

***MANET+***  
**Malawi Network of People Living with HIV/AIDS**

**Voices for Equality and Dignity**

*Qualitative Research  
on Stigma and Discrimination Issues  
as they affect PLWHA in Malawi*

**Report**

18 July 2003  
Lilongwe, Malawi

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We hope that you will enjoy reading the report and appreciate our role in advocating for the respect of the rights and freedoms of people living with HIV/AIDS in Malawi.

MANET+

***The views, opinions and findings of the report are strictly those of the authors alone and do not necessarily represent the views, opinions or policies of USAID or the POLICY Project.***

# Acronyms and Abbreviations

AIDS	-	Acquired Immune Deficiency Syndrome
AMG	-	Alliance Member Group
ARV	-	Antiretroviral
BLM	-	Banja La Mtsogolo
CCAP	-	Church of Central Africa Presbyterian
DAT	-	Data Analysis Team
DCT	-	Data Collection Team
FGD	-	Focus group discussion
GNP+	-	Global Network of People Living with HIV/AIDS
HIV	-	Human Immunodeficiency Virus
IEC	-	Information, education, and communication
KASO	-	Kanengo AIDS Support Organisation
MACRO	-	Malawi AIDS Counselling and Resource Organisation
MANET+	-	Malawi Network of People Living with HIV and AIDS
MAT	-	MANET+ Advocacy Team
MDHS	-	Malawi Demographic and Health Survey
NAC	-	National AIDS Commission
NANO	-	Nkhotakota AIDS Support Organisation
NAPHAM	-	National Association of People Living with HIV and AIDS in Malawi
NGO	-	Nongovernmental organisation
PLWHA	-	People living with HIV/AIDS
PMTCT	-	Prevention of mother-to-child transmission
QRC	-	Qualitative Research Consultant
SG	-	Support group
STI	-	Sexually transmitted infection
UN	-	United Nations
UNAIDS	-	United Nations Programme on AIDS
VCT	-	Voluntary counselling and testing
WHO	-	World Health Organisation

# Executive Summary

Malawi has one of the highest national HIV prevalence rates in the world. The National AIDS Commission (NAC) estimates that the country has an adult (15-49) HIV prevalence rate of 15 percent. There are about one million Malawians who are HIV positive and over 265,000 reported cumulative cases of AIDS. By 1999, approximately 250 Malawians became infected with HIV on a daily basis and 40 percent of all new reported AIDS cases occurred in people under the age of 30.

Stigma and discrimination surrounding HIV/AIDS serve as barriers to the proper care, treatment, and support of people living with HIV/AIDS (PLWHA); discourage people from seeking voluntary counselling and testing (VCT) – an important aspect of prevention efforts and an entry point into care and the facilitation of positive living among PLWHA; and hinder the development of an enabling environment that promotes disclosure and living openly with HIV/AIDS. These results have consequences at the individual, family, community, and national levels as all efforts to prevent HIV transmission and mitigate the impacts of the HIV/AIDS epidemic are undermined by stigma and discrimination.

This qualitative research study is based on data collected through focus group discussions (FGDs) with PLWHA in Malawi. It is part of a broader National HIV/AIDS Advocacy Project being executed by the Malawi Network of People Living with HIV/AIDS (MANET+) in fulfilment of the objective of advocating for the integration of stigma and discrimination-related issues into the National HIV/AIDS Policy. It emphasises three areas: care, treatment, and support services by PLWHA; VCT services; and disclosure of sero-status (by self and others). This report also explores the importance of greater involvement of PLWHA. The purpose of the National HIV/AIDS Advocacy Project is to catalyse the formulation of supportive HIV/AIDS policies, laws, and regulations.

Some of the key findings regarding care, treatment, and support are that access to antiretroviral (ARV) therapy and treatment for opportunistic infections is very limited and, where available, cost is often a prohibiting factor; PLWHA must cope with negative attitudes from health care providers, particularly when they are seriously-ill and providers believe treatment will not work; and PLWHA face discrimination when trying to access financial resources that would help them lead productive lives and gain access to better care and support. Support groups are making significant contributions to prevention and care efforts, yet they often lack financial and human resource capacity. Much of their work is done on a voluntary basis by PLWHA themselves.

In terms of VCT, FGD participants identified some situations understood or portrayed as involving VCT but where the HIV testing has been mandatory; for example, as a prerequisite for eligibility for a scholarship, employment, acquiring insurance policies or

marriage officiating in some denominations. These requirements go against the intended “voluntary” nature of counselling and testing.

Another concern raised by participants is the lack of post-test counselling and services, such as referral networks and access to support groups. Where VCT services are available, they are often hampered by lack of material resources (e.g., rapid test kits and other technology) and human resources (e.g., adequate supply of properly trained staff). The FGD respondents also perceived the long waiting periods at testing centres as leading to stigmatisation by onlookers who sometimes question one’s presence at a VCT centre. As a result, some VCT centre clients experience stigma and discrimination from others because they are seen attempting to access VCT services.

Disclosure of HIV status raises several issues, including the right of PLWHA to control their own personal information and their right to confidentiality and privacy. Unfortunately, in a climate of stigma and silence, FGD participants noted that there might be few obvious advantages to go for VCT or to disclose one’s status. Disclosure can negatively affect a person’s family and personal relationships, as well as educational, occupational, and financial opportunities. Orphans and children affected by HIV/AIDS, the participants report, are often denied or lack access to needed educational, nutritional, and emotional support – increasing their own vulnerability.

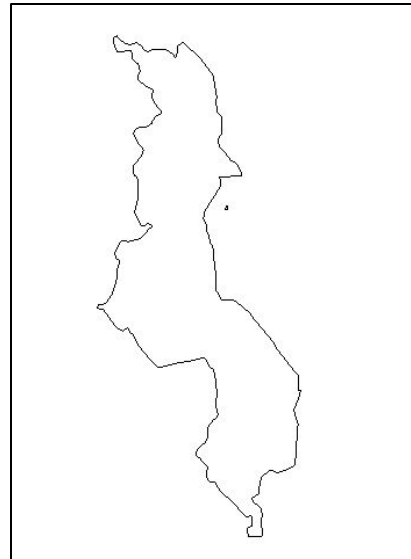
Based on these findings, the Government of Malawi, in collaboration with NGOs and PLWHA support groups, must take steps to reduce stigma and discrimination and to build the capacity of PLWHA to participate, in a meaningful way, in policy and programme development, implementation, and evaluation. These steps, in addition to the adoption of the other recommendations presented in the full report, would go a long way in helping to move Malawi toward compliance with the ideals enshrined in the United Nations Declaration of Commitment on HIV/AIDS, of which Malawi is a signatory, and other principles contained in the Constitution of Malawi. They would also contribute to the success of efforts to prevent the spread of HIV/AIDS, improve care and support, and mitigate the impacts of the epidemic.

# Section 1: Introduction

## 1.1 Background on the HIV/AIDS Epidemic in Malawi

Globally, the HIV/AIDS pandemic continues to spread. UNAIDS and WHO estimate that over 40 million people were living with HIV/AIDS and more than 20 million had lost their lives to AIDS by 2001 (UNAIDS, 2002). Countries in the sub-Saharan Africa region, where Malawi is situated, are the ones most affected by the pandemic. This region comprises only 10 percent of the world's population, yet is home to 80 percent of the total world HIV infections and AIDS cases. Given the 7–10 year lag between HIV infection and the development of AIDS, the worst levels of mortality have not been reached in many of these countries (Hunter, 2001). Mortality levels are projected to plateau in about another 10 years, but will continue at high levels for another decade. In this region, countries have limited capacity for HIV/AIDS prevention and care programmes, let alone access to drugs and other forms of treatment.

Malawi has one of the highest national HIV prevalence rates in the world, estimated at 15 percent among adults 15-49 years of age (NAC, 2001). The epidemic has been characterized by continuous high HIV prevalence, especially among youth; high HIV/AIDS morbidity and mortality rates; increasing mother-to-child transmission of HIV; an increasing number of destitute orphans, child-headed households, and other vulnerable children; and increasing absenteeism and attrition at the workplace (UNAIDS, 2001). The dominant mode of transmission is heterosexual contact, which accounts for 90 percent of HIV infections in the country. Statistics from the NAC reveal that there are about one million Malawians who are HIV positive and over 265,000 reported cumulative AIDS cases.



Socially, Malawi has experienced denial and silence about HIV and AIDS. Stigma and discrimination are rampant, making it difficult for people living with HIV/AIDS (PLWHA) to seek and access medical, psychosocial, and spiritual services. The epidemic has contributed to a rise in illnesses and deaths, which has caused a steady increase in the number of orphans. This has also severely affected the education sector – which is critical for Malawi's national development. Economically, the country has registered acute declines in productivity. Agriculture, the backbone of Malawi's economy, has been negatively affected by the epidemic owing to the loss of the vital human resources to HIV/AIDS. At the household level, the epidemic has led to a higher number of child-headed families. There has also been an increase in the number of single parents. The burden of morbidity on health care facilities is evidenced from estimates and



anecdotal reports of AIDS patients occupying around 60 percent of hospital beds (UNAIDS, 2001).

*“The future course of the Malawi AIDS epidemic depends on a number of important variables, including the level of public awareness about HIV/AIDS, the level and pattern of risk related behaviors, access to high quality services for sexually transmitted infections, and provision of HIV testing and counseling. The impact of AIDS is now affecting all sectors of the Malawian society, and the nation’s response needs to be matched with multisectoral strategies and interventions.”*

National Statistical Office (NSO), 2000

## 1.2 Terms of Reference

This qualitative research is part of a broader National HIV/AIDS Advocacy Project being executed by the Malawi Network of People Living with HIV/AIDS (MANET+) in fulfilment of the objective of advocating for the integration of stigma and discrimination-related issues in the National HIV/AIDS Policy, with an emphasis on three areas: voluntary counselling and testing (VCT); disclosure of sero-status (by self and others); and access to care, treatment, and support services by PLWHA. This report also explores the importance of greater involvement of PLWHA. The purpose of the National HIV/AIDS Advocacy Project is to catalyse the formulation of supportive HIV/AIDS policies, laws, and regulations. These, it is hoped, will protect the rights and freedoms of PLWHA in the country from human rights violations in the three focus areas described above. Box 1 outlines the qualitative research project’s scope of work.

### Box 1. Scope of Work

- Review 1998, 1999, and 2000 PLWHA survey findings by MANET+ to identify any other issues;
- Develop a focus group discussion (FGD) guide and procedures in collaboration with the Project Manager;
- Conduct training for the Data Collection Team (DCT) on how to conduct FGDs;
- Carry out the FGD field test in Lilongwe and revise guide as necessary;
- Manage the process of data collection through FGDs;
- Conduct orientation in data coding and analysis;
- Facilitate the transcription of FGD tapes and translation into English;
- Code and analyse data collected together with the Data Analysis Team (DAT), identifying and describing issues and problems that require policy formulation, review, or development;
- Provide policy recommendations in the three focus areas (e.g., VCT, disclosure, and access to care, treatment, and support services);
- Suggest draft policy statements based on the policy recommendations;
- Compile a draft report and disseminate it to the MANET+ Advocacy Team (MAT) and alliance member groups (AMG) for review; and
- Incorporate MAT and AMG comments into the final report to stakeholders.

## **1.3 Methodology**

Focus group discussions (FGDs) served as the primary methodology for data collection for this project. Participants included PLWHA who were members of their respective AIDS support groups (SGs) in the four selected sites (as described in Section 1.4). The participatory and exploratory nature of the FGD methodology merited its selection. It offered PLWHA an opportunity for appreciative reflection, analysis, action, and learning regarding issues pertaining to stigma and discrimination and their general experience with positive living.

With the guidance of a semi-structured FGD guide, facilitators posed open-ended questions to explore the views of PLWHA in Malawi regarding stigma and discrimination as it relates to care, treatment, and support services; VCT; and disclosure of sero-status. Two FGDs were conducted in each site, one for men and another for women with each one facilitated by male and female facilitators and note takers, respectively. This was done to identify possible gender-related variations that would otherwise fail to emerge in a mixed focus group.

Discussions were recorded on tapes and in notebooks to ensure that data were not lost. Information contained in the tapes was transcribed, translated, coded, and analysed by the Qualitative Research Consultant (QRC) with the help of research assistants who were also involved with data collection in August 2002. This option was taken in order to broaden our insights for data analysis.

## **1.4 Sample Frame**

The FGDs were conducted between PLWHA from SGs in four districts (one pre-test site and three post-test sites), namely, Phalombe in the southern region; Nkhota-kota and Lilongwe in the central region; and Mzimba district in the northern region. Lilongwe was the pre-test site. Selection criteria included the availability of a MANET+ network member SGs with PLWHA who are open about their HIV-positive sero-status in the district; the presence of other structures actively involved with HIV/AIDS-related issues; the accessibility of the sites; and regional balance, meaning one district in each of the three regions of the country (plus the pre-test site). The other condition considered was that at least one member from the districts selected had participated in the Advocacy Skills Training that was conducted by MANET+ with support from the USAID-funded POLICY Project in October 2001.

## **1.5 Limitations**

The criteria used to select the study sites does not have a scientific basis in that it did not specifically consider socio-cultural, economic, and political factors that may normally have a bearing on the susceptibility of PLWHA to stigma and discrimination. For MANET+ to adequately address these issues would have required more time and resources than were available for this project. One of MANET+'s objectives for this

project was to provide timely input based on the results of this research into the national HIV/AIDS policy formulation process. This requirement placed the activity on a tight timetable. Limited time and financial resources also required that the number of study sites be reduced from the original eight to four (one field test and three study sites). Because of these issues, the socio-cultural, economic, and political factors are, therefore, not a specific focus of the analysis presented in this report.

## **1.6 The Concepts of Stigma and Discrimination**

Stigma and discrimination are very elusive terms to comprehend, particularly in vernacular. It is, however, widely agreed that PLWHA experience different forms of stigma and discrimination as a result of their sero-positive status.

Some people have defined stigmatization as an act of identifying, labeling, or attributing undesirable qualities to those who are perceived as being “shamefully different” and deviant from the social ideal. It is an attribute that is significantly discrediting and used to set the affected persons or groups apart from the normalized social order (separation meaning devaluation). Discrimination refers to any distinction, exclusion, or preference that is based on any ground such as race, HIV sero-status, gender, sexual orientation, age, and so on. Discrimination has the purpose or effect of nullifying or impairing the recognition, enjoyment, or exercise of all rights and freedoms by all persons on an equal footing. Such acts come in the form of sanctions, blame, harassment, and violence based on, for example, infection or association with HIV/AIDS.

PLWHA interviewed during the study perceive the concept of stigma with another quite interesting dimension based on the experiences they encounter. They strongly believe that the worry and anxiety associated with sero-positive status, which they regularly go through, is a form of stigma – an internally directed stigma, which is in turn reinforced by others exhibiting stigmatising attitudes and behaviors directed towards them. FGD participants reported feeling or experiencing this stigma before one is attended to at a VCT centre, when one is made to wait for long periods before his or her HIV test results are released, or when people associate one’s appearance at a VCT centre with HIV-positive status.

Many Malawians fear and experience HIV-related stigma and discrimination, which in turn limits their ability and willingness to seek VCT and learn their sero-status. They are reluctant to openly disclose their HIV status because of the perceived and real threats of stigma and discrimination. At the same time, it is not uncommon for those with access to information regarding others’ sero-status to disclose this information, failing to respect people’s right to privacy and confidentiality. This environment also affects Malawians’ willingness to seek proper care, treatment, and support services when they are ill.

Stigma and discrimination function, quite literally, at the point of intersection between culture, power and difference – and it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and discrimination not merely as an isolated phenomenon, or expressions of individual

attitudes or of cultural values, but as central to the constitution of the social order (Parker and Aggleton, 2000). Stigma and discrimination are linked to inequalities of power, make social inequalities seem reasonable, create a social hierarchy, and create or reinforces social exclusion. From the beginning, of the HIV/AIDS epidemic, a series of powerful metaphors were mobilized around the disease, which serve to reinforce and legitimize stigmatization. These include AIDS as death; AIDS as horror (in which infected people are demonized and feared); AIDS as punishment (e.g., for immoral behavior); AIDS as crime (in relation to innocent and guilty victims); and AIDS as war (e.g. in relation to a virus which needs to be combated), among others. Together with the wide spread belief that AIDS is shameful, these various metaphors and linguistic maneuvers have constructed a series of “ready made” (but subjective and socially-constructed) explanations that provide a powerful basis for stigmatizing and discriminatory responses.

As a result of stigma and discrimination associated with HIV/AIDS, a number of challenges have arisen:

- There is denial of HIV status – individually, socially, and nationally, leading to delayed treatment, care and support.
- There is fear, anxiety, depression, apathy, anger, suicidal attempts, and revengeful behaviours.
- The social integration process for PLWHA is disrupted.
- Certain groups are also marginalized.
- Old prejudices have resurfaced and new resentment towards HIV-positive individuals, households, or community members has emerged.

The undesirable differences and spoiled identities that HIV/AIDS stigma causes do not naturally exist, they are created by individuals and by communities. HIV/AIDS-related stigma simply builds upon and reinforces existing prejudices. It creates and is reinforced by social inequality. Due to stigma and discrimination the rights of PLWHA and their families are frequently violated. Every individual, organization, community, and state has an obligation to respect and protect the rights of people infected or affected by HIV/AIDS.

Reducing stigma and discrimination will therefore empower people (particularly PLWHA) to recognize the benefit of the various services and, therefore, be more willing to seek voluntary HIV counseling and testing; access care, treatment, and support services; and disclose their sero-status.

## 1.7 Understanding PLWHA

As noted above, statistics from NAC reveal that there are about one million Malawians who are HIV positive and over 265,000 reported cumulative cases of AIDS. By 1999, approximately, 250 Malawians became infected with HIV on a daily basis and 40 percent of all new reported AIDS cases occurred in people under the age of 30. Of these, almost 60 percent occurred in women and girls. The majority of new cases reported were women under the age of 30. Among newly infected persons ages 15 to 19 years old, female cases outnumbered males by almost 4 to 1. Among those ages 20 to 24 years old, female cases outnumbered males by almost 3 times. However, after age 30, new cases of HIV infection have been primarily found among males, with more than 60 percent of all new infections reported occurring in men. Projections have shown that AIDS will account for 75 percent of all deaths among the most productive age group, those who are 15 to 49 years old, in the urban areas by year 2010 (UNAIDS, 2001).

PLWHA can be divided into two categories, namely: those who have disclosed their seropositive status and those who have not disclosed, albeit, for various personal reasons. PLWHA live among us. Some may only be carrying the virus and are still very healthy, leading a productive life. Others may have developed AIDS and are suffering from opportunistic infections. They are family members, farmers, youths, professionals, employees, politicians, businesspersons, clergy, and so on. They are our parents, sons, daughters, spouses, uncles, aunts, nephews, and nieces. In other words, everyone, in one way or another, is affected by the HIV epidemic (HIV and Development Regional Project, 1994). We will see someone we love die, we will have to care for a person with AIDS, and we will see children left without parents. In this sense, we are all living with HIV/AIDS.

Hence, like every noble citizen of Malawi, PLWHA are equally entitled to basic human rights as enshrined in the Constitution of Malawi. Some of those entitlements include:

- The right to liberty, security, and freedom of movement;
- The right to freedom from inhumane or degrading treatment;
- The right to equal protection of the law;
- The right to privacy;
- The right to marry or have relationships and children;
- The right to equal access to health care;
- The right to education;
- The right to shelter, social security, and housing;
- The right to work and security; and
- The right to life.

PLWHA are not sitting idle and helpless in the face of the epidemic in Malawi. They are undertaking extensive work, most of it on voluntary basis, to mitigate the impacts of HIV/AIDS. Through community-based support organisations in the country and a host of other bodies, they are undertaking such activities as:

- HIV/AIDS outreach education programmes;
- Group therapy meetings to promote positive living among themselves;
- Provision of counseling services;
- Home-based care and support;
- Information, education, and communication (IEC) activities;
- Condom distribution;
- Managing income-generating activities and revolving drug funds;
- Care for orphans and other children affected by HIV/AIDS;
- Formation and management of anti- AIDS organisations;
- Managing resource centres;
- Performing advocacy work on HIV/AIDS issues; and
- Mobilizing resources.

The contribution of PLWHA to HIV/AIDS mitigation work is crucial to the control of the epidemic as they are a living testimony of the epidemic to all the people of Malawi. Therefore, any tendency towards stigmatization, discrimination, or failure to respect their human dignity must be absolutely rejected. Such negative attitudes and actions towards PLWHA undermine all efforts to limit the transmission of the virus and reduce its impact on individuals, families, and communities.

## Section 2: Care, Treatment, and Support Services for PLWHA

### 2.1 Overview

Care, treatment, and support for PLWHA takes on many forms. Ideally, it involves palliative care for lesser symptoms; prophylaxis or preventive treatment for the opportunistic infections that often accompany HIV/AIDS (see Box 2); treatment for opportunistic infections when they do occur; antiretroviral (ARV) therapy to reduce viral load and improve quality of life; and ARV therapies (e.g., Nevirapine) for the prevention of mother-to-child transmission (PMTCT) of HIV. There is as yet no cure and no vaccine for HIV/AIDS, which contributes to the stigma and fear surrounding the disease. The ARVs and other drugs that have been developed for treatment are largely unavailable and unaffordable for most PLWHA in developing countries (as are most drugs, in general) (Hunter, 2001).

Important supplements to these efforts include programs that address financial and legal support needs, encourage capacity development and positive living, and meet emotional and spiritual needs. A comprehensive approach that comprises the types of programs and services noted here would go a long way in providing support for PLWHA and mitigating the impacts of the epidemic at the individual, family, community, and national levels. As will be explored in Section 2.2, PLWHA face several barriers when trying to access care, treatment, and support services.

#### Box 2. Understanding HIV and AIDS

AIDS stands for acquired immune deficiency syndrome. It is a disease caused by the human immunodeficiency virus or HIV. The virus erodes the body's immune system over time, exposing the infected person to a range of lung diseases, cancers, opportunistic infections (such as tuberculosis), wasting, rashes, sores, and other painful and debilitating conditions. A person is said to have developed AIDS when there has been significant deterioration of the immune system and the person has been affected by one of the AIDS-defining illnesses. Eventually, AIDS-related illnesses overpower the body's ability to fight back, causing physical – and sometimes mental – ruin and death.

A person may be infected with HIV for a considerable time without showing any symptoms. There is often a lengthy incubation period from initial infection with HIV to the development of AIDS – typically about 8–10 years. A person may live as long as 20 years with HIV infection, while others may develop AIDS within two or three years and die soon after. Since symptoms may not appear for a number of years, many people do not know that they are infected with HIV. During all of this time, however, people are capable of transmitting the virus.

The primary mode of HIV transmission is heterosexual contact (e.g., between spouses, between sex workers and their clients). Other modes of transmission include intravenous drug use, mother-to-child transmission, forced sex (e.g., rape or defilement without consent), and the use of blood or blood products that have not been properly screened.

The course of the disease in poor societies parallels its course in the individual. HIV/AIDS is one of the most serious threats to human health and life that the world

community has ever had to face. Following below are some of the factors that contribute to the challenge of addressing the HIV/AIDS epidemic, particularly in Malawi:

- Poverty, poor nutrition, and lack of clean water and safe sanitation.
- Interrelationships with other diseases worsen the impact of HIV/AIDS.
- Limited access to health and social services.
- Confidential VCT services are not generally available in many parts of the country. Where they are available, people cannot afford them, do not know why it is important to be tested for HIV, or fear discrimination after they are tested. As a consequence, many PLWHA unwittingly transmit the virus because they do not know they are HIV positive.
- HIV transmission is primarily through heterosexual contact, which means it can become “generalised” or spread from groups that practise high-risk behaviours to the population at-large.
- Additionally, this means that HIV is transmitted through behaviour that most people do not view as risky behaviour. While the urge for physical intimacy is fundamental in human beings, transmission is aggravated by historical factors and cultural traditions that make it hard for women and men to protect themselves. Such traditions include:
  - Widow and widower inheritance;
  - *Fisi* – hiring of an emissary to have sex with a woman who fails to conceive by another man; or have sex with a young girl who has just undergone puberty phase to unveil her maturity; or furthermore, have sex with a woman who has just been widowed to exorcise evil spirits (bad omen);
  - Cases were cited where older women who are not sexually active and can no longer bear children lose to a younger bride. This calls for urgent need to invest in education for men and women as marriage laws are also being revisited.
  - Heavy alcohol consumption increases the chance of not exercising sound judgment and, as a result, people may be more likely to engage in unprotected sex.
  - Men’s desire to prove manhood and virility by having sex with multiple partners.
  - Fraudulent use of sex as a treatment therapy for women seeking medical help from traditional healers.
  - Use of non-sterile cutting and piercing tools by a number of practitioners and victims of sorcery by traditional healers to heal the patients, remove potential damage to patients’ lives, and dispense the practitioners’ prowess in sorcery.



- Men can indulge in sex without their wives' consent because married women are expected to be submissive to their husbands as they are considered junior partners in marriage. Additionally, it is less socially acceptable for women to be unfaithful to their husbands than vice versa.
- Another important means of transmission is from an infected mother to her child (either while in the womb, during delivery, or through breastfeeding following birth). The means for preventing mother-to-child transmission are not likely to be widely available for some years to come, given the poor state of Malawi's health care system.
- The period between infection with HIV and development of AIDS can last many years. In the absence of widespread HIV testing, this means that infected people who do not know their status can pass the infection on to many partners.
- There is no cure. Prevention depends on changing behaviour, which in part depends on the surrounding social, economic, and political conditions. (Hunter, 2001.)

With the above factors in perspective, care, treatment, and support services for PLWHA are faced with this challenge: to strike a balance between prevention and care/mitigation efforts with neither one overriding the other. In fact, policymakers and program planners must come to embrace a “continuum of care” perspective that appreciates the inherent links between successful prevention activities and high quality care and support programs.

## **2.2 Findings**

During the qualitative research study, FGD participants highlighted several stigma and discrimination-related issues, for which they recommended various actions.

### ***Home-Based Care***

Respondents felt that government and mission hospitals take different approaches in caring for the chronically ill. They observed that mission hospitals generally provide care to chronically ill patients within a hospital setting for longer periods than do government hospitals, while government hospitals seem to discharge such patients to home-based care (HBC) programmes, where they exist, at the earliest opportunity. They noted, however, that few of these HBC programmes are adequately supported to provide appropriate care. Respondents felt that mission hospital HBC programmes were of much better quality than those of government hospitals; participants in all the study sites viewed government hospitals as using HBC programmes as “dumping grounds” for people living with AIDS.

At the community/home level, HBC programmes/providers face problems with access to/availability of resources, e.g., human (skills, willingness, attitude) and material (financial, equipment, structures, information), for the provision of proper care to patients. FGD respondents highlighted problems with HBC programmes such as lack of adequately stocked HBC kits, lack of transportation for seriously ill patients needing

treatment at health facilities, and poor or non-existent referral systems between health facilities and the communities they serve. An Umoyo Network assessment of several HBC programmes in Malawi supports these observations (Marum et al., 2000). FGD respondents indicated that the poor state of HBC programmes has resulted in some health care providers and relatives rendering inadequate care, which has likely led to the premature deaths of some PLWHA. Respondents acknowledged that home-based care (HBC) has an essential role to play in the care, treatment and support of PLWHA, but not if the programmes are poorly supported.

Interviewee comments indicate that provider attitudes and misconceptions about HIV/AIDS have influenced the care provided to PLWHA and impacted their overall well being. Respondents noted that some HBC providers perceive AIDS patients as sinners and deserving punishment from God, which has left some HBC patients feeling rejected and discriminated against. Similarly, some participants reported that their own relatives have not wanted to eat together with them, borrow any of their belongings, or simply visit them for fear of contracting the virus. One respondent who travelled all the way from Rumphi to attend the FGD in Mzuzu alluded to this:

*“I used to host a lot of relatives in my home before I publicly declared my sero-positive status. Now that I have disclosed my status, most of them have either completely stopped visiting my family or have reduced the number of visits. They have even advised their children not to associate with my children for fear of contracting the virus.”*

### **Access to and Quality of Treatment**

Treatment services for PLWHA are undermined by a general lack of ARVs and essential drugs for treatment of opportunistic infections and minor illnesses, particularly in government health facilities. In such a situation, PLWHA are left to imagine where they can access such treatment. While the drugs may be available in mission health facilities, shops, and privately owned pharmacies, most PLWHA do not possess the financial resources to purchase them. Such a situation increases chances for anxiety and worry for PLWHA because they cannot take care of essential needs, including treatment, food, and education, among other things.

Currently, ARVs cost slightly over K2, 500 (equivalent to about US\$28.00)<sup>1</sup> per month in government health facilities. At the same time, average per capita income for Malawi is US\$1.00 per day (or US\$30.00 per month). All of the PLWHA interviewed as part of this study said they were not on ARVs because they could not afford the cost. Participants reasoned that if such drugs were made readily accessible, this would act as an incentive for people to go for VCT services, disclose their sero-positive status and access treatment.

Respondents argued that PLWHA in SGs contribute immensely to HIV prevention and AIDS impact mitigation activities in the country, and that since this work is volunteer and

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<sup>1</sup> At the prevailing exchange rate of K90 to US\$1.

the members are largely poor, the provision of free ARVs would be a reasonable compensation for their efforts. They stressed that the high cost of the drugs was an unfair barrier and perpetuated discrimination against PLWHA.

### ***Prevention of Mother-to-Child Transmission***

Access to PMTCT services is extremely limited in Malawi, but most especially in rural areas. While respondents appreciated that PMTCT programs were being piloted in the country, they noted that the government programs were located in urban areas, and the few operating in rural areas were run by mission hospitals and NGOs. They said that the government should be operating pilots in rural areas as well. Participants felt that the lack of government programs in rural areas was a sign of discrimination against people living in those areas. Furthermore, they felt that the government should give PMTCT a higher priority. They viewed the lack of PMTCT services as a human rights issue because all Malawians alike (urban and rural, HIV negative and positive) have the right to healthcare, and so the government, as key custodian of health services in Malawi, should do more to make the service adequately available throughout the country.

On a different note, respondents made the observation that provision of PMTCT services seems to be in conflict with the message of abstinence. Earlier messages emphasized that PLWHA should refrain from unprotected sex. On the other hand, FGD respondents seemed to assume that PMTCT encourages unprotected sex because the ultimate goal of the intervention is to assist an HIV positive woman to give birth to an HIV negative child. While questioning the conflict, the respondents were also aware of the desire of some of their SG members, particularly young men and women, to have children. No clear position was established on the issue during the discussions. As noted earlier in this document, the right of all people (including PLWHA) to marry and have children is enshrined in the Bill of Rights of the Constitution of Malawi. This further highlights the complexity of this issue.

### ***Attitudes of Health Care Personnel***

FGD participants said that PLWHA frequently must contend with poor attitudes and quality of care from medical providers. Participants cited examples where a patient was deliberately denied proper medication and care when the doctors felt the life of the patient was not recoverable. They said this was particularly common when doctors knew that the patient was a person living with HIV/AIDS. In the words of one of the respondents:

*“Sometimes when health workers realise that a patient on admission is HIV positive and is seriously sick, they deliberately deny the patient strong medication, preferring instead to provide panadol and other pain killers even when proper drugs are available. In worse cases, such patients are simply discharged and referred to home-based care programmes, which I feel are regarded as a dumping ground.”*

One consequence of this lack of proper care is that the patient, upon realizing that he/she is being neglected, loses hope, thereby potentially accelerating his or her death.

Provider burnout due to work overload and lack of proper supplies (e.g., basic medicines, drugs for opportunistic infections, cotton wool, and protective equipment) may be one reason for this negative attitude among some providers towards patients with HIV/AIDS. Respondents suggested that “Care of the Carers” training and services could help improve health care staff attitudes towards PLWHA and other chronically ill patients, but noted that, unfortunately, these were not widely available. The lack of programs addressing caregiver needs hinders efforts to improve care, treatment, and support services for PLWHA. Such programs not only help caregivers develop a greater understanding and appreciation of the needs and experiences of PLWHA trying to live positively with the virus but, just as importantly, assist caregivers in acknowledging and dealing with their own psychosocial support needs in providing care under such challenging conditions.

### ***Examples of High Quality Care***

On a lighter note, respondents showed appreciation for the love and care provided by some health personnel, particularly when PLWHA identify themselves as being HIV positive. Certain medical personnel in some health facilities have unofficially developed a deliberate practice of giving high quality treatment to PLWHA who come to seek treatment services. One FGD participant at Mzuzu NAPHAM cited the example of one medical doctor at Mzuzu Central Hospital:

*“He is one medical practitioner who handles us with a lot of care and love. The moment he recognises us at the hospital, he provides us with very good treatment. Even when he meets you informally in the streets, he shows interest in finding out about your health.”*

However, the same respondents observed that such conduct is not appreciated by some fellow medical staff and patients who make disparaging remarks concerning the PLWHA and their caring medical providers. Examples of such comments include:

*“Who told them to acquire HIV?” “Who are you to deserve preferential treatment?” “They must be receiving a monthly allowance for treating them.”*

Respondents explained that HIV-positive patients find these murmurings of disapproval disheartening and stigmatising. They recommended that the national HIV/AIDS policy should include a special policy statement that encourages medical personnel nationwide to recognize the need to provide quality treatment to those that have identified themselves in health facilities as people living with HIV/AIDS.

### ***Abuses by Traditional Healers and Health Care Personnel***

FGD participants reported cases where some traditional healers and medical personnel in hospitals practice professional deceit with intention to abuse patients, particularly women, sexually and otherwise. According to some respondents, some traditional healers prescribe a treatment therapy that requires the traditional healer or one of his relatives to have sex with the patient to exorcise evil spirits. Some of the study sites reported that some hospital health workers demand sexual, monetary, or other material favours in return for proper medication and care. Those PLWHA who cannot afford to succumb to these requirements are either not attended to or receive sub-standard services. In addition to the human rights violations of these demands, those who give in also run the risk of viral re-infection or transmission.

### ***Access to Financial Resources***

Respondents report lacking access to financial resources, particularly loans, by money lending organisations that block their participation in credit groups – structures through which credit is accessed using social collateral by low-income earners. They said that members of credit groups either do not allow PLWHA to join their groups or deny them access to credit while they are members for fear of increasing the risk of group credit liability through early death. This fear seems to be based on misinformation because being HIV positive is different from having AIDS, and those living with HIV can lead productive lives for a number of years. Unfortunately, this fact does not seem to be well understood or appreciated. As a consequence, PLWHA are denied access to loans, undermining their chances of improving their incomes and accessing better care, treatment, and support services. If they cannot produce enough food due to lack of inputs, if they cannot acquire appropriate technology, if they cannot indulge in petty trading, then they cannot enhance their nutritional status or access ARVs and other essential drugs to live a healthy and productive life.

### ***Support Groups and PLWHA Involvement***

SGs are actively involved in providing care, treatment, and support services in the community, and yet they lack important human resource capacity. PLWHA serving as SG volunteers are overloaded with this work and, yet many people in the wider community and society are making minimal contribution to HIV/AIDS prevention and mitigation initiatives. The heavy workload takes away the necessary rest and feeling of inclusiveness needed by PLWHA for a healthy and productive life. Respondents suggested that professionals and other highly educated people are less involved in these efforts because they are less willing to disclose their HIV-positive status. Similarly, participants said that youth participation in SGs is also limited although some study sites reported that concerns of the youth were being addressed. They cited examples such as condoms being available in health facilities but they did not know if and how the needs of young people are being addressed in national policies and programmes.

Participants said that while they consider the involvement of PLWHA in HIV/AIDS prevention and mitigation initiatives as essential, they expressed worry that the volunteer work of caring for AIDS patients is steadily becoming the exclusive responsibility of PLWHA in their communities, stressing that other people also have a contribution to make.

### **Box 3. Summary of Findings Relating to Care, Treatment, and Support**

- Home-based care is essential for improving care, treatment, and support for PLWHA. However, government involvement of the support and provision of these services is limited. In addition, home-based care runs the risk of becoming a “dumping ground” for chronically ill patients and it faces several resource shortages (e.g., home-based care kits, transportation, referral systems).
- Availability of ARVs, PMTCT drugs, and treatment for opportunistic infections is limited, particularly in rural areas. Where they are available, high cost is often a barrier to access. None of the participants in this study were taking ARV drugs.
- FGD participants said that PLWHA must cope with poor attitudes from health care providers. They are often denied proper treatment and medication, particularly when it is perceived that the patient’s condition is too severe to be effective. This treatment causes PLWHA to further lose hope. Some factors that may contribute to negative attitudes among providers are heavy workload and a lack of training or “care of the carers” services that could bridge important knowledge and information gaps regarding HIV/AIDS and PLWHA.
- PLWHA also report instances of abuse from health care professional and traditional healers who may demand monetary and other material favours, or who recommend fraudulent treatment options (e.g., that sex with the traditional healer can rid the person of their evils).
- In those cases where PLWHA do report receiving high quality care, this is often followed by resentment and suspicion from other health care providers and patients, who suggest that those providing appropriate care are receiving an additional payment or bribe to do so.
- PLWHA face discrimination in trying to access financial resources – which are essential to the ability of PLWHA provide for their education, treatment, nutrition, and family support. For example, they are often not allowed to join or participate in credit groups because it is believed they will die early – thus being unable to repay the loan and increasing the group’s liability.
- Members of PLWHA SGs make important contributions to HIV/AIDS prevention, care, and mitigation efforts in Malawi. However, this is done on a voluntary basis and SGs often lack external financial support. As many professionals and other highly educated people are less willing to come forward about their HIV-positive status, SGs also lack important human resource capacity. In addition, the participation of youth in SGs is limited and it is not clear how their needs are being addressed in national policies and programmes.
- PLWHA are concerned that the burden of volunteer community AIDS care is becoming more and more the domain of PLWHA. While meaningful involvement of PLWHA in the programmes that affect their lives is important, it is also important for others in the community and society to contribute to prevention and mitigation efforts.

## 2.3 Recommendations

### ***Policy Recommendations***

While appreciating that Malawi has a National Strategic Framework on HIV/AIDS for 2000–2004, there currently are no national policies and laws that protect PLWHA specifically from stigma and discrimination. It is important, therefore, that comprehensive and supportive national HIV/AIDS policies, laws, and regulations are formulated and put in practice to bridge the gap. Based on FGD responses, the following recommendations are put forth:

1. A special policy statement should be made as part of a code of best practices to guide and encourage medical personnel and traditional healers nationwide to recognise the need to provide proper treatment to PLWHA who have disclosed their HIV sero-status and identified themselves as such in health facilities.
2. It should be made an offence for medical personnel and traditional healers to deliberately deny proper treatment and care for PLWHA, if they are proved to have done so beyond reasonable doubt.
3. It should be made an offence for traditional healers to make false claims of a cure for AIDS, if they are proved beyond reasonable doubt to have performed such acts.
4. The Government should make a provision for the Legal Aid Department to provide specialised legal representation for PLWHA with meagre resources, due to the complex and specialized nature of many HIV/AIDS-related legal cases, including those dealing with inheritance and employment hiring and dismissal issues, and the fact that HIV-infected persons attempting to bring legal cases may die from their condition before their cases are ever heard in court, much less settled.
5. The Government should consider bearing the entire cost of ARVs, including PMTCT services, for PLWHA who cannot afford to pay the high cost of these treatment options, and who have also publicly disclosed their status.
6. The annual national budget for health should make a provision that will guarantee adequate resources for provision of ARVs and treatment of opportunistic infections and minor illnesses, with particular reference to PLWHA. Such a provision will, apart from increasing access to drugs for PLWHA, also act as an incentive for PLWHA to disclose their HIV sero-positive status and make a contribution to society by living positively with the virus.
7. In particular, government should adopt a policy to ensure that ARVs and PMTCT services are free and available in all health facilities in *both* rural and urban areas of the country. Introduction of mobile PMTCT services may be an option if it is

possible in this regard. Proper distribution and management mechanisms will, however, be required to prevent abuse of the services to make sure that those who benefit from the service are HIV positive and meet medical and financial eligibility qualifications.

8. Government should adopt a policy that encourages the creation of youth-friendly services to improve young PLWHA access to reproductive health services in health facilities in the country.
9. Government should enact legislation to expand free education and other necessities for all orphans and vulnerable children. Such a programme should continue up to the university and vocational skills training levels.

### ***Programme Recommendations***

1. “Care of the Carers” services should be introduced for medical personnel and traditional healers to fill the existing information and knowledge gaps in dealing with PLWHA. Such services will also contribute to the transformation of the attitudes of care and treatment providers toward PLWHA.
2. Deliberate strategies should be developed to reduce the imbalance that exists between the voluntary contributions made by PLWHA towards HIV prevention and mitigation efforts and those contributions being made by other players, while at the same time considering the limit to which PLWHA can sustain their voluntary contribution in view of their status.
3. Activities should be undertaken to develop the capacity of PLWHA to access nutritious food by engaging them in productive ventures, which will improve their household incomes and, consequently, their nutritional status as a precursor to taking any medication. FGD participants contend that drugs will not work effectively without proper food, which they cannot afford unless empowered economically.
4. Government, NGOs, and others should undertake comprehensive treatment and care IEC campaigns alongside provision of ARVs and PMTCT services targeting PLWHA to fill information and knowledge gaps regarding these services.
5. Government, NGOs, and others should extend information and education on care for PLWHA, children affected by HIV/AIDS, and their families to teachers, community care groups, churches, and the world of work so that they become knowledgeable and better positioned to provide necessary support.
6. Education and information on the rights of young PLWHA to reproductive health services should be developed targeting care providers and beneficiaries.



7. Government entities should play an expanded role in HBC provision to ensure PLWHA access to high quality care, treatment, and support services in both rural and urban areas. In particular, it is necessary to develop a viable schedule to equip HBC kits regularly, supported by proper monitoring and supervisory mechanisms by HBC nurses. A strong link between health facilities and PLWHA support is another crucial element of improved HBC services.
8. There is need to provide clear information and intensive education regarding messages about PMTCT (which is seen to involve unprotected sex) and those about PLWHA abstaining from unprotected sex. This must be done in the context of the right of PLWHA to marry and have children – otherwise it remains contradictory to the needs and wishes of most PLWHA and the messages disseminated by most SGs.
9. PLWHA SGs, in collaboration with the government and NGOs, must develop their capacity to mobilise and manage resources to effectively support HIV/AIDS prevention and mitigation initiatives.
10. There is need to promote positive living (prevention of infection and re-infection, early treatment, good nutrition, etc.).

## Section 3: Provision of VCT Services

### 3.1 Overview

The 2000 Malawi Demographic and Health Survey (NSO, 2001) found that 8.5 percent of women and 15.2 percent of men interviewed reported that they had taken an HIV test. The difference between men and women is most pronounced between the ages 25 to 29 years, whereby 23.7 percent of men and 10.6 percent of women had been tested. Having been tested at least once correlated closely with education and place of residence, with respondents with more formal education and those living in urban areas being more likely than their counterparts to have been tested.

FGD interviewees noted that growing numbers of people are seeking and using VCT services, especially at the Malawi AIDS Counselling and Resource Organisation (MACRO), an NGO with testing centres in the urban areas of Lilongwe, Blantyre, and Mzuzu. A respondent from NAPHAM Mzuzu reported anecdotally that at MACRO Mzuzu, the newest MACRO testing branch, over 100 clients were patronising its centre each business day. The MACRO *Annual Report 2000* reported that MACRO's Lilongwe and Blantyre branches were serving 1,000 clients per month each. The popularity of MACRO VCT services could be attributed to a number of factors, including:

- Ability to provide same day results in less than one hour with the introduction of whole-blood HIV rapid test kits;
- A major MACRO radio advertising campaign; and
- Information campaigns promoting VCT mounted countrywide by various organisations and individuals, including PLWHA organisations.

FGD participants stressed that VCT utilisation would increase if more people were oriented on the advantages of being tested and if VCT barriers were better addressed. They remarked that people are generally concerned about confidentiality and are not willing to wait long for results. Most FGD participants also identified long distance to test centres as a barrier to accessing VCT services. Currently, VCT facilities are confined to MACRO, four referral hospitals (Queen Elizabeth, Zomba, Lilongwe and Mzuzu), selected mission hospitals, and selected district hospitals, mostly in urban and semi-urban areas.

### 3.2 Findings

While FGD participants remarked on the high numbers of people accessing VCT services, especially at MACRO, they also cited several issues affecting the availability, quality and utilisation of VCT. These issues are explored in this section.

## **Limited Access and Resources**

Respondents said that many people, particularly in rural areas, would like to go for VCT but are unable to do so because the service is not available in the vicinity. They also reported of cases regarding hospitals where the services were supposedly available, but where the facilities lacked the necessary testing reagents or gave priority for their use to blood donors over VCT clients. As a result, prospective clients were denied a service which would have otherwise determined their sero-status and put their anxiety to rest. Respondents noted that positive results are rarely provided with a CD4 count.<sup>2</sup> Thus, clients who test positive remain anxious to know the level of their immunity so that they can make informed decisions about their health. FGD participants considered the limited access to VCT services in the country overall, and especially in rural areas, as well as the cases where other types of testing were accorded priority over VCT in terms of reagent use, as discriminatory. They said this, in turn, fuelled internal stigma in VCT seekers unable to get the service, especially in rural areas.

## **Counsellors**

The quality and adequacy of counselling services are important factors in reducing the impact of stigma and discrimination among VCT patrons in testing centres. High quality pre-test and post-test counselling services can also be a major determining factor to positive living by PLWHA. In general, respondents reported that counselling services among most VCT providers could be much improved. They identified the quality of counselling provided in hospitals as especially poor. FGD participants suggested that these counsellors are not skilled enough and, in most cases, not available on a full-time basis because they are committed to the delivery of other health services, unlike at MACRO.

Participants believed that health workers may not necessarily be the best counsellors, particularly in VCT, and yet hospitals do not exercise substantial flexibility to accommodate lay counsellors. The respondents suggested that hospitals employ PLWHA and others qualified to provide counselling services to VCT clients. They believed that PLWHA could make a significant contribution in this area because they have adequate time and are able to share their experiences and knowledge of living with HIV/AIDS. One respondent from NAPHAM Mzuzu suggests:

*“Counselling services in government health facilities are poor because workers are inadequate. They use Clinical Officers and other medical personnel to do counselling and yet they are also supposed to attend to seriously ill patients in wards and outpatient departments. As a result, they do not have enough time to attend to clients, hence counselling is rushed and ineffective.”*

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<sup>2</sup> A measure for level of immunity in the body.

According to the FGD participants, improved counselling – both in terms of staff time and skills – will increase people’s access to adequate and high quality services in all hospitals and health facilities in the country.

Participants reported that there is greater access to quality counselling services at MACRO than any other centre and, therefore, they would prefer to take tests there. Additionally, counsellors at MACRO are readily available on their working days.

However, in one rare case of questionable counselling services provided at MACRO Mzuzu, an HIV-positive pregnant woman was referred to NAPHAM Mzuzu to obtain reference papers recommending her to seek abortion at Banja La Mtsogolo (a family planning service provider) in early August 2002. A respondent from NAPHAM Mzuzu explains:

*“Last month, a counsellor based at MACRO referred an HIV-positive pregnant woman to Mzuzu NAPHAM on advice that she would be assisted with a referral letter to have her pregnancy terminated at Banja La Mtsogolo (BLM). In trying to persuade this woman not to go ahead with her plans and that Mzuzu NAPHAM does not provide such referral letters, I, as a counsellor, found it difficult because the counsellor at MACRO had already done significant damage. I tried to reason with her not to terminate the pregnancy but wait until delivery since it was possible, with proper treatment, to prevent transmission from the mother to the newborn baby, but the woman could not take any advice. When things came to a dead end, I simply took her in person to BLM and left everything to be dealt with between BLM and the pregnant woman, and avoid, thereby, involvement of Mzuzu NAPHAM in the matter. Although I advised her to join our support group after her ordeal with BLM, she has since not come back to talk to us”*

NAPHAM Mzuzu refused to act on the woman’s request but she insisted, although the issue was clearly outside NAPHAM’s mandate. After protracted persistence and failure to convince her through counselling, NAPHAM Mzuzu could only refer her to Banja La Mtsogolo without referral papers. The woman was lost for follow-up by NAPHAM Mzuzu. Hence, there is no report on what transpired at Banja La Mtsogolo.

### ***Waiting Periods for Receiving Test Results***

Rapid tests, like those conducted at MACRO, are proving to be the preferred option for most clients because they do not have to wait for a long time in order to know their results. Unlike in most hospitals, where it takes a week or more due to lack of modern testing technology, rapid tests at MACRO and some selected centres allow the client to be informed about their sero-status on the same day as the test. FGD participants said that the amount of time one has to wait for test results has a strong bearing on the amount of worry and anxiety the client experiences. They also noted that long waiting periods at testing centres can lead to stigmatisation from onlookers questioning one’s presence at a

VCT centre. Some VCT clients experience stigma and discrimination from others simply because they are seen attempting to access VCT services.

Some respondents also reacted to an advertisement by MACRO, which suggests that a test is done within a period of only 15 minutes. They said that this advertisement gives clients the false impression that they will only spend that period of time waiting before their results are released. This 15 minutes, however, does not take into account initial waiting time, or the time required for pre- and post-test counselling. Participants recommended that these advertisements should give a complete picture of the time needed for VCT without isolating a single laboratory activity, which cannot be conducted without the pre-test and post-test counselling sessions.

### ***Reaching a Variety of Target Groups***

According to PLWHA interviewed during the study, VCT services are largely patronised by married women and youth.<sup>3</sup> They suggested that married women are mostly driven by the suspicion that their husbands are promiscuous and, hence, have infected them with the virus. FGD participants felt that the youth seek to learn their status after they become sexually active, especially if they are engaging in unprotected sex and drug use.

Respondents said that most of the VCT patrons are of low education levels and that professionals do not visit the public testing centres. This is also reflected on the fact that most HIV/AIDS SGs have little or no representation of high-level professionals among their ranks. Respondents said fear of stigma and discrimination is the major contributing factor in the unwillingness of these professionals to undergo HIV testing, or for those that do test and are found to be HIV positive, to disclose their status. A case in point was cited by one respondent concerning refusal by medical doctors to go for an HIV test in order to qualify for a scholarship award for further studies. The respondent said:

*“Even medical doctors themselves refuse to go for an HIV test. Conditions of the award demanded that those interested should undergo an HIV test and if found to be HIV positive, one would not make it for the award. According to reports in the media, all of them opted out of the scholarship for fear of the impact an HIV positive result would have had on their lives. These are the people who disappoint us most because, as senior medical practitioners, we expect them to act as role models.”*

This only emphasises the amount of fear of stigma among professionals, who are supposed to be role models. They were more than ready to forgo a good scholarship, which would otherwise have enhanced their earning potential as well as status in society.

Some respondents said that men are largely reluctant to go for VCT services because of an “I don’t care” mentality. Participants observed that some men, with their dominant position entrenched in the culture, have developed the attitude that since every person

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<sup>3</sup> This contradicts actual MACRO records that show more men testing than women.

will die one day it does not matter if they know their HIV status; an HIV test will not keep them from dying. This attitude helps to justify their promiscuous behaviour and also their unwillingness to seek VCT services. It is because of this culturally-entrenched, dominant position of men in the Malawian society that the FGD respondents believed that men do not patronise VCT services as much as do women and young people. They said such men are generally reluctant to face reality and do not usually accept failure or advice easily from their spouses or others.

Respondents explained that the dominant factor in motivating people to take an HIV test is when they become ill. At this point, however, the immune systems of many will have deteriorated to the point where they are developing AIDS. Therefore, it may be too late to make decisions that could benefit the person living with HIV/AIDS and those around him or her. However, respondents believed that the benefits of accessing VCT services go beyond learning whether one is positive or negative. These benefits include:

- Helping one to prepare a good future for children and dependants by organising assets, savings, and any other social support systems necessary for them to live a normal life;
- Helping one to get even closer to God through regular prayer, which prepares one for eternal life;
- Helping one to make important decisions necessary to live a longer and healthy life with the virus. Such decisions include avoiding sex with multiple partners, eating a proper diet, using condoms, and accessing ARVs, among other decisions; and
- Helping to free oneself from anxiety.

According to participants, the only disincentive for getting an HIV test is the potential stigma and discrimination that one may face upon receiving a positive result. This would include feelings of rejection by society and uncertainty about a future that may seem to be lost. Examples of losses PLWHA must cope with include the prospect of not being there to raise their children, not ever having children, or not even having a spouse or partner.

Hence, while it is important for everyone to learn his or her status, making the decision to access VCT is not insignificant, especially given the state of the existing care, treatment and support structures and services in the country. Men, women, youth, professionals, and others in society need an enabling environment to support their coming forward for HIV testing. Freire's concept of conscientisation – the process of raising the level of awareness by promoting self-realisation, ultimately leading to action for transformation – is relevant here. Engaging in a comprehensive and highly critical process of conscientisation could bring about broader social change, resulting in an enabling environment where individuals and communities are positively motivated to take an active role in HIV prevention initiatives in the country.

## ***Mandatory HIV Testing***

Some statements provided by FGD participants indicate that there may be confusion and disagreement among respondents and others about the purpose of VCT and other types of testing, and the circumstances in which they should be permitted. Participants in all the focus group sites contend that what should be a “voluntary” decision to test has actually amounted to “forced counselling and testing” in a number of cases. Instances and examples of mandatory testing were reported where people were instructed to go to VCT centres to get test results in order to apply for educational opportunities, employment, insurance benefits, and religious services. Respondents contend that such requirements undermine the voluntary nature of VCT.

Access to education is a basic right enshrined in the Constitution of Malawi. This is a right that government is mandated to protect for all its citizens without discrimination on grounds of race, disability, property, birth, or other status. It should, therefore, be considered a violation to require an HIV test and a negative result for a person to access educational opportunities, such as scholarships. According to respondents, scholarships can apply from Standard 1 up to the university level as a result of government subsidy. If one has to access a scholarship on the basis of HIV negative results, it implies that tests may be conducted on anyone benefiting from government subsidy on education from primary school through secondary school and university. Participants noted that this arrangement only works to perpetuate stigma and discrimination of those who test positive.

In terms of the world of work, linking an HIV test to gainful employment both in the public and private sectors is against one’s equal right to employment. Participants contended that being HIV positive does not mean that one has developed AIDS – and is, therefore, affected by AIDS-defining illnesses that might limit work productivity and contributions. In addition, respondents believe that linking acquisition of life insurance policies to HIV testing and ultimately denying PLWHA the right to acquire the policies, which are meant to benefit both insurance companies and their clients, is an act of discrimination.

With regard to faith-based organisations, respondents discussed a requirement by some religious denominations that couples undergo VCT before taking matrimonial vows in the church. It is contended that the decision to go for an HIV test in such a case is driven by church conditions and, therefore, not out of free will as purported in VCT. Another similar case is the controversial scholarship programme for girls by Blantyre Synod of the Church of Central Africa Presbyterian (CCAP). While CCAP contends that the programme is an incentive scheme to encourage girls to adopt healthy behaviours and protect themselves from HIV infection, it has serious flaws, particularly affecting those girls who are diagnosed as HIV positive. The programme is a recipe for stigma and discrimination against young PLWHA.

## ***Post-testing Support and Services***

Although it may seem that SGs are found in many parts of the country, they are not as accessible to PLWHA as respondents would expect or hope. The absence of these post-test support services can render PLWHA more prone to stigma and discrimination because they may lack skills for positive living, which could have been strengthened and developed through SGs. Such post-test support services include counselling, group therapy, and sharing ideas for generating income for their livelihood and treatment, among other things. According to those interviewed, cases of suicide and promiscuity, among others, by PLWHA are very much associated with the absence of post-test support services.

As a strategy to deal with stigma and discrimination, the FGD participants were of the opinion that MACRO and similar other institutions should extend their mandate to include post-test support for PLWHA. This is suggested to bridge a gap, which respondents feel works to perpetuate stigma and discrimination of those found HIV positive. There is a strong feeling that the mandate of MACRO, for example, is too limited, as PLWHA may feel abandoned immediately after their sero-positive results are revealed to them. Such support, it is suggested, should be in the area of care, treatment, and support services to enable people to live positively with HIV/AIDS. It may take the form of direct support, or at least a facilitation role, to create viable linkages between PLWHA and care, treatment, and support service providers.

### **Box 4. Summary of Findings Relating to Voluntary Counseling and Testing**

- Facilities that provide VCT services are limited, particularly in rural areas. They also face resource shortages (e.g., test kits, reagents) and results are rarely provided with CD4 count results, which is an important piece of information for helping PLWHA make informed decisions about their health and treatment.
- VCT services are hampered by the lack of human resources devoted to counselling and testing. In hospitals, VCT staff are said to often lack the time and skills to provide high quality services. FGD participants recommend that hospitals hire PLWHA and other qualified individuals to provide counselling services.
- VCT clients may experience stigma and discrimination from others just from being seen trying to access VCT services. Long waiting periods before receiving HIV test results add to the anxiety felt by VCT clients and is viewed by the FGD participants as a form of stigma. Rapid tests, which provide results the same day, are preferred.
- Participants report that men and professionals are reluctant to seek VCT services. This is tied to both personal attitudes (e.g., a fatalistic mentality) and the fear of stigma and discrimination.
- Despite provisions for “voluntary” counselling and testing for HIV, FGD participants noted examples of mandatory testing, including those relating to educational opportunities, the world of work, insurance, and faith-based functions and programmes.
- Post-testing services to help people live positively with HIV/AIDS and to link PLWHA with care, treatment, and support services are needed. These types of counselling and referral services should be integrated with the other services provided by VCT centres.
- FGD participants believe that improving VCT services, as well as educating the public about the advantages of going for HIV tests and knowing one’s status, can help increase use of VCT services.



### **3.3 Recommendations**

#### ***Policy Recommendations***

1. Mandatory HIV testing as a pre-condition to accessing employment, educational opportunities, and life insurance policies is discriminatory and should, therefore, be made illegal at any cost and subject to prosecution in a court of law.
2. The Government should adopt a policy that ensures availability of comprehensive free VCT services and expands the service to health facilities in both rural and urban centres, as well as encourages the development of post-test services to PLWHA for mitigation of HIV/AIDS, including SG formation, counselling, treatment, and survival skills development, among other activities.

#### ***Programme Recommendations***

1. Promote rapid tests in hospitals, SGs (e.g., Salima AIDS Support Organisation), and other VCT centres to reduce the waiting period before results are released to clients.
2. Explore the possibility of introducing mobile VCT services so that they are closer and more accessible to clients.
3. Improve VCT services so that they are equipped with appropriate technology for CD4 count and liver function test in all VCT centres at no cost to PLWHA.<sup>4</sup> These are necessary for PLWHA in helping them make important decisions about their health, such as the option of taking ARVs.
4. Develop an IEC strategy to fill any information and knowledge gaps regarding VCT services. In particular, this information must be accurate (e.g., how long it will take to do the test and receive results) and should promote the advantages of seeking testing.
5. Extend the mandate of centres offering VCT services to include post-testing support for PLWHA. Post-test services may include developing community-based counselling programmes; promoting the rights of clients; helping PLWHA seek – and build capacity to succeed in – employment as lay counsellors in mission and government hospitals; and facilitating linkages between PLWHA and care, treatment, and support service providers.

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<sup>4</sup> Currently costs about K2, 400 (equivalent of US\$27) at Lilongwe Central Hospital.

### ***Cross-cutting Recommendation***

Review and revise existing VCT advertisements in the media and all other HIV/AIDS-related information packages to ensure that they present truthful, accurate, comprehensive, user-friendly information.

## **Section 4: Disclosure of Positive Sero-status**

### **4.1 Overview**

Every person has the right to personal privacy and dignity. Every person has the right to decide what aspects of his or her life are private and what can be made public. Unfortunately this is a principle that is frequently broken when it concerns a person's HIV status. Most breaches of confidentiality occur in hospitals or clinics. In occupations where HIV testing is still mandatory, such as in the military, and in major insurance companies that require people to test for HIV, breaches of confidentiality are also becoming common (GNP+, 1998).

### **4.2 Findings**

#### ***Confidentiality***

Sharing the knowledge that a person has HIV with those closest to him or her is important. Each individual, however, must feel that he or she is in control of passing on this very private information, as respondents reacted in all the focus groups:

*The decision as to whom PLWHA inform of their HIV status is theirs and theirs alone.*

The FGD participants suggested that disclosure of sero-status by medical personnel or counsellors without informed consent of the person living with HIV/AIDS only serves to generate fear among prospective VCT clients. If their confidence in medical personnel and counsellors decreases, they may refrain from having an HIV test.

#### ***Factors that Influence Personal Decisions Regarding Disclosure***

According to FGD participants, more people are seeking out VCT services, but a large proportion of them do not disclose their sero-status, especially when they are found to be HIV positive. Participants noted a number of factors that influence people to disclose or not disclose their sero-positive status. Some of these factors include access to group therapy; access to care, treatment, and support services; involvement in prevention initiatives; and participation in support groups. Their participation in support groups encourages people to disclose their status because of the sharing of experiences and psychological support they give each other during group therapy meetings.

Respondents, however, allude to the fact that there are seemingly very few incentives to motivate PLWHA to disclose their sero-status. It is not easy to disclose one's sero-

positive status. Participants explained that it requires a lot of courage and, hence, very few people have come in the open about their status. For example, NAPHAM Mzuzu has 69 members, 20 of whom are not active. According to respondents, on average, more women than men disclose their sero-positive status. Among the reasons, the male FGD respondents said that after being tested HIV positive, they would not want to discontinue having sex. They also reported that they fear losing their respect in society. If they informed their wives of their being positive, some fear that there may be disagreements in their marriages, which could lead to divorce. On the other hand, respondents said that because of the earlier association of male promiscuity with HIV infection, the women feel that those around them will blame their husbands for their HIV infection. Still, some women have experienced divorce as a result of disclosing their HIV status.

In general, however, FGD respondents reported that they appreciate the benefits that disclosure brings to themselves and society in general. These include:

- Alerting those who would want to have unprotected sex with a person who is HIV positive;
- Serving as a psychological shield to oneself not to indulge in unprotected sex;
- Helping to clear one's conscience; and
- Helping to encourage others to go for VCT.

It is, however, interesting to learn from participants at all the study sites that some people do not trust that those PLWHA who have been public about their sero-status and do not believe they are really honest. It is suggested that they are only doing so to deceive and trick donors and other well-wishers so they can benefit financially or materially from their support. The quote below by one of the respondents highlights this view:

*“They claim that there is a lot of money in AIDS activities. They believe that we deliberately associate with positive sero-status to draw sympathy from people who in turn dish out money even though we don't receive a single coin from performing our voluntary work.”*

### **Misconceptions about HIV and AIDS**

There are widespread misconceptions about HIV and AIDS. FGD participants said that people generally lack understanding of the differences between HIV and AIDS. They are not aware that a person infected with HIV can remain healthy for 10 years or more with no physical signs or symptoms of infection. The situation is especially aggravated when a person discloses his or her HIV sero-positive status. PLWHA are perceived as sick and unable to contribute to societal development work through their prevention and mitigation activities. This is a big challenge to the work of PLWHA in most communities because some people still do not believe that PLWHA can live productive lives and make valuable contributions to the society. Unless the situation is arrested, such misconceptions will continue to undermine PLWHA outreach activities.

In a reference to the same issue, one respondent pointed out how some high-profile slogans for HIV prevention on the national radio are misleading. One such slogan, featuring the voice of the Head of State, speaking in vernacular language, was referenced specifically. The slogan says:

**Tipewe... (Let's avoid...) - State President**  
**Tipewe AIDS chifukwa ilibe mankhwala! (Let's avoid AIDS because it has no cure!) - Chorus of responses**

In trying to feature a high-profile figure in Malawian society, the State President asks people what we should prevent, to which people respond in a chorus that it is AIDS that has to be prevented because there is no cure for the disease. While it is good that the Head of State is at least speaking out, the argument put across by FGD respondents against the content of the slogan is that a person living with HIV is more dangerous to others than one who has developed AIDS because the former may not be aware of his or her status or may deliberately pretend he or she is not infected. Hence, respondents propose to have the slogan changed to reflect prevention of HIV and not AIDS, per se. One FGD participant suggested:

*“When one develops AIDS, every person knows and sees the signs clearly. It is, therefore, more plausible to say prevent HIV because even healthy looking people may be HIV positive. By doing so, we will be sending the right message of prevention.”*

### **Reactions from Family and Community Members Following Disclosure**

Respondents spoke of some PLWHA being denied parental and family care when they are known to be HIV positive. When a person is diagnosed as HIV positive, some parents and family members believe the person was promiscuous and, therefore, deserves little or no attention from them. A Phalombe interviewee reported that, in one village in the district, family members relocated a widow living with HIV to a small hut, taking her good house to accommodate goats. In another instance in the same district, an HIV-positive married couple has had their children shared among relatives in the town and cities on the pretext of conducting normal inter-family exchanges. However, the parents came to learn from other sources that the children were taken away because of the parents' HIV status. In Rumphi district, the relatives of an HIV-positive married couple and their immediate family refuse to visit them.

FGD participants reported that PLWHA who have disclosed their status are the ones that undertake care, treatment, and support services, yet, they are called by such names as “*ma pwa*<sup>5</sup>”, *moving corpses*, *apaulendo*<sup>6</sup>, *sufferers*, *victims*, *shati pa hangala*<sup>7</sup>,

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<sup>5</sup> A short form derived from a vernacular word, ‘*mapwala*’ which means testicles. It is, therefore, used to identify PLWHA with lust for sex.

<sup>6</sup> Someone on the road to death.

<sup>7</sup> A shirt on a hanger.

*chirombo*<sup>8</sup>, etc. As a result of this treatment, it is believed, some PLWHA fail to join SGs because doing so would reveal that one is HIV positive. Unless this conduct of ridicule is made an offence, a very significant number of people will continue on the path of denial and silence, which will not serve to slow the spread of the epidemic or improve the quality of life for PLWHA and their families.

Other consequences of disclosure include denial of employment and access to financial resources. According to respondents, PLWHA are sometimes denied leadership positions in various community-based organisations, as well as employment and promotion opportunities in the world of work. It is assumed that they will not be able to perform their duties well enough given their potentially poor physical health. It is also sometimes believed they will only bring disgrace to the organisations that employ them. In addition, respondents provided reports of PLWHA being denied loans. By denying PLWHA access to loans, aside from denying them opportunities to engage in income-generating activities, the chance to increase their incentive base to come into the open about their sero-status is undermined. Cases of denial and silence increase and PLWHA may go underground – all of which contribute to the spread of the epidemic.

### ***Impact of Disclosure on Intimate Relationships***

As a result of failure to accept responsibility, FGD participants said some married women and men divorce when either of them discloses their sero-positive status. Unmarried couples are also said to have separated following disclosure. Respondents noted that this is usually a result of failure of either or both partners refusing to accept the reality of the situation, denying their status and seeking to blame the other for their infection. Participants said that in the end, a feeling of rejection develops, which can lead to disastrous consequences for both parties. In such cases, women or men will go for a test to prove their own innocence and their spouse's infidelity. Anger generated as a result of an HIV-positive result leads to turmoil in the family, which can lead to divorce, especially when a woman tests positive. Respondents remarked that the woman's unfaithfulness weighs heavier than that of the man because of the societal expectation that she be submissive to the man. This is culturally engineered in that society tolerates a man having more than one wife or engaging in extra-marital relationships, even though this does not go down well with the woman.

### ***Men and Disclosure***

Men are usually heads of most Malawian households with immense influence over decisions at various levels. Most women will decide to come out in the open about their HIV status out of frustration, knowing that their infection is attributed to the behaviour of their spouses. Unless men begin to appreciate the value of breaking denial and silence over the epidemic and decide to join the family of PLWHA in SGs, progress towards preventing the spread of HIV and mitigating the impact of the epidemic on individuals, families, and societies will be undermined.

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<sup>8</sup> Reference to the virus that causes AIDS.

## ***Children Affected by HIV/AIDS***

Respondents provided reports of school-going children being ridiculed by fellow pupils or teachers when they or their parents are known to be HIV positive. These acts happen in primary schools, secondary schools, colleges, and universities. Such children (particularly those in primary school) will usually have lost both their parents to the epidemic. Orphans, particularly young ones, may themselves be HIV positive as a result of mother-to-child transmission. AIDS orphans and children living with HIV/AIDS may be denied educational opportunities, proper food, essential treatment, clothing, emotional support, and general care. Their continued victimisation only serves to worsen their desperate situation, which may lead to an early death for those living with HIV/AIDS and increase vulnerability for others.

## ***Disclosure by Young PLWHA***

It was the perception of FGD participants that reproductive health services for young PLWHA are not youth friendly. Staff who dispense STI treatment drugs in health facilities are actively involved in stigmatising young clients, blaming them for indulging in sexual activity at an early stage when they were supposed to be preoccupied with school and other acceptable activities. In addition, in certain cases, young PLWHA are not comfortable talking to health care personnel of the opposite sex or older age about their problems and may be reluctant to seek medical support. The result is that they do not get the reproductive health support necessary to lead a healthy life.

Another concern raised by FGD participants is that the representation of young PLWHA is lacking in most SGs. And yet statistics from NAC reveal that youth are among those with the highest HIV prevalence rates in the country. Young people are afraid to face the wrath of their parents if they disclose their sero-positive status or even that they need to continue treatment for STIs at home. FGD participants said that because society perceives access to reproductive health as the strict domain of adults, girls and boys access the services without telling their parents or relatives for fear of retribution. HIV/AIDS prevention and mitigation initiatives are undermined in the long run because young PLWHA are denied access to resources that could help them live positively with the virus.

## ***Support Group Membership***

Fear of stigma and discrimination may be one reason for the lack of involvement of professionals in PLWHA SGs. The study team noted that people with lower incomes and less formal education dominate membership of SGs. From the four districts visited, the average level of education for members interviewed is Standard 8<sup>9</sup>, with most of them widowed and not in formal employment. No support group boasts membership of a post-graduate. The well to do and professionals are not willing to join these support groups

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<sup>9</sup> The highest education level being Form 4 and the lowest, Standard 3. Refer to the profile of members in appendix.

and yet, FGD participants said, their presence would potentially make an immense difference to the cause of PLWHA. Respondents were also quick to note that apart from giving credibility to the work of SGs, professionals and others with higher social status would be role models to fellow members of the SGs as well as those who may have been afraid to go for VCT or to disclose their status. Some of the PLWHA interviewed expressed such sentiments:

*“We yearn to hear one day that the State President, his cabinet ministers, or anybody held in high esteem in society say publicly, ‘I went for an HIV test and I have been found HIV positive or negative’.”*

### **Box 5. Summary of Findings Relating to Disclosure**

- The decision as to who to inform about their HIV status is the right of PLWHA, yet others such as health care providers and employers sometimes violate their right to confidentiality and privacy.
- There are few incentives to disclose one’s HIV status, and many FGD participants believe fear of stigma and discrimination is one reason why people – particularly professionals and others with higher social status – choose not to disclose.
- FGD participants note that there are many misconceptions about HIV and AIDS. One such issue is the perception that people living with HIV cannot lead healthy and productive lives for a number of years (before developing AIDS or being affected by AIDS-defining illnesses). Once PLWHA disclose their status, they are faced with the challenge of convincing others that they can still make valuable contributions to society in a variety of realms.
- Following disclosure, PLWHA may lose the support of their families and community members. They have also been denied employment and financial opportunities.
- Disclosure can have a serious impact on both married and unmarried couples. Often, couples struggle with either placing blame on their partner or not accepting responsibility for their own actions. This can lead to resentment, frustration, and the eventual divorce. The situation is often more severe when the woman is the first to disclose – even when she has contracted HIV from her spouse or partner.
- Participants note that men are reluctant to disclose their HIV status, perhaps owing to a fear of losing their position within the society and family.
- AIDS orphans and other children living with or affected by HIV/AIDS face stigma and discrimination from their fellow peers and teachers at school.
- Youth involvement in SGs is limited and reproductive health services are often not youth-friendly, according to the FGD participants.
- Professionals and others with higher social status are reluctant to disclose their HIV status. The lack of their involvement in SGs negatively affects their human resource capacity to carry out a variety of functions, including high-level policy decision-making.



## **4.3 Recommendations**

### ***Policy Recommendations***

1. The Government should create a supportive environment for PLWHA and enforce protective and anti-discrimination laws for disclosure at all levels to ensure PLWHA fully enjoy their rights and freedoms.
2. The Government should recognise and foster effective coordination and collaboration with the Network of People Living with HIV/AIDS and allocate resources towards HIV/AIDS prevention and mitigation work undertaken voluntarily by registered PLWHA SGs throughout the country.
3. It should be made an offence for VCT providers to reveal the HIV test results of their clients, if it is proved beyond reasonable doubt that they did so without the informed consent of the concerned clients.
4. It should be made an offence for people, in general, to discriminate against PLWHA, including HIV infected or affected orphans and children, on the basis of their HIV status at work, at home, in loan-lending institutions, and any other place, if they are proved beyond reasonable doubt to have performed such acts.

### ***Programme Recommendations***

1. Build counselling capacity in local communities with the aim of enhancing positive living among PLWHA in the country. Professionals and others with higher social status who are HIV positive should be trained in counselling and those interested should be encouraged to form SGs to attract their colleagues.
2. Design education and counselling programmes specifically targeting married couples to help them appreciate that being HIV positive should not be cause for divorce or other acts of frustration to the detriment of the marriage institution.
3. Develop a comprehensive IEC strategy to raise awareness among the general public regarding, among others: civil rights and freedoms that PLWHA are entitled to exercise even after disclosing their sero-positive status; consequences of denying them the right to exercise their rights and freedoms; the difference between HIV and AIDS; and the types of care, treatment, and support needed by PLWHA who have disclosed their status.
4. Develop strategies to increase membership of PLWHA SGs with particular focus on men, youth, professionals, political figures, religious leaders, and those with higher incomes in Malawi. While giving weight to the role of SGs, such influential figures would enhance the technical, material, moral, and financial support of SGs.

## Section 5: Involvement of PLWHA

### 5.1 Overview

Involvement and participation of PLWHA in policymaking bodies in Malawi is a big issue. They are rarely (or not at all) represented in the local-, district-, regional-, and national-level development and policymaking institutions in Malawi. If there are PLWHA in policymaking bodies, identification of some of the so-called “representatives” is done without consulting the constituency they claim to represent. Often, they are considered to be there in their own capacity by their colleagues, and not to be representing the interests of a wide spectrum of PLWHA. In some cases, PLWHA reported being denied representation in workshops where there is discussion on policy formulation and implementation issues and, yet, they possess a living testimony of the epidemic and its effects. By denying PLWHA such representation in policymaking processes, they feel excluded from exercising their right to participate in activities that affect their lives.

### 5.2 Findings

FGD participants reported that:

1. PLWHA are involved in local bodies, such as the Village Development Committees and Community Development Committees.
2. PLWHA are represented in policymaking bodies at district, regional, and national levels by people whose HIV-positive status is not known and without any consultations.
3. PLWHA are only involved in activities, such as workshops and meetings, not necessarily in planning and policy decision-making.
4. HIV/AIDS programmes are being designed for them.

While respondents acknowledge that there are some PLWHA that are involved and participate in some policymaking bodies, they still contend it is inadequate. They argue that involvement in policymaking bodies as a process of empowerment can help to amplify traditionally unacknowledged voices, such as those of PLWHA. They said it can strengthen their confidence and may foster their ability to question and contribute to both local and international systems of knowledge. FGD participants in all study sites said PLWHA are also members of society and they are individuals who have the right to be involved in policymaking bodies.

Says one participant:

*“We, too, should have a say in matters and decisions that affect our lives, our communities, and the larger society.”*

Involvement of PLWHA means raising consciousness and knitting together a shared understanding of problems and a vision for the future that leads to commitment and ownership by PLWHA. The ultimate objective of engaging PLWHA in policymaking processes is to share control over power, resources, and institutions with them. FGD respondents reiterated the same feeling:

*“We cannot say that we are being involved in decision-making because when they plan HIV/AIDS programmes we are not there. We are only told what has been put in place.”*

By involving PLWHA in policymaking processes, listening to them, and giving them responsibility in the development, implementation, and evaluation of HIV/AIDS policies, countries can enhance the possibility of developing policies that are relevant to the target group (e.g., policies and programmes that ably address important issues, such as stigma and discrimination). Says one participant from KASO:

*“It is our belief that we are in the best position to know and explain what our needs are in terms of HIV/AIDS prevention, care, and mitigation. But often we are neglected in the development, implementation, and evaluation of HIV/AIDS policies, because our technical or scientific understanding of the epidemic, as well as other issues, is considered limited.”*

So, in short, involving PLWHA in policymaking and implementation processes can contribute to better and more relevant policies and programmes.

But the involvement of PLWHA also has other benefits beside those directly associated with the formulation and implementation of HIV/AIDS policies. Involving PLWHA and ensuring their active participation will create opportunities for others to go public about their sero-positive status as well as develop skills and confidence in PLWHA for living positively with HIV and AIDS, which might benefit them and their communities, in general. The involvement of PLWHA provides a way of empowering them. Moreover, it is important for PLWHA to meet other people in a similar situation, thereby helping them realise that they are not alone and that they can support each other.

**The United Nations Declaration of Commitment on HIV/AIDS, of which Malawi is a signatory, recommends:**

*“By 2003, ensure the development and implementation of multisectoral national strategies that involve the full participation of people living with HIV/AIDS.”*

*“By 2003, enact, strengthen or enforce, as appropriate, legislation, regulations, and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of, all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups.”*

## **5.3 Recommendations**

### ***Policy Recommendations***

1. The Government should develop a code of best practices that provides guidance to local and national policymaking bodies on how to actively involve PLWHA at various levels.
2. The Government should recognise and effectively involve PLWHA as a special interest group in various political and development institutions, such as village development committees; area development committees; district, town, and city assemblies; district AIDS coordinating committees; the Cabinet; and Boards of Parastatals, among other groups.
3. The Government should create a special government ministry, or at least department, in the President’s Office to be responsible for PLWHA, which should be headed by a person living with HIV/AIDS. As a special interest group whose needs and potential to contribute toward prevention and mitigation initiatives are growing by the day, attention at the executive level will help address fundamental issues affecting PLWHA.
4. As part of the National HIV/AIDS Policy, the Government should mandate that PLWHA must be represented in every workshop addressing HIV/AIDS issues that concern them. If PLWHA or their representatives cannot be accommodated in person, it should be made a requirement that they be consulted.

### ***Programme Recommendations***

1. Identify strategies to develop the capacity of PLWHA to participate in the policymaking arena.
2. Strengthen the coordinating role and capacity of MANET+ and its partners in the policy advocacy process so that they are better able to advocate for the reduction or elimination of stigma and discrimination against PLWHA.

## Section 6: Conclusion

Stigma and discrimination are key factors with significant influence on the ability of PLWHA and others to live positively with HIV and AIDS in Malawi. Unfortunately, there are currently no policies or laws to specifically protect PLWHA against stigma and discrimination. HIV/AIDS prevention and mitigation initiatives will continue to suffer significant setbacks if the status quo is sustained. As indicated earlier, the contribution of PLWHA to HIV/AIDS mitigation work is crucial to the control of the epidemic, as they are a living testimony of the epidemic to all the people of Malawi. Therefore, any tendency towards stigmatisation, discrimination, or failure to respect their human dignity must be absolutely rejected. Such negative attitudes towards PLWHA undermine all efforts to limit the transmission of the virus and to reduce its impact on individuals, families, and communities. It is with this conviction that the Malawi Network of People Living with HIV/AIDS (MANET+) calls upon authorities to seriously consider the recommendations contained in this report for inclusion in the National HIV/AIDS Policy, which is currently being formulated, as well as in other HIV/AIDS policy, planning and programme efforts.

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## Appendix A: Names of Responding Support Groups

<u>Date</u>	<u>Support Group</u>	<u>District</u>	<u>Status</u>
Thursday – 16/08/2002	Kanengo AIDS Support Organisation (KASO)	Lilongwe	Pre-test site
Tuesday –28/08/2002	Mzuzu NAPHAM	Mzimba	Study site
Tuesday – 28/08/2002	Likulezi NAPHAM	Phalombe	Study site
Thursday - 30/08/2002	Nkhotakota AIDS Support Organisation (NASO)	Nkhotakota	Study site

# Appendix B: Focus Group Discussion Guide

## INTRODUCTION:

1. **Greetings.**
2. **Self-introductions:** All group members shall cite their full names, organizations they represent, positions held and where they have come from.
3. **Clarify goal of the visit:** The goal of our visit is to conduct discussions with you to generate information, which will feed into the National HIV/AIDS Policy to ensure that the needs of PLWHA are taken care of. This policy document will form a legal framework for all future HIV/AIDS programmes in the country. It is therefore important for you to contribute your views towards this important document since you are the ones who have the experience of living positively. Please feel free therefore to respond honestly and accurately to the questions that the facilitation team will pose.
4. **Clarify methodology and the future:** Let us also clarify that during the discussion, we will be asking questions, taking notes and recording your responses. This is meant to help us generate your views and avoid leaving out any of them. Discussions will be done in separate groups of men and women with male and female facilitators respectively so that all members feel free to talk and share their views. The information we will collect today will be analyzed together with that from other regions to obtain a national picture of your opinions. A report will be compiled to document these views.

This report will be presented to National AIDS Commission for synthesis of ideas and subsequent inclusion into the National HIV/AIDS Policy.

All that we will discuss here will be treated with respect and confidentiality. Emphasize that they are free to voluntarily participate in the discussions.

5. **Negotiate for time:** Discuss how long they would like the discussion to take in view of their other engagements. Negotiate for more time when you feel their proposal is inadequate. Emphasize the significance of the exercise to impress upon them as you negotiate for time. Indicate that there may be need at the end of time allocated for more discussion and that you will seek their consent to that effect.
6. **Final statement:** At the end of the discussion, we will have refreshments together and a little something for your transport back home.
7. Are there any questions before we begin posing questions?



**DISTRICT:**.....

**NAME/S OF SUPPORT GROUP/S**.....

**No of RESPONDENTS:**.....

**SERO STATUS OF RESPONDENTS:**.....

**(Positive and disclosed, tested but not disclosed, negative and disclosed)**

**NAME OF FACILITATOR:**.....

**NAME OF NOTE TAKER:**.....

**DATE OF INTERVIEW:**.....

<b>THEMATIC AREA</b>	<b>ISSUES FOR DISCUSSION</b>
<b>(1) General Information on HIV/AIDS</b>	<ul style="list-style-type: none"><li>▪ What is the situation of HIV/AIDS in this district (<i>Probe what is the more affected group in terms of gender {male/female}, marital status {married Vs single}, age {youths Vs adults}</i>)?</li><li>▪ What are the factors that continue to promote the spread of HIV/AIDS in your community (<i>Probe for cultural practices such as fisi, kuchotsa fumbi, widow inheritance, polygamy, labour migration, etc.</i>)</li><li>▪ What measures are you taking to prevent?</li><li>▪ What measures are you taking to live positively with HIV/AIDS?</li></ul>
<b>(2) Care and support services</b>	<ul style="list-style-type: none"><li>▪ What type of care, treatment and support services are available to PLWHA and orphans in your community? (<i>Probe those intra-family, inter-family, from community, from medical section etc, such as treatment for other opportunistic infections like TB, pneumonia, shingles etc</i>)?</li><li>▪ What type of care, treatment and support services do you think PLWHA need in your community?</li><li>▪ What type of treatment services do you think PLWHA need in your community?</li><li>▪ What has been the experience of PLWHA seeking care, treatment and support services in your community? (<i>Probe provision of care and support services at family level, community level, government level etc</i>)</li><li>▪ What other support services exist in your community for the</li></ul>

THEMATIC AREA	ISSUES FOR DISCUSSION
	<p>chronically ill people who have developed AIDS? (<i>Probe, among others, for issues regarding transport to the hospital</i>)?</p> <ul style="list-style-type: none"> <li>▪ What is the level of knowledge about Anti Retroviral drugs (ARVs) for PLWHA?</li> <li>▪ What suggestions would you make to increase knowledge about ARVs among PLWHA?</li> <li>▪ What is the level of access to ARVs for PLWHA?</li> <li>▪ Are there cases of discrimination in the provision of ARVs?</li> <li>▪ What suggestions would make ARVs more accessible to PLWHA to address the discrimination?</li> <li>▪ Are there any services to prevent mother to child transmission (PMTCT) of HIV in your community? (<i>Probe knowledge and access to PMTCT</i>).</li> <li>▪ What would make PLWHA increase their access to quality PMTCT services in Malawi?</li> <li>▪ What should be done to improve care for PLWHA at family and community level to reduce stigma and discrimination?</li> <li>▪ How are young PLWHA in your community treated when seeking Reproductive Health (RH) services (STI, family planning, HIV/AIDS)?</li> <li>▪ What recommendations can you make to improve the quality of these RH services in your area?</li> </ul>
<p><b>(3) Voluntary Counselling and Testing (VCT)</b></p>	<ul style="list-style-type: none"> <li>▪ What are your views about VCT services in your community? (<i>Probe for the numbers of people seeking the services – few or many, gender, age, and education level</i>)</li> <li>▪ What are the short falls in the VCT services?</li> <li>▪ What needs to be done to improve VCT services in the area to reduce cases of stigma and discrimination among PLWHA?</li> <li>▪ What are the advantages of people knowing that they are HIV positive or negative?</li> <li>▪ What are the disadvantages of people knowing that they are HIV positive or negative?</li> <li>▪ If you made the decision to have an HIV test, where would you feel more comfortable to access such a test?</li> <li>▪ What would you recommend the government to do to promote VCT? (<i>Probe, among others, discrimination from acquiring life</i></li> </ul>

THEMATIC AREA	ISSUES FOR DISCUSSION
	<i>insurance policies, pursuing education studies, accessing employment, accessing quality counseling services, accessing parental care etc)</i>
<b>(4) Disclosure of sero-status</b>	<ul style="list-style-type: none"> <li>▪ How easy would it be for a person diagnosed HIV+ to disclose his/her status? (<i>Probe for number of cases of disclosure, pattern of disclosure between men and women and reasons behind it</i>)</li> <li>▪ What are the factors that have facilitated people to come out in the open or not about their HIV status in your community?</li> <li>▪ What has been the reaction of your community to people known to have HIV/AIDS (<i>Probe towards young people, adults, married women, school going children, HIV/AIDS orphaned children etc</i>)</li> <li>▪ What are the advantages of disclosure of one's sero status? (<i>Probe to oneself, family, community</i>)</li> <li>▪ What are the disadvantages of disclosure of one's sero status? (<i>Probe to oneself, family, community</i>)</li> <li>▪ What mechanisms should be put in place to promote disclosure of sero status among PLWHA? (<i>e.g., among married couples and partners</i>)</li> </ul>

## Appendix C: Profile of Respondents

No.	Gender	Age	Marital status	Variables		District
				Education level	Occupation	
1.	Male	41	Married	Form 2	Farming	Mzuzu
2.	Male	42	Married	Std. 8	Building	Mzuzu
3.	Male	40	Married	Form 2	Counselling	Mzuzu
4.	Male	40	Married	Form 2	Nothing	Mzuzu
5.	Male	38	Married	Form 3	Supervisor	Mzuzu
6.	Male	31	Married	Form 4	Teaching	Mzuzu
7.	Male	35	Married	Std. 8	Unemployed	Mzuzu
8.	Male	43	Married	Std. 8	Nothing	Mzuzu
9.	Male	45	Married	Form 2	Business	Mzuzu
10.	Male	35	Married	Form 2	Working	Mzuzu
11.	Male	43	Married	Std. 8	Unemployed	Mzuzu
12.	Female	50	Widow	Std. 3	Unemployed	Mzuzu
13.	Female	29	Married	Std. 8	Business	Mzuzu
14.	Female	32	Married	Std. 6	Housewife	Mzuzu
15.	Female	39	Married	Std. 6	Unemployed	Mzuzu
16.	Female	45	Widow	Std. 8	Farmer	Mzuzu
17.	Female	34	Widow	Std. 7	Unemployed	Mzuzu
18.	Female	37	Widow	Std. 8	Housewife	Mzuzu
19.	Female	34	Single	Form 2	Unemployed	Mzuzu
20.	Female	34	Widow	Std. 8	Unemployed	Mzuzu
21.	Female	39	Widow	Std. 3	Unemployed	Mzuzu
22.	Female	DM <sup>10</sup>	DM	DM	DM	Mzuzu
23.	Female	DM	DM	DM	DM	Mzuzu
24.	Female	DM	DM	DM	DM	Mzuzu
25.	Female	DM	DM	DM	DM	Mzuzu
26.	Male	38	DM	Form 2	Group therapist	Nkhotakota
27.	Male	34	Married	Tertiary	Project Director	Nkhotakota
28.	Male	46	Divorced	Form 3	Carpentry	Nkhotakota
29.	Male	46	Married	Std. 8	Building	Nkhotakota
30.	Male	31	Married	Std. 3	Fishing	Nkhotakota
31.	Female	36	Single	Std. 3	Farming	Nkhotakota
32.	Female	39	Divorced	Form 4	Nurse	Nkhotakota
33.	Female	40	Single	Std. 7	Farmer	Nkhotakota
34.	Female	32	Single	Form 4	Co-ordinator-NASO	Nkhotakota
35.	Female	40	Widow	Form 4	Nurse	Nkhotakota
36.	Female	32	Divorced	Form 2	Home-craft worker	Nkhotakota

<sup>10</sup> DM stands for Data Missing.

No.	Gender	Age	Variables			District
			Marital status	Education level	Occupation	
37	Male	34	Married	Std. 8	Farming	Phalombe
38	Male	27	Divorced (after HIV+ test)	Std. 4	Tailoring	Phalombe
39	Male	32	Married	Form 2	Unemployed	Phalombe
40	Male	41	Married	Std 3	Farming	Phalombe
41	Male	28	Married	Form 2	Tailoring	Phalombe
42	Male	32	Married	Std. 3	Farming	Phalombe
43	Male	32	Married	Std. 5	Farming	Phalombe
44	Male	31	Married	Std 8	Farming	Phalombe
45	Male	39	Married	None	Farming	Phalombe
46	Male	36	Married	Std. 1	Farming	Phalombe
47	Male	32	Married	Std. 8	Farming	Phalombe
48	Male	40	Divorced (long sickness)	Std. 8	Farming	Phalombe
49	Male	34	Married	Form 2	Court Clerk	Phalombe
50	Male	57	Married	Std. 5	Farming	Phalombe
51	Male	51	Widowed	Std. 4	Farming	Phalombe
52	Female	39	Divorced	None	Unemployed	Phalombe
53	Female	35	Widowed	None	Unemployed	Phalombe
54	Female	30	Divorced (long sickness)	None	Unemployed	Phalombe
55	Female	24	Widowed	Std. 5	Unemployed	Phalombe
56	Female	32	Widowed	Std. 6	Unemployed	Phalombe
57	Female	41	Widowed	Std. 3	Business	Phalombe
58	Female	32	Divorced (long sickness)	Form 2	Farming	Phalombe
59	Female	40	Widowed	Std. 8	Farming	Phalombe
60	Female	43	Widowed	Std. 6	Business	Phalombe
61	Female	31	Widowed	Std. 5	Business	Phalombe
62	Female	28	Divorced (after HIV+ test)	Std. 8	Business	Phalombe