



Qualitative Research of

***The Role of HIV Positive  
Community in  
Providing Antiretroviral  
Therapy in Myanmar***

**For the Myanmar Positive Group  
(MPG)**

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## **ABBREVIATIONS**

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CBO	Community-based organisation
CSO	Civil Society organisation
FGD	Focus group discussion
FXB	François-Xavier Bagnoud
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV
HIV	Human immunodeficiency virus
IDI	In-depth interview
INGO	International non-government organisation
IOM	International Organisation for Migration
KII	Key informant interview
LNGO	Local non-government organisation
MDM	Médecins du Monde
MPG	Myanmar Positive Group
MSF	Médecins Sans Frontières
MSM	Men who have sex with men
M-HSCC	Myanmar Health Sector Coordination Committee

NAP	National AIDS Program
NGO	Non-government organisation
OI	Opportunistic infection
PLHIV	People living with HIV
PWID	People who inject drugs
SEG	Sunday Empowerment Group
SHG	Self-help group
STD	Sexually transmitted disease
SW	Sex worker
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
WHO	World Health Organisation

## **EXECUTIVE SUMMARY**

### *Background*

It is estimated that around 199,000 people (including adults and children) are living with HIV in Myanmar as of 2013. Over 120,000 people living with HIV were in need of antiretroviral therapy (ART) in 2013. Despite rapid expansion of ART provision in recent years, coverage remains low, with only 75,000 or 62% of PLHIV in need accessing treatment by mid-2014. Rapid expansion of ART provision inevitably requires additional resources to manage the significant increase in number of service users and to maintain quality services at all sites. Hence a meaningful involvement of PLHIVs is crucial if services are to meet the needs of PLHIV and country commitments and targets are to be achieved. Experiences in other countries have demonstrated that partnerships and coalitions between positive communities and other stakeholders benefit both sides and create effective collaborative responses to HIV. Evidence has shown that, with adequate skills and resources, PLHIV can, if provided with an opportunity, play a meaningful role at many levels of the HIV response.

The Myanmar Positive Group (MPG) (National PLHIV Network) was established in March 2005. Nearly 170 self-help groups (SHGs) across the country are networked with the MPG. MPG feels the strengths of existing PLHIV SHGs and networks can contribute to the scale up of the ART coverage for PLHIVs in Myanmar as there remain gaps that need to be filled. In the last quarter of 2013, MPG carried out a qualitative research study in six selected areas to gain a better understanding of the current and potential role of PLHIV in ART service provision.

### *Aims and Objectives*

The ultimate aim of the research was to promote greater and more meaningful involvement of PLHIVs in HIV responses in Myanmar. The specific objectives of the study were:

- To assess the perceptions of positive people on ART services and the level of participation of the positive network in delivery of care for PLHIVs
- To identify gaps that members of the positive network can help fill in to improve the

coverage and quality of ART services

- To identify key obstacles preventing members of the positive network to participate in a meaningful way in the delivery of ART services.

### *Methodology*

The qualitative study involved 12 focus group discussions (FGDs) with SHG leaders, 60 in-depth interviews (IDIs) with HIV positive individuals and PLHIV volunteers and 11 key informant interviews (KIIs) with both public and non-governmental ART service providers and non-ART service providers, and local authorities. The six study areas were Yangon, Patheingyi, Taunggyi, Lashio, Mawlamying and Mandalay, Sagaing, Magway (as one area). The data collection was done in October and November 2013 by 17 trained MPG members. This study received ethical approval from the Ethical Review Committee on Medical Research Involving Human Subjects, Department of Medical Research (Lower Myanmar).

### *Summary of Findings*

#### *Self-Help Groups for People Living with HIV*

All six study areas had PLHIV SHGs who were actively engaged in community-based, as well as facility-based, activities. Many PLHIV SHGs were based in large urban areas. SHGs were composed of both HIV positive and HIV negative persons.

Depending on organizational capacity and the level of funding available, SHGs provided psychosocial support to positive peers, took on caregiver roles through home and hospital based care, assisted as peer counselors or volunteers for ART service providers at clinics and hospitals, implemented peer-based prevention activities, linked PLHIVs to available support sources, gave nutritional support, established microfinance support, coordinated income generation activities through membership fees, and conducted regular monthly meetings or gatherings. At the national level, MPG members were members of Myanmar Health Sector Coordination Committee (M-HSCC).

KIIs and FGDs indicated good coordination among PLHIV SHG was maintained, through formal and informal channels, by regular networking activities among groups, monthly coordination meetings, sharing information, experiences and interlinking different services. An active and strong “working hand-in- hand” approach among PLHIV SHGs and between PLHIV SHGs and NGOs and NAP was generally reported.

The MPG secretariat office in Yangon provided technical support through trainings, organised and facilitated coordination meetings, forums, events and for strengthening of the MPG network, and led advocacy meetings with local authorities.

Support from local service providers to PLHIV SHGs and networks were in the form of technical assistance and financial support.

#### *HIV Treatment Needs and Availability of Services*

Peers and local SHG members were identified as the most common sources of information on available treatment services. The importance of a supportive environment in relation to awareness of and access to ART services was expressed.

In all six areas, at least two organisations were offering HIV treatment services. The majority of them were international non-government organisations (INGOs), government-owned hospitals and NAP AIDS/STD teams. These providers were mostly based in well- populated strategic locations.

All service providers offered free antiretroviral drugs, opportunistic infection prophylaxis and treatment, and laboratory diagnostics. In addition to preventive and treatment measures, INGOs provided a broader range of services than the public sector.

In general, the majority of respondents were satisfied with the quality of services obtained from INGOs and local non-government organisations (LNGOs) because of the larger offering of services. Many respondents suggested room for improvement from public sites in relation to communication skills, limited available services, waiting time at health centres and quality of

counselling. From the service provider's side, key informants agreed that, even though the number of ART sites had increased, limitations existed.

PLHIV respondents indicated access to treatment, care and support services was sometimes mitigated by stigma and discrimination, lack of social support from family, poor awareness of services, poor economic status, distance from available services and availability of services in their towns.

Discrimination was mostly absent in selecting patients to start ART. All respondents confirmed that ART was provided to PLHIV who had a CD4 count equal to or below 350 regardless of the type of service providers.

Respondents identified a number of important factors affecting treatment adherence, including self-awareness, quality of counselling, individual perceptions of the value of drug treatment, fears of stigma and discrimination and associated social support, educational status and side effects of drugs.

When asked about service quality, some respondents mentioned supportive attitudes, the absence of discriminatory treatment, encouragement for regular drug taking and preserving human dignity.

#### *Perspectives on the Potential of Greater Involvement of HIV Positive Groups*

Many respondents valued the presence and support of PLHIV networks and SHGs, especially when no family member was there for PLHIV during hospitalisation or when they were sick at home. Positive progress in community perception towards PLHIV SHGs was reported.

It was reported that PLHIV representatives participated as members in their respective township ART selection committees, although their roles were quite limited.

Many expressed the view that a peer-to-peer approach could lead to better information sharing in relation to available services, effective referrals to existing services and support sites, increased health literacy, and stronger relationships of trust between PLHIV and ART providers.

For effective PLHIV participation to occur, interview respondents repeatedly pointed out that solidarity among SHGs was crucial.

Respondents said PLHIV SHG members had many strengths, including team spirit, social conscience, motivation to help others, collectiveness, empathy, strong networking skills, the ability to facilitate linkages and referrals, good will, faith, and the ability to build trust between peers.

Regarding barriers and challenges to HIV positive community participation, respondents pointed out that maintaining a regular income was quite important to PLHIV. Financial insecurity prevented many PLHIV from fully bearing their role in the national HIV response. Stigma and discrimination (including internalized stigma) and poor treatment by service providers were also listed as barriers to participation at the individual level. A number of challenges were also identified at the organisational level, including limited technical capacity, limited financing, weak cohesion and solidarity, shortage of leadership skills, irregular and disjointed collaboration among PLHIV networks and SHGs, lack of personal awareness and failure to take personal responsibility.

The need for technical capacity development was mentioned by service providers and PLHIV. The second most common need expressed by respondents was sufficient financial assistance in the form of a monthly salary to PLHIV volunteers, which would permit PLHIV to spend more time at service delivery sites and undertake effective outreach activities.

Many respondents agreed that more SHGs were needed to reach people from remote areas and small rural townships. They suggested experienced and well-established SHGs help newly founded groups. Respondents recommended improving unity among SHGs, building strong discipline among members, effectively sharing information within and between groups, continuous advocacy (with tactfulness) to authorities; adopting a team, social and voluntary spirit; and ensuring of the sustainability of organizations. Respondents said they would also like to see stronger leadership from MPG, including the development of regulations and frameworks for SHGs.

PLHIV respondents wished for positive treatment from health facility staff. They believed PLHIV also had the rights to express their opinions in relation to ART provision. They requested technical assistance from NAP and its partner NGOs to maximise SHG engagement within the public and non-profit sectors.

The majority of SHG members seemed unaware of the GIPA principle and could not describe its essence.

### *Summary of Recommendations*

#### *Immediate Actions*

MPG should share relevant findings with study participants and other stakeholders at the township level. This should also be carried out by dissemination of the research report.

MPG should collect and document the ideas, practices and models of the well-functioning SHGs and include them in developing standard guidelines for SHGs. It should share them with both SHGs and groups requiring strengthening.

PLHIV SHGs and networks should continue increasing HIV awareness, and reducing stigma and discrimination at the community level, through involvement in health and community development actions.

#### *Intermediate Actions*

MPG should take a leading role to assess the organizational development needs of SHGs, creating capacity development plans and mobilize resources for their implementation.

MPG should encourage and support the formation of SHGs in smaller towns to ensure psychosocial support for PLHIV and to promote care and treatment services.

PLHIV SHGs and networks should be prepared for a range of roles, and coordinate with the MPG secretariat office for organisation growth and management.

NAP and NGO partners should develop a minimum standard guideline of service quality at decentralized levels.

NAP and NGO partners should provide education to staff on quality improvement of services, and conduct regular monitoring of service quality (including communication, confidentiality, code of conduct employed when dealing with service users). Regular feedback from service users should also be requested.

NAP and NGO partners should reinforce their existing technical support to SHGs.

NAP, NGO partners and MPG should identify strategies to reach out “healthy” PLHIV and inform them of available HIV treatment services.

NAP, NGO partners and MPG should ensure the availability of psychosocial support mechanisms at community level to achieve the desired treatment outcomes and to mitigate the socio-economic impacts of HIV on PLHIV and their families.

NAP, NGO partners and MPG should work together, at national and township levels to see how the existing PLHIV SHGs can contribute to scale-up of ART, while adopting a chronic care approach. For instance, more SHG members could be engaged as care givers, counsellors, support staff, outreach workers at township level.

NAP, NGO partners and MPG should increase community awareness and address HIV-related stigma and discrimination by disseminating comprehensive information on HIV and AIDS to improve knowledge among community members and eventually reduce stigma. At the centre of these actions, PLHIV SHGs should participate as positive role models within the communities to lessen stigma and discrimination.

NAP, NGO partners and MPG should work closely with each other to promote stronger coordination among government and NGO service providers to address common issues identified at ART decentralization sites.

NAP, NGO partners and MPG explore potential ways to improve both the quality of counselling services and the number of available counselors (setting minimum standards of service

provision, increasing the number of counselling trainings, including a budget line for regular technical backstopping and refresher trainings, increasing annual targets of trained counsellors).

NAP, NGO partners and MPG should consider and allocate financial resources for a capacity development plan for PLHIV SHGs in new National Strategic Plan and National Operational Plan.

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*Policy level*

MPG should advocate for the inclusion of a backup plan for sustainability of existing PLHIV networks in the national health budget plan.

TMPG should continue advocating for the inclusion of PLHIV rights in relation to equal employment and health care benefits in labour laws and workplace policies and HIV law.

## 1. INTRODUCTION AND STUDY RATIONALE

It is estimated that around 199,000 people (including adults and children) are living with HIV in Myanmar as of 2013. According to official estimates by National AIDS Programme (NAP) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), there were about 7,000 new cases among that year.<sup>1</sup> Over 120,000 people living with HIV are in need of antiretroviral therapy (ART) in 2013. Despite rapid expansion of ART provision in recent years, coverage remains low, with only 75,000 or 62% of PLHIV in need accessing treatment by mid-2014.<sup>2</sup> This demonstrates the need for further scaling up of ART provision. In the next few years, ART coverage will continue increasing significantly with funding support from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and domestic funding.

Rapid expansion of ART provision inevitably requires additional resources to manage the significant increase in number of service users and to maintain quality services at all sites. Hence a meaningful involvement of PLHIVs is crucial if services are to meet the needs of PLHIV and country commitments and targets are to be achieved. Under the leadership of the NAP, government, civil society and international development partners must work together in the provision of ART, while ensuring meaningful involvement of people living with HIV (PLHIV), and maximizing the coverage and quality of services. With their involvement, AIDS-related deaths and new HIV infections can be significantly reduced and eventually eliminated. This idea is reflected in the guiding principles of the Myanmar National Strategic Plan on HIV and AIDS 2011-2015 which aims to achieve universal access to HIV prevention, treatment and care, improved partnerships and coordination, and a greater involvement of PLHIV according to the Greater Involvement of People Living with HIV (GIPA) principle.<sup>3</sup>

Research done in other countries has shown that barriers to HIV treatment access include a lack of adequate knowledge about ART, poor information on the availability of ART services in

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<sup>1</sup> HIV Estimates and Projections, Asian Epidemiological Model, Myanmar 2010-2015

<sup>2</sup> Treatment eligibility is based on less than 350 CD4 count.

<sup>3</sup> Myanmar National Strategic Plan & Operational Plan on HIV and AIDS (2011-2015), Concise version, National AIDS Programme

their local areas, limited financial resources (for treatment, laboratory testing and transportation), distance to ART facilities, provider attitudes, denial of health services and fear of drug interactions and side-effects.<sup>4</sup> Although PLHIV network and self-help groups may not have much medical expertise, they can play strategic roles in encouraging and supporting PLHIVs to obtain proper treatment and to adhere to their treatment regimens. Also, no one is in a more suitable position than they are, as peers, to gather information about the treatment, care and support needs of spouses and partners. PLHIV can play a vital role in positive prevention strategies. PLHIV networks and self-help groups are, therefore, an excellent resource for the scale up of HIV treatment and care. A guide note from the Asia Pacific Network of People Living with HIV/AIDS (APN+) recommended government institutions, non-government organisations (NGOs), community-based organisations (CBOs), donors, and other institutions forge stronger partnerships with PLHIV organisations and groups.<sup>5</sup>

Experiences in other countries have demonstrated that partnerships and coalitions between positive communities and other stakeholders benefit both sides and create effective collaborative responses to HIV. In South Africa, for instance, the existence of extensive networks of community-based treatment monitors from different geographical areas significantly reduced loss to follow-up of ART patients and strengthened ART adherence.<sup>6</sup> Moreover, PLHIV networks and SHGs can provide links between HIV positive people seeking treatment, and existing service providers, thereby leading to improved target group access, follow-up and feedback in care and support initiatives. For example, in Pakistan, the New Light AIDS Control and Awareness Society (a HIV positive people's network) acts as a bridge between positive people seeking treatment and service providers.<sup>7</sup>

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<sup>4</sup> Asia Pacific Network of People Living with HIV/AIDS (APN+). Access to HIV-related health services in positive women, MSM, transgender and IDU, research finding highlights, August 2009 Report

<sup>5</sup> Asia Pacific Network of People Living with HIV/AIDS (APN+), UNDP. Working in partnership with networks of people living with HIV in Asia and the Pacific, a guidance note for development practitioners

<sup>6</sup> Asia Pacific Network of People Living with HIV/AIDS (APN+), UNDP. Working in partnership with networks of people living with HIV in Asia and the Pacific, a guidance note for development practitioners

<sup>7</sup> Asia Pacific Network of People Living with HIV/AIDS (APN+), UNDP. Working in partnership with networks of people living with HIV in Asia and the Pacific, a guidance note for development practitioners

Evidence has shown that, with adequate skills and resources, PLHIV can, if provided with an opportunity, play a meaningful role at many levels of the HIV response.<sup>8</sup> Individuals living with HIV should not be regarded only as passive beneficiaries and target audiences, but must be considered as active contributors, implementers, experts, speakers and decision makers. A policy paper on GIPA has categorised four levels of PLHIVs involvement: access to services as beneficiaries; inclusion as support staff or as volunteers in service delivery; participation as sources of expertise; and greater participation as significant policy and strategic development actors, with significant representative roles.<sup>9</sup>

In Myanmar, the GIPA Initiative Group was established in March 2005 with the help of nine PLHIV founders from various international and local NGOs and support from the International HIV/AIDS Alliance and the United Nations Development Program (UNDP). The group changed its name to Myanmar Positive Group (MPG) (National PLHIV Network) in 2006. The main objectives of MPG are (1) building skills and capacity for PLHIV based on the GIPA concept, (2) networking between PLHIVs and SHGs, (3) reducing stigma and discrimination among PLHIV and community, (4) representation for PLHIV in Myanmar and advocating for PLHIV rights to access treatment and quality services and (5) developing more PLHIV SHGs. These SHGs are a fundamental component of the mobilisation effort by PLHIV in Myanmar.

When MPG was established, only 47 SHGs were networked. Currently, nearly 170 SHGs across the country are networked with MPG. MPG has become a strong and visible network that conveys the voice of PLHIVs not only in Myanmar, but in the Asia Pacific region and globally. A lot of its members have been trained in positive dignity, health and HIV prevention, treatment literacy, peer counseling, among other subjects. Some members are providing volunteer services to CBOs and NGOs. Representatives from the HIV positive community are already actively participating as important members in Myanmar Health Sector Coordination Committee (MHSCC) (Previously known as Myanmar Country Coordinating Mechanism or M-

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<sup>8</sup> Gooley, Suzanne Lou. The Greater Involvement of People Living with and Affected by HIV and AIDS (GIPA), NGO experiences and implications for the work of Oxfam international and Oxfam Australia, July 2006

<sup>9</sup> Stephens, David. Out of the shadows: Greater involvement of people living with HIV/AIDS (GIPA) in policy, Policy working paper series number 14, October 2004

CCM). However, MPG feels the strengths of existing PLHIV SHGs and networks are still underutilised and much more could be done by MPG members. In particular, MPG and SHGs can contribute to the scale up of ART coverage for PLHIVs in Myanmar as there remain gaps that need to be filled. MPG believes that PLHIV themselves, and their organisations and networks, have great potential as partners in the national HIV response. They can identify gaps and meet the needs of PLHIV, thereby contributing to expansion of ART in a context of limited resources, and to improvements in the quality and sustainability of services.

In the last quarter of 2013, MPG carried out a qualitative research study in six selected areas to gain a better understanding of the role of PLHIV in ART service provision. The study assessed the experiences, needs, contributions and challenges of PLHIVs, both those who were already receiving ART and those who were not yet on treatment. It studied the viewpoints of existing SHGs. This research should shed light on the possible expansion of the role of MPG and of SHGs in supporting public and non-profit ART service providers to facilitate ART scale up across the country.

## **2. AIMS AND RESEARCH OBJECTIVES**

The ultimate aim of the research was to promote greater and more meaningful involvement of PLHIVs in HIV responses in Myanmar.

The specific objectives of the study were:

- To assess the perceptions of positive people on ART services and the level of participation of the positive network in delivery of care for PLHIVs
- To identify gaps that members of the positive network can help fill in to improve the coverage and quality of ART services
- To identify key obstacles preventing members of the positive network to participate in a meaningful way in the delivery of ART services.

### **3. METHODOLOGY**

#### *3.1. Process and Study Design*

An outline of this study was presented by MPG to the Technical Working Group (TWG) on HIV/AIDS whose members welcomed the initiative. Following technical comments from TWG members, the proposed sample size of 30 was further increased. In June 2013, MPG appointed a national consultant as the principal investigator for this study. The principle investigator developed a complete research protocol, with data collection instruments, for submission to the Department of Medical Research (Lower Myanmar) for ethical review. This study adopted a purposive sampling strategy. It took place in six selected areas. These were: 1) Yangon; 2) Mandalay, Sagaing and Magway as one area; 3) Taunggyi; 4) Mawlamyaing; 5) Lashio and 6) Patheingyi.

The study involved focus group discussions (FGDs) with SHG leaders, in-depth interviews (IDIs) with HIV positive individuals and PLHIV volunteers and key informant interviews (KIIs) with both public and non-governmental ART service providers and non-ART service providers, and local authorities.

Seventeen members of MPG (including 12 from MPG Secretariat office in Yangon, 5 local network representatives from selected States and Regions) collected qualitative information through a total of 12 FGDs, 60 IDIs and 11 KIIs. Each research team was formed with four members (one supervisor, one local network representative and two team members). All members had previous experience with similar studies. The principal investigator provided three days training to research teams in October 2013, focusing on basic concepts of qualitative research and related techniques, the importance of research ethics, an overview of the study and its objectives, and necessary preparation to undertake research in the field. Interview guides were pre-tested with PLHIV respondents at the MPG secretariat office in Yangon. These participants were not recruited again in the actual data collection phase.

Data collection teams commenced information gathering in October and November 2013. Some key informant interviews had to be re-scheduled for January 2014 because selected

service providers were not available on planned dates.

### *3.2. Participants and Sampling Procedures*

Representative from selected study areas recruited the required quantity of IDI respondents, FGD participants and informants for KIIs. Sixty IDIs (10 in each area) took place. In each site, to ensure different experiences and opinions of PLHIV were captured, a stratification approach was employed by selecting: six PLHIV on ART [two or three belonging to key affected populations – sex workers (SWs), male who have sex with men (MSMs), people who inject drugs (PWIDs)]; two PLHIVs waiting for ART or not needing ART at present; and two PLHIV volunteers from ART service providers. Equal number of male and female PLHIVs were drafted to understand experiences based on gender. Study samples were also evenly selected based on distance from study areas (in town, and outside of town) and economic status (high and low economic classes). Only respondents above 18 years of age were interviewed.

Twelve FGDs (two from each area) were conducted with SHG leaders. Eleven KIIs were done in five areas excluding Lashio. Five KIIs in Yangon and one KII in Mandalay were with local and international NGOs, public service providers from NAP and a public specialist hospital while one KII in Patheingyi and one in Taunggyi were with non-ART service providers and three KIIs in Mawlamyine were with a local administrative authority, respondents from a locally based United Nations (UN) project and a LINGO.

All interviews and discussions were carried out by 17 trained MPG members with technical guidance from the principal investigator. Local network representatives were not involved as interviewers in their local areas to control potential bias. Each interview has conducted by two trained MPG members (an interviewer and a note taker) while three people were assigned for FGDs (an interviewer and two note takers) using semi-structured interview guides.

### *3.3. Data Processing and Analysis*

Interviews were digitally recorded with the permission of the participants. Note takers started to write transcripts in the field by expanding field notes and listening to recordings. Transcripts

were thoroughly examined by the investigators for completeness and consistency. Coding was done. Qualitative data was put into a matrix according to themes and sub-themes after reading through all the transcripts. Emerging themes were incorporated into the matrix and recurrent themes were combined. Thematic data analysis was done manually. The principle investigator and research teams reviewed analysis of research findings during a validation meeting to ensure internal and construct validity. Qualitative analysis provided detailed information and a comprehensive understanding of ART access, existing involvement of the HIV positive community at different levels, barriers and challenges to PLHIVs engagement and areas for improvement. Findings from the KII, IDIs and FGDs were triangulated to come up with conclusions and recommendations.

#### *3.4. Ethical Considerations*

The research protocol was presented to the Ethical Review Committee on Medical Research Involving Human Subjects, Department of Medical Research (Lower Myanmar) on 26 August and a revised version was submitted, based on the committee's suggestions. Ethical approval was secured on 3 October 2013. Study participants were provided with clear explanation of the purpose and expected outcomes of the study, the importance of voluntary participation, and the research team's guarantee of confidentiality on information being shared by study recruits. Interviews were commenced only after obtaining signatures of individual participants on written consent forms (also signed by interviewers).

#### **4. LIMITATIONS**

Study respondents were contacted and recruited through local PLHIV SHG networks linked with MPG. Hence all respondents have received services provided by these SHGs and many were SHG members. Their experiences may not be similar to PLHIVs who have no connection with local SHG networks.

The peer-to-peer approach used in interviews posed as drawbacks because interviewers were often familiar with the subject matter and did not prompt respondents to clarify and elaborate on some of their responses. As the interviewers were members of MPG, some informants may have been reluctant to share their perspectives frankly regarding PLHIV networks and SHGs and their work.

## **5. FINDINGS**

In this section, the interwoven nature of issues can result in recurring information under some subheadings.

### ***5.1. Self-Help Groups for People Living with HIV***

#### ***5.1.1. Self-Help Groups Composition and Geographical Coverage***

All six study areas had PLHIV SHGs who were actively engaged in community-based, as well as facility-based, activities. In Mandalay, Yangon and Mawlamyine, there seemed to be at least 10 SHGs existing and functioning. Some respondents in Mandalay guessed nearly 50 SHGs in their region, while a series of participants said no less than 30 SHGs were currently operational in Yangon. But in Patheingyi and Taungtha, even though the number of SHGs was small, some groups had about 300 members, namely *Nay Chi Phoo* in Taungtha, Southern Shan State. In Patheingyi, one SHG called *Arr Man Thit*, under the umbrella of LINGO, had over 300 members. Similarly, a couple of SHGs in Mawlamyine claimed to have more than 100 members. Small SHGs contained about 15 members. Though some groups had considerable large numbers of SHG member, the number of core members was fewer (often between 30 and 50), who contributed monthly fees and provided regular services to the group, while the rest acted more like beneficiaries and were often also members in other PLHIV SHGs. In areas like Yangon, Mandalay and Monywa, some groups categorised their organizations as CBOs, and as recipients of technical and financial support from NGOs to implement HIV-related prevention and treatment, care and support projects.

Many PLHIV SHGs were based in large urban areas. For instance, in Northern Shan, over 20 SHGs were currently working and about 75% of them were concentrated in Lashio, according to FGD participants. Quite a few PLHIV SHGs were found in smaller towns hence creating some challenges for PLHIV seeking information on HIV related services. But in Mon State, an INGO called François-Xavier Bagnoud (FXB) backed its Sunday Empowerment Group (SEG) members to visit villages to form SHG memberships to help fellow PLHIVs. In Yangon, according to a network representative, there used to be an estimated 60 SHGs in the past but that number

had fallen to about 30-40 due to decreased funding resources. SHGs which were formed under the umbrella of NGOs were particularly affected. Not all PLHIV SHGs were listed under the MPG network. SHGs among key populations existed also. HIV positive key population networks linked with the MPG. However some sex worker respondents wished more SW SHGs were formed in rural towns.

SHGs were composed of both HIV positive and HIV negative persons. Affected family members were also involved. However, this composition was not usually observed in key affected population SHGs due to poor social acceptance of SWs, MSMs and PWIDs by their families and communities. Some SHGs were established under the umbrella of INGOs, LNGOs and government programs. A number of groups were led by active HIV negative individuals, for instance, *Myitta Swann Arr* in Kyauk-Mel township, which may be due to disclosure issue. According to SHG leaders in Mon, active members were usually those who could willingly give their time for HIV related activities, those who were quite comfortable with being seen in public or those who did not have to worry about earning a living.

Since many local organisations and groups working in Myanmar have no registration, and encountered challenges obtaining one due to the lengthy and prolonged processes, some civil society organisations have actively worked to address this issue. It has been discussed at the national level and in parliament. A manager from a LNGO explained that these efforts would hopefully to help PLHIV networks and groups too.

### ***5.1.2. Nature of Self-Help Group Activities***

Local SHGs disseminated existing service information to PLHIVs who were in need of HIV-related health services and linked them to the locally based service delivery sites of LNGOs, INGOs, NAP AIDS/STD teams and government owned hospitals. Depending on organizational capacity and the level of funding available, SHGs provided psychosocial support to positive peers, took on caregiver roles through home and hospital based care, assisted as peer counselors or volunteers for ART service providers at clinics and hospitals, implemented peer-based prevention activities, linked PLHIVs to available support sources, gave nutritional support, established microfinance support, coordinated income generation activities through

membership fees, and conducted regular monthly meetings or gatherings. Sometimes, SHGs were also involved in financial aid activities, like providing PLHIVs and their families with small amounts of cash for hospital stays and funeral costs. Some SHGs helped PLHIVs with transportation expenses associated with accessing treatment services in cities, like what was being done by a Thaton-based SHG. A Mawlamyine based SHG said each member saved 500 kyats (which is about 0.5 USD) everyday to have group funds to assist PLHIVs with treatment and care related needs. Some SHGs connected with CBOs to assist PLHIV's families by finding donated blood for hospitalised cases. They also gave health education. Many SHG members took on roles in treatment clinics by assisting in patient registration, providing counseling and also helping out at drug dispensary sites. In some cases, PLHIV traced ART defaulters. However financial support was needed to do this task because some volunteers had to use their own money. Some proactive SHGs did not limit themselves to HIV related activities alone but were actively involved in local community social activities.

*“For example in Dawei,....some SHGs are involved in social activities of their wards. The community sees goodness in their work....The people depend on these groups, not just only for HIV issues but also for community social affairs.” (Key Informant # 3)*

A series of public and NGO key informants confirmed that recent years had seen increased involvement of CBOs and PLHIV SHGs. The efforts of SHGs in relation to care and support of HIV positive people often reduced the burden on PLHIV's families. A government health officer concurred that many SHG members were involved in different parts of the HIV response as counselors, care takers, expert patient trainers, health educators, support staff engaging patients who have been lost to follow up, and ART selection committee members. At national level, MPG members were members of Myanmar Health Sector Coordination Committee (M-HSCC). Hence, key informant agreed PLHIV involvement was found at different levels: from decentralized sites at the township level and in large and medium sized cities to district, State and Region hospitals.

### **5.1.3. Coordination and Linkages among Self-Help Groups and with Other Stakeholders**

KIIs and FGDs indicated good coordination among PLHIV SHG was maintained, through formal and informal channels, by regular networking activities among groups, monthly coordination meetings, sharing information, experiences and interlinking different services. SHGs also met at ART service delivery sites and during capacity building trainings. FGD participants indicated PLHIVs who were quite active within their own HIV positive community met with each other quite often.

Some SHGs worked closely with local CBOs and social support groups. CBOs referred patients to SHGs for home-based care, and SHGs contacted CBOs (such as blood donation groups) or medical social service department in hospitals whenever required. An active and strong “working hand-in-hand” approach among PLHIV support groups and between PLHIV SHGs and NGOs and NAP was generally reported.

Respondents from the public sector stated one of the keys to success of an ART program being well-establishment of good coordination and collaboration among SHGs and with other stakeholders. Local PLHIV networks were reported to have good working relationships with government programs. They met on a regular basis to discuss the needs of PLHIVs and the gaps identified. Some areas were reported to have quite strong relationships with their counterpart, local administrative stakeholders. For example, in Patheingyi, a well-known SHG had secured good coordination and collaboration with local authorities and mutual respect was recounted. This SHG is under the umbrella of a local NGO and that NGO acted as a medium to strengthen these relationships. A series of respondents from Mandalay stated good coordination and collaboration existed between SHGs, CBOs and the NAP. An INGO service provider indicated two large SHGs in Mawlamyine had beneficial and effective coordination and linkages with the local AIDS/STD team. Coordination with MPG was undertaken by local PLHIV SHG network representatives and executive committee (EC) members from respective regions and states. Communication and coordination occurred through meetings and by phone.

#### ***5.1.4. Support from Myanmar Positive Group (MPG) Secretariat Office***

The MPG secretariat office in Yangon provided technical support through trainings to its network of SHG members. Among them, some PLHIV SHGs received financial assistance from

external donors where MPG acted as an intermediary. The respondents were referring to European Union funded project to eight SHGs. MPG also organised and facilitated coordination meetings, forums, events and for strengthening of MPG network. They also led advocacy meetings with local authorities to address pressing needs in some areas. For example, MPG assisted in finding a shelter for PLHIVs in Mon State. The respondents who had been exposed to MPG appreciated the advantage of MPG's existence. However some groups stated they had limited communication with MPG. For example, they did not request technical or financial assistance and did not submit activity reports to MPG either.

In Taunggyi, some FGD participants mentioned infrequent technical backing was received from the MPG secretariat office, compared to the past, but SHG leaders from Lashio said they had received capacity development trainings from the MPG secretariat office. A possible explanation for this could be that only a couple of local representatives were invited to the trainings and therefore SHGs may not have been aware of them. Some SHG leaders from rural towns indicated services from MPG were more accessible to Yangon groups. They suggested newly established SHGs should at least receive training on positive prevention. Sometimes, when SHGs were under the umbrella of a LNGO or an INGO, weak linkages with MPG was observed. For instance, in Mawlamyine, SHG members did not seem to be aware of MPG and its role.

#### ***5.1.5. Support from Local Service Providers***

Several SHGs were founded with support from both public and non-profit service providers. Some respondents reported NAP AIDS/STD teams and NGOs gave counseling training to local SHG members who worked as peer counselors at those sites. Some NGOs provided financial resources for nutritional support and other trainings like home-based care, vocational training, and management trainings. In Yangon, Médecins Du Monde (MDM) and Rattana Metta provided care giver trainings. Even when some institutions did not implement HIV- related projects directly, they invited local SHGs to participate in capacity development training, like the United Nations High Commissioner for Refugees (UNHCR) did in Mon State. In some areas, service providers (such as the Pakkoku AIDS/STD team and the World Vision project office in

Mandalay) provided gave a space for regular meetings among SHGs or financial support to local SHGs to ensure regular meetings among groups.

## **5.2. HIV Treatment Needs and Availability of Services**

### **5.2.1. PLHIV Awareness of ART Services**

HIV treatment, care and support services were available in all six study areas. Interview respondents became aware of HIV- related services available in their localities or in nearby large cities, through informal information sharing from peer friends, SHG members, NGO outreach workers and key affected population networks. Peers and local SHG members were identified as the most common sources of information on available treatment services. However, this may be due to the fact that respondents were recruited through local PLHIV networks. Key affected populations usually learned about available health services from peers and peer outreach workers. A respondent from Muse said they received information about the Médecins Sans Frontières – Holland (MSF-Holland/AZG)ART clinic after networking with a local SHG. Good coordination among community-based service providers also benefited PLHIVs. For instance, staff from Danish Red Cross directed PLHIVs to World Vision to get care and support services. However, instances of late diagnosis were not rare as some PLHIV lacked of knowledge of available services, and did not come forward for testing and treatment, especially those residing in distant towns or locations without PLHIV SHGs. The importance of a supportive environment in relation to awareness of and access to ART services was expressed. The following excerpts from data FGD reinforced this point.

*“To get ART, the surrounding environment is important, so we give awareness raising on ART related information.” “It’s very important that peers help each other along.” “It’s quite significant for us to receive [informative] support from peer groups” (FGD participants, Lashio)*

### **5.2.2. ART Service Providers**

In all six areas, at least two organisations were offering HIV treatment services. The majority of them were INGOs and government-owned hospitals and NAP AIDS/STD teams. These providers

were mostly based in well- populated strategic locations. When asked to name ART service providers in their local areas, respondents most frequently mentioned regional and state and district level hospitals and AIDS/STD teams, MSF-Holland/AZG , The International Union Against Tuberculosis and Lung Disease (UNION), MDM, Marie Stopes International (MSI), Pyi Gyi Khin (PGK), International Organisation for Migration (IOM), FXB and International HIV/AIDS Alliance. Within the public sector, there were more than 50 sites delivering ART services. By 2016, NAP anticipated that this number would be increased to 72 sites or more. Respondents reported MSF-Holland/AZG clinics were concentrated in Northern Shan, Kachin and Yangon areas, while MDM service delivery sites were found in Kachin and Yangon, and Pyi Gyi Khin ART centres were located in Patheingyi, Myingyan and Aung Mye Thar, Government-owned large hospitals in Mingaladon and Thakayta were well-known treatment facilities for many PLHIV residing in Yangon.

### **5.2.3. Available Services**

Public hospitals with ART services in major cities provided antiretroviral drugs, opportunistic infection prophylaxis and treatment, and laboratory diagnostics (most importantly blood testing for CD4 count). NAP AIDS/STD teams provided prevention, treatment and care services such as health education, sexually transmitted infection (STI) treatment, HIV counselling and testing, ART and related laboratory investigations. Compared to the public sector, in addition to preventive and treatment measures, INGOs provided a broader range of services, such as nutritional support when needed, financial support for transportation, laboratory tests, home-based care, capacity development and paying for drugs when they had to be purchased from private pharmacies. CD4 testing was offered at ART clinics and public hospitals, and sometimes, arrangements were made to send blood samples to reliable local private laboratories or those from nearby large cities.

### **5.2.4. PLHIV Impressions of the Quality of Services Received**

PLHIV respondents were asked about the quality of treatment, care and support services they had received, and about the attitudes of service providers from different sectors. In general, the majority of respondents were satisfied with the quality of services obtained from INGOs

and LNGOs because of the larger offering of services. Many respondents suggested room for improvement from public sites in relation to communication skills, limited available services, waiting time at health centres and quality of counselling.

The quality of counselling at ART centres is integral in initiating treatment. All those being interviewed expected higher quality from counselling services. Some respondents recounted feeling reluctant to return to the services due to counselors' skills. In Lashio, a volunteer said confidentiality was breached when she went for counselling in an INGO ART clinic because whatever was being discussed in the room was later known by everyone including PLHIV peers. Limited space available for counselling at AIDS/STD teams affected the quality of counselling, confidentiality and the privacy of patients. Several participants indicated they received pre-ART counselling but when they started ART, some hospitals only offered group-counselling sessions, which did not allow PLHIV to have private one-on-one discussions with counselors and clarify unclear points. Peer counselors usually did not receive regular refresher and updated trainings.

*"The counselors in the hospitals should be well-trained before appointing them." (35 years old female, not on ART, Yangon)*

A Mandalay respondent recounted her experience:

*"I got counselling two times before I started ART but after that I received none. May be there are a lot of people, I don't know. They don't have a separate counselling space. They provided group counselling. Even if I don't understand, I can't ask back." (45 year old married woman on ART, Mandalay)*

Some respondents complained there were occasions at some Tuberculosis (TB) sites where blood testing was done without counselling. Some reported antiretroviral medications were being given without proper counselling. In those cases, patients commenced ARV drugs with little understanding of treatment and positive prevention literacy. Since these patients were insufficiently prepared themselves to life-long treatment, they usually demonstrated poor commitment to treatment.

According to respondents, shortage of human resources in the formal health system and large patient caseloads did not permit health professional to spend adequate time with each service user. Therefore, the system of a couple of days in each week for counselling and large number of patients caused insufficient individual sessions and long waiting times. On the one hand, more and more PLHIVs had access to ART thanks to the scaled-up program. On the other hand, ART service providers had very little time to discuss treatment with each patient.

A couple of respondents said some of their friends were unwilling to utilize treatment services due to the attitudes of some staff members within the public system. Certain peer volunteers from some INGO providers also needed to strengthen the quality of services. Many individuals complained of being shouted at, or experiencing poor treatment by medical staff. Some service users revealed they had received very little help on information about prescribed medications from clinic employees. Lack of patience from clinic staff and the absence of user-friendly environments caused intimidated feelings and disappointments among service users.

Many respondents yearned for empathy, understanding and patience to ensure better comprehension by PLHIV of the treatment that they were receiving.

*“They are too technical. Regarding us, PLHIV, equally like them is almost non-existent. I think the staff need to have warm attitudes because they are doing HIV project activities. I think their attitudes will change eventually.....Those of us, who contracted with HIV, are experiencing a psychological ordeal. If the doctors, nurses and health staff did not treat us warmly, we would be afraid to go to the clinics” (38 year old male respondent, Lashio)*

*“We were miserable, not because of the disease but because of discrimination experienced at service delivery sites.” (FGD participant, Yangon)*

*“In the hospital, there is a few nurses and many peers. It’s pleasant environment, happy to visit there. We are everywhere and taking care of everything because we are huge crowd, the hospital staff are minority, so we are alike. (FGD participant, Taunggyi)*

From the service provider's side, key informants agreed that even though the number of ART sites had increased, limitations existed in relation to counselling, adherence support, tracking defaulters, regular monitoring of patients, and outreach worker meetings with positive patients through home-based care and home visits. In addition, technical training of health staff, availability and maintenance of CD4 machines and provision of other laboratory investigations were inadequate.

Long waiting times at service delivery sites presented challenges for all respondents. Disproportion between the number of providers and service users unsurprisingly created long waiting hours at clinics and hospitals. Many respondents said they often had to wait at least two hours or more hence creating discontent towards services. Sometimes they returned home without seeing a consultant because they had to catch a public transportation on time. However, many service providers demonstrated consideration for patients coming from out of town by prioritising them during consultation times. Some FGD participants compared longer opening hours and availability of medical staff at NGO clinics with limited service hours and staff shortages at public health facilities.

Some respondents wished mid-level medical professionals and nurses would strengthen clinical skills related to HIV treatment. They also complained that in some areas they had to go to hospitals every month to get their drug supply, whereas such visits to NGO clinics were three-monthly.

#### ***5.2.5. Factors Affecting PLHIV Use of ART Services***

PLHIV respondents indicated access to treatment, care and support services was sometimes mitigated by stigma and discrimination, lack of social support from family, poor awareness of services, poor economic status, distance from available services and availability of services in their towns.

##### ***5.2.5.1. Socio-cultural factors***

Focus group members confirmed that stigma and discrimination were still widespread although intensity might have been a bit less compared to the past. Many said a reduction in stigma and

discrimination was more likely to be observed in large urban towns than in small rural towns or villages. Fear of discrimination often led PLHIVs to disclose their HIV status at later clinical stages. A female PLHIV related the need to lie about the cause of death of her spouse and their young infant, as she was concerned about stigma and discrimination attached to HIV from her community. Members of key populations said they faced more blunt prejudice from their family than other people.

Fear of rejection from relatives and community members was not uncommon. Stigma and discrimination from the family often resulted in some PLHIV taking ARV drugs outside of their homes and a potential risk of missed doses, losing motivation for life-long drug compliance and omitting follow-up visits to treatment services. Therefore understanding and encouragement from family members of PLHIV is very important.

*“Some patients took antiretroviral drugs behind their family’s back. Some have to take these hastily on the streets on their way to work.....Some did not get understanding from the family and only received harsh treatment. Family members accused, ‘We were humiliated because of you! If you have HIV, don’t stay at our house!’ and banished them from their homes. These behaviours still remain in some households.” (42 year old male, Mandalay)*

Some PLHIV did not want to attend group counselling services for fear of social rejection. SHG leaders said some referred patients were failed to show up at peripheral health centers which were located near to their residence.

#### *5.2.5.2. Distance from Service Sites*

The distance between service delivery sites and users’ homes served as a significant feature in treatment seeking behaviours of PLHIV for HIV-related health services. In all six areas, everyone agreed that those living in the large cities, or within the same township where ART facilities were based, had several advantages over those from far away areas and rural villages, namely

easy access to PLHIV SHGs, health providers, less travel time and low or no travel costs. People used different types of transport to travel to ART clinics, including walking, motorcycle taxis, buses and boats during rainy seasons.

This was particularly a hurdle for those living out of towns as they had to spend several hours travelling to ART sites. For example, people from villages in Kyauk Mel had to leave very early in the morning to catch the bus to Lashio and sometimes could not wait for their CD4 test results because they had to return home before mid-day. Traveling time, plus two or three hours waiting time at the clinics often required PLHIVs to find overnight lodging, so they inevitably needed extra money to rent a place and buy food. People from Thaton recounted that PLHIV from villages encountered more difficulty than the most. Similar experiences were shared by other areas. Those living in Mogoke, Thabaik Kyin and Mine Shue in Mandalay Region had to travel to Mandalay a day ahead of the clinic appointment date. Depending on the season, those in Delta region used several forms of transport.

FGD respondents said although antiretroviral drugs were available at INGO clinics and public hospitals, travel costs and arduous trips to ART facilities hampered PLHIV's access to treatment. There were many PLHIV who simply gave up getting ART services once they learned the distance between health facilities and their homes and related transportation costs. Provision of a place for PLHIV while waiting for treatment is something most support groups were unable to offer.

#### *5.2.5.3. Financial Burden Related to Accessing Services*

All respondents appreciated that antiretroviral drugs, medical consultations and laboratory tests (but sometimes, PLHIV had to share the cost of laboratory tests) were being provided free of charge. In the past, PLHIVs had to spend at least 30,000 kyats for CD4 testing, and more for purchasing medicines each month. But now, treatment-related costs have dropped down to about 2,000-3,000 kyats each month, an amount PLHIV needed for monthly travel cost to clinic to pick up drugs or undergo laboratory investigations like CD4 testing. Depending on the location, the amount varied. Those in towns or nearby spent 2000-3000 kyats for clinic visits but amount surged in based on locations. PLHIV with regular income experienced less financial

burden for travel and accommodation, but the hardest hit were those who had low or no earnings and have little family backup. Some reported many patients stayed at home, rather than accessing ART in nearby cities because they could not spare 2,000-3,000 kyats regularly for monthly travel and accommodation costs. Some recounted that PLHIV from areas where treatment services were not present needed to sell their assets so they could afford to stay in the cities to undergo the ART preparatory phase before treatment initiated.

*“To get antiretroviral drugs, clients need to come to Lashio, so some people sold cows. Some even had to sell their farms.” (FGD participant, Lashio)*

One respondent said she sold sex to get money to travel to the ART site. However, some PLHIV could no longer work due to illness and had no regular income. Therefore, even the 3,000 kyats needed to go to ART clinics could pose a huge financial burden for PLHIV even when they did not need to pay for antiretroviral drugs, OI treatment, laboratory investigations or other services. In addition, financial constraints in public hospitals often meant PLHIV had to pay for transportation costs associated with sending blood samples to private clinics for CD4 testing if there was no machine, the machine was broken or there was a shortage of reagent. PLHIV had to pay about 16,000 kyats if the blood sample was tested in private labs.

People with daily income said, on clinic appointment days, their income was lost due to spending at least half a day travelling and waiting for hours at clinics. But those who are working as volunteers in non-profit and public sectors or as NGO staff said they did not experience opportunity cost like others.

*“I don’t have money to travel from Ayetharyar to Taunggyi to get ART. I roll cheroots as an earning. [If I go to ART clinic] I will not have income for that day.”*  
**(FGD participant, Taunggyi)**

To mitigate no-income periods due to illness resulting from side-effects of antiretroviral drugs, some participants who were waiting for ART were advised to save money before starting treatment. Fragile health condition prevented many PLHIV from earning money through hard labour and some said they did not have enough capital to start a home-based small business.

#### *5.2.5.4. Other Complications Encountered in Seeking and Using ART Services*

Several positive individuals taking antiretroviral medications from public service settings reported not receiving regular CD4 testing. Some said about a year had passed without a test. It was often the case when the machines in the public sector were broken, there was a shortage of laboratory reagents, a lack of technicians to handle the machine, or limited number of machines versus large numbers of clients.

As described earlier, those living in areas with limited services were compelled to take trips to other areas. For instance, HIV positive people in Kayin State have to go to Mawlamyine for CD4 testing. Poverty and lack of nearby services have negative outcomes on treatment seeking behaviours of PLHIV leading to loss of lives. However, some INGOs mitigated these impacts by covering the cost of CD4 testing. For example, IOM provided reimbursement to PLHIV living in its project townships in Mon State although such assistance was restricted by geographic boundaries. According to statements from some interviewees, localization of project townships prevented people from non-project locations from obtaining antiretroviral drugs.

The study found poor health knowledge sometimes resulted in low or irregular utilization of treatment services. There were some instances where PLHIV refused to take antiretroviral medications due to mistrust of drugs even when they had received home-based care by SHG members. A requirement for PLHIV to bring a caregiver when accessing services also caused some clients to think twice about accessing treatment measures, especially among sex workers, MSMs or PWIDs.

Members of key affected populations experienced additional barriers to treatment. Sex workers who were under the control of pimps found it hard to go to treatment sites and get the regular drug supply. Some requirements at INGO service points, such as asking contact addresses and phone numbers, prevented members of some key affected populations from disclosing their HIV status. These requirements unintentionally pushed back some sex workers

instead of supporting them to come forward for available services targeted for more vulnerable groups. A respondent pointed out:

*“To get ART, sex workers have to answer many questions. Of course this clinic is for sex workers, that was why she came here! But she has being asked so many questions. That sex worker won’t come back to the clinic again just only because to get antiretroviral drugs.” (38 year old female, IDI respondent, Yangon)*

Vacant posts of specialists in district hospitals and no AIDS/STD team in some townships required HIV positive patients to travel to nearest large cities to get ART initiation. However, financial difficulty did not allow them to go and receive the treatment. For instance, in Shan State, during cold season, PLHIV were forced to spend a night in the city because CD4 tests were conducted only in the mornings. Also, the number of patients was limited for such testing.

Age can be an important factor affecting people’s willingness to come forward to receive health services. A group discussion with SHG leaders indicated that young people living with HIV sometimes feared abandonment from their parents so did not disclose their status or get timely treatment.

When travelling to treatment sites, people without family support at home needed to consider issues such as child care, cooking, sending kids to school and closing shops. Some female respondents said, although they had no income, social support from their in-laws and family helped them a great deal, especially on clinic follow up days.

The most common suggestion from participants was to urge healthcare providers to ensure availability of medicines for all PLHIV in need of ART shortly after counselling and testing.

*“We wish antiretroviral drugs were accessible to PLHIVs at all township hospitals. If they could provide like that, it would be very good.” (FGD participant, Lashio)*

Inadequate drug reserves at ART facilities often led PLHIV to come to public ART sites to collect antiretroviral drugs every month, instead of three monthly, which created inconvenience in terms of finance and time.

*“It’s not a problem for those living in towns but people coming from faraway places faced transportation difficulties because, at present, we receive one month drug supply only, but in the past they provided three month supply.” (25 year old male respondent from Sint Guu)*

In contrast, a respondent from Lashio said, in the past four years, he never needed to purchase antiretroviral drugs from private pharmacies because of HIV medicines available at NGO service delivery sites. Having said that, several respondents said it was not rare for them to buy drugs for OI prophylaxis and treatment, as well as multivitamins, from private pharmacies.

SHG leaders said, to enhance treatment access for people in needs, efforts were still needed to raise health knowledge, increase awareness of the availability of counselling and treatment services, and improve the knowledge of community leaders on HIV issues. According to them, decentralisation of ART services was essential because many people could not travel from their small hometowns to large cities where ART facilities were largely concentrated. It was also difficult for volunteers based in large cities to track patients from small townships.

*“For better access, treatments should not only be reachable in the cities but also in smaller towns because right now it is a burden for patients to come to Set San Htun Hospital. To trace defaulters, for example, from Loilin, Yet Sought, it’s more than 50 miles. Sometimes, especially in the rainy season, PLHIVs can’t undergo CD4 testing because the buses arrive late.” (FGD participant, Tauggyi)*

They suggested volunteers should regularly monitor and remind PLHIVa about drug intake and provide psychosocial support to reduce drug resistance and loss to follow up.

Respondents from Pathein recommended continuous ART counselling for those who have commenced antiretroviral medication. Generally, participants from all study areas were more content with counselling services from NGOs than those received from the public sector.

Several respondents suggested peer-to-peer counseling would be more appropriate for key affected populations. A sex worker respondent said:

*“One of their staff gave counselling. I think the way they provided is not right...the principle...We, sex workers, feel embarrassed [receiving counselling from other people]. I guess it’s probably more comfortable getting counselling from a peer. Those appointed counselors, I don’t feel like coming back here again and continue receiving services. Between sex worker and sex worker or MSM and MSM is more suitable.” (27 year old sex worker, waiting for ART, Sagaing)*

## **5.2.6. PLHIV Perceptions of ART Service Arrangements**

### **5.2.6.1. Eligibility for ART**

According to respondents, discrimination was mostly absent in selecting patients to start ART. All respondents confirmed that ART was provided to PLHIVs who had a CD4 count equal to or below 350 regardless of the type of service providers. In the past, due to limited funding, only those who had a CD4 count under 200 were eligible for ART but this is no longer practised. Many participants said whoever was in need of ART (based on CD4 testing) received the medications. Priority was given to PLHIV with co-infection (TB/HIV), pregnant women, and advanced clinical signs and symptoms according to World Health Organisation (WHO) guidelines. The importance of social support was highlighted in findings. Some providers asked PLHIV to bring a care taker or a family member with them to the clinic before starting ART, which constituted a barrier for some people. Preference was reportedly given to PLHIV who came for counselling sessions regularly, demonstrated good compliance with OI prophylaxis drugs, and followed medical professionals’ advices. A series of respondents disclosed that those living within ART clinic townships were favoured over those in rural towns. Hence, equitable access may still be an issue in some areas. Mobile populations (for example, those working in border towns like Myawaddy) faced inconveniences in accessing ART due to the nature of their

work. There were also cases where health sector employees were hesitant to prescribe antiretrovirals to sex workers due to the mobile nature of their work.

*“There’s no discrimination. I don’t know up to which criteria they use to give ART. But I see all three ART sites provide antiretroviral drugs to those who really in need.” (38 year old male respondent, Lashio)*

Most respondents who were still waiting for ART had positive feelings about their current situations. Almost all of them had high CD4 count and did not need for a medications apart from OI prophylaxis. These respondents needed to spend less time at clinics than those accessing ART. They sounded quite grateful about their good physical condition, and had few health complications.

#### *5.2.6.2. Factors Influencing Adherence to ARV Therapy*

Respondents identified a number of important factors affecting treatment adherence, including self-awareness, quality counselling, individual perceptions of value of drug treatment, fears of stigma and discrimination and associated social support, educational status and side effects of drugs. Many respondents said treatment adherence mainly depended on the patients themselves. Thus self-awareness was seen as very important. But at the same time, quite a number of people pointed out the importance of quality counselling. They said an initial series of counselling sessions followed by regular ongoing sessions were required for assessing commitment and readiness to commence treatment, and identifying factors which could interfere with treatment adherence. Some believed everyone (counsellors, doctors, volunteers, patients, families) could help prevent treatment disruption and strengthen adherence.

*“Many patients take the drugs to prolong their lives but have no idea about which drugs they are consuming, their benefits and adverse effects. Staff didn’t explain these either. They just told the drugs were for controlling HIV. They need to give precise and succinct messages to PLHIVs.” (28 year old male respondent currently on ART, Yangon)*

Some respondents implied that PLHIV themselves must value the antiretroviral drugs they received.

*“If you are required to start taking antiretroviral medication, you need to have a clear understanding and to value it. For me, unless I had the trust that the drugs would prolong my life, I wouldn’t have taken them.” (33 year old female volunteer, Lashio)*

A lot of PLHIV had fears their HIV status would be discovered by family while other has fears surrounding the daunting responsibility of the life-long treatment compliance. Hence psychosocial and emotional support from service providers and support groups was seen as essential.

The life-long commitment to take antiretroviral daily and at regular hours often caused boredom and demotivation for PLHIV. Even those who had actively sought ART to live longer admitted they felt depression when they actually took the drugs and came to realise how they must do it everyday at precise hours. A score of participants said they often forgot to take the drugs and have to set an alarm to remind themselves. A study respondent pointed out some PLHIV from rural villages did not even know how to read the clock. Low education resulted in low levels of treatment literacy, therefore it led to limited understanding of the drugs, and of the importance of taking them at the same time each day, which then lead to poor adherence. One respondent suggested provision of comprehensible and concise information would overcome this shortcoming.

The existence of HIV-related stigma also influenced the drug adherence and social support seeking behaviours. A female respondent who was diagnosed with HIV twelve years ago said:

*“I was working in a factory. It was difficult for me everyday when I need to take medicines. I’m a daily wage earner. Every morning at 8:00, I needed to take drugs and people started to ask questions which I couldn’t stand anymore.” (38 year old woman on ART, Yangon)*

To make it worse, in the past, physical changes due to drug side effects often drew unwanted attention from family and community members.

Quite a lot of participants expressed the need for emotional support. They also stated peers reminded and encouraged each other of regular drug intake to adhere to treatment.

#### *5.2.6.3. Understanding and Defining Service Quality*

Respondents were asked to define HIV treatment, care and support and service quality taking into account services they were currently receiving. Treatment was often defined as giving drugs, and treating diseases while care and support were understood as giving moral support to depressed patients, caring for ill patients, and offering a helping hand when needed. When asked about service quality, some respondents mentioned supportive attitudes, the absence of discriminatory treatment, encouragement for regular drug taking and preserving human dignity. For others, service quality meant medical and psychosocial services were accessible at the same service sites, like one stop service, where psychosocial support, medicines and laboratory diagnostics were available.

*“If there is discrimination, you can’t say it’s a quality service.” (45 year old married woman on ART, Mandalay)*

*“I think quality and comprehensive service should prioritize equality. That’s the main thing.” (58 year old male respondent, Yangon)*

### **5.3. Perspectives on the Potential of Greater Involvement of HIV Positive Groups**

#### **5.3.1. Acceptance of HIV Positive Community Participation**

Many respondents valued the presence and support of PLHIV networks and SHGs especially when no family member was there for PLHIV during hospitalization, or when they were sick at home. Positive progress in community perception towards PLHIV SHGs was reported. SHG leaders recounted decreased stigma and discrimination being experienced by SHG members. They said local communities learned PLHIV SHGs worked hard for their peers, and became accepting and acknowledging of these efforts. SHG leaders from Mawlamyine said local

communities approached them and sought their advice in relation to HIV testing. Local people also got in touch with SHGs when someone in their family was HIV positive. Hence many respondents believed that SHGs would help reduce negative attitudes from family and community members.

*“(As a result of SHG actions) people living in the quarter recognised these groups as volunteers.” (24 year old motorcycle taxi driver, Pathein)*

Service providers also expressed confidence that harmonious work and solidarity among SHGs could positively change the public’s view towards the HIV positive community. A key informant from a local NGO recounted receiving significant assistance of a large SHG in Taunggyi. Likewise, in Dawei, some SHGs were well recognized for their active role in social work and local community development. A LINGO respondent advised that SHGs’ independence and ability to make their own decisions would draw high regard and recognition from the public.

*“To get respect and reduce stigma and discrimination, PLHIV groups should lead themselves, should stand on their own and should able to make own decisions.”*

***(Key informant # 4)***

He also mentioned that with time, organisational maturity was observed in some SHGs, and that they were acknowledged and accepted by both local and international NGOs. A Mawlamyine-based LINGO said they accepted members of key affected populations in their project activities and ensured PLHIVs were involved in budgeting and project implementation. A female respondent said she felt happy when SHG members visited her home. One key informant gave an example of a strong SHG in Dawei and its success.

*“Their advocacy skill is very strong. They can demonstrate their capability well. They have strong technical competence. They have integrity. So the local authority trusts them. They can do advocacy up to regional minister level.” (Key informant # 3)*

### **5.3.2. The Role of PLHIV in ART Selection Mechanisms**

It was reported that PLHIV representatives participated as members in their respective township ART selection committees. However, in most areas, their roles were limited only to signing documents while major decisions were made by others such as medical specialists and NGO health personals.

*“NAP asked us to get involved in the board. Our involvement is just to listen what they say...more like a “doll”. We don’t have the rights to make decisions as PLHIV. We can tell them where the needs are. Just only informing role.” (FGD Participant from Mawlamyine)*

Only a few PLHIV said their voices were acknowledged in these selection committees. In those few sites, the relationship between SHGs and national programs seemed to be quite mature. Also these groups were already working at different levels and receiving recognition from local service providers. Some key informants agreed that irregular committee meetings were held, and that PLHIV were given little opportunity to take part in decision-making. A program manager questioned whether these committees were relevant and beneficial, considering the current growth of the ART scale-up program.

### **5.3.3. The Role of HIV Positive Community in ART Provision & Associated Benefits**

Both ART providers and PLHIV agreed that involvement of the positive community in treatment provision was very beneficial. They pointed out that the positive community’s active engagement would bring nothing but more effective outcomes. Many expressed the view that a peer-to-peer approach could lead to better information sharing in relation to available services, effective referrals to existing services and support sites, increased health literacy, and stronger relationships of trust between PLHIV and ART providers. They said positive people could reassure each other and provide emotional support, while listening with better understanding, sharing their own experiences, and giving practical and supportive advice. Many wished for peer counselors as they explained there still seemed to be an emotional gap when they disclosed life events, ordeals and concerns to a HIV negative person.

Some respondents said a bridge could be built between PLHIV patients and doctors by using PLHIV SHG members. FGD participants said some patients who lived outside of project areas received ART because SHGs mediated between service providers and service users. Findings from IDIs revealed that the existence of SHGs created a tremendous help for out-of-towners and those without social support.

Participants also indicated that SHGs could support service providers by regularly monitoring those taking antiretroviral drugs, working at dispensary sites, giving psychosocial assistance for better treatment adherence, strengthening the momentum of defaulter tracing and supporting preventive responses. Some SHGs had actively involved in these areas. Therefore, it is undeniable that HIV positive peers could help fill gaps in the public sector, for instance, by sitting together with PLHIV and providing counselling before the commencement of ART, and during treatment to support adherence. A key informant thoughtfully said,

*“A PLHIV used to listen more to another PLHIV [than advice from medical staff]. They trust their peers more.” (Key informant # 4)*

He trusted that it was more effective when a peer on ART shared his or her own experiences with another PLHIV who was in preparation for life-long therapy.

KIs indicated that fears of visiting hospitals and clinics could be mitigated if PLHIV learned about the presence of peer support groups at these sites. ART service providers said that it would be beneficial to current decentralization efforts, if PLHIV SHGs were ready by working hand-in-hand with the public sector.

Everyone believed that efforts from PLHIV SHGs would promote a reduction of stigma and discrimination towards PLHIV and their families, both at individual and national levels. This could also enhance HIV awareness in their families and communities. FGD members suggested that better visibility of HIV positive community endeavours would have a positive impact on HIV-related stigma and discrimination among negative individuals.

*“Yes, it (HIV positive community’s involvement) is beneficial. In this way, many patients would regularly take antiretroviral drugs. To get ‘Zero’ HIV, only they*

*can do it. Without their involvement, we won't obtain 'Zero'.* **(37 year old female volunteer, Lashio)**

*"If we take the example of the MPG, we can show HIV positive people can work like that. They can decide. They know how to live. They sympathise. If PLHIV involve extensively, it can be beneficial for preventive and treatment responses."*  
**(FGD respondent, Mandalay)**

#### **5.3.4. Effective participation**

For effective PLHIV participation to occur, interview respondents repeatedly pointed out that solidarity among SHGs was crucial. They said SHGs should always keep in mind the importance of working together for a common goal. They proposed that PLHIV working in SHGs should adopt the right attitude ("for us", not "for myself"), as well as devotion, dedication, a voluntary spirit, self-motivation and empathy for fellow peers. They also indicated the necessity of active participation by well-educated and technically competent PLHIV.

The need to expand the number of SHGs in different locations was expressed. Some providers and PLHIV recommended SHGs spread out to smaller towns with limited support services. SHG leaders said effective linkages among PLHIV SHGs and networks could broaden the scope of their current work.

Key informants suggested SHGs would experience greater acceptance by service providers if they worked proactively to demonstrable their capability rather than passively waiting for invitations.

*"Outstanding SHGs did not sit around and wait for the invitation. Providers accepted them more because they demonstrated they were initiative and showed their skills. Stigma and discrimination is no longer there. Service providers regard those SHGs as the ones who help their work. These groups work effectively. Unlike that, if you are waiting for the invitation, I think the involvement can't be progressed."* **(Key Informant # 2)**

Strong voices from a couple of participants expressed the importance of broadening PLHIV engagement:

*“Inviting PLHIV just for fake image is not meaningful involvement. Inviting and letting them make their own decisions, having the rights of active discussion, ensuring the rights to do, and reallocating the responsibilities to them is what we called meaningful involvement.” “At the end of the day, INGOs will leave this country and only civil society networks will remain in the community. We need to consider this fact”. (28 year old respondent on ART, Yangon)*

*“Without the civil society, we can’t do anything. Not letting civil society for their meaningful involvement, the State would have no power if the civil society had no power.” (38 year old female respondent from Yangon on effective participation of SHGs in Myanmar)*

A couple of service providers said PLHIV SHGs should be aware of their potential roles. Likewise, SHG members pointed out that, for effective involvement, PLHIV should have the ability to understand their potential roles and identify how to fulfill them. In Yangon, some PLHIV served as expert patient trainers in ART public hospitals. A service provider recommended this kind of practice should be embraced by other local health facilities to create a helpful relationship between patients and service providers.

Self-stigma is quite common among PLHIV. However for effective participation, respondents recommended that PLHIV nurture self-confidence to voice their thoughts, share their indispensable experiences and provide suggestions and advice when communicating and advocating with policy makers, ART providers and community members.

HIV positive community groups said financial support, technical strengthening, and recognition and approval from local authorities were necessary for effective PLHIV participation. Several individuals emphasised the need for MPG’s active role in facilitating this process.

Some respondents said the requirement of official registration for local organisations had restricted some groups from expanding their activities, or increasing membership. Instead, these groups kept a low profile, leading to less visibility and awareness among the community.

Financial insecurity prevented many PLHIV from fully bearing their role in the national HIV response. Some volunteers said inadequate income made it hard for them to concentrate on volunteering opportunities. Therefore, consideration of these practical issues by relevant stakeholders could allow PLHIV to become more involved in ART provision, according to a key informant. They received about 2.5 dollars for their daily work as volunteer at public sites only for eight or ten days a month.

### **5.3.5. Strengths of PLHIV Self-Help Group Members**

Respondents said PLHIV SHG members had many strengths, including team spirit, social conscience, motivation to help others, collectiveness, empathy, strong networking skills, the ability to facilitate linkages and referrals, good will, faith, and the ability to build trust between peers.

*“As they have it [(HIV)], they have this spirit...self-sacrifice, lending a hand for others and compassion.” (43 year old male, Pathein)*

*“Peers can share among themselves about antiretroviral drugs. Peers trust in each other. If we can show them what we can do for each other, their morale shall be boosted. There is a need of creating a “bridge” between doctors and patients.” (FGD respondent, Mandalay, Sagaing, Magway)*

A score of participants said some PLHIV SHGs used their own money to assist others. Empathy towards peers was also evident when PLHIV undertook care taker roles in hospitals, a key informant observed.

A service provider suggested education was a strength thus well-educated PLHIV could take on larger roles.

*“Since they’ve already contracted HIV, they work with this inner self. We can’t work like that. Their goodwill is not to let others experience like them. It is a strength. In this way, they can also forget about their own disease. For the involvement at the policy level, there are graduates among them. They can work extensively for social duties. They searched and help patients. They did it even under the rain. I think they can be involved in legal matters too because educated people are in their groups.” (Key informant # 6)*

### **5.3.6. Barriers and Challenges for HIV Positive Community Participation**

At the individual level, the majority of respondents pointed out that PLHIV had to earn a living for themselves and their families. Therefore, maintaining a regular income was quite important. Even though some wanted to contribute, working long-term in service sites with little or no pay imposed financial insecurity on the family. Many respondents said a supportive mechanism for PLHIV could facilitate their effective and meaningful participation in care and treatment services.

Stigma and discrimination was another key factor. Stigma from others, as well as internalised stigma was quite common. Self-stigma leads to poor self-confidence, which in turn hampers PLHIV’ motivation for active involvement in ART provision. Interestingly, HIV positive respondents did not mention their own health status as a barrier but some service providers pointed it out as a potential barrier to regular and long-term involvement of PLHIV in HIV response.

Poor treatment was not infrequent. Some INGOs gave unmanageable workloads to volunteers who got blamed if these targets were not met. For example, some volunteers were required to deliver home-based care to nearly a hundred patients. Predictably, misunderstanding and strained relationships developed between the two parties in this instance.

Limited participation of PLHIV at the national level was also mentioned. SHG leaders said discrimination from authorities still occurred. SHGs had to follow several procedures to get official permission to do HIV- related activities.

A number of challenges were also identified at the organisational level, including limited technical capacity, low educational status of staff and volunteers, limited financing, weak cohesion and solidarity, shortage of leadership skills, irregular and disjointed collaboration among PLHIV networks and SHGs, inefficient organisational management, lack of personal awareness and failure to take personal responsibility, poor readiness for changes in the national HIV epidemic and response, difficulty in getting a registration, narrow scope of mission and vision, and a tendency to depend on external organisations.

*“Those who were trained no longer work, so members, who are currently working, don’t know what to be done. It’s important to uplift their capacities.”*

***(FGD participant, Taunggyi)***

*“Participation from educated HIV positive people is quite infrequent.”* ***(Key informant # 1, Yangon)***

### **5.3.7. PLHIV Network and Self-Help Group Assistance Needs**

The need for technical capacity development was mentioned by both service providers and PLHIV. According to them, without technical competency, the effectiveness of PLHIV participation would be low. They suggested counselling as well as other knowledge improvement trainings. Respondents said skill development in relation to organizational management, financial management, resource mobilisation, leadership, systematic documentation of information and quality reporting, information technology and English language.

A LNGO key informant stressed that technical assistance needs were more visible among SHGs in rural areas, than those based in large urban cities due to a lack of access to capacity development opportunities. A public sector specialist cautioned that, without skill and capacity building, PLHIV would have limited influence over decision-making at local and national levels.

The second most common need expressed by respondents was sufficient financial assistance in the form of a monthly salary to PLHIV volunteers, which would permit PLHIV to spend more

time at service delivery sites and undertake effective outreach activities. SHG leaders said financial support was necessary to maintain the momentum of current services.

SHG leaders wished the MPG secretariat would play a stronger role in supporting PLHIV who had strong motivation and a willingness to be involved. They also demanded MPG lead advocacy efforts through parliament.

### ***5.3.8. The Role of the HIV Positive Community at the National Level***

At national level, members of MPG network held four seats on. Likewise they could be seen in national stakeholder meetings, district and township level advocacy and coordination meetings, events but could still broaden their roles at the national level. However, the degree to which they could influence policy is yet to be explored.

### ***5.3.9. Suggestions to the Myanmar Positive Group and Self-Help Groups***

Many respondents agreed that more SHGs were needed to reach people from remote areas and small rural townships. They suggested experienced and well-established SHGs help newly founded groups. Respondents recommended improving unity among SHGs, building strong discipline among members, effectively sharing information within and between groups, continuous advocacy (with tactfulness) to authorities; adopting a team, social and voluntary spirit; and ensuring of the sustainability of organizations.

Participants suggested that MPG should provide regular technical assistance to SHGs to support organizational growth. They would also like to see stronger leadership from the MPG and development of regulations and frameworks for SHGs.

*“I think demanding (the service providers) to open the door is not enough. From our side, we need to knock the door. And I think, from our side, we need to strengthen our capacities.” (38 year old male waiting for ART, Lashio)*

*“There is a need for capacity building of SHGs, especially, SHGs are under networks... If you want to strengthen the network, the first thing is to increase the capacity of SHGs.” (28 year old male from Yangon)*

A key informant pointed out an absence of workplace policies for PLHIVs in many settings. Therefore, they suggested reforming labour laws to protect PLHIVs could be an important mission that PLHIV community could undertake in collaboration with other stakeholders.

Service provider said documented evidence of results was important if they wanted to receive financial assistance from donors. They also highlighted the importance of systematic project management, proper management of financial resources, sound technical competency, transparent decision-making, and willingness to take responsibility for program outcomes. According to key informants, these capacities in an organisation would inspire trust, not only from external donors, but also from the local community. They also agreed that wider coverage of SHGs across the country was needed. They said PLHIV networks and SHGs should move away from stand-alone HIV programming, in favour of mainstreaming HIV into broader development activities within the wider community.

*“For more involvement from SHGs, provision of technical training, lending office spaces and financial aid are required...At the same time, from our side, we must take responsibility. Some groups disappeared after accepting financial assistance. If we can use our capability efficiently, the capacity of SHGs will be improved.” (34 year old male working in a CBO, Yangon)*

*“Taking responsibility is mandatory in an organisation. For the development of an organisation, it should have some characteristics, structure, policies, to accomplish.” (Key informant # 3)*

Since social support is very important for ill PLHIV, a specialist said effective interventions can be implemented by SHGs to cover the period where PLHIV felt most vulnerable socially and financially. Key informants also emphasised the important roles of SHGs during task-shifting period, where international development partners gradually reduce their assistance to Myanmar, potentially resulting in human resources gaps that are unable to be covered by public sector. Therefore, ART service providers suggested current SHGs could be utilized in HIV treatment, care and support system strengthening, and in a reduction of stigma and discrimination. The participation of SHGs was greatly in need in home-based care, follow-up

tracing, referral and linkages (either in person or via hotlines) and other related tasks. A public service provider suggested misunderstandings between SHGs, NAP and public health facilities should be decreased and supportive thinking should be nurtured.

#### **5.3.10. Suggestions to Other Stakeholders**

PLHIV respondents wished for positive treatment from health facility staff. They believed PLHIV also had the rights to express their opinions. They said discrimination should not come from health staff and requested mutual understanding and compassion. Many participants wanted to shorten the time between the HIV testing and ART initiation. FGD participants as well as IDI respondents wished for continuous provision of ART adherence counselling to those on ART to reduce defaulters. They said this was not usually happening.

*“People still thinks HIV has nothing to do with them. If a PLHIV is not bed-ridden, he/she can work normally. If we advocate for this, PLHIV can regain normal life. The government should need to consider this fact.” (35 year old female, not on ART, Yangon)*

They requested technical assistance from NAP and partner NGOs to maximise SHGs engagement with in the public and non-profit sides. Many counsellors did not receive regular refresher and updated counselling training. Due to inadequate income, some trained peer counsellors had left the jobs and replacement individuals often lacked requisite skills. An INGO service provider suggested inclusion of a technical capacity building plan for PLHIV network in the National Strategic Plan on HIV and AIDS. A couple of key informants demanded a cross-country referral linkage system (bridging non-profit and public, SHGs) to retain mobile PLHIVs in treatment, care and support services. A service provider suggested HIV care and support should be provided within a chronic care model.

#### **5.3.11. Knowledge of the GIPA Principle**

The GIPA principle refers to the meaningful involvement of PLHIV in the programmatic, policy and funding decisions that impact on their lives by ensuring PLHIV participating in important decisions. The majority of SHG members seemed unaware of the GIPA principle and could not

describe its essence. Only individual respondents who were well-educated and had been exposed to national level PLHIV network activities could discuss the principle of GIPA, although their interview questions did not directly address this knowledge.

## 6. DISCUSSION

### ***6.1. PLHIV Perceptions and Utilisation of ART services***

By mid- 2014, about 75,000 persons in need were receiving antiretroviral drugs , which is a significant scale up of ART coverage.<sup>10</sup> In Myanmar, the provision of ART is mostly done by the non-profit and public sectors. With funding support from GFATM, NAP is currently scaling up the national ART program by increasing the number of ART quota targets in existing service delivery sites, as well as expanding geographically, to achieve its coverage target of 86% of those who are eligible for treatment based on the current national treatment guidelines by 2016. To increase the uptake, a decentralization strategy was employed to ensure HIV care and treatment services at township and peripheral levels.<sup>11</sup> The Government of Myanmar also pledged domestic funding of five million US dollars for HIV treatment, care and support.

This study found that more PLHIV received ART in recent years in all six sites, which reflects the well-intentioned treatment scale up efforts undertaken under the leadership of NAP. It was reported that the WHO guidelines on providing ART at CD4 count 350 and below was applied in most sites. Generally, ART service users were very satisfied with the availability of free antiretroviral drugs. Both government and NGO sectors facilitated free diagnostic tests as well whenever funding allowed. However, more needs to be done to reach national treatment benchmark.

Findings from the study were quite similar to other countries' assessments and reviews regarding barriers to treatment such as stigma and discrimination, lack of social support, poverty, distance from care and treatment sites and related travel costs, quality of services including counselling, and providers' attitudes.<sup>12,13</sup>

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<sup>10</sup> Global AIDS Response Progress Report, Myanmar , National AIDS Programme, Reporting Period: January 2012 – December 2013

<sup>11</sup> Joint rapid assessment of HIV treatment in Myanmar, Final report (September 2013), NAP, WHO, Save the Children, PEPFAR (Unpublished)

<sup>12</sup> Asia Pacific Network of People Living with HIV/AIDS (APN+). Access to HIV-related health services in positive women, MSM, transgender and IDU, research finding highlights, August 2009 Report

Fear of stigma and discrimination stopped PLHIV from opening up about their status at ART clinics and utilizing testing and treatment services. These concerns prevented them from coming to clinics located near their homes. PLHIV from key affected populations were most vulnerable, compared to the general population. Therefore, service providers should consider the strategies for overcoming these barriers which affect treatment seeking behaviours of potential services users. Also the strategies should address retention of the PLHIVs in the treatment program to reduce defaulter rate. NAP, together with its partners, should not only raise awareness of available ART services, but also address HIV-related stigma and discrimination by disseminating information to the community. These efforts can improve community knowledge and pave the way for reducing stigma and discrimination. To support these actions, studies in other countries recommended PLHIV SHGs participate as positive role models to lessen stigma and discrimination at the community level.

Other crucial factors associated with treatment seeking behaviours were poverty and distance from ART delivery sites. The relationship between distance and finance meant that even when patients did not pay for drug expenses, indirect costs like transportation imposed a huge burden for potential service users who needed to travel from distant and remote areas. Therefore, patients from rural areas faced difficulties in accessing medical care. Many PLHIV could not afford long-term lodging in large urban towns when waiting for initial counselling and in preparing for ART initiation. Also, frequent trips to ART clinics to get monthly drug supplies and for laboratory investigations put financial strain on service users with low income. Expanding the number of decentralized ART sites in townships and peripheral levels should ease indirect cost for service users and increase treatment uptake and adherence trend. Importantly, shortening the ART enrollment process facilitated by NAP should increase retention of patients and save lives of late presenters. In addition, cooperation among all partners (Government, NGOs, CSOs, and donors) should be improved.

However, all of these efforts may not achieve desired treatment outcomes without appropriate psychosocial support mechanisms. Respondents felt 'quality service' was not just about physical

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<sup>13</sup> PLHIV League of Moldova, GNP+ (2011). The GIPA Report Card Moldovan Country Assessment 2010. Chisnau, PLHIV League of Moldova.

care but also psychological and social care and the emotional sensitivity of service providers. Psychosocial support is required to assist PLHIV, their families and communities to cope with the socio-economic impacts of life-threatening disease.<sup>14</sup> It also enhances the spiritual well-being of PLHIV through regular contact with PLHIV SHGs and participation in activities. Therefore national programs should make greater use of existing SHGs and their networks. Support groups can discuss fears and strategies for overcoming of these, give practical advice on HIV treatment, form ‘buddy’ relationships with patients and build self-confidence to go through the treatment process.

To achieve the national targets of ART scale-up, HIV counselling and testing is an entry point. It is essential that people at potential risk should be encouraged to access HIV counselling and testing to facilitate early enrolment in the ART program. However, poor quality of PLHIV counselling services was revealed in the study, especially within the public health sector. In addition, there was a shortage of trained counselors to provide counselling services to large numbers of PLHIV, particularly in the public sector. Even though peer counsellors were filling some human resource gaps, most of them needed to receive proper, systematic and updated training. Every year, NAP counselling experts provided trainings in Yangon and Mandalay. However, the limited number of trained counsellors was not sufficient to address the shortage of counsellors at ART service sites. Some experienced counsellors had left the jobs and replacements were needed. NAP and NGO partners should therefore explore potential ways to improve, both the quality of counselling services, and the number of available counselors. This might include setting minimum standards of service provision, reviewing of the budget for training of counsellors, inclusion of a budget line for regular technical backstopping and refresher trainings, and increasing annual targets of trained counsellors.

To minimize ART failure, poor adherence must be controlled. Findings indicated that self-awareness, presence of social support mechanisms, routine counselling and recognition of the value of treatment were critical for treatment adherence. A study done in Africa cited that one

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<sup>14</sup> Fact sheet – HIV/AIDS Care and support, United Nations Special Session on HIV/AIDS, Global Crisis-Global Action, 25-27 June 2001 New York

key supportive family member could make a significant difference to treatment adherence and overall well-being of PLHIV.<sup>15</sup> This indicates the importance of regular capacity strengthening and supervision of health staff, and the availability of psychosocial support mechanisms at the community level. These factors were crucial because pre-ART counselling sessions alone were not enough. Lack of emphasis on post-testing and adherence counselling in the public sector may risk poor treatment adherence and ART drug resistance as well as weak positive prevention. Likewise, in NGO service delivery sites, even though sufficient numbers of counsellors were appointed, frequent counselling that do not meet the needs of PLHIV may not be useful. For instance, if a client's CD4 count drops while they are on ART, a change of drug regimens may not be the answer. The counsellor and medical staff may need to explore the underlying cause, together with PLHIV.

Respondents mentioned a number of areas for improvement in relation to ART service provision, including poor attitudes of providers, prolonged waiting time at health centers, staff shortages, lack of infrastructure, confidentiality and privacy issues, the limited range of services, poor qualifications of staff and infrequent CD4 testings. The difficulties were less prominent in NGO clinics thus many PLHIV preferred to receive services there. It is unrealistic to expect significant changes in public health settings in a short period of time. However, a minimum requirement of quality of care should be met. Provision of education to staff on quality improvement of services, and regular monitoring of service quality are recommended. Regular feedback from service users should also be requested. Identifying informal resources available (for instance, PLHIV networks and groups), to fill human resource gaps within the public sector should be considered. Effective linkages and referral mechanisms should be built with regular coordinating meetings to learn patients' needs and identify accessible resources.

## **6.2. Level of PLHIV SHGs Participation in ART Provision**

At all study sites, SHGs for PLHIV were actively engaged in a wide range of facility- and community-based peer support activities. Some SHGs were quite small, while some were quite

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<sup>15</sup> K.Scott, C.Campbell, C.Madhanhire, M.Skovdal, C.Nyamukapa and S.Gregson (2013), "In what ways do community support optimal antiretroviral treatment in Zimbabwe?", Health Promotion International, March 15, 2013

large in size, composed of more than 200 members. Depending on the size of the group, the scope of work was different. Geographical coverage of SHGs was uneven and respondents recommended the establishment of new groups in smaller towns and remote locations to address the needs of PLHIV.

This study demonstrated that the HIV positive community in Myanmar was involved in ART provision at different levels. Many PLHIV were beneficiaries of ART services, while some were working as NGO staff or as volunteers in service delivery. A few of them were engaged in providing technical expertise while a small number of PLHIV were engaged as significant policy and strategic development actors. Representation of PLHIV at the national level has increased in recent years, though it is still limited and further exploration is needed to ascertain how meaningful such representation is.

Findings showed SHGs were involved in day- to-day operational activities like counselling, care and support provision, facilitation at ART clinics, patient tracking, health education and health sector training. Therefore their involvement at township level is visible while there is still potential to expand their roles at regional and national levels. The WHO operation manual recommended formal health systems should utilise informal resources in the community, such as PLHIV SHGs as these can play a significant role in delivering quality HIV services. Accordingly, deciding on a variety of means to involve PLHIVs shall result in effective and sustainable services.<sup>16</sup>

Even though HIV-related stigma still remains, there were positive perceptions and recognition from local communities towards the significant work done by PLHIV SHGs and networks. Fellow PLHIVs appreciated and praised SHGs in all areas. Therefore, PLHIV networks should continue increasing HIV awareness, and reducing stigma and discrimination at the community level, through involvement in health and community development actions. Through working hard, serving as positive role models and being of assistance to each other, PLHIV will contribute to reducing stigma and discrimination. The regional and state development plans should include the roles of CSOs, including SHGs.

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<sup>16</sup> Operation manual for delivery of HIV prevention, care and treatment at primary health centres in high prevalence, resource-constrained settings, WHO, 2001.

The increase demand for ART in Myanmar is putting a strain on the formal health system. Chronic shortages of staff in the public sector, inadequate infrastructure, and financial constraints usually lead gaps and limitations in service provision at government-owned health facilities. These issues can be alleviated to some degree by effective utilisation of informal resources in the community, such as PLHIV SHGs. Government staff can focus on treatment while PLHIV SHG members concentrate on prevention, care and support services, such as counselling, care giving, psychosocial support, defaulter tracking, referral, and health education, because these are the areas where human power is most lacking. Therefore, the PLHIV networks and the public health sector should jointly engage, without delay, at national and township levels to see how existing SHGs can contribute to scale-up of ART. Also PLHIV networks should discuss what PLHIV SHGs need, which should be practical and reasonable, considering existing limitations of the formal health system.

ART selection committees were present in study areas but limited PLHIV representation in these committees was recounted. Decision-making was mainly done by service providers. It is important to note, however, that these ART quota systems using committees are no longer practised in the majority of ART sites. Standard operation procedures of ART decentralization are disseminated to peripheral levels. At the policy level, while national PLHIV network representatives held M-HSCC membership, their influence on policy issues was rather limited. Some policy makers were reportedly still reluctant to take serious consideration of the suggestions of PLHIV leaders and representatives. This can slow down the progress of effective implementation of the GIPA principle at the country level. Limited participation of PLHIV community in decision-making may result in a lack of ownership of programs. Thus the quality of participation of HIV positive community should be improved to strengthen their civil responsibilities.

To improve effective participation of the HIV positive community, the study discovered the importance of addressing self-stigma normally felt by PLHIV and nurturing self-confidence, identifying their capacities, demonstrating of solidarity among groups, receiving technical and financial support from service providers and securing official registration of SHGs and networks.

From the side of government and NGO, active listening to suggestions and feedback from HIV positive groups is required. PLHIV groups should take the initiative to assess their own capability and how to proceed, while considering the Myanmar context.

### ***6. 3. Identification of Gaps for Improved coverage and Quality of Care***

To achieve the national target of providing ART to 86% of PLHIV in need, all partners of NAP should work together. The formal health system needs to meet the current volume of patients with over-stretched resources, staff shortages, poor infrastructure, and inadequate diagnostic equipment. Staff shortages make it difficult for ART services to do outreach activities like home visits, home-based care, tracing of defaulters, provision of health education and closed-setting services like HIV counselling and testing, ART counselling, adherence support, family counselling, facilitation at clinic receptions and drug dispensary areas and documentation of services. At present, PLHIV were involved in day to day operational activities such as counselling, care and support provision, facilitation at ART clinics, assisting with patient tracking, health education, and health sector training.

Literature from different countries suggested that, for PLHIV, peer support groups are essential.<sup>17</sup> These groups offer a confidential and safe space for PLHIV to share their own experiences, as well as, practical suggestions relating to personal coping skills. Their members can gradually grow into positive role models. Their identified strengths were collectiveness, team spirit, motivation to contribute to HIV positive community, desire to give hope to other PLHIV, social spirit, empathy, strong networking skills, ability to make linkages and referrals, good will, faith and the capacity to build trust with PLHIV. Similar to this study, evidence in other countries demonstrated that PLHIV listen to their peers more than to regular health professionals.<sup>18</sup>

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<sup>17</sup> Gooley, Suzanne Lou. The Greater Involvement of People Living with and Affected by HIV and AIDS (GIPA), NGO experiences and implications for the work of Oxfam international and Oxfam Australia, July 2006

<sup>18</sup> PLHIV League of Moldova, GNP+ (2011). The GIPA Report Card Moldovan Country Assessment 2010. Chisnau, PLHIV League of Moldova.

Both service providers and users confirmed the advantages of HIV positive groups involvement. PLHIV SHGs know local communities and represent a vital link between community members and services by providing education about HIV and ART, identifying those most in need of health care and other support, and helping them access needed services.<sup>19</sup> PLHIV SHGs created an effective bridge between providers and beneficiaries, provided additional resources to cover counselling, supported home-based care, helped out with defaulter tracing, built trust with peer PLHIV, increased awareness of service delivery and encouraged treatment intake. Even though decentralization of ART services would decrease the workload congestion at health facilities in large cities, the decentralised sites would still need additional resources to manage ART provision at their local areas. NGOs have already started stationing their staff at the public sites for ART services. However, PLHIV are generally more comfortable accessing treatment services at large hospitals for fear of discovery by their community members. Therefore, attracting PLHIV to use decentralised sites would greatly need the advocacy and encouragement by PLHIV SHGs and networks. This would include collaborative efforts to reach out “healthy-looking” PLHIVs and recruit them to services. Involvement of PLHIV increased people’s willingness to access HIV testing because they felt encouraged when they saw that PLHIV were able to live a positive life.<sup>20</sup> Service providers should identify how to maximize the use of human resources of local SHGs, while adopting a chronic care approach to HIV care and treatment.

A noteworthy advantage of HIV positive community involvement in ART provision is the reduction of stigma and discrimination. PLHIV networks should take this as an opportunity to correct the negative beliefs of the public, which sometimes view PLHIVs as immoral persons. Therefore, it is recommended that PLHIV groups and service providers jointly assess, coordinate

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<sup>19</sup> Joint rapid assessment of HIV treatment in Myanmar, Final report (September 2013), NAP, WHO, Save the Children, PEPFAR

<sup>20</sup> Global AIDS Response Progress Report, Myanmar , National AIDS Programme, Reporting Period: January 2012 – December 2013

and mobilise existing resources which can fill in the gaps identified at health centres and hospital services.

#### **6. 4. Key Obstacles Preventing Meaningful Involvement of HIV Positive Groups**

This study found, at the individual level, poverty, stigma and discrimination, and self-stigma resulted in low levels of active participation by PLHIVs. Very similar results were mentioned in a desk review conducted among various projects across the globe.<sup>21</sup> At organizational level, meaningful involvement of PLHIV was mitigated by limited technical capacity and skills, low educational status, limited financing, weak cohesion and solidarity, shortage of leadership skills, irregular and disjointed collaboration among groups to share information and experiences, inefficient organisational management, lack of awareness and failure to take responsibility, poor readiness for changes in the national HIV epidemic and response, difficulty getting a registration, narrow scope of mission and vision, tendency to depend a lot on external organisations, and poor understanding of the GIPA principle.

MPG should take a leading role in assessing the organizational development needs of SHGs, creating capacity development plans and mobilize resources for their implementation. NGO and government partners should reinforce their existing technical support to SHGs. SHG leaders and members should be prepared for a range of roles and coordinate with the MPG secretariat office for organisation growth and management. It is important that PLHIV SHGs and networks understand the formation of good organisational governance structures, and continue to utilise technical support from other stakeholders. GFATM's new funding model is focused on strengthening CSOs in Myanmar. With GFATM's financial support, the MPG secretariat office has opened field offices. MPG field staff are implementing capacity strengthening of SHGs. Using these experiences, MPG may consider asking NGO partners to mobilise resources to empower PLHIV SHGs through, for example, provision of technical support and allocation of funds to cover salaries for PLHIV counsellors, care-givers and trainers. Looking beyond GFATM

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<sup>21</sup> Gooley, Suzanne Lou. The Greater Involvement of People Living with and Affected by HIV and AIDS (GIPA), NGO experiences and implications for the work of Oxfam international and Oxfam Australia, July 2006

funding, it is about time that a concrete plan to ensure continuous resources for HIV treatment, care and support is developed.

This study observed a limited degree of PLHIV participation at policy level. This represents a missed opportunity to improve policy at different levels of society, strengthen HIV-related research, and improve effective communication strategies for PLHIV and the wider community.

## **7. RECOMMENDATIONS**

### ***Immediate Actions***

(1) MPG should:

- Share relevant findings with study participants and other stakeholders at the township level. This should also be carried out through dissemination of the research report.

- Participate in the NAP's review of ART decentralization and highlight key points of this study. It should explore how PLHIV SHGs and networks might contribute to ART provision at decentralized sites.

- Document the ideas, practices and models of the well-functioning SHGs and include them in developing standard guidelines for SHGs. It should share them with both SHGs and groups requiring strengthening.

- Inform and encourage PLHIV to utilize HIV treatment, care and support services at peripheral levels.

- Coordinate with NAP and NGO partners to reinforce the counsellors in the field offices of the MPG to HIV treatment, care and support sites.

(2) The PLHIV SHGs and networks should:

- continue increasing HIV awareness, and reducing stigma and discrimination at the community level, through involvement in health and community development actions.

### ***Intermediate Actions***

(1) MPG should:

- Take a leading role to assess the organizational development needs of SHGs, creating capacity development plans, and mobilize resources for their implementation.

- Encourage and support the formation of SHGs in smaller towns to ensure psychosocial support for PLHIV and to promote care and treatment services.
- Reinforce its leadership role by effectively undertaking networking among SHGs, and between SHGs and MPG, conducting mapping to identify PLHIV needs and assistance available, and building a regular feedback mechanism.
- Ensure better comprehension and implementation of the GIPA principle by civil society, government, development partners and PLHIV SHGs and networks.

(2) PLHIV SHGs and networks should:

- Be prepared for a range of roles and coordinate with the MPG secretariat office for organisation growth and management.
- Discuss what PLHIV SHGs need, which should be practical and reasonable, considering existing limitations of the formal health system.
- Take the initiative to assess their own capability, and how to proceed, while considering the Myanmar context.

(3) NAP and NGO partners should:

- Develop a minimum standard guideline in relation to service quality at decentralized levels.
- Provide education to staff on quality improvement of services and conduct regular monitoring of service quality (including communication, confidentiality and code of conduct employed when dealing with service users). Regular feedback from service users should also be requested.
- Reinforce their existing technical support to SHGs.

(4) NAP, NGO partners and MPG should

- Identify strategies to reach out to “healthy” PLHIV and inform them of available HIV treatment services.

- Ensure the availability of psychosocial support mechanisms at community level to achieve desired treatment outcomes and to mitigate the socio-economic impacts of HIV on PLHIV and their families.
- Build effective linkages and referral mechanisms through regular coordination meetings to learn client needs and identify accessible resources.
- Work together, at national and township levels, to see how the existing PLHIV SHGs can contribute to the scale-up of ART, while adopting chronic care approach. For instance, more SHG members reinforce as care givers, counsellors, support staff and outreach workers at township level.
- Increase community awareness and address HIV-related stigma and discrimination by disseminating comprehensive information on HIV and AIDS to improve knowledge among community members and reduce stigma. At the centre of these actions, PLHIV SHGs should participate as positive role models within their communities to lessen stigma and discrimination.
- Work closely with each other to promote stronger coordination among government and NGO service providers to address common issues identified at ART decentralization sites, with the participation of the MPG (to advocate PLHIV and to raise awareness of available ART services, the rights of patients regarding quality service, selection of service providers, participations at different levels).
- Explore potential ways to improve both the quality of counselling services and the number of available counsellors by setting minimum standards of service provision, increasing the number of counselling trainings, including a budget line for regular technical backstopping and refresher trainings and increase the annual targets of trained counsellors.
- Allocate additional financial resources for PLHIV empowerment and capacity building. When the new National Strategic Plan and National Operation Plan are developed, a capacity development plan for PLHIV SHGs should be considered and budgeted.

***Policy level***

The MPG should advocate for the inclusion of a backup plan for sustainability of existing PLHIV networks in the national health budget plan.

The MPG should continue advocating for the inclusion of PLHIV rights in relation to equal employment and health care benefits in labour laws, workplace policies and HIV law.

The MPG should advocate for the inclusion of the roles of CSOs, including SHGs in the regional and state development plans at country level.

## APPENDIX

### Annex 1. Profiles of In-Depth Interview Respondents

	Age	Sex	Occupation	Education	Study area	ART
1	29	M (MSM)	Spiritual medium	10 <sup>th</sup> std	Pathein	+
2	28	F	Volunteer	6 <sup>th</sup> std	Pathein	+
3	41	F	Volunteer	10 <sup>th</sup> std	Pathein	+
4	44	F (SW)	Sex worker	3 <sup>rd</sup> std	Pathein	-
5	36	F	Farmer	4 <sup>th</sup> std	Pathein	-
6	25	F (SW)	Sex worker/vendor	3 <sup>rd</sup> std	Pathein	-
7	43	M (MSM)	Spiritual medium	8 <sup>th</sup> std	Pathein	+
8	24	M	Cycle taxi	10 <sup>th</sup> std	Pathein	+
9	20	M	Dependent	University	Pathein	+
10	40	M	Cycle taxi	7 <sup>th</sup> std	Pathein	+
11	43	F	Counsellor	University	Taunggyi	+
12	43	F	Tailor, volunteer	8 <sup>th</sup> std	Taunggyi	+
13	42	M	Volunteer	10 <sup>th</sup> std	Taunggyi	+
14	48	F	Volunteer	Graduate	Taunggyi	+
15	25	M	Volunteer	10 <sup>th</sup> std	Taunggyi	+
16	31	F (SW)	Sex worker	Illiterate	Taunggyi	+
17	33	M (PWID)	Odd jobs	10 <sup>th</sup> std	Taunggyi	+
18	41	M	Driver(own car)	6 <sup>th</sup> std	Taunggyi	-
19	35	F	Vendor	8 <sup>th</sup> std	Taunggyi	+
20	36	F	Vendor, widow	8 <sup>th</sup> std	Taunggyi	-
21	40	M	Volunteer/ room rental business	10 <sup>th</sup> std	Mandalay	+
22	27	F (SW)	Sex worker/street vendor	8 <sup>th</sup> std	Mandalay	-
23	41	F	Odd jobs/Sex Worker	8 <sup>th</sup> std	Mandalay	-
24	34	F	Volunteer	10 <sup>th</sup> std	Mandalay	+
25	34	M	Dependent (living with parents)	10 <sup>th</sup> std	Mandalay	+
26	25	M(MSM)	Beautician	8 <sup>th</sup> std	Mandalay	+
27	39	F	Volunteer/government service	Graduate	Mandalay	+
28	32	F	Dependent	4 <sup>th</sup> std	Mandalay	-
29	45	F	Outreach worker/ tailor	4 <sup>th</sup> std	Mandalay	+
30	42	M	Taxi driver	4 <sup>th</sup> std	Mandalay	+
31	37	F	Volunteer	8 <sup>th</sup> std	Lashio	+
32	52	F	Vendor	8 <sup>th</sup> Std	Lashio	+
33	45	M (MSM)	Beautician	10 <sup>th</sup> std	Lashio	+

34	52	F	Dependent (living with children)	8 <sup>th</sup> std	Lashio	+
35	34	M	Taxi driver	5 <sup>th</sup> std	Lashio	+
36	33	F	Volunteer	10 <sup>th</sup> std	Lashio	+
37	31	M (PWID)	Dependent	8 <sup>th</sup> std	Lashio	-
38	38	M	Furniture shop	University	Lashio	-
39	32	M	NGO staff	10 <sup>th</sup> std	Lashio	+
40	40	F	Volunteer	5 <sup>th</sup> std	Lashio	+
41	42	M (MSM)	Volunteer	Not available	Mawalamyine	+
42	53	M	Volunteer(no income)	Not available	Mawalamyine	+
43	53	M (PWID)	Dependent (living with children)/ volunteer	Not available	Mawalamyine	+
44	39	M	Dependent (living with siblings)/ Volunteer (no income)	Not available	Mawalamyine	+
45	41	F	Dependent/ Volunteer (no income)	Not available	Mawalamyine	+
46	28	F (SW)	Dependent/ ex-sex worker	Not available	Mawalamyine	-
47	36	F (SW)	Sex worker	Not available	Mawalamyine	+
48	36	F	Dependent/Widow	Not available	Mawalamyine	-
49	32	F	Dependent/ Volunteer	5 <sup>th</sup> std	Mawalamyine	+
50	40	M	Vendor	Graduate	Mawalamyine	+
51	34	M	Administrative officer	Graduate	Yangon	+
52	35	F	Finance officer	University	Yangon	-
53	28	M	Program officer	Graduate	Yangon	+
54	58	M	Social worker	10 <sup>th</sup> std	Yangon	+
55	46	M (MSM)	Peer counselor	10 <sup>th</sup> std	Yangon	+
56	57	F	Peer counselor	9 <sup>th</sup> std	Yangon	+
57	39	M (PWID)	Dependent (Living with siblings)	University	Yangon	+
58	44	M	Security head	10 <sup>th</sup> std	Yangon	+
59	38	F	Secretary (Network), Jr Project Officer	10 <sup>th</sup> std	Yangon	+
60	-	M	Peer educator	10 <sup>th</sup> std	Yangon	+

## **Annex 2. Questions Guide**

### ***Focus Group Discussion Questions Outline***

#### *Background information of Existing Self-Help Groups*

- How many self-help groups are currently active in your location?
  - Who are they?
  - Their geographic coverage
  - Nature of activities
  - Number of members
  - What kind of coordination or linkages among these self-help groups?
  - What kind of support do they receive from MPG secretariat office? From local service providers?

#### *Treatment Needs of Positive Community and Availability of ART Services*

- How do PLHIV seek and use ART treatment in your community?
  - Where do they get ART?
  - How do social, financial and cultural factors affect how PLHIV use ART?
  - What difficulties do PLHIVs experience in seeking and using ART treatment services?
  - How could access to ART be improved?
- Who is involved in providing treatment for PLHIV in your community?
  - How many organizations are involved in HIV/AIDS related treatment in your community and what type of organizations are they?
  - What treatment services are they offering to PLHIVs? Where are they providing?
  - What is the quality of their treatment work –
    - Effectiveness (strengths, weaknesses, gaps, duplications)
    - Acceptability
    - Efficiency
    - Attitude to clients

### *Role of Self-Help Groups and Perceptions on Potential Greater Involvement*

- Is there ART selection committee in your community?
  - What are the selection mechanism and eligibility criteria for initiating ART and the application in your area?
  - What is the role of HIV positive community in the selection committee?
    - How effective is your participation in these committees? What is the level of acceptance of your participation? The decision making degree by PLHIV representatives in the committee?
- What do you understand by GIPA?
  - Are you aware of GIPA principle?
  - If so, what is your understanding of this principle?
- What are your roles in ART counseling?
- How do you feel about greater involvement of positive community in ART provision?
- Is it important to have an involvement of PLHIVs in ART provision? Why do you think so?
- Are there benefits from this involvement? What are these benefits?
  - To other PLHIVs
  - To general community
  - To national response
- Which areas can they fill in for effective participation?
- What are their strengths for greater involvement and effective participation? How can these be applied? (experiences of HIV, existing linkages, knowledge, expertise, policy level roles, etc.)
- What were/are challenges for positive people to involve in ART provision services? How do you think they can be overcome?
- Please describe what you consider to be major barriers to positive community's role in ART provision in Myanmar?<sup>22</sup>

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<sup>22</sup> Some possible examples: legitimacy of PLHA organizations, leadership, sustainability due to illness, lack of capacity, resistance to the involvement by other stakeholders and communities, lack of evidence on value of PLHIV, prevailing stigma and discrimination, public voice

- For example, how do general community attitudes towards it?
- How does capacity and skill level of positive community affect their ability to become involved?
- Do you think you have necessary skills and capacities?
- If no, which ones are needed for effective participation?
- How can these be overcome?
- What kind of assistance needs for more fully involvement? Please list them as examples.
- Is there anything you would like to add/issues you feel are important?

## ***In-Depth Interview Questions Outline***

### *Background personal information*

- Age
- Marital status
- Currently employed or not (if employed, check the occupation)
- Average monthly income
- Who is the bread winner of the family

### *HIV/AIDS related treatment services particularly ART*

- Knowledge of Existing Service Providers and utilization of ART services
  - Are there HIV/AIDS related treatment provision services at your township?
    - If so, who are the providers? (NGOs, GPs, Public hospitals, others)
    - Do you know what kind of services are they providing? If so, what are these?
    - How did you come to know these services? Who tells you about the treatment service availability in your township?
    - Are you currently accessing them? If yes, which services are you taking? If not, what are the reasons that you are not accessing them?
  - Are you currently on ART? If yes, from where do you get ART? How many ART service providers in your township? If not on ART, what are the reasons that you are not accessing or taking ART services?
  - Where do you need to go for testing CD4 count or viral load?
  - What is your impression on the attitudes of the service providers?
  - What is your understanding on the meaning of “services” (Treatment, care and support services)? What is the meaning of “quality HIV/AIDS related treatment services” to you? Why do you think it is important?
- Distance from Service centres and Related Cost
  - How far is the service centre from your home (miles, kilometres)?
  - How do you go there?

- Can you explain more about the day when you need to get ARV treatment services/ HIV/AIDS related treatment services?
  - How much do you need to spend for transportation cost?
  - How much do you need to spend monthly for ARV drugs or other drugs? (pay from own pocket, cost sharing, free drugs)
  - How much time do you need to spend?
  - Do you need to take leave from work or ask someone to look after your kids or do you need to close your business on that day? Any income loss on that day?
  - What about if you need to go for CD4 test or viral load test (means of travel, the transportation cost, laboratory tests cost, the time spent, any income loss)?
- Perception on ART Service provision arrangements
  - Who are receiving ART? On what criteria?
  - What is your impression on current ART provision arrangements?
  - In your understanding, what factors are playing important roles in receiving ART?
  - If you are on ART, what factors are affecting treatment adherence? What are the challenges? How these can be overcome?
  - If you are not on ART, what is your feeling about it?

*Knowledge on local Self-help groups and Perspectives on the potential of their greater roles*

- Do you know any self-help groups in your township?
  - If so, who are they?
  - How do they support you?
  - What is your general impression on them?
- How do you feel about greater involvement of positive community in ART provision?
- Is it important to have a meaningful involvement of PLHIVs/self-help groups in ART provision? If so, why do you think so?
- Are there benefits from this involvement? What are these benefits?
  - To other PLHIVs
  - To general community

- To national response
- What are their strengths for greater involvement and effective participation?
  - How can these be applied?
  - Which areas can they fill in for effective participation?
- What are the challenges for positive people to involve in ART provision services?
  - How do you think they can be overcome?
- Is there anything you would like to add/issues you feel are important?

## ***Key Informant Interview Questions Outline***

### *Background Information on Service Provider*

- Geographical coverage
- Range of activities and services providing
- Type of organization
- Linkage with self-help groups

### *Perception on Greater Role of Positive Community in ART provision*

- In your opinion, what is the current level of positive community involvement in national response of HIV?
- How do you feel about greater involvement of positive community in ART provision?
- Is it important to have an involvement of PLHIVs? Why do you think so?
- Are there benefits from this involvement? What are these benefits?
  - To other PLHIVs
  - To general community
  - To national response
- Which areas can they fill in for effective participation?
- What are their strengths? How can these be applied? (experiences of HIV, existing linkages, knowledge, expertise, policy level roles, etc.)
- Have you experienced challenges working with PLHIV in ART services? Please can you describe what these challenges and how do you think they can be overcome?
- Please describe what you consider to be major barriers to positive community's role in ART provision in Myanmar?<sup>23</sup>
  - For example, how do general community attitudes towards it?

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<sup>23</sup> Some possible examples: legitimacy of PLHA organizations, leadership, sustainability due to illness, lack of capacity, resistance to the involvement by other stakeholders and communities, lack of evidence on value of PLHIV, prevailing stigma and discrimination, public voice

- Is there a potential of institutional resistances from other stakeholders (like INGOs, donors, national AIDS program, policy makers circle) and why?
- How does capacity and skill level of positive community affect their ability to become involved?
- Do you think they have necessary skills and capacities?
- If no, which ones are needed for effective participation?
- Any other factors or challenges?
- How do you think these can be overcome?
- Is there anything you would like to add/issues you feel are important?