PMTCT, IO and so on. It is not an easy choice. In one hand, it is very clear that some treatments tend to be very expensive in nature and most people living with HIV/AIDS cannot afford it, which in turns, impede the government efforts to reverse or stop HIV/AIDS infection. In other hand, there are lot of public complaint that people living with HIV/AIDS are ill but it is not them who have to pay all medical cost for examination, medication and treatment and care. Public and actors in health service industry pose a question: what is so special with people living with HIV/AIDS?

The development of universal access to health service should be an important issue in a developing country, as every citizen of the country has to be healthy and capable so the they can be competitive development capital. But people living with HIV/ AIDS should also think whether it means that all services for them are free. Does it mean that freeing them from financial responsibility could encourage them to utilize such free services and maintain their participation in having such services? There are some people who also of the opinion that public or client participation in financing the service for them – though at minimal level – may be able to encourage people to come and use the services and be responsible in maintaining their health condition. Is it true? That is more or less one of the reflections that must be thought over as a result of the research.

B.2. Service Provision

This research reveals that accessibility – in terms of location, distance, and financial reason, is considered as one of important factors in using or quitting the available services. Statistics that figures out the coverage of the existing services is not available at the moments. Due to the stigmatization and huge investment in developing services for people living with HIV/ AIDS, it is possible that the coverage is very small. As all the services mentioned in this research is essential in nature, the needs for improving the service coverage is unavoidable.

Another problem that influences the behavior of people living with HIV/ AIDS in taking benefit of the services is integrated service availability. (See, Irwanto, 2005). Complicated procedure in service delivery or scattered location for inter-related services is very disturbing, especially when the client is in unhealthy condition. In particular, the complain was filed by the people living with HIV/ AIDS regarding the location for VCT and taking blood sample, ARV treatment, Viral Load and CD4 examination.

Program continuity and medicine availability is also another issue to complain. Many programmes were launched and disappear (for example support group) and availability of ARV medication is unreliable. With support and donation from government and NGOs, it seems that the problems are not difficult to solve.

B.3. Health Services

Health service is the front line that serves the people living with HIV/ AIDS. In this research, a lot of positive impressions were stated by respondents. Sufficient knowledge, friendly attitude, accessible and willingness to listen are highly appreciated by respondents. This point of view is relieving, especially when in terms of financial benefits and career prospect, serving people living with HIV/ AIDS promises them almost nothing. It seems that the chance to improve knowledge and helping other people who are in difficult situation are the strongest motivation that keep their high spirit.

However, some respondents show that the knowledge, standards and protocol in health service still vary. People living with HIV/ AIDS are of the opinion that there are some service providers whose knowledge about HIV/ AIDS and addiction are not sufficient so that they are in difficulties in understanding the needs of the people living with HIV/ AIDS. This lack of knowledge can be felt particularly by female respondents whose needs are different from male respondent. Such also applies to the people living with HIV/ AIDS in prisons who lack of services and if there is, the service is low in quality. Standardized service procedure needs to be set up so that the people living with HIV/ AIDS will know their rights and obligations.

Some elements in the community complain on the role of the government in implementing Social Safety Net (JPS). Difficulties in accessing GAKIN card and in finding hospitals or clinics that recognize the value of government programmes make people living with HIV/ AIDS even more vulnerable as they are not well served and apathetic, and end up with death. One of the problem causing difficulties in accessing JPS BK is the fact that the program

was administered through block grant, the implementation of which is associated with the population status of the grantee. Most people living with HIV/ AIDS have long been stigmatized and socially isolated; therefore their population status is not their primary priority in their life. Whereas, most people living with HIV/ AIDS need this kind of services when their health condition deteriorates quickly. That is why the policy of the local government that improves the accessibility to government subsidy could help people living with HIV/ AIDS in maintaining their high quality of life and keep giving their contribution to the community. Unfortunately, a number of local governments are still not aware of the problems, and people living with HIV/ AIDS who live far away from the available facilities have to bear all the consequences. Central and local government have to realize these problems and find the solution as HIV infections have been found and reported in nearly all provinces, and it is clear that people with HIV/ AIDS live not only in the urban but also the rural area. UN supports and donor assistance needs to reach these areas, either through KPA (AIDS Commission) or the available health service systems.

Another issue that should be considered in improving the access and the quality of service for people living with HIV/ AIDS is the need to expand and improve the capacity of those who care about HIV/ AIDS – health staff/ provider in the community, NGO staff, or volunteers from the community of people living with HIV/AIDS themselves. Exit interview and Focus Group Discussion (FGD) indicate that good service will be provided if the patients were accompanied by others. This can only be achieved if the information and education about HIV/ AIDS problems could penetrate the formal institution and the structure of bureaucracy. Media is one of the most effective instruments and its participation is encouraged. Through extensive public education, family and community could be reached and assisted so that they have better understanding on the situation and condition of the people living with HIV/ AIDS and hopefully, they will be more sensitive to the issue and show better self- initiative or be participatory through the existing programmes. Unfortunately such public education and continuous media coverage are not the priority of the national and local media due to the strong privatization and commercialization trends in this sector.

Recommendation is formulated in two ways; the first is specifically made for the people living with AIDS and the second one is aimed to the development of service for their program.

C.1 Capacity and involvement of the people living with HIV/ AIDS.

Bearing in mind the importance of supervising and controlling the quality of health service in general and people living with HIV/ AIDS in particular, the participation of people living with HIV/ AIDS in evaluation and reflection activities on various services designed to meet their needs is necessary. The capacity of PLHIV participation can be improved through their significant involvement in several research and evaluation activities so that in the future, PLHIV can initiate research and evaluation by themselves. In relation to this research, the research participants need to compare the data collected in one region and other data derived from other regions in order to improve the service quality.

C.2. Developing Service

There are four major challenges in developing services for PLHIV. First, more services must be provided and moved closer to the client and they must be designed so carefully that in terms of distance, location and cost, they are affordable. Second, the capacity and the attitude of the service providers need to be given more attention and improved so that their standard of quality can be higher and they are able to avoid stigmatization and discrimination. Highly appreciated services can be detected from the client's cooperation and retention in taking benefits of the program. Third, subsidiary mechanism, ultimately JPS-BK, should facilitate the availability of the access for the people living with HIV/ AIDS. Therefore, an alternative should be offered in order to solve the problems, should the program implementation through block grant find an obstacle. Fourth, nineteen years of the epidemic has been long experience so that the knowledge of the community and health providers on HIV/ AIDS should be better. Government and care community should be able to use various media available in the community so as to take optimum benefits of public education in this field in terms of its substance, consistency and continuity.

Bibliography

APN+ (January 2004). **APN+ position paper 2, GIPA.**

APN+ & APCASO (No dates and year). **Valued voices: GIPA Toolkit –A manual for the Greater involvement of People Living with HIV/AIDS.**

Day, Rosmini (2005). **Aspek program pemberian ART untuk IDU di Indonesia.** Presentasi dalam pertemuan Tindak Lanjut Lokakarya Aspek Medis Dalam Pengurangan Dampak Buruk, Surabaya, 12-14 September 2005

Ditjen PP&PL (2005). **Laporan Triwulan Pengidap infeksi HIV dan Kasus AIDS s.d 31 Desember 2005.** Jakarta: Ditjen PP & PL, Depkes RI.

Djohani, R, & Moeliono, I. (1996). **Berbuat bersama. Berperan setara. Acuan penerapan partisipatori rural appraisal.** Bandung: KPMDMT Studio Driya Media

Irwanto (2005). **Ringkasan: hasil: Pembelajaran aspek teknis program pencegahan HIV/AIDS pada kelompok IDU.** Jakarta: Monograph untuk ASA/FHI.

KPA (2003). **Strategi Nasional Penanggulangan HIV/AIDS 2003-2007.** Jakarta: Kementerian Koordinator Bidang Kesejahteraan Rakyat, Komisi Nasional Penanggulangan AIDS.

MAP (2004). **AIDS in Asia: Face the Facts. A comprehensive analysis of the AIDS epidemics in Asia.** MAP report.

Mesquita, F. (2004). Giving injecting drug users access to highly active antiretroviral therapy as a response to HIV/AIDS epidemic. In IHRD. **Breaking down barriers: Lessons on Providing HIV Treatment to Injection Drug Users.** New York: Open Society Institute and International Harm Reduction Development.

WHO/UNAIDS (June 2005). **Summary country profile for HIV/AIDS treatment scale up: Indonesia.**

WHO (2005). **Expanding access to HIV/AIDS Treatment. Mission Report – Indonesia January 2004.** New Delhi: South-East Regional Office.

FGD Summary Report With PLHIV Community in A Number of Cities

attachment **1**

Jakarta

1. CIPINANG PENITENTIARY GRADE 2: DRUGS UNIT

The problems of PLHIV

Individual/ internal problem:

- PLHIV feel incapable of having better services in the penitentiary with PLHIV status and following the prevailing procedures. This due to the limited health facilities and poor bureaucracy systems in the penitentiary. Their status as prisoner is burdensome, and their fellow inmates' interest in taking test adds more psychological pressure.
- They are worried that their HIV status to be known when accessing health services outside the penitentiary. They also afraid to disclose their HIV status.

Family

- They feel unsecured that they will not be supported by their family if their HIV status is known by them due to the lack of information the family members have.

Community

- They are concerned about discrimination in the prison community and double stigma labeled by the community when they are free. (Inmates, for example, keep their distance to those whose HIV status is positive).

Constraints regarding health service provision inside the penitentiary.

Cost

- Accessing HIV related tests ((HbsAg, Sgot/Sgpt, CD4 etc.) are expensive.

Availability of medicine

- CTM, Paracetamol and balm are available free from the prison authority but for other kind of medicine, inmates have to buy by themselves.
- ARV are not always available, and should an inmate needs it, his/her family members have to collect the medication from the referral hospital and drop it to the clinics in the penitentiary in order to be accessed by the inmate concerned. Without family members' help, inmate who needs ARV cannot access the medicine. NB. Advocacy is important.

Health Staff

- Health Clinic sometimes opens at the same time as the inmates' schedule to attend briefing and/or other activities. (*"Sometimes the penitentiary systems limited us to access health service, for example,... doctor who supposed to serve the inmate from 10 a.m to 1 p.m arrives at 1 p.m, while we are taken from our cell at 3 p.m. So, we cannot make it. What can we do when the ARV is not available and we are put in cell?"*).
- Discrimination against the poor and the rich inmates. (*"If you give some money you will be served, but if you don't, you will be ignored"*).

Procedure

- It is difficult to access support group due to the location and bureaucratic constraints. (They must have a letter of notification from the prison staff).
- Inmates are not allowed to keep the medicine by themselves they are only allowed to take the medicine in the prison health facilities. ARV sometime cannot be accessed according to the schedule.)
- Visits mean extra cost.

Expectation and suggestion

1. Nutrient improvement program. Inmate with HIV positive needs to improve his stamina so that they needs better diets and food to improve their health condition. (vitamin and food supplement should be provided). In the penitentiary, even sick inmate does not receive any additional food/ diet. Families tend to avoid bringing in additional food as it means that they have to pay more extra money.
2. Medication. Inmates should be allowed to keep their personal medications so that when they need them they can consume them without to be dependent on the clinic schedule. Prison authority should provide more kinds of standard medicine.
3. HIV and other relevant tests should be able to be administered in the penitentiary.
4. ARV should be accessible inside the penitentiary.
5. Support group visits should be more often and their procedures must be simplified. (At the present time, meeting with support group is conducted fortnightly).
6. Coordination with the relevant government agencies such as Dinkes, Dinsos, and NGOs should be strengthened so as to improve services such as support group meeting and health services for PLHIV.
7. Capacity building and training for ADHA community such as becoming buddies, persons in charge of monitoring side effects and drug adherence should be conducted.
8. It is necessary to provide support and information to the family of PLHIV in order to avoid unnecessary pressure on them from the family members.

Penitentiary officials

- Capacity building for the penitentiary staff. (interview).
- ARV stock should be made available in the prison.
- Simple laboratory equipment should be made available (for SGOT, Hb, HbsAG test).

2. DHARMAIS HOSPITAL (FOCUS GROUP DISCUSSION WITH WOMEN GROUP WHO ACCESS HEALTH SERVICES AT THE HOSPITAL)

Problem faced by PLHIV

Individual/ internal problems

- Most of them are concerned about the fee for pap smear test and caesarian operation.
- They are worried about their daily living costs such as for health services, child care, and meeting their basic needs.
- They are worried about the expense they have to spend when accessing ARV therapy. (For example, transport fee, hospital fee, doctor/medical consultation fee, necessary test fee and so forth).
- Sometimes their drug adherence is poor as they frequently forget to bring the medicine with them.

Problems related to community

- They are afraid that community members are discriminatory against their children.
- They are worried that the employers know their health status and discriminate them in the workplace.
- They are not willing to access ARV treatment in the nearest hospital as they are worried that community members will be discriminatory against them.

Service access

- A number of health staff show lack of understanding on HIV/AIDS issues, one of them can be found in a big hospital like Dharmais.

Expectation and suggestion

- Government should provide free services for those who give a birth or taking necessary health tests. (such as pap-smear test and caesarian operation).
- Ensure the continuity of free ARV treatment (long-life service). Advocacy should be targeted to important actors such ministry of health, donor agency, and hospitals.

3. EXCEED COMMUNITY. MOST OF FGD PARTICIPANTS WORK FOR NGOS (YAYASAN MITRA INDONESIA, PPKUI, ETC.)

Problems faced by PLHIV

Individual

- They are worried about side effects and allergy resulted from therapy. (*"I used to take ARV therapy but then stopped for two years because of the side effect such as "eye sore", so that I quit the therapy the following day. I could do anything at the time because I feel like flying and since then, I quit the therapy...and never have another therapy until now"*).
- Difficulties in accessing health services from GP and dentist. (*"In 2005 I had severe toothache, and I was worried if I had to tell my HIV status to any private dentist, so I went to RSCM. When I meet the dentist I was asked many questions and the dentist said that he has to perform operation. He asked me about my medical history, asking what kind of diseases I had. As I said that I had a history of using drugs, so he asked me whether I was an IDU and I had Hepatitis C. And then he stopped asking questions. In that case, said the doctor, please wait outside, and you will be called for an x-ray. And I waited for such a long time and the doctor did not do anything. Then the nurse appeared and I asked whether I could be ex-rayed but she answered that they could not handle the case there. And then I was given a reference, and that's it". – RSCM)*

Family

- They are worried that the family would not support them when they knew their HIV status due to the lack of information in the family.

Service related constraints

- In VCT service, there is no follow up available.
- Laboratory tests are very costly.
- Unclear Information regarding the service location for HIV treatment. (*"Once one of my friend who has got children -- her husband passed away—had VCT twice and proved to be positive. Then her children are also recommended to take VCT and brought to one of the referral hospitals, but the hospital authority said that her children could not take VCT but viral load test. She asked for the reasons why her children could not take VCT test while her first child is 4 years old and the second one is 2 and half years of age. She argued that the children should take VCT." Fatmanwati Hospital).*
- There is no such a clear bench-mark regarding the consultation fee. (The rate keeps changing at Dharmais Hospital).
- ARV therapy is tackled by many different doctors. (*"For example he/she asked, "Doctor, this is what I feel" and the doctor responded, "Oh yea...who took care of you yesterday?" RSCM).*

- There is no such a clear information on how to get SKTM.
- They are worried about the process and fee for accessing CD4 service (transport fee), although the CD4 service itself used to be free of charge.

Supporting Factors

- There is a free CD4 service provided by SANDAR (coalition consisting of: Pokdisus AIDS, YAKITA, YPI, Spiritia, Yayasan Mitra Inti) for 100 patients and have been used.

Procedure

- HIV test without counseling
- Pre and post ARV counseling and information sharing are not available.

Expectation and Suggestion

- Location for accessing ARV services should be close to the patient residence.
- With the issuance of trained doctor's prescription, patients should be able to access ARV services in all referral health facilities.
- Free or affordable IO medication and laboratory test should be available to community at large.
- Increasing the variety of ARV medicine.
- Abolishing discrimination in accessing treatment.
- Resistance test should be made available.
- Clear information on PMTCT should be made available (the location and how to access, for example).
- Implementation of VCT services should be clearly followed up.

4. STIGMA

Problems faced by PLHIV

Individual/internal problems:

- The process to access JPS –BK is long and complicated (with possibility of paying administrative fee etc).
- PLHIV are not covered by Akses or government insurance.
- It is difficult to follow therapy as they are still active drug users. (the problem associated with adherence, regimen substitution, ineffective medication).

Service-related constraints

- PUSKESMAS staff at sub-district level lacks of skills for anticipating HIV issues.
- There is no such a standardized rate for medical consultation (different rate is applied to the same service).

- Accessibility of, availability of and budget for IO (Flukonazol, Biozole) are not reliable; it is sometimes difficult to get as IO is only available at RSCM but expensive.
- Laboratory test fee is expensive; they tend to be reluctant to take ARV therapy.

Supporting factor

- Sub-district PUSKESMAS has been equipped with simple laboratory facility that may support the medical examination of the PLHIV.

Expectation and suggestion

- Insurance should cover the outreaching workers with high vulnerability.
- Capacity building for sub-district staff of puskesmas in dealing with PLHIV.
- Equipment for Viral Load, CD4 and resistance tests should be made available at the respective province.
- Advocacy for economic empowerment of PLHIV, for example vocational training, should be developed and planned.
- Communication, Education and Information Media should be made more specifically. (example for lubricant, female condom, etc).
- HIV/AIDS information should be integrated into school curriculum (Guidance and Counseling).
- Special hospital for PLHIV should be made available, and it should be free of charge.
- PLHIV should be allowed to sit in the parliament. (GIPA)
- There should be support groups for PLHIV.

5. PITA

Problems faced by PLHIV

Individual / internal problems

- PLHIV delay the therapy due to the availability of ARV supply.
- They lack of drug adherence when taking ARV therapy.
- Discrimination in health service against PLHIV in the hospitals

Constraints

- Limited number of staff who know about ARV training. (Only one person who understands ARV and HIV in the hospital of Tarakan).
- It is difficult for resistant PLHIV (indicated by their stable result of CD4 test for 6 months), to access second line ARV.
- There is no such supervision for taking ARV for those who take ARV therapy for the first time.

- Budget for CD4 test is not available.
- PLHIV with JPS scheme are not always welcomed by health staff.
- Out patient procedure for JPS holder is too complicated (meanwhile, he/she should be treated at least 2 x 24 hours. (RS Dharmais)
- Hospitals apply different procedure in dealing with patients under JPS scheme. (Payment must be made before treatment).

Expectation and suggestion

- ARV therapy should be accessible in all clinics.
- Capacity building should be conducted for health service provider, especially those who work at puskesmas level.
- ARV should be accessible at puskesmas level.
- In-patient rooms in referral hospitals especially class III should be increased in number. (Many hospitals has limited number of room class III so that PLHIV are referred to VIP, class I and class II room).
- JPS-GAKIN scheme should be accessible in all hospitals.
- Private hospitals should also provide class III in-patient room for PLHIV.
- The following elements should be the target of advocacy: Family for supporting their economy and medication; Health Authority; Manpower Authority for opening employment opportunity; relevant donors for medications; DINSOS/ DEPSOS; and community for anti-discrimination and stigma campaign.

West Java

Problems faced by PLHIV

Individual / internal problems:

- They are afraid of the side-effect of the ARV therapy. (*"I am continuously afraid of the side- effect, I know it from friends who have started having therapy"*).
- They get bored/ burned out.
- They feel that the ARV therapy is useless. (*"There are two alternatives, but I prefer ARV therapy which is better. Once I try an alternative medication, something like massage therapy and also herbal therapy. I got the information (about it) from friends who did not take ARV therapy. And then my CD4 cell count from five, that is a small number, increase by 230 to 235 after few months of herbal therapy"*).

Family

- They feel that it unfair to burden their parents (*"I am afraid that if my parents know my condition, they will get sick. So it better for me if other member of the family, not my parents,*

know this condition, as they know better and I can share my feeling with them. I am just afraid to be burden for my parents as they may be ill’).

Constraints

- Doctors have different understanding regarding the requirement for accessing ARV therapy. (*“I have my CD4 checked up by Dr. X, and my CD4 is 350, but I feel that I am not fit enough and weak. Sometimes, I got sick for two days in a week. Then I went to Dr. Y, because there is something wrong with my gland so he recommends me to have ARV therapy. When I told the Dr. X, he said that it not necessary to have ARV therapy when my CD4 has not reached 200 yet. I am confused.”*)
- Health service providers show discriminatory attitude. (*“This is my personal experience when I was starting TB therapy. I register myself, and when she knew that I am from an institution, she asked about my (HIV) status, and ultimately about PLHIV. Then she referred me to other person, and then the second person refers me to different officials, and finally a nurse appears and told me that they are about to close.”*)
- For PLHIV, referral hospital is too far away. (*“It is too far away. From Jatinangor, for example, the hospital is too far away. We hope that there should be ARV service in the nearest hospital”*).
- Doctor stigmatize IDU when they want to start therapy. (*“Once, there is a case that involve a friend. His CD4 is already two digits, but he/she is from lower—class society. We try to help her/him to access ARV therapy, but the doctor said that the patient seems to be unprepared for a therapy as his/her characteristics is like this or that.”*)

Expectation

- There should be a standardized rate. (*“Do not discriminate OPHA against non-PLHIV. We also want to be served. If we have to pay, we will pay. If we could get the service free, why do we have to pay?”*).
- ARV should be accessible in all hospitals.
- In each district, there should be a reference on how to deal with HIV/AIDS.

Sukabumi

SUKABUMI POSITIF COMMUNITY - ESTABLISHED ON THE FIFTH OF JANUARY 2006. FGD PARTICIPANT: PEER SUPPORT GROUP

Problems faced by PLHIV

Individual / internal problems:

- ARV Adherence is very poor.
- They are ashamed as PLHIV.

- Discrimination against PLHIV occurs because the community is not well informed on HIV.
- Diagnosis tends to be late. Most of PLHIV died because when the case is disclosed, it has been at terminal stage. (*"For sure, the client is referred to the hospital... but none should be blamed as they are admitted to hospitals while they are at the third stage, so they die"*)

Service-related constraints

- The medicine lacks of variation. (*"I did not consumed various medicine, so I will find some in Bandung"*)
- Doctors have limited knowledge about the disease. (*"Sometimes, doctors are not sure about our illness. For example, doctor just gives me vitamin, probably vitamin B when there is a pain in my foot. Then, he/she asked me about how I feel, and if he/she found that my SGOT or SGPT goes up, he/she would give me curcuma. Meanwhile, for the foot, the doctor just give me vitamin B, and then again he ask some more questions and suggest me to take some medical test..."*)
- When taking an HIV test, confidentiality are not well kept by the laboratory staff (*"Dinkes gives me reference and they said that it should not be opened, but when I came to collect the result, it was first opened by laboratory doctor."*)
Counselor and health staff shows lack of understanding on HIV/AIDS. (*"I took an HIV test in Sukabumi and referred to Bandung, but when I received the result, (the staff) in Sukabumi could not determine whether I am HIV positive or negative, so I went to Jakarta, and have a test again and the doctor is not sure about the result"*).
- CD4 test is expensive. (*"Yesterday I take CD4 test and pay 200 thousands, the sample is then brought to Bandung. If you take the test in Bandung it cost you 125 thousands rupiah"*).
- Administrative cost for accessing ARV is too much. (*"It's too much, my parents, both of them are not working anymore"*).
- Staff who supervise and help client when he/she starts having ART is not available. (*"I saw two friends who could not continue the therapy and finally died. That was because of the lack of health provider who could supervise and help them I think. Even I called the hospital to remind them about her medicine but I was just ignored and they died. At that time, I was so sad..."*).
- Doctor's attitude in handling PLHIV who access ARV put them into second priority. (*"When I visit an internist and I came early in the morning, but I was served in the afternoon. I have to wait until his last patient, and then my turn comes although I am the first person to register"*).
- Children could not access ARV in the region as it is unavailable. At the moment, they are still referred to RSCM Jakarta.

- The existing HIV/ AIDS programmes are not well coordinated.
- Lack of doctors who understand PLHIV medication.
- Jamsostek did not cover PLHIV claims. (*"And I have Jamsostek insurance but my claim was once rejected. Jamsostek's staff said, "It (HIV/ AIDS) is because of your own fault, not natural cause, so we (Jamsostek) cannot pay my claims"*).

Expectation

- CD4 test should be more accessible. (*"The equipment should be available and the rate is affordable"*.)
- In each region, there should be a location for accessing ARV, for example at a puskesmas. (*"I think referral systems is not always necessary, so I am happy if I can access ARV in Bandung or Sukabumi because I study at a university in Bandung and am now enjoying my holiday in Sukabumi. I run out of ARV now so I think if the ARV is available at puskesmas level, I just show my card and get the medicine"*).
- There should be a one-stop-centre in hospital.
- There should be one day seminar for hospital advocacy.
- Service systems for accessing ARV should be improved.

Tasikmalaya

FGD PARTICIPANT: KELOMPOK DUKUNGAN TASIK+, ONE OF THE PARTICIPANTS IS A MOTHER OF A CHILD LIVING WITH HIV/ AIDS

The problems of PLHIV

- Lack of information about HIV/AIDS

Constraints in Referral and health service (Such ARV etc).

- ARV are not accessible in Tasik. PLHIV has to access the service in Bandung or Jakarta. (*"PLHIV must go to Bandung or Jakarta to collect ARV, and it takes time and money. It should be accessible in Tasik, I think"*).
- Transport cost for accessing health services and ARV are very expensive. (*"I have to spend 300,000 IDR - 400.000 IDR every month just to get served in Bandung. That is a minimal figure. If I have to go to Jakarta, the cost will be higher"*).
- ART stock is unreliable and sometimes the medicine is not available. (They once run-out of stock, or sometimes, the medicine are not given in full package, enough for five days).
- Doctor who is an expert in dealing with HIV cases is not available in Tasik.

("In Tasik, such a doctor who is expert in dealing with the patient at risk is not available...").

- At RSHS Bandung, clients who come from Tasik, sometimes have to wait for the doctor.
- HIV test without VCT (many HIV test are conducted without VCT).
- Some health staff (such as nurse) react inappropriately and afraid. In Tasikmalaya, for example, a nurse run away when she saw the patient shivering. *("They are afraid...").*
- Counseling for taking medicine is not available.
- Doctor who could handle children (with HIV/ AIDS) cases are not available. *("The obstacle is that we have to go to Jakarta many times. If a doctor with the same capacity is available in Bandung, of course we prefer to go to Bandung. And if they are available in Tasik, we will go there").*

Expectation

- Health facilities and laboratory in Tasik should be improved.
- In the future. KDS should hold a weekly meeting.
- Pediatrician should be available here.

Semarang

RUMAH DAMAI – SEMARANG (FGD PARTICIPANTS – PLHIV, MOST OF THEM ARE FROM JAKARTA WHO TAKE THERAPY IN SEMARANG)

Problems faced by PLHIV

Individual/internal problems

- Withdrawing and afraid when they know that they get infected. But after they get information and support, they feel better.
- After they know that they get infected, they are more cautious.
- They have shown some physical symptoms (diarrhea etc).
→ HIV/AIDS information is very helpful for minimizing their psychological impact.

ARV Access

- It is easy to access ARV because they know some doctors who care about them (RS Karyadi), so that they do not have to go to RS Karyadi every month to collect the medicine. They even get new stock before the previous package is finished.

Service- related constraints

- CD4 test and VL check are expensive as they are accessible only in Jakarta.
- ART side- effect during the first few months of medication. (*"It was like a hell in the first month..."*)
- Discriminatory attitude from the family and friends. (*"They never show the attitude directly but from the way they behave I know there is... just a little bit. For example, my family. Although they said it's okay, but they start to separate my personal belongings such as the shaver without my consent. And friends also keep a distance"*).
- Service discrimination between the rich and the poor clients. (*"But the doctors, nurses...their attitude are different if they are in Garuda ward. PLHIV knows that they pay when admitted to the place. But their mental condition are different, some PLHIV were not demanding, while other may be mad at the service they have. In Garuda ward, that is fine they are demanding as they pay for the service, but in PLHIV ward, they (doctor and nurse) may think that patient do not have to pay so when the patient complain they behave as if they said, "you don't pay, do not expect too much...we can see it"*).
- In-patient rate in high. (*"Those who are HIV positive are in Garuda annex, but actually, I want to be in the ward too."*)
- No confidentiality in the rehabilitation centre.
- Laboratory staff are poor in keeping client's confidentiality. (*"As far as I know, the information does not leak at Rumah Damai, but in the laboratory. When PLHIV do a presentation, someone who is not from Rumah Damai but he know all the name of us in Rumah Damai. So those who took a test were disclosed, and one of the name on the list is me ha ha ha."*)
- For accessing ARV, the service systems are still too complicated. (*"For illiterate people, it is difficult for them to access ARV in the hospital. Look at the language they use...there are some illiterate clients while in RS Karyadi, it is a bit complicated"*).
- There are not many ARV varieties available in Indonesia. (*"X uses a kind of ARV therapy which I do not know... something like neviral with its duviral replaced. Ok, the ARV medicine in Semarang indicate its content (in mg), isn't it? The hospital in Semarang only has certain stocks, while he/she actually needs other medicine but not available there, so he has got to buy the medicine in Jakarta, it is not free of charge."*)

Supporting factors

- Community member in the rehabilitation is a good peer support in overcoming the side effect of ARV therapy.
- Most FGD participants are not living in Semarang, so it is not a problem if they disclose their HIV status. (*"In Semarang, I don't mind disclosing my HIV status. Through some seminars, I disclose my health status. But in Jakarta, as I live there and have so many friends, I am not ready to disclose my health status"*).

Expectation

- Drug and HIV/AIDS issues should be included in curriculum.
- Special HIV/AIDS Hospital should be made available.
- There should be CD4 test equipment.
- There should be a self- preparation training for ARV user.
- HIV/AIDS Campaign and information dissemination in the community should be intensified.

Surabaya

1. FGD AT RS DR.SUTOMO, PARTICIPATED BY PATIENTS

Problems

- PLHIV are afraid of the side – effects of ARV and medicines for opportunistic infections. Because of such fear, they do not consume IO.
- Lack of "buddies" for PLHIV who is taking part in a therapy so that they have to take care of themselves. Lack of support for patients.
- Lack of information on the side effects of the medicine they consume, such as permanent rash.
- Lack of sufficient information for PLHIV who live in district level (For example, Kediri). (*"When I know that I am HIV positive, I visit the best doctor in Kediri, and he didn't know what he has to do with the test result of mine. Later, I got the information about HIV from newspapers. Meanwhile, it is estimated that there about 50 PLHIV in Kediri"*).

Case: The situation was a bit difficult when I was first admitted to a hospital, but there is a nurse who cares so, I got helped. Services and supports in hospitals depend on the persons (staff) not the established systems.

- A lot of infections among PLHIV occur because their anger and lack of information.
- People tend to blame IDU with HIV / AIDS, ultimately the family. (*"It is your fault to be an IDU!"*).
- As the service is only available in Surabaya, the transport cost becomes extremely high.

Constraints in ARV Service

- Medication for opportunistic infections is costly.
- Hospital authority does not pay enough attention to in-patients who are not accompanied by their family.

- The procedure for accessing hospital services is too complicated, except when they are accompanied by NGO.
- First time patient find it difficult to access the service due to the lack of information available for new patients.
- Patient under JPS scheme tend to be served last. (*"It takes such a long time to deal with JPS administrative matter, and in the clinic, those who come first but using JPS card, they will be served later"*). Health staff tend to be discriminatory and give priority to the PLHIV they know personally.
- Under JPS scheme, clients have to pass through longer and more complicated bureaucratic things. (*"I was going to collect medication in a pharmacy but I was told to go here and there. Despite the fact that the doctor has given the right prescription, the pharmacist who serve me said that the medicine is wrong. Then, I returned to the doctor, and found out that the doctor has already left"*).
- JPS-Gakin is difficult to get and must be collect it in the place in where the clients live, so that the clients must travel many times. This is not easy for the patients whose health conditions were deteriorating. In addition, they are afraid of being stigmatized and discriminated when they collect their JPS card as they will be interviewed in detail for verification. PLHIV are afraid of being exposed in the mass media. (*"We are afraid to get our JPS card in the place we are from as we have to tell them the truth about our health status (illness), and if they know that we are PLHIV, we will be exposed in the local media"*).
- Treatment in the Tropik Room is not good enough. (*"Nurses are often unavailable, and it takes time to change IV"*). Nurses in Tropik Room are still afraid of being infected and some are discriminatory in nature.
- Six months ago, patients received vitamins, but now, they don't.
- Sometimes, the prescribed medications are not provided in full package (They are written in the prescription but not provided), because anytime the clients asked for the prescribed medication, they said that they run out of stock. So, clients have to buy the medication in other location.
- There is an improvement with regard to ARV service in the new pharmacy, but they have to go through two similar counseling session. (They receive the same information when the doctor handed over prescription and collect the medication in the pharmacy). As result, it takes time to line up.
- Efavirenz 600mg is not available, although lighter dosage, i.e. 200mg is ready stock. This, in turns, is burdensome for patients.
- Doctors' and paramedics' skills and knowledge are still insufficient. For example, *"I am ordered to take ARV for two weeks. It affects my nerve systems, and then I was asked to stop taking ARV"*. (Doctor did not give any explanation).

- Many side-effects from free Nevirapine are intolerable, so that PLHIV must use Evavirenz (which is not free of charge).
- Although advocacy has been done, there is no such real HIV/AIDS supports yet given by Dinkes, BNP, KPAK, Bupati, and Walikota (Major).

Expectation and suggestion

- UNAIDS should operate in the region for empowering PLHIV, ultimately in Nganjuk and Kediri. (If possible, UNAIDS should reach the district level as it is there that information is difficult to get. When they get the test result, they do not know where they can get help).
- There should be special treatment and attention for poor patient in order to get help under JPS Scheme.
- ARV counseling should only be conducted when prescription is given. (It is not necessary to repeat the same session when collecting medications in pharmacy).
- Evavirenz 600 mg should be made available and free of charge. Free vitamin should be provided again.
- Information and support for PLHIV should be provided in order to improve their spirit.
- Revive "Prana" activities for PLHIV as an alternative therapy. (There was such an activity in the past.)
- Local government should not misuse its authority by collecting detail data on PLHIV when they asked for JPS recommendation letter. (The officials should be informed that they must keep all the information confidential.)
- Local government should give more concrete support, for example by upgrading RSUD as referral hospital in district of Nganjuk and Kediri. (Patients do not have to go to RS Dr. Sutomo in Surabaya.)
- Information about HIV should be disseminated in many areas in Surabaya. (It should not only be at RS Dr. Soetomo).
- There should be no discrimination against PLHIV by health providers' staff.

2. FGD PARTICIPANT: IDU, TRANSGENDER, AND WOMEN WHO ACCESS THE SERVICE AT RS.DR. SOETOMO)

Problem faced by PLHIV

- A lot of PLHIV do not know or lack of understanding of the procedure to produce JPS letter.

Supporting factors

- Sometimes, government programmes such free VCT and CD4 test are available.
- Peer support and solidarity among PLHIV has been well established.
- In the hospital, ARV service can be accessed easily and the service is good.

Constraints

- It is not easy to access JPS and ASKES. (*"It is just too bureaucratic. We have report to RW and village office and a lot of other procedures must be followed in the hospital".*)
- Access to IO medication such as TB, is not easy. (*"We feel like in an experiment, doctors are rotated every three months, regiments change. It seems that it is an experiment".*)
- There is a discriminatory treatment between JPS patients and non - JPS patients. (*"If you are under JPS scheme, you will have to wait for three hours, but if you pay by yourself, you will be served quickly".*)
- Young doctors seem to lack of understanding about HIV. (*"Once, 4 doctors enter our room and wearing their medical outfit, I almost file a complaint, but that may be their rights to do so or they just don't understand".*)
- Access to Stavudine (d4t) 40mg is not available. (*"It is said that if you weigh more than 60 kgs, you have to consume Stavudine (d4t) 40mg, but here, it only Stavudin (d4t) 40mg that is available. Don't you think it is resistant?"*)
- Schedule is a serious problem. (*"Doctors came in the afternoon, while PLHIV need to be served in the morning".*)

Expectation

- There should be a specialist that is always available around the clock.
- Stop stigma and discrimination, especially from health providers.
- People should not be discriminatory. (*"When I am going to get married and I disclose my HIV status, his parents do not agree".*)
- ARV stock should always be available.

3. FGD PARTICIPANT: TRANSGENDER GROUP AND THEIR OUTREACH PROVIDER WHO ACCESS SERVICE AT RS DR. SOETOMO

Problems faced by PLHIV

Individual/internal problems

- Patients do not come (to see a doctor) if they feel all right. Despite the fact that hospitals offer different kind of activities, they just come to collect the medications.
- They are worried that they will be discriminated if accessing services outside Dr. Sutomo Hospital.

- Patients do not stick to the schedule. They often come late so they are suggested to go home.
- In accessing Gakin facilities in Puskesmas, patients must disclose their HIV status, and most of them prefer to keep silent so that they cannot access the GAKIN facilities.
- Afraid of being discriminated when accessing health service, they tend to avoid disclosing their HIV status.
- They are worried about the side effect, but after being supported, they start taking ARV.

Supporting factors

- In RS dr.Soetomo, Askes could be processed after the patient is admitted to the in-patient facilities.

Service related constraints

- Nurses are not quite helpful. For example, the patients have to change their bed sheet by themselves. It takes too long time to replace IV.
- It is too far away to access a service that is only available at Dr. Sutomo Hospital, especially IO treatment.
- In order to be able to access ARV in the hospital, they must have registration number. If they do not bring their registration number, they are not served. (Tight procedure).
- Transport cost for accessing service are not cheap.
- Not all PLHIV/ Transgenders have ID (KTP) as many of them are non-resident. This prevents them from accessing Askes.

Expectation

- Hospital at district level should be accessible to PLHIV. (At the moment, they always referred to Dr. Sutomo Hospital.)
- Free medication programmes should not be terminated. It may be stopped as long as the price is affordable for the poor.
- The medication should be better. If ARV is finished, there should be other free medications.
- Services should be made simple and easy.
- Government should provide facilities for PLHIV.
- There should not be any stigma and discrimination.
- Patients should explain his physical condition in detail.
- Infected persons should keep themselves from infecting others.

4. FGD PARTICIPANTS: TRANSGENDER GROUP ACCESSING SERVICE AT DR. SUTOMO HOSPITAL

Problems faced by PLHIV

Individual/internal problems

- Afraid of the long-term side-effects of ARV therapy.
- Ashamed because people look at them when lining up for collecting medications.
- Afraid that they could not use JPS when they got ill.

Supporting factors

- VCT and CD4 test, free food supplements and exercise are available. (on Wednesdays).
- Availability of a care, open doctor.

Constraints

- Too far away (distance).
- It takes longer time to collect medication.
- It is rather difficult to access JPS scheme.
- Lack of transport fee for accessing a facility which is far away. (At Dr. Sutomo Hospital).

Expectation

- ARV medication desk/section should separated from children desk/section.
- ARV should be keep sustainable.
- JPS should be made easy and available.
- IO medication should be cheaper.
- There should be special pharmacy for HIV medication.
- PLHIV services at hospitals should be made easier. (They should not be required to produce JPS card).
- Free CD4 test should be improved.

D.I. Yogyakarta

ARV access and medical service

- PLHIV was not appropriately served after waiting for quite sometime although he/has been referred by another doctor. Nurses are not well behaved.
- Service and care are not quite good.
- It is difficult to get medications on public holiday. Although the doctor has places an order, but pharmacist is not quite responsive. (he did not know the medication and for whom). So, the hospital needs to set mechanism for collecting medication on public holiday.
- PLHIV complains about the side - effect of the therapy (duviral, nefiral) such as nausea, skin rash, high fever; after consultation with a doctor was stopped, she/he doesn't receive any alternative therapy.
- PLHIV did not know how long the government and Kimia Farma can provide medication stock. (*"We need medication for the rest of our life. I don't know whether our government is ready to supply the medicine forever?"*)
- PLHIV was move from one to another place due to the fear of health provider
- Some health providers did not follow UP. (*"Few (staff) don't know the regulation they have to abide, i.e. UP. They have to wash their hand first, and they have to wear gloves when taking blood sample. That's for their own safety. In my point of view, this due to lack of information and education for paramedics".*)
- Nurses are not friendly: (*"When taking CD4 test, the nurse seems to avoid administering it. A nurse told me to wait for a second, and few minutes later, different nurse appeared".*)
- Nurse was terrified: (*"When my IV was accidentally pull out and bleeding a lot".*)
- Blood test is conducted in separately location. It used to be in the room with separator only (RS Sarjito).
- Doctors are not available or busy in the wards, so they cannot access the service. Meeting doctors must be scheduled.

Supporting factors

- Doctors give explanation when PLHIV begin their therapy, including side – effects.
- After the explanation, PLHIV should consider the therapy before making decision.
- Explanation is good and comprehensive.
- There some kind of medications to minimize side-effects such as Radin and Nickok – but they must be purchased – not subsidized.

- There are 10 kinds of IO medications believed to be free of charge, including TB.
- Some Jogja hospitals provide more privacy in their counseling and exams rooms.
- Exams procedure is not as complicated as it used to be; Service points at Sarjito Hospital are well integrated and close to each other. Problems exist, but services are getting better.
- For PLHIV who is not accompanied by NGO, she/ he is directly allowed to meet doctor or case manager who stand by at the Sarjito Hospital.

Expectations and Suggestion

Rated between 1-10, in which 1 is the least important and 10 is the most important, our suggestions are as follows:

- Pharmacy that open 24 hours a day, 7 days a week should be available so that clients could collect medications, even during public holiday. (9)
- There should be a commitment that ARV will always be subsidized. (9)
- Subsidized medication for minimizing ARV side-effect should be available. (9)
- Additional kind of ARV therapy should be subsidized (9)
- Nurses' knowledge and skills should be improved so that they could provide friendly services to PLHIV and they could keep themselves from being infected with HIV. (8)
- The status of the client should be informed in a supportive way (7). Some cases were reported by PLHIV (the information is not recorded under the clients' request) that they are informed in uncomfortable way, and that they do not use positive language, but otherwise.
- ARV access should be improved. Puskesmas should be empowered so that PLHIV who live in remote areas or districts or small cities do not have to go to Yogya for ARV treatment or test. (7)

Results of Exit Interview attachment **2**

Institution	Objective	Supporting Factor	Constraint	Suggestion
RSKO	<ul style="list-style-type: none"> ■ To collect Methadone 	<ul style="list-style-type: none"> ■ Friendly services. ■ Strategic location. ■ You don't have to pay in advance. ■ Short and simple procedure. ■ Support from NGOs and doctors. ■ Person in charge gives necessary information about the medicine ■ Good facilities. ■ Rooms are clean and smell fresh. 	<ul style="list-style-type: none"> ■ Distance, costly transport fee. ■ Not strict enough. Lack of monitoring for out-patient. ■ Inconvenient waiting room. ■ Nurse and paramedics are not friendly during rush hour. ■ Open a bit late, but close on time. ■ The price (15,000 IDR) is too expensive. ■ Unfair line-up. Old patients do not have to line up. ■ Doctor treats those who like bringing gift differently. ■ Lack of Privacy ■ The person in charge is not on-time. ■ Annoying, a bit fussy and stuck-up. . ■ Once running out of stock. 	<ul style="list-style-type: none"> ■ Open more branches. ■ Queuing number should be provided. ■ There should be number card for collecting medicine. ■ Glasses for drinking medicine should be replaced monthly. ■ Procedure should be clear. ■ Clinics should be larged. ■ Satellite program should be available. ■ Sufficient security. ■ Health staff should be developed. ■ Economically not authoritative and discriminatory. ■ Patient should be checked first in order to prevent them from bringing in drugs.
RSCM	<ul style="list-style-type: none"> ■ Checking health and RV Access 	<ul style="list-style-type: none"> ■ Accessible. ■ Strategic location. ■ Quick services. Easy to get information about in and out-patient treatment. ■ Laboratory is already available.. ■ CT scan is available and comprehensive. 	<ul style="list-style-type: none"> ■ Service a bit slow, have to wait about an hour. ■ Difficult to reach cause it's too far. ■ Expensive, but the procedure is not clear enough. ■ Administrative staff are not friendly. ■ With the new director, HIV unit service deteriorates. 	<ul style="list-style-type: none"> ■ Doctor should be more than one. ■ Opening hours should be extended. ■ Waiting room should be expanded.

Table11:
Result of Exit
Interview in Jakarta

Table 11 (continue)

Institution	Objective	Supporting Factor	Constraint	Suggestion
RS Dharmais	<ul style="list-style-type: none"> ■ CD4 check up. ■ Health check. ■ Blood test. ■ Collecting ARV. 	<ul style="list-style-type: none"> ■ Good laboratory facilities. ■ Qualified nurse and paramedics. ■ Good, simple services. ■ Air Conditioned rooms. ■ Respect patient's privacy. ■ Free medication, government subsidized program ■ The best with easy and simple procedure. ■ Cheap consultation fee. 	<ul style="list-style-type: none"> ■ It is too far away from home. ■ A bit expensive. ■ Patients have to wait longer when there are many. ■ Laboratory check takes time. ■ Waiting time can be 2 hours. ■ Bad traffics. ■ Few health staff members are not ready to anticipate drugs and HIV/ AIDS issues. 	<ul style="list-style-type: none"> ■ Special room should be provided. ■ If possible, administrative desk should be in front of the laboratory. ■ Service should be quicker. ■ Rate should be lower. ■ If possible, another location that offer similar services should be developed. ■ It should serve patient longer than it is now. ■ Hope that there will be more hospitals offering services for PLHIV.

Institution	Objective	Supporting Factor	Constraint	Suggestion
Unknown - 2 Interview	<ul style="list-style-type: none"> ■ Health check up ■ ARV Access 	<ul style="list-style-type: none"> ■ Accessible ■ Staff treats the patients normally. ■ Sufficient facilities 	<ul style="list-style-type: none"> ■ Only one doctor available and difficult to meet, while he is the only person who is in charge of ARV therapy. ■ Transport fee. 	<ul style="list-style-type: none"> ■ Open more location for ARV Access. ■ Simplify the procedure to access ARV
Unknown (2) - 2 Interview	<ul style="list-style-type: none"> ■ Health check up ■ Access ARV ■ TB medication ■ Access to condom 	<ul style="list-style-type: none"> ■ Friendly health staff ■ Good facility ■ Strategic location 	<ul style="list-style-type: none"> ■ Far away ■ Those who pay shall be served faster than those who are under JPS scheme. 	<ul style="list-style-type: none"> ■ Reduce the CD4 test fee. ■ Expands in-patient room.
Unknown (3) - 1 Interview	<ul style="list-style-type: none"> ■ Health check up ■ ARV Access 	<ul style="list-style-type: none"> ■ Distance is not a problem ■ Friendly staff 	<ul style="list-style-type: none"> ■ Administrative and transport fee. ■ Lack of VL test Service ■ Poor facilities 	<ul style="list-style-type: none"> ■ Expand physical facilities ■ Improve the facilities

Table12:
Result of Exit Interview in East Java

Table 12 (continue)

Institution	Objective	Supporting Factor	Constraint	Suggestion
Unknown (4) - 1 Interview (didik)	<ul style="list-style-type: none"> ■ ARV Access ■ IO Access ■ ARV counseling (PMO) 	<ul style="list-style-type: none"> ■ Simple procedure 	<ul style="list-style-type: none"> ■ Distance is a problem ■ Accessible only in the morning ■ transport fee ■ Slow service 	<ul style="list-style-type: none"> ■ The number of staff should be increased. ■ Pharmacy for PLHIV should be available. ■ Control room should be enlarged

Institusi	Keperluan	Supporting Factor	Constraint	Suggestion
RS Sarjito	CD4, SGOT & SGPT, VCT, ARV tests and medications	<ul style="list-style-type: none"> ■ Simple procedure and good doctor. ■ Good staff and outreaching is available. 	<ul style="list-style-type: none"> ■ In-patient facility is available. ■ Counseling is conducted in a hurry. ■ Confidentiality is not protected. ■ Clients are disappointed as the staff hold meeting and they are asked to return again. ■ Paramedics are not friendly in taking blood sample. 	<ul style="list-style-type: none"> ■ Subsidy for IO ■ Offering in-patient facilities for PLHIV. ■ Counseling should be on the 4th floor.
RS PKU Muhammadiyah	Health check-up, VCT	<ul style="list-style-type: none"> ■ Simple and good procedure for meeting doctor and counselor. ■ good laboratory staff. 		
Griya Lentera PKBI	IMS check up, HIV and VCT test.	<ul style="list-style-type: none"> ■ The facility is far away. ■ Good service, straightforward. 	<ul style="list-style-type: none"> ■ It is not easy to get Information ■ VCT and blood sampling are separated. 	<ul style="list-style-type: none"> ■ If possible, CD4 test and ARV could be conducted at the same place. ■ Blood sampling and VCT should not be separated.
RS Bethesda	VCT	<ul style="list-style-type: none"> ■ Accessible location ■ simple procedure ■ Good service 		

Table 13:
Result of Exit Interview
in Yogyakarta

attachment **3** Action Plan

1. This report will be disseminated among research team (PAR) in order to get some feedbacks.
2. Draft will be sent to the chairman of the institutions in which the research is conducted under permission of UNAIDS (for example Dharmais, RSCM, etc) on condition that it is treated confidentially and not to be disseminated to public. Ask feedback from the respective institution.
3. Activities in the respective region that will be in accordance with the research results. – What next?
4. If possible, the findings will be published for limited audience.
5. It necessary to think about the format of presentation of the findings. If the meeting is conducted in Jakarta, we have to think about agenda so that it can be used as a mean for advocacy.

FORM A

Service Provider Semi-structured Interview Guide

Control

Region :	Respondent:	Sex: M/F
Interviewer:	doctor /counselor/nurse/pharmacist	
Day/Date/time:	No. ID:	

WHAT KIND OF SERVICES? a. VCT b. Addiction counseling c. Advance counseling d. Basic health service	a. Oral Substitution b. HIV/AIDS treatment c. CD4 test d. Others (please specify)
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TASK DESCRIPTION:	INSTITUTION: <ul style="list-style-type: none"> • RS/Puskesmas/ LSM/Pusrehab • You work since: ____ • Work days: ____Hr/Mg • Office hours: ____ to ____ • Number of colleague _____ • Number of PLHIV client per day: _____
PREVIOUS TASK DESCRIPTION:	

HIS/HER PERCEPTION ABOUT HIS JOB:

HIS/HER POINT OF VIEW ABOUT PLHIV:

YOU ARE NOT SATISFIED WITH YOUR JOB. WHICH ASPECTS?

YOU ARE SATISFIED WITH YOUR JOB. WHICH ASPECTS?:

Information For Respondent

Anticipating rapid increase in the number of HIV/ AIDS infection in Indonesia, the government of Indonesia, under assistance from several international donor agencies is developing various services needed by PLHIV. Because you are the subject of the services, you are entitled to express your voice or opinions regarding the quality of the existing services.

This simple questionnaire is designed to help you to express your opinion. We hope that you can take benefits from this opportunity. Your participation could influence the plan and policy in service provision for PLHIV, in which you are one of them. We assure that your confidentiality so you do not need to write down your name and your address.

Should you have any objection regarding the questions we ask, please feel free to skip them. It is also up to you whether you are going to participate in this survey or not.

Thank you very much for your time and your useful opinion.

This survey is conducted by UNAIDS.

FORM B
PLHIV Survey

Control

Region:		Location:	
Interviewer:		Day/ Time: /	
1. Sex: M/F 2. Age:	4. The closest person a. Parent b. Girl/boyfriend c. Friend	5. Do parents know: Yes/ No	
3. Sero status: a. HIV b. Hepatitis B c. Hepatitis C		6. Does girl/ boyfriend know: Yes/ No. (N/A - go to no. 6)	
7. Know that the following services are available (you may choose more than one answer) a. VCT b. Medical check / medical care c. Oral substitution d. CD4 test e. ARV therapy f. Hepatitis C medication		8. Services he/she has use/ taken: (you may choose more than one answer) a. VCT b. Medical check / medical care c. Oral substitution d. CD4 test e. ARV therapy f. Hepatitis C medication	
9. Free services he/she has accessed: (you may choose more than one answer) a. VCT b. Medical check / medical care c. Oral substitution d. CD4 test e. ARV therapy f. Hepatitis C medication		10. Internal constraints: a. Fear b. Shame	
		11. Still feel being rejected? a. Yes b. No	
12. When did you access service for the last time?: a. Less than three days ago. b. Last week. c. Less than a month ago. d. More than a month ago.		13. Constraints in accessing services (you may choose more than one answer) a. Distance b. Rate c. Staff' attitude. d. Complicated procedures e. Afraid to meet relative of friends f. Feeling it's useless. g. Forbidden by _____	

(For ARV - see No.7)

14. You start having ARV
- a. Less than a month ago.
 - b. Less than three months ago.
 - c. Less than six month ago.
 - d. A year ago
 - e. More than a year ago.

15. How do you get ARV?

- a. Dropped by health staff/
outreach staff
- b. Collect them from clinics
- c. Collect them from pharmacy
- d. Collect them at NGO
- e. Collect them from a GP.

-
16. Are you still accessing ARV service now?
- a. Yes, continuously.
 - b. Yes, but not continuously (proceed to 17)
 - c. I quit (proceed to 18)

-
17. Your reasons for quitting ARV (you may choose more than one answer)
- a. Unreliable stock of ARV.
 - b. Too far away (lack of time and money)
 - c. Personal constraint (addicted)
 - d. Needs money (ARV sold).
 - e. Complicated procedure
 - f. Unfriendly services
 - g. Feeling it' s useless
 - h. No one support and supervise him/her
 - i. Others_____ (please specify)

-
18. Your reason for not continuing ARV (you may choose more than one answer))
- a. Unreliable stock of ARV.
 - b. Too far away (lack of time and money)
 - c. Personal constraint (addiction)
 - d. Needs money (ARV sold).
 - e. Complicated procedure
 - f. Unfriendly services
 - g. Feeling it's useless
 - h. No one support and supervise him/her
 - i. Feeling healthy
 - j. Others_____ (please specify)

-
19. Your constructive suggestion for improving the quality of ARV service in your region?
-

Exit Interview Guideline

Objective

1. Collecting fresh / fist hand information from clients who have just left the service location.
2. Completing observation data

Procedure

1. Put on your ID.
2. Read this GUIDELINE and prepare the questions.
3. When arriving at the observation scene, observe the location as detailed as possible.
4. After you have finished with your note-taking, approach one (or more) client(s) and introduce yourself and explain your reasons for visiting the place. Ask his/ he time (10 minutes) after he/she left the service room for a brief interview.
5. You can also approach the client who has just left the service point for interview – although this will be a bit surprising and he/she may refuse your request.
6. Do not discuss the topic of interview before the client finishes his/her treatment or other services. (so that your observation will not be mixed up with the client's opinion).
7. Interviewer should not check client's identity.
8. Check whether he is a client or someone else-our target is the client.
9. Interview should not be recorded – it must be jotted down.

List of questions:

1. What service(s) is (are) available from the location?
2. How far is it from the client's house – also, ask the client to find out the difficulties he/she has.
3. How often does he use the facility?
4. What is his / her opinion about the procedure in accessing the facility?
5. What is his opinion about the location of the service facility?
6. What does he/ she think about the service quality with regard to the staff and the facility?
7. What is his/her suggestion for improving the service quality?

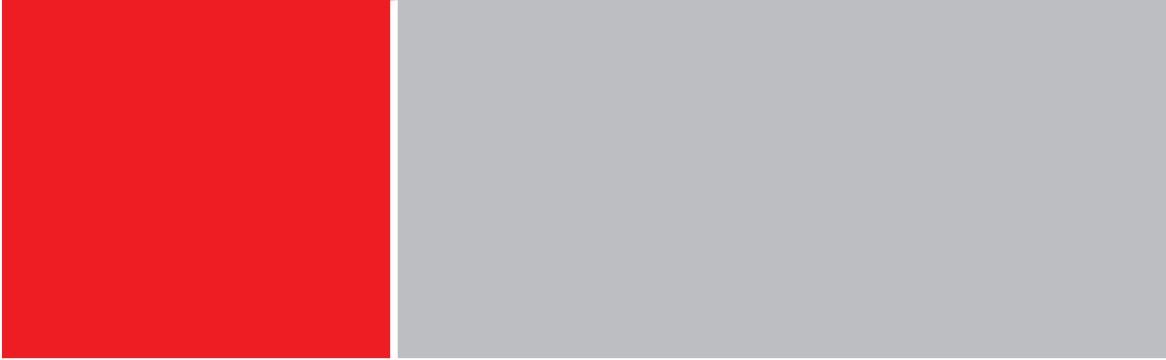
Observation Guideline

Objectives:

1. To collect data without disturbing human activities and the institution in which we conduct our research.
2. To add and complete interview and group discussion data – as well as conducting triangulation.

Procedures:

1. Prepare your research equipment – at least notebook and pen. You may bring compact camera with you as long as you do not take photograph that may attract their attention.
2. Take a note about the location – assess its accessibility and facilities it has.
3. Inside the facilities describe the client's convenience in terms of the lighting; size and dimension, color, cleanliness, furniture, etc.
4. Observe and take a note about the quality of human relation/ communication: ho long they communicate; the quality of communication, facial expression, tone and intonation, and so forth.



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