

**Factors that facilitate or constrain adherence  
to antiretroviral therapy among adults at four  
public health facilities in Botswana:  
a pre-intervention study**

Joyce Kgatlwane  
Botswana Essential Drugs Action  
Programme  
PO Box 639, Gaborone, Botswana  
Tel. +267 3632070 cell: +267 72565815  
E-mail: [jkgatlwane@gov.bw](mailto:jkgatlwane@gov.bw)  
[jkgatlwane@yahoo.com](mailto:jkgatlwane@yahoo.com)

Robert Ogenyi  
Mahalapye District Hospital  
PO Box 49, Mahalapye, Botswana  
Tel. +267 4710333 cell: +267 71427344  
E-mail: [robagumu@yahoo.com](mailto:robagumu@yahoo.com)

Cosmas Ekezie  
Sekgoma Memorial Hospital  
PO Box 120, Serowe, Botswana  
Tel. +267 4630333 Cell +267 71446186  
E-mail: [costee\\_akataka@yahoo.com](mailto:costee_akataka@yahoo.com)

Haruna Ngbo Madaki  
Scottish Livingstone Hospital  
Private Bag 001, Molepolole, Botswana  
Tel: +267 592 0333.  
Cell: 267 71461135 Fax 5920335.  
E-mail: [harmadaki2@yahoo.com](mailto:harmadaki2@yahoo.com)

Sikhulile Moyo  
Botswana-Harvard School of Public  
Health  
AIDS Initiative Partnership  
Private Bag BO 320, Gaborone  
Botswana  
Tel: +267 3902671 cell: +267 71400471  
E-mail: [smoyo@bhp.org.bw](mailto:smoyo@bhp.org.bw)

Tirelo Modie Moroka  
University of Botswana  
Social Work Department  
Private Bag 0022 Gaborone, Botswana  
Tel: +267 3550000  
E-mail: [modiet@mopipi.ub.bw](mailto:modiet@mopipi.ub.bw)



# Contents

<b>Acknowledgements</b>	<b>5</b>
<b>Acronyms and abbreviations</b>	<b>7</b>
<b>Executive summary</b>	<b>9</b>
<b>Chapter 1: Introduction</b>	<b>13</b>
1.1 Research problem	13
1.2 Research questions	14
1.3 Study objectives	14
<b>Chapter 2: Background</b>	<b>15</b>
2.1 History of HIV and AIDS in Botswana	15
2.2 Botswana's ART programme	15
2.3 Literature review	16
2.4 Definition of concepts	19
<b>Chapter 3: Methodology</b>	<b>21</b>
3.1 Introduction	21
3.2 Study design	21
3.3 Study population	21
3.4 Description of study sites	21
3.5 Inclusion and exclusion criteria	25
3.6 Selection and training of data collectors	25
3.7 Qualitative data collection	25
3.8 Observations	25
3.9 Semi-structured interviews	26
3.10 Exit interviews	27
3.11 Focus group discussions	28
3.12 Quantitative data	29
3.13 Data analysis	29
3.14 Emic perspective	31
3.15 Ethical considerations	31
3.16 Feedback	32
<b>Chapter 4: Quantitative results</b>	<b>33</b>
4.1 Adherence measurement tool results	33
4.2 Rates of adherence to ARVs	34
4.3 Reasons for skipping medication	35
4.4 Factors affecting adherence to ART	36
4.5 Predictors of adherence to ART	38
4.6 Quantitative results of exit interviews	39
<b>Chapter 5: Qualitative results</b>	<b>41</b>
5.1 Constraints to adherence to ART	41
5.2 Facilitators of adherence to ART	47
5.3 Observation of health facilities	50
5.4 National level policy issues	52

<b>Chapter 6: Discussion, conclusion and recommendations</b>	<b>53</b>
6.1 Discussion	53
6.2 Conclusions	59
6.3 Recommendations	60
<b>References</b>	<b>61</b>
<b>Annex 1: Mean of rates adherence</b>	<b>65</b>
<b>Annex 2: Multivariate logistic regression analyses on the predictor variables</b>	<b>67</b>
<b>Annex 3: Questionnaires</b>	<b>69</b>
1. Focus group discussion (FGD) for antiretroviral users: Questionnaire	69
2. Focus group discussion for community members: Questionnaire	71
3. Semi-structured interview with health care workers.	72
4. Semi-structured interview with ARV users	75
5. Adherence measurement tool for antiretroviral users: Questionnaire	78
6. Exit interviews with ARV users.	82
7. Guide for observation of health facility	86
8. Observation of consultation with health workers	87
9. Semi-structured interview with site manager	90
10. Questionnaire guideline for key informant interview.	92
11. Semi-structured interview with national level policy-makers	93

## Acknowledgements

The study was carried out with financial support from the World Health Organization (WHO) and technical support was provided throughout by the University of Amsterdam (Netherlands). The support and assistance provided by members of these organizations, especially Anita Hardon, Richard Laing and Trudie Gerrits (advisers and coordinators of these studies), John Kinsman, Kathleen Hurst and Nicole Schulp are highly appreciated. We also greatly appreciate the assistance of Monika Zweygarth of the Medical University of South Africa, who designed the database used for quantitative data collection and provided ongoing support with data analysis. We thank our other colleagues in Uganda, Tanzania and South Africa for their constructive criticism throughout the project, which contributed greatly to the success of this study.

We acknowledge the support of the Botswana Ministry of Health in facilitating the study, in particular the assistance provided by Botsang John, the Chief Pharmacist, and by the staff of the Health Research Unit. The study team also acknowledges the contributions of our data collectors: Moremi Dodo, Motsamai Austin, Dikeleko Nchadi and the late Samuel Khubile. We thank the management and health workers of the health facilities where these surveys were conducted, namely Maun, Serowe, Mahalapye and Molepolole. In addition, we extend our appreciation to the management, health workers and ART patients at Palapye Primary Hospital who allowed us to pilot our research tools. Special thanks go to all the ART patients, the AIDS coordinators and members of the community at Maun, Serowe, Mahalapye and Molepolole who willingly participated in the interviews. Lastly, we thank our families and the families of the data collectors for their support and encouragement throughout the study period.



## Acronyms and abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ACHAP	African Comprehensive AIDS Partnership
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
BHP	Botswana Harvard Partnership
BOTUSA	Botswana-USA project
CSO	Central Statistical Office
EDM	Electronic drug monitoring
FGD	Focus Group Discussion
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	Human Immune Deficiency Virus
IDCC	Infectious Disease Control Centre
KITSO	Knowledge, information and technology shall overcome (HIV and AIDS)
MoH	Ministry of Health
NACA	National AIDS Coordinating Agency
PLWHIV	People Living with HIV
pMTCT	Prevention of Mother-to-Child Transmission
Portakabin	Prefabricated building used in treatment centres
SOP	Standard Operating Procedures
STG	Standard Treatment Guidelines
UNAIDS	United Nations Joint Programme on AIDS
VCT	Voluntary Counselling and Testing





## Executive summary

### Introduction

Botswana is one of the countries hardest hit by the HIV epidemic, with a prevalence of 37.4% among pregnant women attending Government antenatal clinics (National AIDS Coordinating Authority (NACA), 2003). In 2002, Botswana became the first country in sub-Saharan Africa to launch a free national antiretroviral therapy (ART) programme in the public health sector.

While ART has improved the lives of many worldwide, lack of adherence to ART is still a major challenge to AIDS care and has serious public health consequences. Lack of adherence to ART often leads to treatment failure and is likely to accelerate the emergence of drug-resistant strains of HIV. As Botswana scales up access to ART in all health facilities, there is a critical need to estimate and monitor the rates of adherence. It is also important to understand factors that influence adherence in order to design appropriate interventions. This study was part of a three-country study on adherence to ART carried out in Botswana, Tanzania and Uganda.

### Study objective

To determine adherence levels and identify factors which facilitate or constrain adherence to ART among adults in Botswana, and to identify and recommend possible interventions to improve adherence.

### Methods

The study used a cross-sectional survey method, with both quantitative and qualitative research methods of enquiry. Adherence rates were measured using patient self-report methods (two-day recall, one-month visual analogue) and one-month pharmacy pill count. Information on how certain factors influenced adherence was collected using in-depth interviews, semi-structured interviews and focus group discussion (FGD) with ARV users, policy-makers, health care providers and the community.

### Results

A total of 514 patients were interviewed, using a structured questionnaire. The mean adherence measures were: two-day recall 98% (N=508), one-month self-recall (visual analogue) 92% (N=496); and one-month pharmacy pill count 93% (N=443). The optimal adherence rates (defined as the proportion of those who take their medication at least 95% of the time) were 75% using the pharmacy pill count, 60% using the self-report (visual line), and 96% using the self-report (two-day recall method). The composite optimal adherence rate (average of the optimal adherence rates using the three

methods) was estimated to be 77%. The quantitative data revealed that the most common reasons cited for missing medication were: forgetfulness (18%), logistics and costs (13%), work and home duties (12%), stigma (7%), lack of care/support (4%), misunderstood instructions (3%), lack of food (2%) and alcohol abuse (2%). There was no association observed between gender and adherence. A higher proportion of those who were employed (65%) achieved optimal adherence rates than those who were unemployed (55%).

The qualitative data suggested that some of the facilitators of adherence were: acceptance of HIV status and disclosure; self-motivation to adhere to medication (self-efficacy and the ability to take and adhere to ART); belief in the efficacy of treatment (ARVs); pre-treatment health state; the need to care for others (especially children and the elderly); perceived availability of social support; and an effective adherence counselling programme. Factors that constrain adherence were identified by interviewees as: non-acceptance of HIV status; non-disclosure of HIV status and of being on ART; perceived lack of social support; stigma; logistics; treatment-related costs; and alcohol abuse. While concerns about long waiting times at the health facilities and lack of food were brought up during the interviews and discussions, these were viewed as inconveniences and not necessarily linked to sub-optimal adherence. In addition, information from policy-makers suggests that the unreliable availability of ARVs at Central Medical Stores and some health facilities could have an impact on patients' ability to adhere to ART.

## **Conclusions and recommendations**

The adherence rates found in this study are comparable to other studies in developing countries. Adherence is a complex issue and multi-dimensional approaches are required to both address the constraints and strengthen the key facilitators of adherence. Efforts to determine the level of adherence among patients on ART is complicated by the general methodological difficulties of adherence assessment. There is no gold standard of adherence assessment. While the two-day recall measure may be useful for on-the-spot individual patient adherence counselling, we recommend using the visual analogue scale and the pill counts for routine adherence monitoring.

In this study the critical barriers to adherence identified were: forgetfulness, lack of transport fare to the health facility, non-acceptance of HIV status, fear of discrimination and stigma, alcohol abuse, and non-supportive home and work environments. Although side-effects occur in a significant proportion of users, this was not perceived as a barrier to adherence.

Facilitators of adherence were found to include self-efficacy, social support, an effective adherence counselling programme, perceived benefits of the medication, and a desire to stay alive for the sake of others.

Efforts to improve the level of adherence require a collaborative approach involving the patient, the community, health workers and policy-makers, and a focus on ways of addressing environmental and structural constraints.

Some of the recommendations identified include the development of practical guidelines for implementing adherence management strategies. These should include guidelines for: continuous adherence counselling; bringing treatment closer to home; adoption of a family care model approach to ART; use of practical reminders; adherence case management; and the use of medication organizers (pill boxes partitioned to display the daily or weekly sequence of pills to be taken). In addition, the establishment of a transport voucher scheme should be considered for people who genuinely cannot afford the cost of transport to collect their medication. Such interventions should be evaluated to assess their effects on adherence.

Furthermore, since acceptance of HIV status, disclosure and gender were found to be the main emerging themes in the qualitative data, further studies are needed to explore these variables in greater depth. Programmes targeting men to inform them about HIV-related issues should also be developed. This would help increase the enrolment of men in ART programmes, help them to better understand the gender issues around HIV, and mobilize them to be protectors and supporters of women in the fight against HIV.



## **Chapter 1: Introduction**

In 2005, Botswana had a population of almost 1.8 million people, of whom an estimated 350 000 people were living with HIV (UNAIDS/WHO, 2005). In 2002, Botswana became the first country in sub-Saharan Africa to launch a national antiretroviral therapy (ART) programme in the public health sector. The ART is provided free to all citizens who are eligible for treatment.

While ART has improved the lives of many worldwide, lack of adherence to ART is still a major challenge to AIDS care. Failure to achieve optimal adherence to ART may lead to an increase in the replication of HIV and the development of viral mutations. This can result in treatment failure and accelerate the emergence of drug-resistant strains of HIV, with severe consequences for public health (Bangsberg et al., 2000; Turner, 2002).

As Botswana scales up access to ART in all its health facilities, there is a critical need not only to estimate the rates of adherence but also to understand the key factors (motivators and barriers) that influence adherence, and to apply the lessons learnt in order to improve both existing and future ART programmes. In order to do this, this study targeted antiretroviral (ARV) users, health workers, policy-makers, community members and other stakeholders in an effort to identify key factors which influence adherence. It was designed to facilitate the development with other stakeholders of specific interventions to improve adherence.

### **1.1 Research problem**

Antiretroviral therapy has been available through the public sector in Botswana since 2002. But there is continuing concern at the level of adherence. Studies conducted in Botswana have reported adherence levels of 83% (Nwokike, 2004) in the public sector and 54% (Weiser et al., 2003) in the private sector – rates below the minimum level of 95% required for treatment success and to help delay the emergence of drug-resistant strains of HIV.

To date, studies in Africa have mainly reported on adherence rates (Gill et al., 2005). However, qualitative studies are also needed in order to identify barriers and facilitators to adherence. Kumarasamy et al., (2005) identified the main barriers as treatment-related costs, privacy, and stigma, while the facilitators were the perceived benefits of ART, awareness of the consequences of sub-optimal adherence, and social support mechanisms.

## **1.2 Research questions**

- ◆ What is the rate of adherence to ART?
- ◆ What constitute barriers to adherence in patients on ART?
- ◆ What are the facilitators of adherence to ARVs among patients on ART?
- ◆ What factors at the community, facility and national level influence adherence to ART?

## **1.3 Study objectives**

To identify factors which facilitate or constrain adherence to ART among adult ARV users in Botswana.

### **1.3.1 Specific objectives**

- ◆ To quantify rates of adherence to ART.
- ◆ To determine what motivates and sustains good adherence.
- ◆ To determine barriers to good adherence.
- ◆ To determine factors at the community, health institution and national levels that influence adherence.
- ◆ To determine the relationship between the factors identified and adherence.
- ◆ From the lessons learnt, to identify and recommend possible interventions to improve adherence.

## Chapter 2: Background

### 2.1 History of HIV and AIDS in Botswana

Botswana's first AIDS case was reported in 1985 and since then HIV prevalence has continued to rise dramatically. Today, HIV prevalence in Botswana is among the highest in the world. In 2003, Botswana's second generation surveillance system (National AIDS Coordinating Agency (NACA)) Technical Report, November 2003: Botswana 2003 Second Generation HIV/AIDS) estimated HIV prevalence to be 37% among pregnant women aged 15-49 attending Government antenatal clinics. This level appears to be stabilizing at around 30%-40%. In 2004, a first population-based survey estimated that 17% of the population aged 1.5-89 years were living with HIV.

Botswana mounted a strategic response to the HIV epidemic in three phases. The first phase (1987-89) focused mainly on the screening of blood to eliminate the risk of HIV transmission through blood transfusion. The second phase (1989-97) saw the introduction of an information, education and communication (IEC) programme. The third phase (1997-2002), was multi-pronged, with a focus on areas including education, prevention, comprehensive care and the provision of ART. The NACA, which was established in 2000, was given responsibility for mobilizing and coordinating a multi-sectoral national response to HIV (NACA, 2003).

### 2.2 Botswana's ART programme

In March 2001, the President of Botswana, Festus Mogae, announced that the Botswana Government would provide ARVs free of charge to all citizens of Botswana who qualify for treatment. The programme became known as '*Mas*' (the Setswana word for 'dawn'). An assessment of the Botswana health care system and infrastructure was carried out in May 2001, led by NACA, the Ministry of Health (MoH), African Comprehensive HIV/AIDS Partnership (ACHAP), and consultants from McKinsey & Company. The consultants concluded that a national AIDS treatment programme could be realistically and practically implemented using a phased roll-out approach to reach a total of 110 000 people in need of treatment over the next 6-8 years. The strategic recommendations to implement the programme concerned the wide-scale recruitment of skilled human resources, strengthening capacity for HIV diagnosis and testing, the implementation of counselling, education and support services and development of an information technology (IT) infrastructure.

The UNAIDS-brokered Accelerating Access Initiative was established at the international level in May 2000 to help increase access to AIDS care and treatment in developing countries, including high-burden middle-income nations. It is now a partnership of the UN with seven pharmaceutical companies (Abbott Laboratories, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, F. Hoffmann La-Roche,

Gilead Sciences and Merck & Co., Inc.). The initiative provides a framework for bilateral company-government negotiations, and does not necessarily involve UNAIDS or other UN organizations. The MoH and the supplying companies in Botswana have individual agreements with the companies participating in the Accelerating Access Initiative (except for Merck, which is handled via ACHAP). In 2001, the Government of Botswana set up a cross-Government Task Force for ARV Drugs Price Negotiations to prepare for the launch of an ART programme in 2001–2002. The Task Force met with individual company representatives to agree on initial supply arrangements and prices, according to the framework of the Accelerating Access Initiative. Since then, companies have continued to offer price reductions to Botswana, in line with overall company discount strategies. The government-negotiated prices are for distribution in public sector or Government-supported health facilities. Significant (but lower) discounts are also negotiated by wholesalers serving the private market, particularly for use by the insured sector.

In 2002, Botswana officially launched an ART programme on a national scale. The national ARV roll-out in Botswana also involved a public-private partnership arrangement. The major partnership involved the Government, the Bill and Melinda Gates Foundation, the Merck Company Foundation/Merck & Co., Inc. and ACHAP. Other key partnerships include the Botswana Harvard Partnership (BHP) and the Botswana-USA (BOTUSA) project. Established in July 2000, ACHAP supports the goals of the Government to reduce the incidence of HIV and significantly increase the rate of diagnosis and treatment of the disease, by rapidly advancing prevention programmes, access to AIDS treatment and care, and patient management. The Bill and Melinda Gates Foundation and the Merck Company Foundation have each dedicated US\$ 50 million over five years towards the project. Merck & Co., Inc. is donating two ARVs for appropriate treatment programmes developed by the Government for the duration of the initiative. The BHP provides training and technical support for health care workers involved in the programme, and directs operational research for programme improvement.

The ART programme was launched initially in four sites in Botswana, two referral hospitals and two district hospitals. The programme expanded to such an extent that by end-2004, all 32 district and primary hospitals throughout the country were providing ART. By end-2005, an estimated 85% of those in need of treatment were reported to be on ART (WHO, 2006). Overall, approximately 63% of the ART patients are female and most are aged 30-40 years. The next phase involves plans to roll out ART to clinics that serve as satellite clinics and also to strategically target areas from which the current sites are inaccessible.

## **2.3 Literature review**

A dramatic reduction in HIV-related morbidity and mortality has been recognized in countries where ART has been made widely available (Anna et al., 2002). However it is also recognized that extremely high levels of adherence to ART (at least 95%) are needed to ensure optimal benefits, and that this may often be complex in terms of the pill burden, dietary restrictions and dosing frequency. Where adherence is sub-optimal,



HIV rapidly selects for resistance (Papella et al., 1998), in part due to rapid and error-prone replication (Perelson et al., 1996) but also often aided by the low genetic barrier of several ARVs to resistance (Kuritzes et al., 1996). Though effective adherence levels have not been fully defined for ART, levels of adherence below 95% have been associated with poor virological and immunological responses (Paterson et al., 2000; Orrell et al., 2003). Other data suggest that 100% adherence levels achieve even greater benefits (Fischl et al., 2000). Estimates of average rates of adherence to ART range from 50% to 70% in many different social and cultural settings, and the risks associated with sub-optimal adherence are extensive at both individual and societal levels (Chesney et al., 2000; Bangsberg et al., 2000; Liu et al., 2001; Nemes et al., 2004; Saferen et al., 2005).

Concerns about low adherence have been cited by those who question the feasibility of rapid scaling up of ART programmes in resource-poor settings (Stevens et al., 2004; Gill et al., 2005). Harries et al. (2001) argued that adherence problems would constitute a perceived significant barrier to the delivery of ART in sub-Saharan Africa. They warned that unregulated access to ARVs in sub-Saharan Africa could lead to the rapid emergence of drug-resistant viral strains and individual treatment failure, curtailing future treatment options and leading to the transmission of drug-resistant strains of HIV. The authors also maintained that, at present: there are few health care providers skilled in the provision of ART and in the management of patients who are on treatment; the existing health infrastructure is incapable of monitoring viral load, immune status, or the side-effects of ARVs; medicine procurement and distribution systems are weak; and interruptions in the medicine supply chain are likely. In addition, they highlighted current concern about the theft of medicines from health institutions for sale in the market, shops and private clinics, and across national borders.

### **2.3.1 Measurement of adherence**

There is no gold standard by which to measure adherence to medication. Many studies employ a number of methods, either alone or in combination to measure adherence. The most common include: electronic drug monitoring (EDM) devices, pill counts, biochemical markers, pharmacy refill records and various self-reporting tools such as questionnaires and visual analogue. According to Gill et al. (2005) the hierarchy of adherence measures ranks physician and self-assessment report the least accurate, pill count intermediate and EDM the most accurate adherence marker. However, no single measure is appropriate for all settings or outcomes. It has been found that the use of more than one measure of adherence allows the strength of one method to compensate for the weakness of the other and to more accurately capture the information needed to determine adherence levels (Vitolins et al., 2000).

Studies in African settings have indicated optimal adherence rates (i.e., the proportion of patients who adhered to their ART schedule at least 95% of the time) ranging from 54% to 98% depending on the measure used: Botswana (Weiser et al., 2003: 54%); Nigeria (Daniels, 2004: 79%); South Africa (Ferris et al., 2004: 77%; Darder et al., 2004: 80%); Uganda (Byakika-Tusime, 2003: 67%; Munganzi, 2004: 98%); and Rwanda (Omes, 2004: 87%).

### **2.3.2 Factors affecting adherence**

A number of factors have been associated with adherence to ART and are commonly divided into five intersecting categories (Reiter et al., 2003). These categories are: patient variables, treatment regimens, disease characteristics, patient-provider relationship, and clinical setting.

#### *Patient variables*

Patient variables include sociodemographic factors (age, gender, race, income, education, literacy, housing status, HIV risk factors) and psychosocial factors (mental health, substance abuse, sociocultural issues and support, knowledge and attitude about HIV and its treatment) (Carrieri et al., 2002; Nemes et al., 2003; Murphy et al., 2004; Machtinger and Bangsberg, 2005).

Sociodemographic and psychological issues have great potential to impact on adherence. For instance, family support and religious beliefs about illness and medication may influence motivation and adherence (Becker, 1990; Haynes, et al., 1996; Chesney, 1997). The issue of disclosure has also been found to have serious implications for adherence (Ormazu, 2000; Klitzman et al., 2004; Zea et al., 2005). For example, the use of medication may inadvertently reveal a person's HIV status; poverty may prevent individuals from following treatment-related dietary advice; drug and alcohol abuse may impair judgment and the ability to adopt and maintain routine medication use; and family responsibilities may require adults to place the health care needs of others before their own. Mental health problems such as depression have been associated with low adherence in HIV-positive adults and adolescents as have other psychological variables such as perception of one's ability to follow a medication regimen, or self-efficacy (Singh, 1996; Eldred, 1998; Murphy, 2001; Tuldra, 2002). Beliefs about health and illness, in particular about the necessity of medication to ward off illness and concerns about potential medicine-related adverse events have been found influential in both HIV and other disease areas (Horne, 2001).

Although side-effects have been cited by some studies in developed countries as predictors of adherence, experience of symptoms and views about medications may be complex and may vary according to the type of regimen (Chesney, 2000; Carr and Cooper, 2000; Ammassari et al., 2001; Carr, 2002; Murphy et al., 2004). Symptoms may stimulate the use of medications by acting as a reminder or reinforcing beliefs about the necessity for treatment. However, patients' expectations of symptom relief are also likely to have an important effect. This could be problematic if expectations are unrealistic, or where treatment is given for asymptomatic disease, as occurs with HIV infection (Horne, 2001). In addition, patients' concerns about the potential harm of ART may be entirely rational. Horne and colleagues have proposed that for some individuals missed doses may be a logical attempt to moderate this risk by taking fewer medications (Horne, 2001). Patients who understand the rationale for ART and treatment failure report higher adherence levels than those without this information (Anderson, 1999; Horne, 2001). Efforts both to reinforce information provided verbally with written information to take home and to check that information has been correctly understood are likely to be beneficial, as patients commonly misunderstand their

health care provider's instructions. One study found that 13% of patients prescribed ART were not taking their medication correctly, despite believing that they were (Bangsberg, 2001).

However, studies investigating the role patient variables play as predictors of adherence have produced largely inconsistent results. The tendency to ascribe low adherence to (often deprived) social groups is a well-established trend in the general literature (Horne, 1998). However, as later experience with antibiotics would demonstrate, low adherence is not restricted to certain social classes but is widespread and unpredictable (Lerner, 1998). Moreover, adherence rates vary not just between individuals but within the same individual over time (Carrieri, 2002). Adherence is therefore best thought of as a variable behaviour rather than as a stable characteristic of an individual. Most people will exhibit low adherence some of the time (Horne, 1998).

#### *Treatment regimens*

These include the number of pills prescribed, the complexity of the regimen (dosing frequency and food instruction), the specific type of ARV and medication side-effects. The complexity of the regimen and side-effects caused by it are clearly associated with sub-optimal adherence (Machtinger and Bangsberg, 2005).

#### *Patient-provider relationship*

This includes the patient's overall satisfaction and trust in the provider and clinic staff; the patient's opinion of the provider's competency; the provider's willingness to include the patient in the decision-making process; the affective tone of the relationship (e.g. warmth, openness, cooperation); the compatibility of race/ethnicity between patient and provider; and the adequacy of referral.

#### *Clinic setting*

This includes the availability of transport, general environment, flexibility of appointments, perceived confidentiality, and satisfaction with past experience with the health care system. Chesney (2003) found that dissatisfaction with the health services is a predictor of non-adherence.

#### *Disease characteristics*

This includes: the stage and duration of HIV infection, associated opportunistic infections, and HIV-related symptoms. The severity of the illness could impact negatively or positively on adherence to ART.

## **2.4 Definition of concepts**

### *Adherence to ART*

Adherence is defined as the "extent to which a client's behaviour coincides with the prescribed health care regimen as agreed through a shared decision-making process between the client and the health care provider" (KITSO Manual, 2004; Carter, 2004). For the purpose of this study, adherence has been defined as the use of ARVs at the right frequency of dosing. We also checked the number of pills (correct dose) and the time patients were taking them, using a 'sun and moon chart'. Ability to keep to this

pattern of utilization is defined as 100% adherence, while adherence of  $\geq 95\%$  is accepted as optimal adherence. Levels of adherence below 95% are considered to be sub-optimal. A composite adherence measure was computed as the means of the optimal adherence rates of the three measures used.

### *Knowledge about HIV and ART*

The Oxford Dictionary defines *knowledge* as the information, understanding and skills that is gained through education or experience. For the purpose of this study, knowledge shall be assessed in terms of: what HIV is and how it can be transmitted; how ARVs work and how they should be used; whether the ARV users know that ARVs are not a cure and that they have to be taken for life. The level of knowledge was graded on a scale of 0 – 8, with a score of 75% and above depicting good knowledge.

### *Side-effects*

For the purposes of this study, medicine-related side-effects have been categorized according to patient/ARV user and biomedical perspectives. Where pills were missed because a patient assumed that they might be responsible for certain symptoms that are not measurable, this has been classified as a patient/ARV user perspective, while those instances where side-effects can be recorded and assessed in observable terms were regarded as a biomedical perspective.

### *Disclosure*

For the purposes of this research, disclosure was deemed to have taken place if a patient on ART had shared his or her status and the fact of being on treatment with at least one friend and/or any other person (including family members) for the purpose of deriving support if needed.

### *Treatment costs*

Botswana offers ARVs free of charge to any citizen who is eligible for treatment. Weiser et al. (2003) found the cost of ARVs to be a major predictor of low adherence in their cohort. However, since this study is conducted in the public health sector, where there is no longer a charge for ARVs, this study will focus on other treatment-related costs such as transport fares, foregone wages, expenditure on snacks and meals while waiting to be seen at the clinic, and increased spending on food as a result of being on ART.

## Chapter 3: Methodology

### 3.1 Introduction

This study was part of a three-country study on adherence to ART, which included Botswana, Tanzania and Uganda. The study proposals were submitted by participants of a WHO-run workshop on Promoting Rational Drug Use in the Community, conducted in Pretoria, South Africa, in September 2004. The proposals were appraised using a collaborative peer review process, following which research tools were designed at a workshop involving all three countries in Bagamoyo, Tanzania, in February 2005. Fieldwork took place in May and June 2005, and an analysis workshop for the Botswana team was held in Gaborone in July. The report was then prepared and finalized following a third workshop in Jinja, Uganda, attended by all three country teams. Technical advice was provided throughout by the Medical Anthropology Unit, University of Amsterdam, and by WHO.

### 3.2 Study design

This is a cross-sectional study which used both quantitative and qualitative methods to investigate the facilitators of and constraints to adherence to ART among adult patients in four public health facilities in Botswana. The research questions necessitated the triangulation of methods and this procedure was adopted in the study.

### 3.3 Study population

The study was conducted in four district hospitals across Botswana which were providing ART. The study population consisted of policy-makers, patients on ART (18 years and above) at the study sites, health workers and members of the local community.

### 3.4 Description of study sites

Botswana is a landlocked country in southern Africa, to the north of South Africa. Its population is mainly concentrated in the eastern part of the country and it has borders with Namibia, South Africa and Zimbabwe. The country is divided into nine districts and five town councils\*: Central, Francistown\*, Gaborone\*, Ghanzi, Jwaneng\*, Kgalagadi, Kgatleng, Kweneng, Lobatse\*, North West, North East, Selebi-Pikwe\*, South East and Southern. The study sites were located in North West (Maun), Central (Serowe and Mahalapye) and Kweneng (Molepolole) districts. Serowe and Maun were among the pilot sites and Mahalapye and Molepolole were the second generation facilities (Figure 3.1).

**Figure 3.1: Map of Botswana showing the study sites**



### 3.4.1 Maun

Maun is located in the north of Botswana and is a peri-urban tourist village with a population of over 124 000 (Ngami and Okavango) (Central Statistics Office (CSO), 2001). The village is home to a wide range of people of different backgrounds and a number of tourist companies are based there. It is the capital village of the North West district and most of the major council offices are located there. The Government hospital is situated in the central part of the village. At the time of the report, the hospital had 2690 registered patients, of whom most (2492) were on ART. There are three primary hospitals within 300 kilometres which also offer ARVs (Ghanzi to the south-west, Gumare to the north and Gweta to the south-east of Maun).

The ART patients are seen at the Infectious Disease Control Centre (IDCC) clinic which is located in a Portakabin close to the hospital entrance gate. The clinic is open Monday to Friday from 0730 hours. All the different units required to serve the patients are enclosed to form a quadrangle. The building is spacious and clean and has a waiting area that is large enough to accommodate patients. The entrance opens onto the reception area, where patients are registered for the day and given appointment numbers, and patient files are prepared and taken to the relevant officer. The clinic starts with a morning prayer and health talk organized by the staff for all patients in the clinic. The patients then disperse, moving on to the appropriate unit for their appointments.

### **3.4.2 Serowe**

Serowe is a peri-urban village situated in the central part of the country. It is the capital of the Central District Council and many Government offices and other departments are located there. It is home to the Bangwato tribe. There are two tertiary institutions: Serowe College of Education and the Institute of Health Sciences. The Botswana Defence Force training camp is located about 40 kilometres from the hospital.

Sekgoma Memorial Hospital, a district hospital, was built over 75 years ago. However, regular maintenance has ensured that the buildings and surroundings are clean. The hospital serves the over 42 000 residents of Serowe (CSO, 2001), as well as patients from its catchment area which has a population of over 153 000. At the time of the study, the hospital had 3403 patients – all of them on ART. The ART programme was started in the hospital in May 2002. At that time, the treatment centre consisted of a resource centre and a prefabricated unit with a conference room and two consulting rooms with a very small reception area. This unit and what would later be the definitive IDCC building were built through funding from ACHAP. The IDCC is now a very large pre-fabricated structure located by the hospital entrance gate. It has two major entrances, one leading to the reception for consultations and counselling and another leading to the ARV dispensary. The unit provides adequate space for patients and health care workers. The clinic is open Monday to Friday from 0730 hours. It also opens occasionally on public holidays to cater for patients who may have run out of pills. Patients are received within the reception area and issued with numbers on a first-come-first-served basis, although priority is given to very sick patients and emergencies. A member of the health team, invited priests and others lead the patients in morning prayers and devotion. This is followed by a health talk about HIV, AIDS and ARVs which is given by a nurse or lay counsellor (usually a person living with HIV (PLWHIV)). This talk includes the use of audiovisual aids and covers HIV infection, prevention, disease progression, treatment with ARVs and monitoring, side-effects, nutrition and adherence issues. Patients are registered by data clerks, and nurses check their vital signs before directing them to the appropriate room for consultation or counselling. The hospital now has capacity for CD4 testing, but this was not available at the time of the study.

### **3.4.3 Mahalapye**

Mahalapye is a peri-urban village located in the central part of the country. It is the capital of the Mahalapye central sub-district and most of the council's major offices are located here. Mahalapye Government Hospital is in the central part of the village. It is a 95-bed hospital which offers outpatient services, maternity services and general inpatient care. It serves as a referral facility for 44 health facilities in the sub-district, comprising one primary hospital, 15 clinics, 28 health posts and mobile clinics. Mahalapye sub-district has a total population of almost 110 000 people (Mahalapye District Health Team, 2005). It has four satellite clinics which refer patients to the IDCC when treatment is initiated. The hospital is located 200 kilometres to the north of Gaborone, along the main trunk road that runs across the country from the south to the

north. There is one primary hospital within 100 kilometres of this village which also provides ART.

At the time of the report, the hospital had 1960 registered patients of whom 1836 were on ART. Patients are seen at the IDCC clinic which is in a separate block of buildings located behind the main hospital. It is open on weekdays, with the exception of public holidays. All the different units required to serve the patients are grouped together, with the exception of the laboratory which is in the main hospital complex. The clinic is spacious and clean, but has only a small waiting area for patients. Patients meet the nurse on duty and their files are processed from the booking register, according to the order in which they arrived. They then queue to see the medical officer before going to the pharmacy to collect their medications.

#### **3.4.4 Molepolole**

Molepolole is a peri-urban village 50 kilometres to the west of Gaborone. It is the capital village for Kweneng district, which has a population of over 230 000 (CSO, 2001). The Scottish Livingstone Hospital is one of the second generation hospitals to offer ART. At the time of this report, the hospital had 2284 patients enrolled, of whom 1879 were on treatment. Although there is a primary hospital 40 kilometres south of Molepolole which also offers ART, there are no hospitals to the north and west which provide treatment services. As a result, some patients travel up to 200 km to access treatment at the Scottish Livingstone Hospital. The hospital consists of old buildings but a new ultra-modern hospital is currently under construction on an adjacent site. The existing hospital does not have a separate building for ART patients. All outpatients are attended to in the hospital outpatients unit, which has two separate consulting rooms for patients who come for AIDS management.

The ARV clinic operates four days a week from Monday to Thursday. All outpatients have their vital signs checked at the same reception area. Then patients who have come for AIDS management are given a number in a patient card - which is a different colour from the cards given to other outpatients - and join the queue for one of the two consulting rooms reserved for them. After the consultation, the ART patients go to collect their medication from the pharmacy which is housed within the outpatients department, while the other patients go to a different building to collect their medications. Adherence counselling and HIV-related specimen collection are provided at the resource centre, a Portakabin situated very close to the outpatients department. There is a television in the reception area/waiting room, and a conference room where patient education and counselling is done. Some reference books and videos are also available for patients' use. The Portakabin is often packed to capacity and some patients wait outside on the stone-paved area. Ambulances from different health posts and clinics are parked within the hospital. Ambulance transport is provided free of charge for ART patients who are very sick. Other ART patients can sometimes avail themselves of this transport if there is available space or if there is no public transport available to take them to the treatment centre.



### 3.5 Inclusion and exclusion criteria

All adult patients (aged 18 years or above) on ART at the four participating facilities who were willing to take part in the study were eligible for inclusion. Those who had just been referred or transferred from another site to the study site were excluded.

### 3.6 Selection and training of data collectors

The data collectors comprised research associates and social workers. An effort was made to ensure appropriate gender balance, so that any concerns about gender-sensitive issues could be addressed. Prior to data collection, a four-day training workshop was organized for the data collectors, which included the following: an overview of how the study came about; a presentation of the study proposal with a special emphasis on the objectives, methodology and data analysis; and a detailed collective review of the research tools. This involved detailed presentation and discussion in English, followed by discussion of the translated (Setswana) version of the research questions (since the data collectors would be interviewing respondents in Setswana). This training was followed by pre-testing of the tools at Palapye primary hospital, which was not involved in the study. Lessons learnt were discussed by both the data collectors and the researchers to help further modify the tools and clarify some of the issues. The following week, the tools were finalized, centrally coded and sent to the different study sites ready for data collection.

### 3.7 Qualitative data collection

Qualitative data were obtained using observations, semi-structured interviews, exit interviews and FGDs. The selection criteria are discussed under each tool below.

### 3.8 Observations

#### *Health facilities*

These were observed with a focus on issues such as structural outlay, privacy, conducive environment (structure, cleanliness, and workers' attitudes, availability of Standard Treatment Guidelines (STG) and Standard Operating Procedures (SOP); availability of medicines, adherence reminders, and availability of adherence support strategies.

#### *Health workers*

Four client visits (for ART users) per facility were observed during consultation. The type of health workers observed varied from site to site and included: receptionist/data clerks; nurses; doctors; social worker/lay adherence counsellors; and pharmacy personnel. The laboratory personnel were not observed because blood tests relating to AIDS treatment management were done by the IDCC nurses. The duty roster for each cadre was used to randomly select the staff members to be interviewed during the day of the visit. The clients observed were randomly selected from the register or as they waited for their consultation. Patients were observed over two days with two observations per day at different times of the day.

The focus was on the following: attitude; greetings; whether the patient was invited to ask questions and listened to; whether the health worker examined the patient when necessary; whether the patient was allowed to talk about any symptoms they were experiencing; whether patients were told what to do, where to go and when to come for medicine refill and review, and asked about possible side-effects; how well patients understood the instructions given and what kind of questions patients asked.

### **3.9 Semi-structured interviews**

#### *Health workers*

At each study site, four health care workers involved in ART patient care were interviewed. This included the nurse, doctor, social worker/counsellor and pharmacy personnel. The health workers were randomly selected from the duty roster of the day from among health workers who had been involved in the management of AIDS patients for a minimum of three months.



Health workers at Maun Clinic, Botswana, take time from their busy schedules to entertain a young visitor.

The questions focused on the following: level of formal and non-formal training; use of SOP/STG; perception of the job; information and communication; availability of medicines; facilities and technical skills; perceived job satisfaction; problems and possible solutions. The interview also solicited demographic, socioeconomic and cultural information, general assessment of adherence, report of adherence in the previous three months, reasons for low adherence, reasons for high adherence, opinions on the quality of health care provided and on ways of improving adherence. It also assessed the counselling support available for health care workers caring for AIDS patients (care of carers).

*ART patients*

Five semi-structured interviews were conducted at each site. The patients were randomly selected from the register after determining the number of patients expected on the day of the site visit. Since the proportion of female patients among ART patients is higher than that of males, a gender mix of three females and two males was established. These interviews focused on the following: background information on the informant; perceived benefits of ART; adherence problems and possible solutions; social network and support; perception of quality of care in current treatment centre; cost considerations; views and experiences of ART; brief history of diagnosis and treatment.

*Policy-makers*

The interviews with policy-makers proved to be difficult because none of those selected for interview could be contacted. As a result, information was obtained from the Programme Manager of the National ARV Programme (MASA), the Chief Pharmacist at the MoH and the Principal Pharmacist at Central Medical Stores. The questions focused on the following: national roll-out plan; procurement of medicines; availability and sustainability of medicine supply and budgeting; adherence support and maintenance strategies; and national monitoring and evaluation system.

*Key informants*

The teams had planned to interview two to five key informants selected among the community members involved in HIV-related issues, using semi-structured interviews. However, most of the sites did not manage to do so. Only one site managed to interview the health workers who had accompanied patients from the referring facilities and one officer from one of the orphanages which also hosts a PLWHIV support group. The interviews were supposed to be held with community members such as: a church leader, home-based care volunteer, councillor, AIDS support group leader and a traditional healer. The aim was to focus on the following: support for ART patients to help them adhere to treatment; strategies in place to help them adhere; and some of the factors that may lead to sub-optimal adherence. Although these different leaders were not interviewed due to limited time for the data collection, all of the above-mentioned community members were represented in the FGDs.

### **3.10 Exit interviews**

A total of 163 exit interviews were conducted with adult ART patients at the four sites. The selection of patients was done systematically and the interviews were spread out over several days, with five patients interviewed per day. From the determined sample size, the number of patients to be interviewed each day over the five-day period was determined. The number of patients expected in a given day was obtained from the data clerk's registry for those coming for doctors' review and laboratory tests, and from the dispensary for those coming for medicine refill but also for verification of the doctors' appointments. The expected number of patients was then divided by five to determine the  $X^{\text{th}}$  patient who would be picked and then every  $X^{\text{th}}$  patient was picked until five patients had been interviewed per day. If the patient declined, the immediate next patient was selected.

### **3.11 Focus group discussions**

The FGDs were conducted with ART patients and with representatives of the local communities at the different sites.

#### *ART patients*

Administrative records, which include the pharmacy refill register, medical consultation appointment visit, and information from lay counsellors at the health facilities, were used to recruit the participants for the FGDs with ARV users. Efforts were made to include some of the patients who had been identified as having adherence problems. A total of eight FGDs were conducted, two per site, consisting of 8-10 persons per group. At each site, there was one FGD with female ART patients and another with the male patients.

The FGD was designed to provide insight into: patients' knowledge and perceptions of their illness and response to it; knowledge, perceptual understanding and expectations of treatment and social support. The FGDs also explored whether adherence was a problem among ARV users; and if so, what were the causes of sub-optimal adherence and the reasons for failure to adhere; and how some patients managed to maintain high levels of adherence.

#### *Community members*

The participants for community FGDs were selected with the assistance of the district HIV coordinators and leaders of PLWHIV support groups. Most FGDs included representatives from the PLWHIV support groups, traditional healers, members of faith-based organizations and home-based care volunteers. There were two FGDs per site for the community members, one for males and another for females.

The aim of the community level FGDs was to investigate community perceptions and beliefs about HIV, AIDS and ARVs as well as their perception of factors affecting adherence to ARVs. The FGDs also sought to elicit views on possible solutions and interventions that might improve adherence.

At the end of each FGD (for patients and the community), there was a debriefing session to give a general overview of what had been discussed, the problems identified and the possible solutions offered. Plans were made to refer patients, where necessary, for social, clinical or emotional support, but none of the participants needed referral. The focus group meetings were not audio-taped, and the importance of confidentiality was reinforced. The groups were facilitated by one member of the research team, with another member taking detailed notes and recording specific quotations when possible. At times there was more than one note-taker, which enabled the notes to be more detailed. The note-taker and the facilitator debriefed each other after each focus group, and the notes from the group discussion were then typed up.

## **3.12 Quantitative data**

### **3.12.1 Sample size calculations**

The sample size for the quantitative data required to obtain estimated proportions with 95% probability level was estimated using the CSURVEY design in Epi Info 6 version 3.22 (Centers for Disease Control and Prevention (CDC), 2004). The estimated total numbers of adults on ART in the study sites at the time of the study were 1425, 2400, 2055 and 1308 for Mahalapye, Serowe, Maun and Molepolole respectively. This was based on the assumption that 85% of the patients achieve optimal adherence (i.e. have adherence rates of  $\geq 95\%$ ). These estimates were arrived at using the reports from the health care providers and predicted rates for Botswana (Weiser et al., 2003). Using the CSURVEY design in Epi Info 6, version 3.22 (CDC, 2004) (with expected rates 85% and worst acceptable estimate 78%) the sample size was estimated to be 93, 96, 95 and 93 for Mahalapye, Serowe, Maun and Molepolole respectively.

### **3.12.2 Sampling and data collection**

Some of the quantitative data were collected using the exit interview tool, while the bulk of these data were collected using an adherence tool. The exit interview was carried out at the end of the patient's visit after collecting the medication, while the adherence tool was administered at any point during the consultation process but before collecting the medication.

Research associates conducted interviews for health workers, national level policy-makers and carried out the observations of health facilities. The research associates and the social workers conducted the 23 semi-structured interviews, 163 exit interviews and 514 adherence questionnaires with ARV users, while a research associate moderated 16 FGDs for community members and ARV users. Research associates collected the data and supervised the data collectors in a site where they are not resident. This was meant to increase the objectivity of the data collected and to address the issue of bias that might arise if research associates collected data in the facilities where they were employed.

## **3.13 Data analysis**

### *Quantitative data*

Quantitative data were initially stored in an Access database (Microsoft Access, 2003). Statistics were generated using Epi Info and SPSS version 13.0. The crude prevalence of adherence was estimated and its 95% confidence interval calculated. The Chi-square test was used to compare adherence rates among two or more categories. Logistic regression models were used to determine predictors of adherence and to estimate the independent and multiple effects of selected factors on adherence. All hypotheses were tested using  $\alpha = 0.05$  level of significance.

Adherence rates, measured as the percentage of pill intake over a specified time, were estimated using three methods: two-day recall using a 'sun and moon chart', which depicted the sun at different times of the day and the moon at night; visual analogue (a one-month recall using an uncalibrated 10 cm line); and a one-month pharmacy pill count. In the visual analogue, respondents were requested to indicate, by marking on the line, how they perceived their adherence over the past month. The overall adherence rate was estimated as a composite measure (i.e. the average of the one-month visual analogue, pharmacy pill count (one-month) and the two-day recall).

*Pill count (one-month)*

Pill counts were calculated by subtracting the number of pills returned from the number of pills issued. This provided the amount of medication used by the patient during this period. The amount used is then divided by the expected amount and multiplied by 100 to determine the percentage adherence per participant.

*Self-report (two-day recall)*

In the two-day recall the patients were asked to recall the frequency and timing of medication as well as their food intake over the previous two days. The data were captured in the sun and moon chart.

*Self-report (one-month recall)*

Participants were asked to indicate their adherence rate using a visual analogue line measuring 10 cm. The distance from zero to the tick on the line multiplied by 10 was considered to be the estimated percentage adherence rate.

Most of the patients interviewed were on first-line regimens, which include: efavirenz, lamivudine and zidovudine. These do not have any food requirements. However, some patients may choose to take them after meals to reduce nausea. Therefore since most of the ARV combinations used for first-line regimen in Botswana do not necessarily require that they be taken with food, the variable timing of taking medication and whether the drugs were taken with food or not were dropped in the analysis.

*Qualitative data*

The qualitative data collected were analysed with a view to gaining understanding of the factors that influenced adherence to ART. The data analysis process included a four-day workshop, with technical assistance provided by the University of Amsterdam. The work involved reading through the data from the qualitative research tools – which included the semi-structured interviews with health workers and ARV users, and the FGDs with ARV users and the community – in order to identify key themes. Initially, 28 themes were identified. The quotes were then manually pasted onto theme cards for easy perusal. A general thematic analysis was then conducted, focusing on similarities and differences of perspective between different groups of respondents. Further analysis revealed that the themes appeared to be linked, and these were then analysed together. Information was analysed to capture the different perspectives of the different actors: ARV users, health workers and community members. Where there were agreements or conflicting views, these were shown.

### 3.14 Emic perspective

As a research team, we agreed to take into account the emic perspective which assumes that 'there is no one correct view'. This is a helpful premise when considering the thoughts and opinions of ARV users, health care workers and the community, first differently and then collectively. This approach permits a nuanced interpretation of what has been reported by a wide variety of respondents.

Emic perspective is described as the "insider's" or "native's" interpretation of or "reasons" for their customs or beliefs. It describes what things mean to the members of a society. Emic measures focus on local and idiosyncratic content. In this context, the emic assessments provided a qualitative description of the idiosyncratic meaning ascribed to adherence. To understand the cultural context of health problems as it relates to adherence to ART in Botswana, it is essential to work with this key concept. The emic perspectives are useful for examining when we are seeing things from our own point of view and when we are trying to understand someone else's view of things. The emic perspective shows the meaning that people attach to things from their own cultural perspective. For example, some cultures view worms (*Ascaris*) in children as normal and believe they are caused by eating sweets.

Experience shows that health programmes that fail to recognize and work with indigenous beliefs and practices fail to reach their goals. Similarly, research to plan and evaluate a health programme must take cultural beliefs and behaviours into account in order to understand why programmes are not working and what to do about it.

Health and illness are defined, labelled, evaluated and acted upon in the context of culture. If you wish to help a community improve its health you must learn to think like the people of the community. Before asking a group of people to assume new health habits, it is wise to ascertain the existing habits, how these habits are linked to one another, what functions they perform, and what they mean to those who practise them. This approach is relevant to our research since it is based on an intervention outcome.

### 3.15 Ethical considerations

#### *Health research unit approval*

Approval was obtained from the Botswana MoH, through the National Health Research Committee and the managements of the four study sites.

#### *Informed consent*

The informed consent process involved the data collector giving a verbal explanation to each potential participant on the nature of the study, its purpose, the procedures involved, the expected duration, the potential risks and benefits involved, and any discomfort it might entail. Each potential participant was also informed that participation in the study was completely voluntary and that they could withdraw at any time, and that withdrawal of consent would not affect their subsequent treatment or relationship with the facility staff or any other person.

The participants were also assured that all information gathered would be treated as confidential and would be accessible only to the researchers, who would be responsible for its safekeeping. There would be anonymity in the reported findings.

### **3.16 Feedback**

Feedback was given to the health workers in a group discussion in order to share the preliminary results but also to clarify some of the issues where necessary. Study participants, institutions' managements, as well as various stakeholders will be given the study report when it is available. Providing feedback will hopefully be an opportunity for interaction with stakeholders in generating ideas about the possible interventions that may increase adherence. This is also important for ensuring ownership of any intervention strategies that may be developed.



## Chapter 4: Quantitative results

This chapter details the quantitative findings from the adherence measurement tool and the exit interviews from the cross-sectional study of ARV adherence in Botswana.

### 4.1 Adherence measurement tool results

#### 4.1.2 Demographic data and patient characteristics

Demographic data and patient characteristics are summarized in Table 4.1. A total of 514 participants from four study sites participated in this study. Of these, 122 (24.7%) were from Maun, 128 (24.9%) from Mahalapye, 115 (22.4%) from Molepolole and 149 (29%) from Serowe. The mean age was 38.3 years (95% confidence interval 37.4 – 39.2). Most of the patients are in the age range 20-40 (60.2%) and 15% were aged over 50 years. The sample included more women (67.6%) than men (32.4%) consistent with the current pattern of the Botswana statistics on ARV enrolment. Almost 35% had secondary school education level and 42% reported not being in any form of employment.

**Table 4.1 Demographic data**

Finding		No. (%)
Age (years) (n=507)	<30	95 (18.7)
	30-39	211 (41.6)
	40-49	127 (25.0)
	>50	74 (14.7)
Sex (n=510)	Male	165 (32.4)
	Female	345 (67.6)
Level of education (n=505)	None or incomplete primary	152 (30.1)
	Primary	153 (30.3)
	Secondary	178 (35.2)
	Tertiary or Vocational	22 (4.4)
Employment status (n=511)	Employed	298 (58.3)
	Unemployed	213 (41.7)

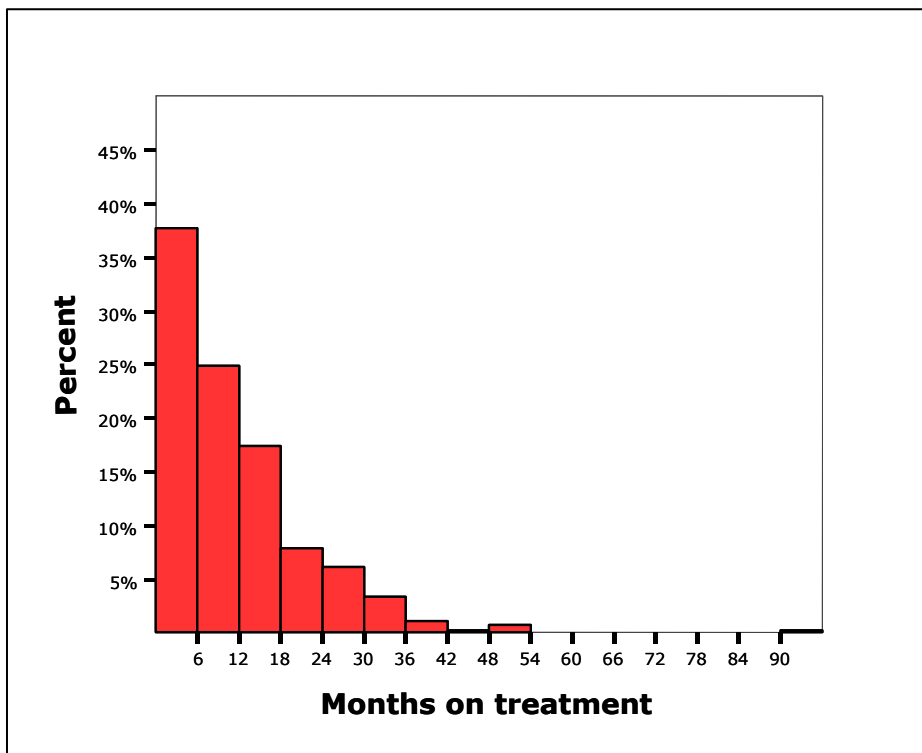
#### 4.1.2 Distance to health facility

About 25% of the participants travelled more than 50 km to the health facility and the maximum distance travelled was 200 km.

#### 4.1.3 Time on treatment

Most of the participants (90%) had been on treatment for less than 24 months, with an average and median of 11 and 9 months respectively (Figure 4.1). This reflects the nature of the expansion of the programme.

**Figure 4.1: Distribution of the months on treatment (N=505)**



## 4.2 Rates of adherence to ARVs

Assessments of adherence to ART are summarized in Table 4.2. The optimal adherence rates (indicative of being adherent at least 95% of the time) using the pharmacy pill count, self-report (visual line) and self-report (two-day recall method) were 75%, 60%, and 96% respectively. The composite mean adherence was estimated at 77%. The raw means of all measures (uncategorized) are summarized in Annex I.

Table 4.2: Adherence rates

Finding	Facility/No. (%)					95% confidence interval
	Maun	Mahalapye	Molepolole	Serowe	Total (%)	
<b>Self-assessment of adherence (visual line one-month recall)</b>	<b>(n=112)</b>	<b>(n=124)</b>	<b>(n=114)</b>	<b>(n=146)</b>	<b>(n=496)</b>	
Optimal adherence (at least 95%)	57 (51)	91 (73)	67 (59)	80 (55)	295 (60)	55.7 – 64.3
Sub-optimal adherence (<95%)	55 (49)	33 (27)	47 (44)	66 (45)	201 (40)	35.7 – 44.3
<b>Assessment of adherence (pharmacy pill count method)</b>	<b>(n=106)</b>	<b>(n=107)</b>	<b>(n=109)</b>		<b>(n=322)</b>	
Optimal adherence (at least 95%)	97 (92)	63 (59)	82 (75)	*	242(75)	70.3 – 79.7
Sub-optimal adherence (<95%)	9 ( 8)	44 (41)	27 (25)	*	80 (25)	20.3 – 29.7
<b>Assessment of adherence (Two -day recall)</b>	<b>(n=121)</b>	<b>(n=125)</b>	<b>(n=115)</b>	<b>(n=147)</b>	<b>(n=508)</b>	
Optimal adherence (at least 95%)	109 (90)	122 (98)	111 (97)	144 (98)	486 (96)	74.3 – 97.7
Sub-optimal adherence (<95%)	12 (10)	3 (2)	4 (3)	3 (2)	22 (4)	2.3 – 5.7
<b>Composite mean (average of 3 measures)</b>						
*Mean optimal adherence (at least 95%)	77.3	76.7	77.0	*75.5	77	73.1 – 80.9
Sub-optimal adherence (<95%)	22.7	23.3	23	24.5	23	19.1 – 26.9

\* Serowe composite mean optimal adherence rate calculated without pill count data because of data quality problems (pill count records) found at the site during data collection.

### 4.3 Reasons for skipping medication

The most common reasons cited for missing medication were: forgetfulness (18%), costs and logistics (13%), work and home duties (12%), stigma (7%), lack of support (4%), lack of food (2%) and alcohol abuse (2%). See Table 4.3 below.

**Table 4.3: Reasons for missed medication**

<b>Reason</b>	<b>No. cited as reason</b>	<b>% reported</b>
Simply forgot	90	17.5
Logistics and costs	67	13
Work or home duties	61	11.8
Stigma	36	7
Lack of care/support	18	3.5
Misunderstood instructions	16	3.1
Lack of food	11	2.1
Distance	10	1.9
Hospitalized	9	1.7
Alcohol abuse	9	1.7
Depressed	6	1.2
Feeling better	3	0.6
Pill burden	3	0.6
Shared pills	2	0.2

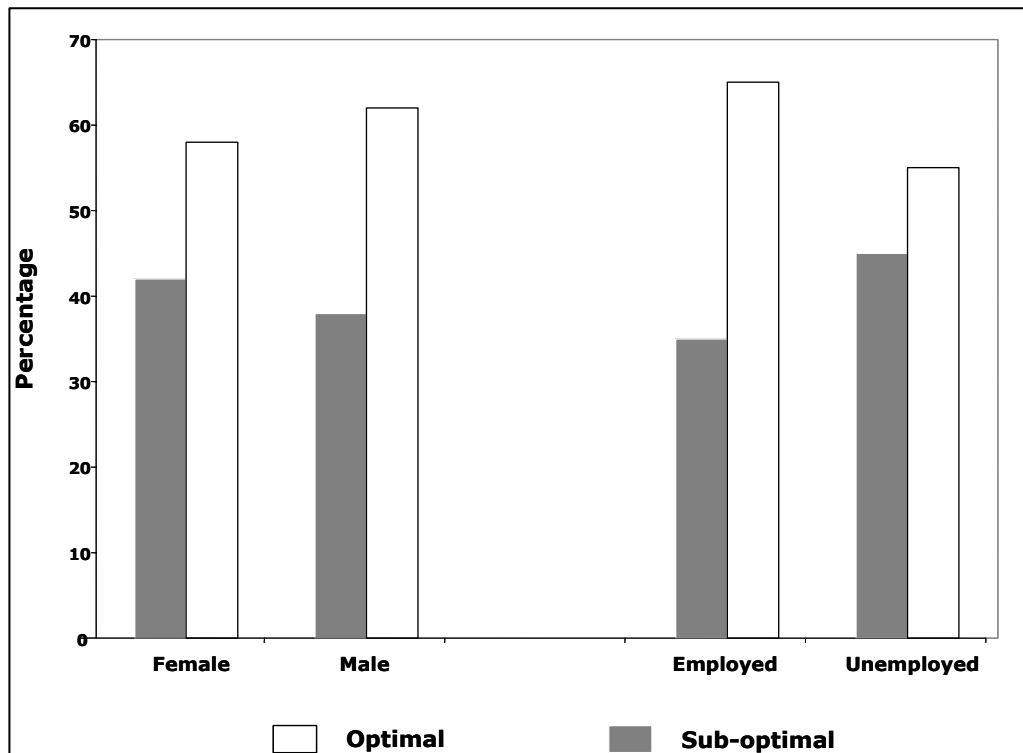
## **4.4 Factors affecting adherence to ART**

### **4.4.1 Costs**

Consistent with the current policy on registration costs, most participants either reported paying 2 pula/P2 (about 40 US cents) or did not pay anything. The P2 charge is the normal administrative fee payable by anyone who visits a health facility. Twenty-nine per cent of the participants indicated that they had experienced a loss of income as a result of coming to the clinic and 57% indicated changes in general expenditures. However, there was no significant association between employment status and reported loss of income ( $\chi^2=1.526$ ;  $p=0.217$ ). The median cost of travelling to the facility was P10 (approx US\$ 2.00) and 80% of the participants reported spending less than P15 (approx US\$ 2.50) for transport. The mean cost of transport was not significantly different between the optimally adherent and sub-optimally adherent ( $t=0.0208$ ;  $P=0.978$ ).

### **4.4.2 Gender and employment**

Using the visual analogue method, no association was observed between gender and adherence ( $\chi^2=0.743$ ;  $P=0.389$ ). However, there is a significant association between employment status and adherence ( $\chi^2=5.116$ ;  $P=0.024$ ), suggesting that people who are employed are more likely to adhere to treatment. A higher proportion of the employed (65%) had optimal levels of adherence compared to 55% among the unemployed.

**Figure 4.2: Adherence rates (measured by visual analogue) by sex and occupation**

#### 4.4.3 Knowledge of HIV and ARVs

The knowledge about HIV and ARVs was rated using eight questions worth one point each. Fifty-eight per cent of the participants got a score of at least 75%. For the purpose of evaluating the impact of knowledge on adherence, a cut-off of 75% was used (>75% good knowledge). A significant correlation was observed between knowledge of HIV and ARVs and adherence level (optimal and sub-optimal) for pill count ( $\chi^2=13.558$ ;  $P<0.0001$ ) and visual analogue ( $\chi^2=3.890$ ;  $0.049$ ). However, there was no correlation between knowledge of HIV and ARVs and adherence levels in the two-day recall measure ( $\chi^2=1.127$ ;  $P=0.288$ ).

**Table 4.4: Association between knowledge of HIV and ARVs with level of adherence and measures used**

Measure	Level of Adherence	Good	Poor	$\chi^2$ value	P-value
Pill count* (N=322)	Sub-optimal	69	11	13.558	<0.0001
	Optimal	156	86		
Two-day recall (N=496)	Sub-optimal	9	13	1.127	0.288
	Optimal	255	231		
Visual analogue (N=508)	Sub-optimal	95	106	3.890	0.049
	Optimal	166	129		

\* Serowe data excluded from the analysis.

#### **4.4.4 Education**

There was no association between educational levels and adherence rates ( $\chi^2 = 3.44$ ;  $p=0.751$ ).

#### **4.4.5 Quality of health care services**

The majority of the participants (92%) were satisfied with the quality of health care services.

#### **4.4.6 Side-effects**

Of the 58% of participants who reported having experienced side-effects, 8% reported having skipped their medication as a result.

#### **4.4.7 Treatment supporters/reminders and appointments**

Most of the participants (74%) said they had someone to remind them to take their medication. Twenty per cent reported having missed some appointments.

### **4.5 Predictors of adherence to ART**

Multivariate logistic regression analysis was performed on the measures of adherence using selected explanatory variables including age, gender, occurrence of side-effects, education, occupation, cost of transport, other treatment-related costs, loss of income, months on treatment, missed appointments, and knowledge of HIV and ART (Annex 2). The variable of missed appointments was a significant predictor of adherence (Wald statistic  $\chi^2=4.851$ ;  $p=0.028$ ) and was associated with levels of adherence to ARV treatment ( $\chi^2=5.86$ ;  $P=0.016$ ). This finding was also reported by Nemes et al. (2004).

Independent t-tests between the sub-optimal and optimal groups for age, distance to facility, cost of transport and months on treatment indicated no significant differences ( $P>0.05$ ) in both one-month recall methods (Table 4.5).

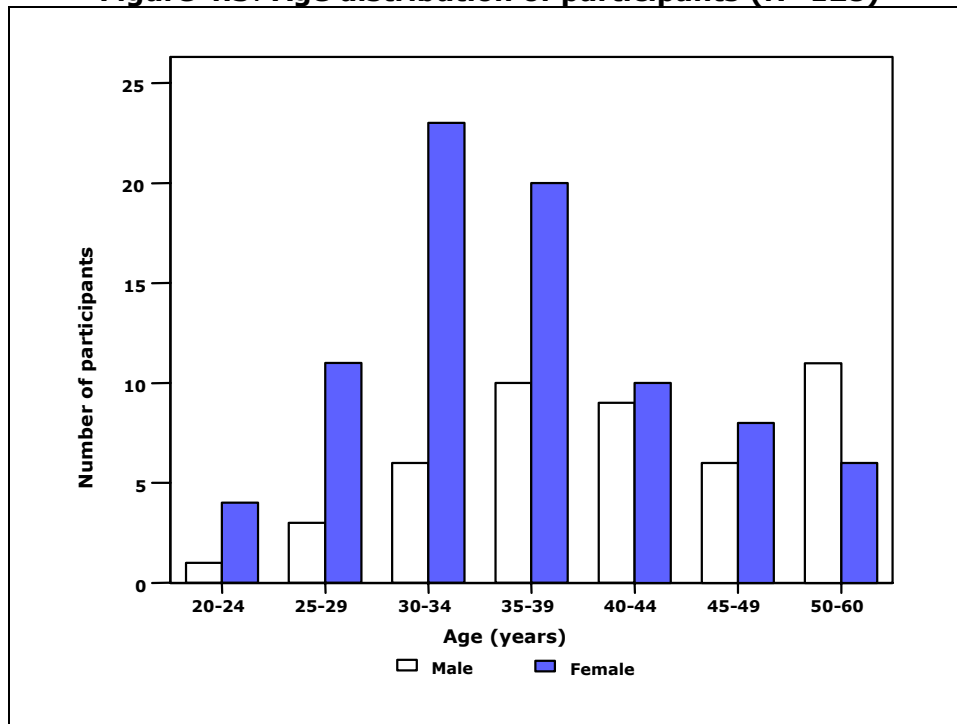
**Table 4.5: Independent t-tests for comparisons between optimal and sub-optimal adherence groups**

Variable	Visual line one-month recall		One-month pharmacy pill count	
	t-test	P-value	t-test	P-value
<b>Age (n=442)</b>	0.031	P=0.975	-0.781	0.435
<b>Distance to facility (n=492)</b>	-0.047	P=0.749	-1.746	0.082
<b>Cost of transport (n=479)</b>	0.028	P=0.978	-1.502	0.134
<b>Months on treatment (n=489)</b>	1.182	P=0.238	0.233	0.816

## 4.6 Quantitative results of exit interviews

Exit interviews were carried out with 133 (63%) participants, mostly females. This gender imbalance may reflect the fact that more females than males are infected with HIV in Botswana and/or the better health-seeking behaviour of females. Most of the participants were in the 30-44 age groups (Figure 4.3), 58% were not employed and over 80% had been on treatment for less than 24 months.

**Figure 4.3: Age distribution of participants (N=128)**



The respondents were asked what issues were covered in their discussion with the health worker during consultation. They reported that the issues discussed with the health workers were counting of pills (97%), side-effects (32%), refill and check-up dates (19%), medication schedule and referral for counselling for any missed doses (32%), and effects of missing doses and other medications taken (18%). Seventy-seven per cent of the participants admitted to have missed some doses since they started treatment. In order to remind themselves to take their medication the participants mentioned the use of mechanical devices (80%) (i.e. radios, cell phones, watches), a partner or family member (11%) and self-discipline (9%).

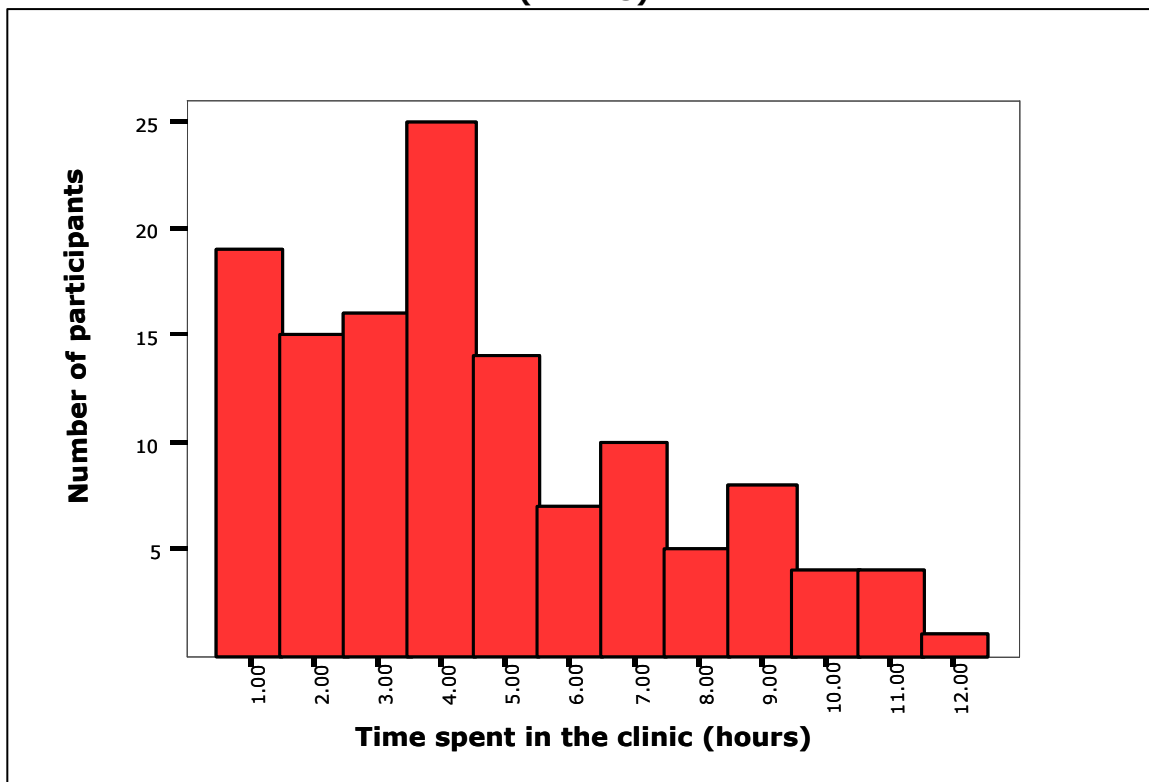
In terms of costs, 44% reported an increase in expenditure and 37% reported loss of income due to clinic visits. Respondents were largely satisfied with the quality of care they received. Generally the participants felt they: were listened to (99%); were given a chance to state their problems and ask questions (99%); were treated with respect (98%); trusted the health workers (94%); and were allowed privacy during consultations (89%). The major issue that was raised by the participants was the length of time they

had to spend waiting to be attended to at the health facility (Figure 4.4). Over half (53%) of the respondents reported spending at least four hours at the clinic. In some cases, participants spent the whole day there after arriving two hours ahead of opening time (Figure 4.5)

**Figure 4.4: Satisfaction with the amount of time spent at the clinic (N=133)**



**Figure 4.5: Distribution of the time spent by participants at the clinic (N=128)**





## Chapter 5: Qualitative results

This chapter focuses on the findings from the qualitative data on the constraints and motivators of adherence to ART among adult patients at the four public health facilities in Botswana (Table 5.1). These data are based on the perspectives of patients on ART, the community and health care workers.

### 5.1 Constraints to adherence to ART

In the discussions on constraints to adherence, the study identified six interrelated themes. These are presented below, without any order of priority.

#### 5.1.1 Gender and non-acceptance of HIV status

Gender was identified as being strongly associated with acceptance of HIV status. Respondents stated that women talk about HIV and test early, and so are more likely to accept their status than men. Men were said to avoid testing for HIV. But when their partners test first, they often blame them for bringing the virus. As a result, men can become angry and violent and tell the partner not to bring the medication into the ('his') home. In Maun, there were stories of women who were hiding their ARVs in a neighbour's house for fear that their husband would discover that they were still taking the pills. This interfered with adherence in that most of the time these women would be dependent on their neighbour's schedule for access to their medication. Women were also reported to avoid telling their partners about their HIV-positive status in order to protect the relationship. This results in re-infection and in the hiding of medication.

Most respondents agreed that individual acceptance of positive HIV status is key to the behavioural changes that are required for a good health outcome. Non-acceptance of positive HIV status and of life-long dependency on ART for survival were perceived by many respondents as a major barrier to adherence. A female ARV user put it succinctly:

*"In life people feel shy to tell other people about their status and that they are on ARVs. People do not advise them because they do not know they are on treatment. When one has a visitor, he/she will start skipping treatment. They end up dying because they fail to take the treatment."*

When an ARV user is in a state of denial, it is difficult to disclose to others, medicines are hidden from friends and relatives, and when necessary they skip medication to ensure that friends and family do not discover that they are HIV-positive. A male ARV user explained:

*“I usually miss my medications when I visit friends because I have not told them about my HIV and so I do not want them to see my medications.”*

Meanwhile, a female ARV user said:

*“My boyfriend did not tell me his status and was against me going to test for HIV because I was pregnant. As a result he hid his ARVs from me. He kept all the other medications on the dressing table but one time when I was cleaning, I saw some bottles of medications hidden away. I wrote the names on the paper and went and asked the nurse about them. She told me they were ARVs. I went back and asked him why he did not tell me. I think he wanted me and the baby to die because he did not want us to get help by testing.”*

Many respondents thought that women were more likely to accept their HIV status than men and that women generally have better health-seeking behaviour than men. Some women consider the better health-seeking behaviour of women to be due to their desire to stay alive in order to care for their children and other loved ones, despite being blamed by men for the disease. Health care workers attributed the greater acceptance of positive HIV status by women and their better health-seeking behaviour to the fact that women have always been very close to the health care system through the maternal and child clinics.

One ARV user in a female FGD explained:

*“Women accept their status easily; we chat and get encouragements from other people. We like to know our HIV status even while still young without having children; we would like to know so that we may help significant others.”*

Another female ARV user said:

*“Men are stubborn. I had a partner and we had a child who later passed away. I tested and my husband accepted me but he refused to test himself. I wonder why he refused.”*

One of the men said:

*“Men are brave, strong. We believe in our tradition/culture. It is not easy for us to go and consult the doctor. Men believe in herbs but the disease doesn't tolerate that.”*

Respondents generally agreed that acceptance of status could result in increased disclosure and possibly in improved adherence.

### **5.1.2 Non-disclosure**

Non-disclosure was one of the themes that emerged as a barrier to adherence. Respondents stated that failure to tell someone (e.g. a friend or family member) could be due to reasons such as: fear of being discriminated against, stigma, job loss or abandonment. It was not uncommon to hear of people who were rejected by their

partners because they had revealed their HIV status. This problem is highlighted by the following quotes from a FGD involving female ARV users:

*“Those on treatment at times do not tell their partners.”*

*“Some women hide their status fearing to be dumped by their partners after disclosing their HIV status.”*

*“A man will leave you if you tell him.”*

Men, on the other hand, complained that women do not disclose their status in order to keep them in the relationship. One of them said:

*“Those who get pregnant while on treatment might not have told their partner.”*

The male respondents also maintained that no man would refuse to use a condom if they knew that the woman was HIV-positive. Meanwhile, young adults who were in relationships also found it difficult to disclose their status, because they are tested independently and do not necessarily know the status of their partner. One ARV user explained:

*“For us the unmarried youth, you will find that even when you know your status, it is not easy to disclose because you do not know your partner’s status. You end up hiding medications because when you tell them, they disappear after a short period. We usually weigh the situation because we would not want our names to be defiled.”*

If one partner is on ART, they may resort to pill hiding, occasional skipping of medications and failing to keep clinic appointments for refills or review, so their partner does not find out that they are on ART.

### **5.1.3 Perceived lack of social support, fears about stigma and privacy concerns**

Many participants discussed issues relating to lack of social support, fears about stigma and privacy concerns that acted as constraints to adherence. These issues are presented under the following three levels: individual, family/friends, and workplace.

#### ***Individual level***

Some respondents identified the personality traits of the individual as being important in determining how they perceive stigma, privacy issues, and the availability of social support. Lack of self-motivation was said to result in low adherence. People who lack self-motivation are less likely to disclose their status and therefore less likely to attract social support. And even where social support is available, there may be a tendency not to use it. This was supported by a female respondent who said:

*“My younger brother who was on treatment refused to take his ARVs, and even to talk to the social workers visiting at home. He never did well and ultimately died.”*

Some respondents perceived the partial integration of ART with other health services as exposing them to the likelihood of being stigmatized, as one ARV user at a semi-integrated health care facility explained:

*"We will like to have our own clinic instead of being mixed with these other people. They are always staring at us, especially when we come to this door (labelled "ARV Dispensary"). I like it at Princess Marina Hospital (in Gaborone) where ARV users are isolated from the rest of the people. Some people fail to come and refill here because they are shy to be seen by their friends."*

### **Family/friends**

Family social support and acceptance of a relative or friend living with HIV/AIDS, was found to depend on the nature of the existing bonds before the illness and how the individual has contributed to the relationship. A male ARV user said:

*"If you don't have a partner you are in trouble. The partner can take care of you when you are sick. The parents may say you only know them when you are sick, you used to go around with other ladies when you were fit. They deny you and offer you negative support."*

A female home-based care volunteer observed that:

*"Some of the patients are suffering. There is one man who is suffering because his wife does not want to care for him. She does not cook for him and does not give him his medicines. We sometimes try to bring him food but when she sees us, she chases us away. The man is so thin."*

Within the same family, some members may be more supportive than others, as a female ARV user explained:

*"I get support from my sister and my children. My nieces, they are always laughing at me and telling people that I have the virus. They would not even give me my medications when I am too sick."*

Most ARV users said they would not disclose their HIV status and the fact that they are on treatment to anyone if they believed it would result in stigmatization and a lack of support. Unresolved family conflicts may also result in lack of support. This was captured in the story of an ARV user, who said:

*"My discrimination did not start with my HIV status but emanated from family conflict. I ended up moving out of the family home with my children. I continued to meet obligation to the family but when I got ill and was hospitalized, they never visited me. Currently my parents have passed away. However, if there is illness or death of one of our relatives I do assist."*

### *Workplace*

The reaction of employers and employees towards HIV/AIDS in the work environment is a reflection of the attitude of the community and its culture. A supportive work environment creates a conducive atmosphere in which PLWHIV do not have to fear about stigma and discrimination.

Many of the respondents interviewed, especially those who worked as shop assistants, farm workers and for safari companies, cited non-release by employers as a barrier to adherence to treatment. Many of these workers said they could not even freely discuss the issue of their HIV status and treatment at work, for fear of being victimized by their employers. One ARV user said:

*"I was once ill-treated in my workplace and forced to transfer to a place about 400 kilometres away but I am supposed to see the doctor. I resigned from the work because I preferred to stay close to my treatment site."*

A female ARV user, who works as a shop assistant said:

*"I resorted to asking my relatives to pick up my medications because my employer refuses to release me to go and pick up my medications."*

In northern Botswana, freehold farms and safari companies are the major employers of unskilled labour. These work settings are sometimes located in difficult terrains, a long distance from the ART clinics. For some safari company employees, access to a treatment centre may be by air. In some of these settings, employees work for periods of three to four months before being entitled to a free flight back to the mainland. For these people, difficulties with transportation to attend clinics for treatment monitoring and medicine refills were major issues of concern.

One of the health workers explained:

*"For the employees in the ranches and cattle posts, transport to health facilities poses a problem. Some employers do not release their workers."*

There were reports of cases where individuals who worked on ranches and for construction companies were forced to take pay cuts for attending clinics. These attitudes by employers were said to constitute a barrier to adherence as people remained at work instead of attending the clinic. Most of the ARV users interviewed believed that more should be done by the Government to protect PLWHIV in the workplace, as this would help improve adherence.

#### **5.1.4 Logistics and costs**

In Botswana, patients do not pay for ARVs offered within the public sector. Logistics and costs were therefore viewed in terms of the availability of transport, transport-related costs, lost wages, money spent on snacks and food while attending appointments, and other treatment-related costs, as perceived by the ARV users.

In the qualitative survey, the health workers reported lack of transport – either no means of transport or no money to pay the fare - as the reason most frequently cited by patients for failing to attend the clinic for treatment review or medicine refill. Many ARV users, especially those who were not employed, said that lack of money to pay for transport was a problem. Some ARV users complained that the treatment centre was too far away and not always easy to access. An ARV user who had to travel from an outlying cattle post to the village to get a medicine refill said:

*“I once missed my appointment for refill because there were no vehicles coming here. I was in the stop from early morning and by noon I went back home. Fortunately I still had some medications.”*

Another ARV user from one of the remote villages said:

*“The clinic vehicle used to transport us. Now they say we are better so we should transport ourselves. I usually get ‘piece jobs’ and use the money to come and pick up my medicines.”*

#### **5.1.5 Misconceptions**

There were some concerns among ARV users about the language used to communicate the results of laboratory tests to patients. As one ARV user said:

*“One of the patients stopped the medicines because he was told that his viral load was undetectable, so he stopped taking his pills because he thought he was cured.”*

#### **5.1.6 Alcohol and substance abuse**

Alcohol abuse was cited as one of the reasons why some patients are not adhering to medication. It was reported that even the local newspapers had on several occasions cited alcohol abuse as one of the reasons for non-adherence. One of the respondents said:

*“Some of the patients who take alcohol end up forgetting to take their tablets or omitting treatment.”*

Another respondent said:

*“Those who take alcohol sometimes lose their drugs in the bars when they are drunk.”*

## 5.2 Facilitators of adherence to ART

In our efforts to identify facilitators to adherence six main themes emerged. These are presented below, not in order of priority.

### 5.2.1 Acceptance of HIV status and disclosure

Most respondents (ARV users, community and health care workers) agreed that individual acceptance of HIV status was key to the necessary behavioural change that is required for good health outcomes.

One of the ARV users said:

*“Since the beginning, I told myself that this disease is just a disease like any other disease. You should accept yourself.”*

Similarly, another ARV user said:

*“As long as one has accepted his/her situation and is committed to treatment, there will be no problems.”*

### 5.2.2 Self-efficacy and the ability to take and adhere to ART

Self-efficacy refers to patients' beliefs about their capabilities and their ability to exercise personal control. Perceived self-efficacy was stated as one of the key variables that was critical to adherence. Some respondents stated that it was important to be convinced that it was possible to take the medication correctly.

One ARV user explained:

*“Taking these medicines is a personal decision. When the time to take them comes, I take them regardless of whether I am hungry or not.”*

One of the strategies suggested by respondents was abandoning a previous lifestyle (e.g. alcohol abuse, womanizing) in order to focus on treatment. Some participants maintained that people who are highly motivated are more likely to be adherent to treatment.

One ARV user described the treatment as one that requires commitment and control:

*“This treatment controls one’s movement. When you go out, you got to return and take them.”*

Another ARV user said:

*“Problem why patients fail to take treatment is because they lack self-discipline.”*

### **5.2.3 Belief in the efficacy of ARVs in treatment/pre-treatment health state**

The fear of relapse or perceived vulnerability to negative outcomes from sub-optimal adherence was considered to be a major motivator of adherence. Most of the respondents stated that, despite being often preoccupied with their own health concerns and fears, the availability of ARVs had given them a “new lease of life.” Some of the respondents stated that individuals were motivated to begin treatment if they experienced a decline in their health status, believed that therapy would prolong life, and believed that they could cope with the treatment regimen and its potential side-effects. One of the respondents, who had recovered as a result of taking the ARVs stated:

*“If you had seen me a few months ago I could hardly get out of bed. I was like this (showing the smallest finger). Now here I am. You cannot even believe it. If you have been there, you will take them (ARVs).”*

Another male ARV user also stated in Setswana that “*rona re ka bo re seyo,*” which means: “*Some of us would not be here if it were not for the ARVs.*”

### **5.2.4 The need to care for others**

The desire to stay alive can be greatly reinforced by the recognition that your loved ones might not cope in your absence. Women were found to be always concerned about their children and aged parents. The desire to continue to be around for them for their sake was found to be a critical motivator for most women. These sentiments were shared by other female respondents:

*“We give birth to children, and we don’t want to orphan our children... I don’t want my children to be raised by a step-mother. Fathers are not good at raising children.”*

*“As women, we feel pity for our aging parents, especially if the other children are irresponsible. You wonder who is going to take care of the parents if you were to die first.”*

*“I feel I’m the best thing for my children. I’m afraid of dying and my baby has to suffer without me. My children are the best things that ever happened in my life. And I’m wondering how they would feel if they had to lose me.”*

### **5.2.5 Social support**

Social support is based on the kind of relationships and interactions that provide individuals with assistance or feelings of attachment. Generally, most respondents agreed that the availability of social support was critical for good adherence to ART.



Children were reported to be among the main providers of social support, with older (primary or secondary school age) children taking a leading role in reminding the parent (often their mother) of pill times. For those in stable relationships, the availability of social support from the partner was determined by whether that partner had tested and, if so, whether they had accepted their status.

One of the respondents said:

*“I once went to my mother and told her that I am taking life-long treatment and she accepted me. My husband also accepted me. He is the one who wakes me up to come for treatment.”*

Another said:

*“My husband is HIV-negative but he always reminds me to take my ARVs. My children also remind me.”*

### **5.2.6 Effective adherence counselling**

Adherence counselling is aimed at promoting adherence to ARVs and preventing further transmission of HIV. The respondents stated that they had received counselling before the initiation of therapy. The issues covered included: HIV and AIDS; mode of transmission; prevention methods; how ARVs work; the importance of adherence; side-effects and how to minimize them; interactions between ARVs and other medicines (including traditional medicines) and alcohol. The effectiveness of the counselling process was highlighted by some respondents who stated that, even though they do experience side-effects, they continue to take the medicines because they were warned about possible side-effects and informed that they would go away. Some also said they were given written information about this to take home.

One of the female ARV users said:

*“I learnt that I should not skip the medicines and I should adhere to the stipulated time. At one stage I skipped them and took them after the stipulated time. I told my nurse and I was assisted.”*

Some of the participants pointed out that there was also a need for continued counselling. One female ARV user said:

*“Even though initially we are given a lot of information, counselling is not adequate because it is only done once. Follow-up at home should be done to find out if one is really taking the medicines.”*

Similarly, a health care provider pointed out that:

*“Patients are given information during the initiation of treatment but it is necessary to continue reminding them.”*

## **5.3 Observation of health facilities**

### **5.3.1 Structural issues**

At the Maun, Serowe and Mahalapye study sites, patients gather at the IDCC clinics for their ARV consultations, adherence counselling, laboratory schedules and collection of their medications. These clinics are largely separate from the rest of the units within the hospital. In contrast, at the Molepolole study site, all outpatients were received at the hospital outpatients unit, which had two consulting rooms for people on ART. Two of the health facilities (Serowe and Maun), which happened to be first generation sites, had adequate space. The structures provided for adequate confidentiality, good counselling, laboratory services with adequate shade, and seats provided for the patients in the waiting area. However, in Mahalapye and Molepolole there was a lack of space, seats and shade in the waiting areas, and patients resorted to sitting in makeshift waiting areas. The little cover and shade that is available is inadequate to shelter patients if the weather is bad. In all four facilities the environment was found to be clean. At each of the facilities posters were strategically placed within the IDCC clinics, mainly explaining the importance of adherence to ARVs and the fact that these medicines suppress the virus but are not a cure for the disease. Some of the posters were in English and others in Setswana.

The service and staffing details are outlined in Tables 5.1 and 5.2.

**Table 5.1: Service details of each participating facility, as of May/June 2005**

<b>Sites</b>	<b>Date started ART</b>	<b>Total no. on treatment at facility by July 2005</b>	<b>Average no. of patients consulted per day</b>	<b>Average no. of patients for ARV medication refilling per day</b>
Maun	July 2002	2492	40	100
Serowe	May 2002	3403	60	150
Mahalapye	Oct 2003	1836	40	90
Molepolole	Oct 2003	1879	50	100

**Table 5.2: Summary of staffing for the IDCC at the time of data collection**

<b>Sites/ numbers</b>	<b>Medical officers</b>	<b>Nurses</b>	<b>Social workers</b>	<b>Pharmacy personnel</b>	<b>Laboratory personnel</b>	<b>Data entry clerks</b>	<b>Auxiliary staff</b>
Maun	4	6	3	4	6	4	3
Serowe	2	8	3	3	6	3	2
Mahalapye	1	6	3	2	6	2	1
Molepolole	1	4	4	3	6	1	3

### 5.3.2 Service provision

All facilities operated Monday to Friday, with the exception of Molepolole which opened only four days per week. The eligibility criteria were the same in all the facilities since they followed the national guidelines for commencement of therapy. The patients were encouraged to come with adherence support partners but the lack of a partner did not disqualify anyone from being put on ART.

At the Maun, Molepolole and Mahalapye sites, pre-treatment adherence counselling was done in a group session, whereas in Serowe this was done on a one-to-one basis. At Mahalapye, adherence counselling was done by a team of health workers consisting of a nurse, pharmacy staff, social worker, and dietician, while at the other sites it was done by one health worker at a time with a group of patients.



Seeking shade from the sun in Molepolole: patients wait for their appointments in the hospital grounds, outside the hospital chapel.

The adherence support mechanisms varied between the sites, in both the method of counselling used and in the follow-up of patients who were not achieving optimal adherence or who had stopped taking the ARVs. The similarities included the use of pill counts (with the exception of Serowe), encouraging patients to bring an “adherence buddy” at the start of therapy, and the use of cell phone alarm settings to remind them to take their medicines. A basket of food rations was also available for patients who were unemployed or no longer working because of illness and who did not have any other source of income. This was determined on the basis of an assessment by social workers, which included home visits.

At the time of the study, equipment for measuring CD4 counts and viral load was not available at any of the facilities. Maun, for instance, sends its viral load and CD4 samples to reference facilities by air courier and the other sites transport their samples by road to their tertiary referral hospitals. Other laboratory investigations, such as haematology, cultures and urine analysis were done on site. Since the completion of the study, Serowe has acquired the capacity for CD4 testing.

Language barriers were observed to be a problem during interactions between some expatriate health workers and patients.

## **5.4 National level policy issues**

The interviews with policy-makers proved to be difficult because the respondents originally targeted could not be reached. The few interviews conducted revealed that the programme roll-out in Botswana has been proceeding according to plan. However, concerns about the availability, affordability and sustainability of ARVs, as well as the shortage of human resources were raised by the respondents and considered to be major challenges for the future.

## Chapter 6: Discussion, conclusion and recommendations

### 6.1 Discussion

This report describes the findings of a study that explored factors affecting adherence to ART in four public facilities in Botswana. The study used both quantitative and qualitative methods. The strength of this mixed-method approach is its usefulness in addressing the complexity associated with issues relating to adherence. The aim of the study was to help design interventions that can assist in maintaining high rates of adherence, a critical need if the danger of widespread resistance to treatment is to be avoided (Paterson et al., 2000; Orrell et al., 2003, Stevens et al., 2005). Paterson reported that ARV patients who achieved less than 80% adherence have a virological failure rate of 87%. As Botswana scales up access to ART, it is important to maintain high levels of adherence.

This section will first present the discussion on the quantitative results and then explore the integration of the quantitative and qualitative results. The quantitative data were collected using an adherence survey tool and exit questionnaires. The qualitative data were collected using exit interviews, semi-structured interviews, FGDs and observations. The respondents included ARV users, health workers, members of the local community and policy-makers.

A total of 514 respondents participated in the quantitative part of the study. Adherence in this study was defined as the number of times that patients actually take their drugs during a given period as a proportion of the number of times that they are recommended to do so. Optimal adherence was defined as an adherence rate of 95% or higher, since this is the level generally deemed necessary for treatment success and to avoid the development of resistance to treatment (Paterson et al., 2000). Levels of adherence below 95% were considered to be sub-optimal.

Three tools were used to measure adherence: pill counts over one month; one-month patient self-report with a visual analogue; and two-day recall using a 24-hour 'sun and moon chart'. The mean adherence rates were 95% for the pill count, 92% for the one-month self-report and 98% for the two-day recall. Using the pill count method it was found that 75% of the ART users achieved the optimal adherence levels of over 95%. Sixty per cent of participants reported optimal adherence using the visual line one-month recall and 96% reported optimal adherence using the two-day recall.

All three of these measures have both strengths and weaknesses. The pill count is in some ways the most 'objective', since it measures the number of pills left over from the previous refill, and can act as a very good proxy indicator for actual pill intake. It is, however, subject to manipulation by patients who may fear a bad response from health workers during dispensing if they have not achieved optimal adherence. In contrast, the one-month self-recall did not involve any health workers in this study. It was administered by researchers who were trained to act empathetically to the potential problems faced by respondents. As a result, ARV users might have been less inclined to overestimate medicine intake. However, a degree of desirability bias is always possible; as is the inability to recall medicine intake over such a relatively long period. The two-day recall has the advantage of a short time-span, which means that memory of medicine intake is likely to be good. However, it can overestimate medicine intake because patients may feel ashamed to admit to forgetting to take their medications so recently. While the two-day recall measure may be useful for on-the-spot individual patient adherence counselling, it may not be useful for long-term adherence monitoring. We recommend that both one-month recall (using visual analogue scale) and the pill counts be undertaken for routine adherence monitoring.

Recognition of the limitations of each of these three individual measures resulted in our calculating a composite adherence rate in the expectation that this would allow the strengths of one method to compensate for the limitations of the others. This composite adherence rate was calculated by taking the mean of the three measures and was found to be 77%. This is comparable to the adherence rates found in other countries (Bangsberg et al., 2000; Chesney, 2000; Liu et al., 2001; Nemes et al., 2004; Safren et al., 2005). Weiser et al. (2003) predicted that if treatment costs were removed as a barrier, adherence rates in Botswana would rise from 54% to 74%. We found that waiting times, costs and logistics are challenges to adherence.

The finding that 23% of patients had sub-optimal adherence rates is still unacceptably high. In view of the serious implications of non-adherence for public health, there is a critical need for targeted intervention strategies to increase the level of adherence. Monitoring and evaluation of the adherence strategies are an important component of any ART programme and can be useful in determining rates and identifying the factors that influence adherence. There is also a need for studies to investigate changes in patient adherence over time. As Horne (1998) argued, adherence should not be considered as a *stable* characteristic of any group of individuals but rather as a *variable* behaviour of an individual that can change over time.

The analysis of qualitative data was by thematic approach and 28 themes were initially identified. Further analysis identified the following key factors as facilitators or constraints of adherence (not in order of importance): the inter-related issues of disclosure: social support; acceptance of HIV status; treatment adherence partner; gender; remembering or forgetting to take the medicines; alcohol/substance abuse; transport costs and distance to health facility; side-effects; food; education; perceived effectiveness of treatment; self-efficacy; counselling; implementation of national guidelines; and a management system for addressing adherence and quality of care.

The study collected data at individual/household, community, health system and national levels. The following key issues relating to adherence operate primarily at the individual and household level, but they also incorporate aspects from the community and health facility.

*The interrelated issues of disclosure, social support, acceptance of HIV status, treatment support partner and gender*

The qualitative data showed that acceptance of one's HIV status and belief in the efficacy of treatment were important facilitators of adherence to treatment, while non-acceptance of HIV status was reported to be a major constraint. Respondents agreed that individual acceptance of HIV status translated into the kind of behavioural changes that are required for a good treatment outcome. For example, when ARV users are in a state of denial about their HIV status, ARVs are often hidden from friends and relatives and medication may be skipped to avoid discovery when other people are around.

The data also suggested that those who had accepted their HIV status were more likely to disclose to other people. Since acceptance is closely related to disclosure, most ARV users felt that non-disclosure of HIV status or of being on ART was a likely predictor of sub-optimal adherence to ART. Without disclosure it becomes difficult to use medication in the presence of other people. In view of the complexity of the medication schedule (in terms of time and consistency), it is difficult to have the privacy that would keep people from noticing regular medicine use. However, even though a significant number of respondents believed that disclosing to relatives and friends had the potential to improve adherence, some of them also perceived that disclosure carried a number of risks such as: emotional injury, loss of intimate relationships and job loss. Other studies have also found that disclosure is a complex process with varying consequences, such as greater intimacy or rejection, feeling of relief or remorse and enhanced status or 'spoiled image' (Ormazu, 2000; Klitzman et al., 2004; Zea et al., 2005). It was generally believed that without disclosure, the level of social support would not be adequate.

Adherence to the treatment regimen was also related to the availability of information material as well as emotional support from family members. The positive role of children in reminding parents when it was time to take their pills was found to be a common facilitating and supportive factor. In addition, the level of family social welfare (income status, collective efficacy, successful resolution of previous conflict, trust) was found to determine the kind of social support an ARV user receives. Men complained that where people had not invested in family social welfare, there was more negative energy/emotion in the family characterized by neglect, sarcasm, negative affective states and constant reminders of the recipient's dependency. Where a husband had previously deserted the family home and where lack of forgiveness prevailed, social support was often lacking. Investment in family social welfare was found to be essential for future social support.

Gender was perceived to have an influence on acceptance of status. Many respondents agreed that women were more likely to accept their status and to seek health care. The desire for women to stay alive in order to care for their children and other loved ones, despite being blamed by men for bringing the disease, was said to be a major facilitator of adherence. The better health-seeking behaviour of women was attributed to the fact that women have always been close to the health care system through the maternal and child health clinics, a system which pre-dates the HIV era. Prior involvement in prevention of mother-to-child transmission (pMTCT) programmes before starting on ART also meant that women were better sensitized and specifically targeted with HIV interventions. While women were thought to accept their HIV status more readily than men and were therefore more likely to seek help from the treatment centres, men were perceived to be difficult, refusing to accept their status or to disclose. This may partly explain why more women than men are on treatment. Since acceptance of HIV status, disclosure and gender were found to be the main emerging themes in the qualitative data, further studies are needed to explore these variables in greater depth.

#### *Positive attitude and belief in the efficacy of ART*

The FGDs revealed that, despite being often preoccupied with their own health concerns and fears, a majority of participants reported that the availability of ARVs had given them a "new lease of life." ARV users tended to have adequate information about the natural progression of HIV. The study also found that one of the strongest qualitative predictors of medication adherence was a personal belief in the efficacy of ART. This belief was also buttressed by the fact that ARVs are potent and as such, better than traditional herbs. There was an overriding belief among ARV users that traditional herbs do not increase CD4 count in the body or decrease the viral load, while ARVs do. This is a critical finding, in a country where patients tend to use both traditional and modern medicine. Those who held this belief also said that HIV was increasingly a manageable disease. In deciding whether or not to start taking ARVs and to continue taking the medication, a patient has to weigh up the costs and benefits of treatment.

Other studies have confirmed an association between adherence and a belief in the efficacy of the pills used in treatment (Eldred, 1997; Ferris, 1996; Smith, 1997). Several studies have shown that patients with a higher level of knowledge about the effectiveness of ART and belief that poor adherence could promote viral resistance and treatment failure have a greater ability to adhere to their medication.

#### *Remembering/forgetting, alcohol and substance abuse*

Forgetfulness was the most common reason cited by those who had problems with adhering to their medication, a finding that is consistent with other studies (Brigido et al., 1998; Chesney et al., 2000; Golin et al., 2002; Turner, 2002). However, the specific reasons for forgetfulness could not be quantified. Respondents cited work and home duties, travelling for work (e.g. cattle posts) or social events (e.g. funerals and weddings) as factors that led to forgetfulness. The qualitative data highlighted alcohol abuse as a major barrier to adherence to ART. ARV users, health workers and members of the community all identified a direct link between alcohol abuse and sub-optimal or non-adherence. The participants acknowledged the use of mechanical devices (radios,



cell phones, and watches), children, parents and partners as helpful ways of being reminded to take their medicines.

### *Distance to health facility, employment status and costs*

The Government of Botswana is responsible for the overall management of the national ART programme and for making treatment available free of charge. However, the study data suggest that patients are burdened by the cost of transportation to and from facilities and by the cost of food while waiting to be attended to. Forty-four per cent of the patients in our quantitative survey reported an increase in expenditures as a result of being on ART, 37% reported a loss of income, and of those who had missed an appointment, 12% said it was for lack of funds to pay for transport to reach the health facility. One in four ARV users interviewed said they had to travel at least 50 km to visit the treatment centre and the maximum distance travelled was 200 km. These findings suggest that many patients have significant treatment-related financial problems, even though the Government is providing ARVs free of charge.

Quantitative data suggested that there was an association between employment and optimal adherence in that respondents who were employed were more likely to adhere than those who were unemployed. It makes conceptual sense that treatment-related costs (e.g. transport) could be a reason why the unemployed failed to achieve optimal adherence. However, the cost of transport can also be a serious problem for workers on a daily rate, the self-employed and casual workers, who not only have to pay for their trip to and from the clinic, but who are also likely to have to forego their daily wage in order to keep appointments at the health facility. Based on this finding, the provision of travel vouchers or reimbursement of travel expenses would be potent facilitators of adherence.

### *Side-effects*

Quantitative data revealed that of the 58% of ARV users who reported having experienced side-effects, only 8% cited side-effects as a reason for failure to achieve optimal adherence. This is contrary to other studies carried out in developed countries where the most frequently cited reason for stopping medication was side-effects. (Chesney et al., 2000; Ammassari et al., 2001). There are several possible reasons for these differences in results. First, in the case of Botswana, the entry level for ART is CD4 count  $\leq$  200. At this level, patients may be so sick that the side-effects experienced could be perceived as a symptom of the disease itself. Second, a sociocultural belief exists among Botswana that it is easy and painless for a disease to get inside the body, but difficult and painful for the disease to get out. According to this belief, the experience of side-effects may be interpreted as the disease exiting from the body and therefore may be tolerated. Third, pre-treatment counselling, where patients are educated about the ARV treatment plan, including possible side-effects, may result in the perception of side-effects as a reasonable risk to be tolerated in view of the magnitude of benefits expected and the alternatives available. These reasons could explain the under-reporting of side-effects/adverse events as stated by one of the health workers in the qualitative interview. This could also suggest that, despite lack of continuity in counselling, this service seems to have an impact on adherence.

The treatment-related increase in food demand did not appear to have a significant impact on adherence. Although 2% of respondents in the quantitative study cited lack of food as a reason for sub-optimal adherence to ART, subsequent interviews revealed that, while lack of food was an inconvenience, it did not stop them taking their ARVs. Education level is usually used as a measure of socioeconomic status but most studies so far did not find education as a predictor of adherence when controlled for other socioeconomic factors (Carrieri et al., 2002; Nemes et al., 2003; Murphy et al., 2004). Our study also confirms this finding and may also be an indicator that information, education and communication is working well.

### ***Health facility level***

Health care workers performed different activities such as: pre-treatment counselling; ongoing counselling; referral to social workers of patients with adherence problems; pill counts; and collation of adherence data and submission of monthly statistics to the national programme. The health workers all maintained that there is no strategic management system for addressing ART adherence problems.

All four of the facilities surveyed use the *Botswana Guidelines on Antiretroviral Treatment*. The current version (2005) recognizes sub-optimal adherence as a common reason for treatment failure and the most important cause of the emergence of drug-resistant strains of HIV. The guidelines recommend seven strategies to improve adherence, including: establish trust with the patient and family; serve as an educator and source of information; provide ongoing support and monitoring; intensify management in periods of low adherence by more frequent visits, recruitment of friends and family and deployment of other team members; utilize a health team approach; provide training to support the ART staff; use the family care model approach and provide care to the family as a unit.

While these recommendations are excellent, there is no clarity as to how the health care worker should achieve the objectives. The guidelines acknowledge the need to involve family and friends in coping with the demands of adherence, but fail to address the ethical issues involved in areas such as privacy, autonomy and confidentiality, which are genuine concerns for patients and health workers.

### ***Study limitations***

It would have been interesting to examine the adherence rates in relation to the timing of drug and food intake. However, due to the fact that most of our study participants were on first-line medication that did not require food restrictions and the fact that a previous question included the times medication were taken, these measures could not be used. This study had several limitations. For example, some of the data collection methods used in this study relied on self-reports of adherence behaviour, which is prone to response biases. In addition, the study used a client sample that was currently on ART and did not include individuals who had discontinued treatment. It is also possible that people who achieved sub-optimal adherence may no longer be visiting the treatment facilities.

## **6.2 Conclusions**

Although the adherence rates found in this study are comparable to those of other studies in developing countries, these rates are still low for good clinical outcomes. Adherence is a complex issue and multi-dimensional approaches are required to both address the constraints and strengthen the key facilitators of adherence. Efforts to determine the level of adherence among patients on ART is complicated by the general methodological difficulties of adherence assessment. There is no gold standard of adherence assessment. While the two-day recall measure may be useful for on-the-spot individual patient adherence counselling, we recommend the use of the visual analogue scale and the pill counts for routine adherence monitoring.

In this study the critical barriers to adherence identified were: forgetfulness, lack of transport fare to the health facility, non-acceptance of HIV status, fear of discrimination and stigma, alcohol abuse, and non-supportive home and work environments. Although side-effects occur in a significant proportion of users, this was not perceived as a significant barrier to adherence.

Facilitators of adherence were found to include self-efficacy, social support, an effective adherence counselling programme, perceived benefits of the medication, and a desire to stay alive for the sake of others.

Efforts to improve the level of adherence require a collaborative approach involving the patient, the community, health workers and policy-makers, and a focus on ways of addressing environmental and structural constraints.

Some of the recommendations identified include the development of practical guidelines for implementing adherence management strategies. These should include guidelines for: continuous adherence counselling; bringing treatment closer to home; adoption of a family care model approach to ART; use of practical reminders; adherence case management; and the use of medication organizers (pill boxes partitioned to display the daily or weekly sequence of pills to be taken). In addition, the establishment of a transport voucher scheme should be considered for people who genuinely cannot afford the cost of transport to collect their medication. Such interventions should be evaluated to assess their effects on adherence.

Acceptance of HIV status, disclosure and gender were found to be the main emerging themes in the qualitative data. Further studies are needed to explore these variables in greater depth. Programmes targeting men to inform them about HIV-related issues should also be developed. This would help increase the enrolment of men in ART programmes, help them to better understand the gender issues around HIV, and mobilize them to be protectors and supporters of women in the fight against HIV.

### **6.3 Recommendations**

- ◆ Development of practical guidelines for implementing adherence management strategies. These should include guidelines for: continuous adherence counselling; bringing treatment closer to home; adoption of a family care model approach to ART; use of practical reminders; adherence case management; and the use of medication organizers.
- ◆ Consideration of the establishment of a transport voucher scheme for people who genuinely cannot afford the cost of transport to collect their medication.
- ◆ Adoption of a uniform adherence monitoring system at all facilities in Botswana, with simple and practical tools such as pill count register and the visual line one-month recall. These measures need to be validated and standardized. Data generated should be reviewed periodically in order to monitor the rate and trend of adherence to ART.
- ◆ Sustained community mobilization aimed at mitigating stigma and discrimination in an effort to create an environment in which people can disclose and take their ARVs without fear of discovery.
- ◆ Enforcement of appropriate legislation to protect the rights of people in employment to access to treatment without fear of discrimination. Efforts are also needed to sensitize people to their HIV-related rights in the workplace, including the establishment of toll-free lines to enable people to complain if their rights are violated.
- ◆ Development of programmes targeting men to inform them about HIV-related issues. This would help increase the enrolment of men in ART programmes, help them to better understand the HIV-related gender issues, and mobilize them to be protectors and supporters of women in the fight against HIV.
- ◆ Development of new tools to sustain and improve adherence rates and influence behavioural change. This includes using radio stations, TV stations and mobile phone operators to send periodic signals with jingles reminding people to take their medication.
- ◆ Continuous operational research on adherence.
- ◆ Development of interventions targeting men to help reduce the HIV-related consequences of alcohol abuse.
- ◆ Behavioural change interventions designed to modify the work and home-related barriers to adherence should be developed and evaluated. For example, patients could be given small medicine envelopes (commonly known as ‘seed bags’) to carry some of their medicines when they go to places where they do not want to be seen taking medicines from original containers (e.g. when visiting friends, going to funerals or to work).
- ◆ Acceptance of HIV status, disclosure and gender were found to be the main emerging themes in the qualitative data. Further studies are needed to explore these variables in greater depth.

## References

1. Ammassari A et al. (2001). Self-reported symptoms and medication side-effects influence adherence to highly active antiretroviral therapy in persons with HIV infection. *Journal of Acquired Immune Deficiency Syndromes*, 28(5):445-449.
2. Anderson W, Weatherburn P. *Taking heart? The impact of combination therapy on the lives of people with HIV (phase 2)*. London, Syria Research, 1999.
3. Bangsberg DR et al. (2000) Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS*, 14:357-366.
4. Brigido LFM et al. (1998). *Low adherence in antiretroviral users at Sao Paulo, Brazil*. 12<sup>th</sup> World AIDS Conference, Geneva, 28 June-3 July 1998. Abstract no. 32370.
5. Byakika-Tusiime J et al. (2003). *Ability to purchase and secure stable therapy are significant predictors of non-adherence to antiretroviral therapy in Kampala, Uganda*. 10th Conference on Retroviruses and Opportunistic Infections. Boston, USA. 10-14 February 2003. Abstract no. 170.
6. Carr A (2002). Improvement of the study, analysis and reporting of adverse events associated with antiretroviral therapy. *Lancet*, 360:81-85
7. Carr A, Cooper DA (2000). Adverse effects of antiretroviral therapy. *Lancet*, 356: 1423-30.
8. Carter M. *Adherence – information series for HIV-positive people*. 2nd ed. London, NAM, 2004.
9. Carrieri P, Caillefon V, Le moing V (2002). The dynamic of adherence to Highly Active Antiretroviral Therapy: Results from the French National APROCO cohort. *Journal of Acquired Immune Deficiency Syndromes*, 28:232-9.
10. Chesney MA (2000). Factors affecting adherence to antiretroviral therapy. *Clinical Infectious Diseases*, 30(Suppl 2):S171-6.
11. Chesney MA, Morin M, Sherr L (2000). Adherence to HIV combination therapy. *Social Science & Medicine*, 50:1599-1605.
12. Chesney MA et al. (1999). Adherence: a necessity for successful HIV combination therapy. *AIDS*, 13(Suppl A):5271-5278.
13. Daniel OJ et al. (2004). *Adherence pattern to ARV drugs among AIDS patients on self-purchased drugs and those on free medications in Sagamu, Nigeria*. XV International AIDS Conference. Bangkok, Thailand. 30 March - 2 April 2004.
14. Darder M et al. (2004). *Determinants of short and long-term adherence to antiretroviral treatment in resource-poor settings*. XV International AIDS Conference. Bangkok, Thailand. 30 March - 2 April 2004. Abstract no. B11852.
15. Eldred I J, Wu Aw, Chaisson RE (1998). Adherence to antiretroviral and pneumocystic prophylaxis in HIV disease. *Journal Acquired Immune Deficiency Syndromes*, 18:117.

**Factors that facilitate or constrain adherence to antiretroviral therapy among adults at four public health facilities in Botswana: a pre-intervention study**

---

16. Ferris DC et al. (2004). *Self-reported adherence to antiretroviral therapy and virologic outcomes in HIV-infected persons in Durban, KwaZulu Natal, South Africa*. XV International AIDS Conference. Bangkok, Thailand. 30 March - 2 April 2004. Abstract no. WePeB5829.
17. Fischl M, Rodriguez A, Scerpella E. (2000). *Impact of directly observed therapy on outcomes in HIV clinical trials*. 7<sup>th</sup> Conference on Retroviruses and Opportunistic Infections, San Francisco, USA. 30 January - 2 February 2000. Abstract no. 71.
18. Gill CJ et al (2005). *No complacency about adherence to antiretroviral therapy in sub-Saharan Africa*. *AIDS*, 19:1243-1249.
19. Gillford AL et al. (2000). Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. *Journal Acquired Immune Deficiency Syndrome*, 23(5):386-95.
20. Golin CE et al. (2002). A prospective study of predictors of adherence to combination antiretroviral medication. *Journal of General Internal Medicine*, 17:756-765.
21. Government through Presidential Directive CAB: 35/93, 17th November 1993. Gaborone. (UNDP, 2001) Botswana human development report, 2000, p.41-42.
22. Harries AD, et al. (2001). Preventing antiretroviral anarchy in sub-Saharan Africa. *Lancet*, 358:410-414.
23. Horne R. Adherence to medication, a review of existing research. In: Myers L, Midence K (eds.). *Adherence to treatment in medical conditions* (pp.285-310). London, Harwood Academic, 1998.
24. Horne R. Compliance, adherence and concordance. In: Taylor K and Harding G (eds.), *Pharmacy practice* (pp.165-184). London, Taylor & Francis, 2001.
25. KITSO. Harvard Institute HIV/AIDS. *KITSO training manual for health workers in Botswana*, 2004
26. Klitzman RL et al. (2004). Intricacies and inter-relationships between disclosure and HAART: a qualitative study. *AIDS Care*, 16(5):628-640.
27. Kumarasamy N et al.(2005). Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: A qualitative study. *AIDS Patient Care and STDs*, 19(8):526-537.
28. Lerner BH, Gulick R M, Dubler NN. Rethinking non-adherence: historical perspectives on triple-drug therapy for HIV disease. *Annals of Internal Medicine*, 1998, 129(7):573-578.
29. Liu H, et al. (2001). A comparison of multiple measures of adherence to HIV protease inhibitors. *Annals of Internal Medicine*, 134:968-997.
30. Machtinger E, Bangsberg DR (2005). *Adherence to HIV antiretroviral therapy*. Available at: <http://hivinsite.ucsf.edu/InSite?page=kb-03-02-09>
31. Muganzi AM et al. (2004). *Adherence to HAART in a rural resource limited country HIV/AIDS treatment programme: the experience of Arua Anti-Retroviral (ARV) Treatment Programme-Uganda*. XV International AIDS Conference. Bangkok, Thailand. 30 March - 2 April 2004. Abstract no.: WePeB5760.
32. Murphy DA et al. (2004). Predictors of antiretroviral adherence. *AIDS Care*, 16(4): 471-484.
33. National AIDS Coordinating Agency (NACA). *Botswana sentinel year book 2003*. Available at: <http://www.naca.gov.bw/about.htm>.

34. National AIDS Coordinating Agency (NACA) website: <http://www.naca.gov.bw>
35. Nemes MIB, Carvalho HB, Souza MFM (2004). Antiretroviral therapy adherence in Brazil. *AIDS* 18(Suppl 3):S15-S20.
36. Nwokike J (2004). *Baseline data and predictors of adherence in patients on antiretroviral therapy in Maun General Hospital, Botswana*. International Conference on Improving Use of Medicines (ICIUM). Bangkok, Thailand. Abstract no. HI012, 2004.
37. Ormazu JA (2000). Disclosure decision model: determining how and when individuals will self-disclose. *Personality and Social Psychology Review*, 4:174-185.
38. Omes C et al. (2004). *Adherence to antiretroviral (ARV) therapy among advanced-stage, indigent patients in the funded ESTHER programme in Kigali, Rwanda*. XV International AIDS Conference. Bangkok, Thailand. 30 March - 2 April 2004. Abstract no. B12315.
39. Orrell C, Bangberg DR, Badri M, Wood R (2003). Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS*, 17:1369-1375.
40. Palella FJ Jr et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *New England Journal of Medicine*, 338:853-860.
41. Paterson DL et al. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*, 133(1):21-30.
42. Perelson AS, Neumann AU, Markowitz M (1996). HIV-1 Dynamics in viro; viron clearance rate, infected cell life span, and viral generation time. *Science*, 271(5255): 1582-6.
43. Poppa A et al. *Guidelines on provision of adherence support to individuals receiving antiretroviral therapy*. London, British HIV Association/British Association for Sexual Health and HIV, 1993.
44. Ramotlhwa (2005). ARV statistics. (Personal communication).
45. Reiter GS et al. (2000). Elements of success in HIV clinical care. *Topics in HIV Medicine* 8:67.
46. Safren SA et al. (2005). ART adherence, demographic variables and CD4 outcome among HIV-positive patients on antiretroviral therapy in Chennai, India. *AIDS Care*, 17(7):853-862.
47. Singh N et al. (1996). Determinants of compliance with antiretroviral therapy in patients with human immunodeficiency virus: prospective assessment with implications for enhancing compliance. *AIDS Care*, 8:261-269.
48. Stevens W, Kaye S, Corrah T (2004). Education and debate: antiretroviral therapy in Africa. *British Medical Journal*, 328:280-2.
49. Tuldra A, Fumaz C R, Ferrer MJ (2000). Prospective randomized two arm controlled study to determine the efficacy of a specific intervention to improve long term adherence to highly active antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndromes*, 25:221-8.
50. Turner BJ (2002). Adherence to antiretroviral therapy by Human Immunodeficiency Virus-Infected Patients. *Journal of Infectious Diseases*, 185(Suppl 2):S143-51.
51. UNAIDS/WHO (2005). *The AIDS epidemic update - Special report on HIV prevention*. Available at: <http://www.who.int/hiv/epiupdate2005/en/>.

**Factors that facilitate or constrain adherence to antiretroviral therapy among adults at four public health facilities in Botswana: a pre-intervention study**

---

52. Vitolins MZ et al. (2000). Measuring adherence to behavioral and medical interventions. *Controlled Clinical Trials*; 21:188S-194S.
53. Weiser S et al. (2003). Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal Acquired Immune Deficiency Syndrome*, 34:281–288.
54. WHO. *Progress on global access to HIV antiretroviral therapy. A report on "3 by 5" and beyond*. Geneva, World Health Organization, 2006.
55. Zea et al. (2005). Disclosure of HIV status and psychological well-being Among Latino gay and bisexual men. *AIDS and Behavior*, 9(1):15-26.



## Annex 1: Mean of rates adherence

Raw averages of the different measures

a) Self assessment of adherence using the visual analogue method

	<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>Minimum</b>	<b>Maximum</b>
Maun	.91	.95	1.00	.50	1.00
Mahalapye	.95	.99	.99	.56	1.00
Molepolole	.91	.98	1.00	.30	1.00
Serowe	.89	.96	1.00	.44	1.00
<b>All</b>	<b>.92</b>	<b>.97</b>	<b>1.00</b>	<b>.30</b>	<b>1.00</b>

(There were problems noted on-site with the Serowe pill count recording).

Self assessment of adherence using patient self-report method (two-day recall)

<b>Facilities</b>	<b>Mean</b>	<b>N</b>	<b>Std. Error of Mean</b>
Maun	.94387	121	.018158
Mahalapye	.99267	125	.004639
Molepolole	.98333	115	.009775
Serowe	.99206	147	.004644
Total	.97876	508	.005227

Pill counts (including Serowe data)

	<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Count</b>
Maun	.972	1.000	1.000	.000	1.000	122
Mahalapye	.930	.963	1.000	.567	1.000	128
Molepolole	.954	.982	1.000	.667	1.000	115
Serowe	.855	.879	1.000	.321	1.000	149
<b>Total</b>	<b>.925</b>	<b>.967</b>	<b>1.000</b>	<b>.000</b>	<b>1.000</b>	<b>514</b>



## Annex 2: Multivariate logistic regression analyses on the predictor variables

Multivariate logistic regression analyses on the predictor variables

<b>Variables</b>	<b>Parameter estimate</b>	<b>Wald <math>\chi^2</math></b>	<b>O.R.</b>	<b>O.R. (95% C.I.)</b>	<b>p-value</b>
Side-effects	-0.0674	0.105			0.746
Distance	0.000589	0.0430			0.836
Sex	-0.185	0.598			0.439
Age	0.0107	0.885			0.347
Education	-0.00298	0.000512			0.982
Occupation	0.370	2.681			0.102
Cost of transport	-0.00711	0.169			0.681
Loss of income	-0.285	1.207			0.272
Other costs	-0.334	2.267			0.132
Months on treatment	-0.0129	1.477			0.224
Counselling	-16.024	0.0000249			0.996
Partner reminder	-0.283	1.298			0.255
Missing appointment	-0.575	4.851	0.572	(0.363; 0.902)	0.028
Implications of missed dose	0.443	1.116			0.291
Knowledge about HIV and ARVs	0.323	2.063			0.151



## Annex 3: Questionnaires

### 1. Focus group discussion (FGD) for antiretroviral users: Questionnaire

- Participants per FGD (6-8)
- Adults (= or >18 years, men and women separately – may want also to split into high- and low-adherers, if easily identifiable, depending on what country teams want to do)
- One moderator, one note-taker (*and* use of tape recorder)
- Neutral venue outside the facility
- Two FGD per facility (one with men and one with women)

#### Short introductory remarks

- Introduction of researchers and participants
- Thank participants for agreeing to participate, all share a common feature – they are on ARV treatment, are here to share their thoughts about ARVs and difficulties in taking ARVs: we want to learn from participants
- Explain purpose of study, purpose of this discussion, reassurance about confidentiality, agree on rules.

#### Topics for discussion

1. What treatments do you know to be available for treating HIV? What is your opinion about these? (e.g. ARVs; herbs; traditional medicines; spiritual healing; prayers; and perceived benefit (s) of treatment).
2. What is your experience of ART? (probe about adherence, adverse effects, pill burden, lack of food, lifestyle issues).
3. How do you think you are being treated (handled) by the health care workers (probe: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services). What is the quality of care provided by health care workers?
4. What do you think about the counselling that you receive? (probe especially on importance of adherence effectiveness of counselling). What support are you given by the health workers to help you adhere better to your medications? Have you disclosed?

**Factors that facilitate or constrain adherence to antiretroviral therapy among adults at four public health facilities in Botswana: a pre-intervention study**

---

5. What support is available for you in the community, in the family, in the workplace? (probe about discrimination, stigma). Probe differences in perceived availability of social support versus social networks? Any negative social support? Any stress exacerbation?
6. What do you think could be done to help people adhere more easily to their treatment?
7. What do you think are the key reasons for non-adherence and good adherence? What are the sources of motivation for adherence?
8. Duration of discussion (1½ hours); provide refreshments
9. Conclusion, thank participants

## 2. Focus group discussion for community members: Questionnaire

1. Explore the role of participants in HIV/AIDS. Explore whether the members know about ARVs; what it is and the current practice of service delivery in ARV use. Explore where people obtain medicines for HIV/AIDS (ARVs) in the area. Assess accessibility to information on ARV.
2. What are the perceptions/beliefs/attitudes of the community on HIV/AIDS, treatment modalities? What are the perceptions of the community on current criteria for inclusion in ARV treatment? Probe for reasons for perceptions. What criteria should be used for starting antiretroviral therapy?
3. How easy/accessible is it for people in your community for people who are taking ARVs? (Probe on stigma, discrimination, logistical issues for reaching the clinic etc.)
4. Can existing infrastructure be modified and strengthened to adapt to antiretroviral provision? What resources are needed to make antiretroviral widely available in your area?
5. In your view, what are the current barriers to adherence for the individuals living with HIV in your community?
  - a) Demography (age, sex, ethnicity/language, socioeconomic status)
  - b) Information (knowledge, self efficacy, coping, etc)
  - c) Motivation (beliefs, depression, drug use)
  - d) Behaviour skills (pill taking, scheduling)
  - e) Provider – expertise, trust
  - f) Regimen – simplicity, toxicity, disruption of daily activities
  - g) Disease stage
  - h) Clinical setting

Probe on how cultural, psychological behavioural and contextual circumstances influence adherence?

6. Solutions: In your view, how can adherence be enhanced in your community? What activities take place at the moment in your community to help people adhere to their medication? (Probe on support, HBC, individual coping capacity. Probe on existing strategies to improve adherence.). How can therapeutic effectiveness, adverse side-effects, and the emergence of drug resistance be monitored?

What should be done to assist people on ARVs to take their medications as instructed?

7. Are there barriers/obstacles different in different health care systems for primary care centres as in private practice? How can the situation be improved?

### 3. Semi-structured interview with health care workers

**Guidelines for semi-structured interviews with health workers  
(to be adapted for use with different type of health workers – medical doctors,  
nurses, counsellors, pharmacists, social workers)**

Name of facility: \_\_\_\_\_  
Name interviewer: \_\_\_\_\_  
Interview number: \_\_\_\_\_  
Date: \_\_\_\_\_

*(Introduction of the interviewer (s), introduction of the study)*

#### Background information on informant (health worker)

a) Sex	M / F
b) Age	_____ years
c) Profession	
e) Role in ARV programme	
f) Involved in programme since ....	

#### Tasks and training

- a) What specific training have you received for this job in relation to ARV programme? Tell me about the training (Details)
- b) Do you think this training has been sufficient? (Details)

#### Drugs, treatment and procedures

- a) Which treatment guidelines for HIV/AIDS management do you use at this facility? (Give details if necessary, e.g. national guidelines etc)
- b) Are the drugs you prescribe always available? (If not, give details – how often, reason, what do you do about it)
- c) Are the drugs in the guidelines you use to dispense always available? (Give details – how often, reason, what do you do about it)
- d) Have you had periods where your patients have not been able to get their medications because they were not available in stock?
- e) How reliable are your lab and diagnostic support services? Do results come in on time? Details.
- f) What is your procedure when a patient is put on ARV drugs for the first time?
- g) What is your procedure when a patient switches regimens?
- h) In what ways are ARV-users informed about and prepared for ARV treatment?



i) What kind of information do they receive? Please describe it to us:

- The disease process (i.e. HIV and AIDS)
- How the disease affects the body
- How ARVs work
- How to use them
- The need to continue treatment
- What to do if a pill is forgotten
- Possible interactions with other drugs  
(including traditional medicines)
- Which side effects can occur & what to do if they occur
- (Breast) feeding requirements
- When and where to get re-supply

Who is giving this information?

### Adherence issues

- a) Generally speaking, do your patients keep their appointments?
- b) How do you think your patients do, generally speaking, in terms of adherence to ART?
- c) Could you estimate the percentage of your patients who you think are “sufficiently adherent” to ART? (Respondent gives their definition of ‘sufficiently adherent’ what level is that?) \*\*
- d) What do you use to determine adherence (probe: appointments, refills?)
- e) We would like to get your views on the following (probe): From your experience
  - How would you compare adherence between women and men?
  - How would you compare adherence between older patients and younger patients?
  - How does a patient’s educational level affect adherence?
  - How do you think that cost to patients influences adherence?
- f) How do you think the distance to the health facility affects adherence?
- g) From your experience how do you think the following affect adherence?
  - Having or not having a treatment-support partner?
  - Duration of treatment?
  - Side effects?
  - Lack of food?
  - Knowledge about ART?
- h) What strategies are in place to monitor adherence?

- i) What strategies are in place to support adherence? (probe: family/community involvement).
- j) What are the main challenges you face in supporting your patients to adhere to ARV drugs (especially for longer term users)?

**Challenges and staff support**

- a) What are the main challenges you and your colleagues face more generally in your work? (if necessary, prompt re workload, stress, burnout)
- b) Have you ever been afraid of being infected with HIV through your work? What were you specifically afraid about? How do you feel now about the HIV-infection risks? Do you take any extra precautions when working with them?
- c) Have these challenges changed in any way since you started working at the ARV clinic?
- d) Is any special support made available for staff engaged in management of HIV/AIDS at this facility? If no, do you think there is a need to have such support?
- e) Is there anything you would like to see done differently in this facility? If yes, what?

*Is there anything else you would like to tell us or ask us?*

Thank you very much for your participation in this interview.

#### 4. Semi-structured interview with ARV users

Name of the interviewer: \_\_\_\_\_  
 Interview number: \_\_\_\_\_  
 Name of health facility where patient contacted: \_\_\_\_\_  
 Date: \_\_\_\_\_

**NB:**

- Informed consent
- ARV-user will be contacted initially at the health facility, but the interview will be conducted at another time and place.

**Introduction of the interview, introduction of the study, consent requested with option not to participate.** Statement of confidentiality.

#### Sociodemographic information on informants

a) Sex	M / F
b) Age	Years
c) Educational level	
d) Who do you live with? (spouse, children, mother etc.)	
e) What do you do for a living	
f) Distance from facility (in time or distance)	

#### Medical history of patient

- a) When were you first diagnosed with HIV?
- b) What made you decide to go for testing?
- c) When did you start treatment for HIV (ARVs)?
- d) How do you feel about your health since you started treatment?
- e) How would you describe your health since you started treatment?
  - Better
  - Same
  - Worse

#### Patient knowledge about HIV/AIDS

We would like to understand what people actually know about the illness that they have. Can you tell me what you know about HIV/AIDS? (Allow patient to say what they want, then probe on the following: cause of HIV infection, cause of AIDS, prevention, life-long infection).

Apart from this, is there anything else you may have heard from your community that explains AIDS in a different way?

## **Patient knowledge about ARVs**

We would like to understand what people know about HIV/AIDS medicines. Could you help us with this by telling me what you know about ARVs? (Allow patient to say what they want, then probe on the following: prolongs life, improves quality of life, life long treatment, knowledge about side effects).

## **Assessment of adherence and non-adherence**

We are trying to find out how patients manage to take their medicines – for some people it's not a problem, but we also know that others don't always find it easy. Please feel free to be open about the problems you face with this. Everything you say here will remain confidential, and will not be shared with anyone at the clinic.

- a) Do you have your medicines with you? May I see them? Please can you tell me when you take each of the medicines?
- b) Are there any other medications you are taking (e.g. traditional medicines, herbs, medicines from other hospitals, clinics, shops/chemist, etc.)
- c) Over the last two days, when did you take your pills? (Not including today – starting from last night and back.) (Complete 'sun-and-moon chart', or other checklist)
- d) Did you perhaps miss any? (Confirming (c), sympathetic manner. Details if yes.)
- e) This is a very important question. We appreciate how difficult it can be to take pills on a daily basis. If you sometimes miss a dose, please can you tell me what causes this to happen? Can you give an example or two? (Include even if 'simply forgot').
- f) On the other hand, what is it that *helps* you to take your pills regularly and on time? (e.g. buddy, relatives, individuals, cell-phone, clock etc.)
- g) Have you disclosed your status to any one? If so, who? Do they help you to take your pills? [If not covered in (f)]
- h) Have you had your treatment changed at any moment since you were started on ARVs? If yes, why? (e.g. treatment failure, side-effects, drug not available).
- i) Have you ever missed an appointment at your IDCC? (Reasons, and details on type of consultation: review/refill, counselling etc.)
- j) What do you think happens in your body if you skip your ARV medicines?
- k) Have you ever thought about stopping HIV/AIDS medicines (ARVs)? If yes, details.

## Perception about HIV/AIDS, ARVs and stigma

Have you ever had any experience of being treated differently because of your HIV status? (in your family, at work, at the church etc)

### Cost considerations

- a) How much do you have to pay to cover your travel expenses when you visit the clinic?
- b) What is the cost of registering at the clinic (if any)?
- c) What is the cost of the ARV medicines that you take (if any)?
- d) Do you lose any income as a result of your coming to the clinic?
- e) Do you incur any other costs as a result of your taking ARVs?
- f) What have you and/or your family had to give up in order to be able to take your medicines regularly?

### Quality of care

- (a) What do you think of the service you receive at this clinic? (General, open-ended, and then prompt, as below: ask for details as necessary)
- Do you feel listened to? Yes  No
  - Are you given the chance to state your problems and ask questions? Yes  No
  - Are you treated with respect? Yes  No
  - Do you feel you can trust the health workers? Yes  No
  - Do you have privacy during consultation and counselling? Yes  No
  - How do you find the environment of the clinic?

---

(b) How long did you spend altogether at the clinic when you last went for review?

(c) How long did you have to wait before being attended to?

---

### Perceived problems and possible solutions

- a) What do you perceive as the biggest problem regarding taking ARV treatment?
- b) What do you think could be done to improve this?

Do you have any questions for me?

Thank you for your time and co-operation!

## 5. Adherence measurement tool for antiretroviral users: Questionnaire

Page 1 of 4

### ARV adherence questionnaire

Date  Interviewer:  Facility:  Study No:

(Introduce yourself)

(Explain purpose of interview:) You have come here to get your ARV medication. We know that it can be very difficult to take this medication every day, and we are doing some research to find out whether patients manage to take their medicines correctly. Would you have a few minutes to answer some questions? We will not record your name, and this information will not go to anyone here at the clinic.

1. Sex:  2. Age:

3. Level of Education (tick:)

<input type="checkbox"/>	None, or Primary not completed
<input type="checkbox"/>	Primary completed
<input type="checkbox"/>	Secondary
<input type="checkbox"/>	Tertiary or vocational

4. Occupation:

4a: Employment category:

5. How far did you have to travel today to come to the clinic (km)   
*(If distance not known, record here where patient lives):*

6. How much to you pay for travel when you visit the clinic? (state amount)

7. What did you have to pay to register at this clinic? (state amount)

8. What do you pay for a month's supply of your ARV medicines? (amount)

9. Do you lose any income as a result of your coming to the clinic? (Y/N)

10. Do you or your family have to give anything up in order to be able to pay for your ARV treatment? (Y/N)

11. Has your being on ARVs resulted in any changes in expenditure?   
(1=same; 2=more; 3=less)

12. When did you start treatment? (approximate date, e.g. mid-May 04)
13. Were you counselled about adherence before starting treatment? (Y/N)
14. Have you experienced any side effects with your ARV medication? (Y/N)  *If yes:.....*
15. Has this been a reason for you to skip your medication at any time?
16. What do you think would happen in your body if you skipped your ARV medication?  
*DO NOT prompt the patient. Record "Yes" if patient mentions one or more of the following: viral load increases, patient's health gets worse, virus becomes resistant (Y/N)*
17. Do you have anyone to remind you to take your ARV medication? (Y/N)
18. Do you use a medication diary or calendar?
19. Have you ever missed an appointment at this clinic? (Y/N)
20. What do you know about HIV infection?  
*(Give 1 point each if patient knows about: cause of HIV, cause of AIDS, prevention, that infection is life-long)*
21. What do you know about antiretroviral medicines?  
*(Give 1 point each if patient knows: Prolong life, improve quality of life, life-long treatment, knowledge about side-effects)*
22. Quality of life (feeling respected, listened to, privacy, given chance to ask questions)  
*3=very good, 2=good, 1 = poor*

**+Have any of the following ever made you skip your medication +:**

- Ask for each box 23-38, mark with "+" if yes*
- (15. Side effects/adverse effects)
23. Felt better:  24. Clinic not accessible  25. Cost of ARVs:  26. Lack of food:
27. Pill burden:  28. Lack of care/support  29. Hospitalized:  30. Depressed:
31. Did not understand instructions:  32. Shared pills:  33. Distance:
34. Alcohol use:  35. Didn't have pills with you:  36. Simply forgot:
37. Feeling that you had to hide your medication from those around you:  38. Other (describe):

**We would like to get your best guess about how much of your ARV medication you have managed to take recently. We would be surprised if this was 100% for most people. We will try several ways to estimate this.**

39. Please make a mark on the line to show how many of your ARV pills you think you managed to take in the last month:

None  All  cm:

**Factors that facilitate or constrain adherence to antiretroviral therapy among adults at four public health facilities in Botswana: a pre-intervention study**

Study No:

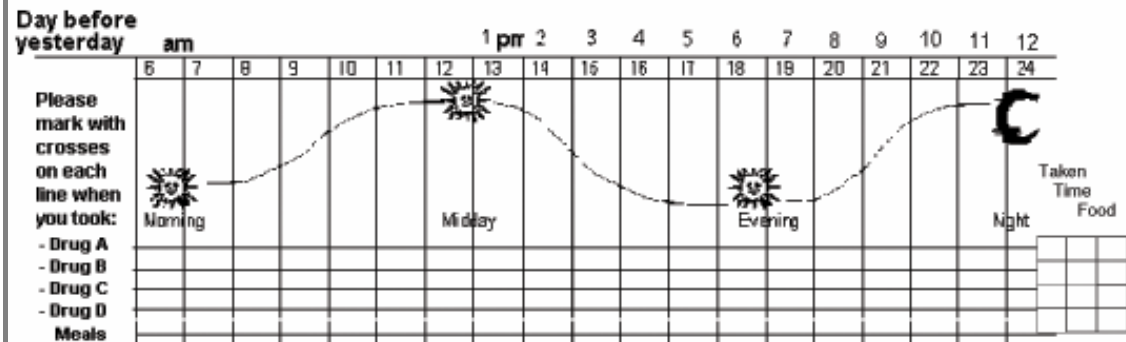
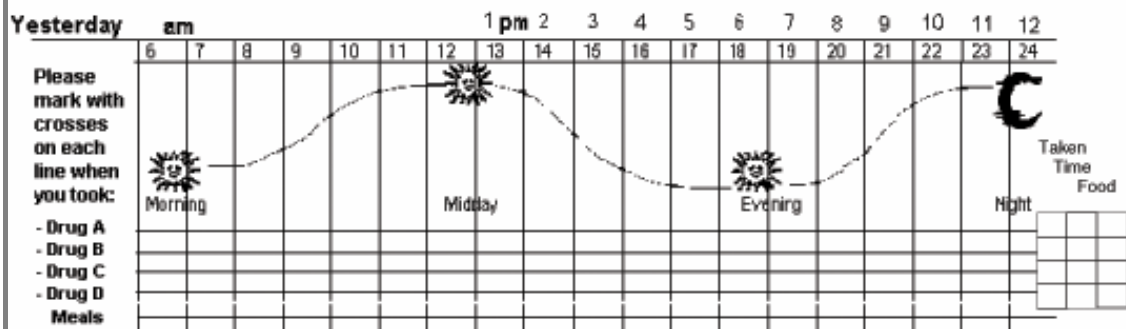
**Can I see your medicine, please? (Complete names and number of pills/day for each medicine)**

Drug A:	<input type="text"/>	Pills per day:	<input type="text"/>
Drug B:	<input type="text"/>	Pills per day:	<input type="text"/>
Drug C:	<input type="text"/>	Pills per day:	<input type="text"/>
Drug D:	<input type="text"/>	Pills per day:	<input type="text"/>

**40. Now remember the last seven days. Did you miss any pills in that time? If yes, how many pills?**

*(If any, ask:) "Can you remember why?" Let patient state reasons, tick boxes 15 and 23-38 on page 1 (again) with "x" if mentioned*

**41. Now, try to remember the last two days. When did you take each medicine, and when did you have meals?**





Study No: 

On the slip below, fill in patient's medicines (as on page 2) and study number (as on page 1).

Please take this slip to the pharmacy to complete. We will collect it from there.  
**THANK YOU VERY MUCH FOR SHARING YOUR EXPERIENCE WITH US.**

**To the pharmacist:**

Please indicate for each antiretroviral medicine:

1. How many pills the patient **should have taken** since his last visit, and
2. How many s/he missed (how many **extra pills were returned**).

You can follow the example given if it helps, but only the two bold, shaded lines need to be completed.

	Example	Drug A	Drug B	Drug C	Drug D	Study number
<b>Drug name (as on page 2)</b>						
Previous Date issued	6 Jan					(as on page 1)
Qty taken home (total)	67					
Qty returned	15					
Date returned	3 Feb					
Days since last issue	28					
Regimen	2 bid					
<b>1. Total supposed to take</b>	56	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
Should have returned	67-56=11					
<b>2. Pills missed</b>	15-11=4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
Percent adherence	$(56-4)/56 * 100$					

## 6. Exit interviews with ARV users

### Guideline for exit interviews with PLWHIV using ARVs

*(To be conducted after pharmacy visit, i.e. when all their business at the health facility is completed).*

Name of facility \_\_\_\_\_  
Name of interviewer \_\_\_\_\_  
Interview number \_\_\_\_\_  
Date \_\_\_\_\_

*(Introduction of the interviewer (s), introduction of the study, consent requested with option not to participate, assurance of confidentiality)*

### Background information on informant

a) Sex	M/F
b) Age	Years
c) Educational level	
d) What do you do for a living	
e) Distance from facility (in time or distance) (NB village or ward)	

### Whom did you visit today? (Can include more than one)

- Counsellor
  - Nurse
  - Medical doctor
  - Pharmacist
  - Other
- 

### What was the reason for your visit today?

- Counselling
- To start using ARV/AIDS medicines
- Routine follow-up, if yes: when did you start using the AIDS medicines?
- Other reason:

### What was the result of the visit?

- I got ARV medicines for the first time
- They gave me a refill of my ARV medicines
- They gave me a different kind of ARV medicines  
If yes, why did the doctor prescribe different medicines?

- Other
-

**If you were given AIDS medicines for the first time *today*, or were given a new kind of AIDS medicine *today*, what did the health worker tell you? (Open ended, then probe on following topics)**

What HIV/AIDS is?	By whom?
How ARVs work?	By whom?
How to use them?	By whom?
The need to continue treatment	By whom?
What to do if a pill is forgotten	By whom?
Possible interactions with other drugs (including traditional medicine)	By whom?
Which side effects can occur with (state the drugs the patient is taking) & what to do if they occur	By whom?
(Breast) feeding requirements	By whom?
When and where to get re-supply	By whom?
What is required when you come for re-supply (bring unused medicines?)	By whom?

**(If client was given a repeat prescription, ask him/her the following; if new patient, proceed to 8)**

What did you discuss with the health worker?

---

**Probe for:**

- a) Did you talk with the health worker about your experience of using your medicines? (Side effects, perceived effects)
  - Did the health worker ask you if you have missed a dose?
 

Yes       No
- b) If yes, did the health worker explain what the effects are of missing a dose?
 

Yes       No
- c) Did your health worker count your pills before giving you a new supply?
 

Yes       No
- d) Did the health worker ask you if you were taking any other medicines?
 

Yes       No

### **Assessment of adherence and non-adherence**

- a) Do you have your medicines with you? Yes  No
- b) May I see them? Please can you tell me when you take each of the medicines?  
(Refer to table with sun and moon, or other checklist)
- c) Are there any other medications you are taking  
(e.g. cotrimoxazole, traditional medicines, herbs etc) Yes  No
- d) Over the last two days, when did you take your pills? (Not including today -  
from yesterday evening and back.)
- e) Did you perhaps miss any?  
(Confirming (c), sympathetic manner. Details if yes.)
- 
- f) What do you do to remind yourself to take your pills?
- 

### **Cost consideration**

- a) How much do you have to pay to cover your travel expenses when you visit  
the clinic?
- b) Do you lose any income as a result of your coming to the clinic? Yes  No
- c) (Do you incur any other costs as a result of your taking ART? Yes  No
- d) Do you and your family have to give anything up in order to be able to pay for  
your ART? Yes  No

### **Quality of care in the ARV Clinic**

**I would like to ask you some more questions about the way you  
were treated in the clinic today.**

- a) What do you think of the service you receive at this clinic? (General, open-  
ended, and then prompt, as below: ask for details as necessary)
- Do you feel listened to? Yes  No
- Are you given the chance to state your problems and ask questions? Yes  No
- Are you treated with respect? Yes  No
- Do you feel you can trust the health workers? Yes  No
- Do you have privacy during consultation and counselling? Yes  No
- How do you find the environment of the clinic? Yes  No

b) How long have you spent altogether at the clinic today?

---

c) How long did you have to wait before being attended to?

(For consultation ... .. min/hours For dispensing .....min/hrs

d) Did you receive any written information? Yes  No

**Perceived problems and possible solutions**

a) What do you perceive as most problematic regarding taking the ARV treatment?

b) What do you think could be done to improve this?

**Anything else to say or ask?**

Is there anything else you would like to tell us or ask us?

Thank you very much for your participation in this interview.

## **7. Guide for observation of health facility**

Name of observer \_\_\_\_\_  
Name of health facility \_\_\_\_\_  
Date/time observation took place \_\_\_\_\_

This observation shall be conducted by the researchers.  
The purpose is to give a descriptive of the setting under which care takes place.

1. Describe hospital setting in general.
2. Describe the location and setting of the ARV clinic and support services (pharmacy, laboratory, social welfare/counselling).
3. Describe the sanitary condition of the environment, how clean or dirty is it, check out the toilets. Describe
4. Where are patients received? Is there privacy? Describe what you see
5. What is the general attitude of health workers, are they receptive and willing to assist clients or are they impatient? Describe what you see what notices or information are displayed for clients to read, describe
6. Specifically look through where patients get ARVs to see if there is any piece of information emphasizing the need for good adherence or telling people how to improve adherence.

## 8. Observation of consultation with health workers

Study no

(Medical doctor, Nurse, Pharmacist, Social worker/Counsellor, Receptionist, laboratory personnel).

**Guide has to be adapted, taking into account the type of consultation to be observed**

*(Don't forget informal, unstructured observations!!!)*

Name of facility \_\_\_\_\_  
 Date \_\_\_\_\_  
 Interviewer \_\_\_\_\_

Consultation: Start time: ----- End time: -----

Observation of consultation with: .....

- Medical doctor
- Nurse
- Social worker/counsellor
- Pharmaceutical staff
- Receptionist
- Laboratory personnel
- Other: .....

### 1. Background information on informant

a) Sex	M/F
b) Age	..... Years (ask or estimate)

### 2. Reason / Aim of the consultation:

- Counselling
- Initiation of active ARV treatment
- Routine follow-up
- Other reason: .....

3. Is patient well received? Yes  No   
 (If not, describe)

---

4. Was the client greeted in a friendly manner? Yes  No

5. Does the consultation take place in privacy? Yes  No

**Factors that facilitate or constrain adherence to antiretroviral therapy among adults at four public health facilities in Botswana: a pre-intervention study**

---

6. Does the health worker ask about any symptoms? Yes  No

7. Is the patient invited to ask questions? Yes  No   
(If yes, what do they ask? Was the question addressed?)

Details:

---

8. Is the patient told what to do next (within the health facility)? Yes  No

Is the patient told where to go for that? Yes  No

9. Is the sequence of events in relation to treatment protocols explained to *new* patients? (Requires training for observer) Yes  No

10a. **If *new* patients, do they receive comprehensive general information about ARVs? (Tick if covered, X if not covered):**

- How ARVs work
- How to use them
- The need to continue treatment
- What to do if a pill is forgotten/missed
- Possible interactions with other drugs, including traditional medicines
- Which side-effects (for the different drugs) may occur
- What to do if they occur
- (Breast) feeding requirements
- When and where to get re-supply
- Requirement to bring unused medicines

10b. Are patients (especially new and those switching regimens) given the following information about ARVs: (Tick if covered, X if not covered):

- Dosage (number of tablets to take and how often)
- Times of when to take the medicines
- How to take them in relation to meals (where necessary)
- What to do if vomit the pill
- What to do if forgets to take medicine on time
- What to do if dose is missed
- What to do if travelling?



- 
- 10c. **For follow-up users only:**  
Does the health worker ask if the patient missed a dose? Yes  No   
If yes, does the health worker explain the effects of missing dose? Yes  No   
Does the health worker offer support to not miss the doses? Yes  No   
If yes, describe
- 
11. Did the provider listen carefully to the client? Yes  No
12. Was any written information given? (**new patients**) Yes  No   
If yes, bring a copy of it if possible.
13. For follow up patients only:  
Does the health worker count the patient's pills before giving him/her a new supply? Yes  No
14. Does the health worker ask the patient if they are taking any other medicines Yes  No
15. Does the patient receive specific tools to remind them to take their medicines? Yes  No

## **9. Semi-structured interview with site manager**

Name of interviewer \_\_\_\_\_  
Place of interview \_\_\_\_\_  
Date of interview \_\_\_\_\_  
Officer interviewed \_\_\_\_\_

Interviewer appropriately greets person to be interviewed, explains purpose of the interview.

The main purpose of these interviews shall be to ascertain to what extent adherence to medication was considered important prior to programme commencement.

- What strategies were put in place to encourage good adherence.
- What strategies were put in place to monitor adherence.
- What strategies are being put in place to improve adherence.

The interviewer shall probe where relevant - the questions below are merely a guide.

*But we shall start with these questions.*

1. When did the facility start providing ART?
2. Number of workers & type of staff involved in ART?
3. Number of staff trained & type of training?
4. Total number of patients on treatment at the facility?
5. Total number of patients seen per day?
6. Availability of reference materials, formularies etc.?
7. Criteria for eligibility to ART (documentary/verbal)?
8. We would like to know about the national roll out of ARVs, when and how did it all happen?
9. How was your office involved in it?
10. What in your opinion do you reckon to have been the greatest challenge you faced with the rollout?
11. How did you overcome the challenge?
12. What number of patients would you be looking at in the next one year by your projections?

13. Do you always receive your order as at and when due?
14. There had been times in the past when your patients had their ARV supply rationed because of inadequate stock, what do you know about this?
15. What mechanisms do you have to ensure availability and sustenance of ARV supply?
16. What do think the adherence levels of your patients' in terms of taking ARVs is?
17. What strategies have you in place to ensure patients receiving ARVs adhere well enough to their treatment?
18. Do you have any reporting and monitoring system for this?
19. Given your experience with your ARV programme is there any thing you would like to see done differently?
20. Do you think there are opportunities for improvement in your programme, if yes probe?
21. The Botswana rollout programme has drawn attention from all over the world, what do you think other countries contemplating national rollout for ARVs can learn from you?

Thank you very much for your time.

## **10. Questionnaire guideline for key informant interview**

### **List of possible key informants and topics**

This is a guide to help researchers remember different issues that may be discussed with key informants of different types. They include general topics, which could be discussed with all these people; and additional topics as under each category. The list could be added to as new issues arise.

#### **General topics**

Handling of misconceptions about ARVs  
Beliefs about illness (HIV)  
Beliefs about ARVs/alternative ways of treatment  
Community participation (pre-intervention sensitisation, communication channels, community response to sensitisation)  
Community support system; Support systems for people living with HIV/AIDS: home-based care, compassionate visits (by whom, for what purposes)  
Stigma/discrimination  
Disclosure  
Workplace  
Employer support

#### **Key informant categories**

Member of council/Local Authority  
Support systems for people on ARV treatment (transport, food baskets etc.)

Chief  
Cultural support/discrimination

Religious leader  
Spiritual support, prayers

Home-based care volunteers  
Collecting medication  
Administering medication  
Pill counts at home

'Family Welfare Educators'  
Education packages available  
Follow up of non-adherent patients

Traditional healers  
Handling of patients being treated with ARVs  
"Referral" of patients

PLWHIV Association  
Support systems  
Stigma  
Issues faced by members in relation to adherence, accessing drugs etc.

## 11. Semi-structured interview with national level policy makers

Name of interviewer \_\_\_\_\_  
 Place of interview \_\_\_\_\_  
 Date of interview \_\_\_\_\_  
 Officer interviewed \_\_\_\_\_

- Interviewer appropriately greets person to be interviewed, explains purpose of the interview.
- The main purpose of these interviews shall be to ascertain to what extent adherence to medication was considered important prior to programme commencement.
- What strategies were put in place to encourage good adherence.
- What strategies were put in place to monitor adherence.
- What strategies are being put in place to improve adherence.

The interviewer shall probe where relevant. The questions below are for guidance only.

### **We would like to know about the national roll-out of ARVs, when and how did it all happen?**

- a) How was your office involved in it?
- b) What in your opinion do you reckon to have been the greatest challenge you faced with the rollout?
- c) How did you overcome the challenge?

### **How many patients nationwide are on ARVs presently?**

- a) What number of patients would you be looking at in the next one year by your projections?
- b) Where do you source your ARVs from?
- c) Who does the procurement?
- d) Do you always receive your order as at and when due?
- e) There had been times in the past when your patients had their ARV supply rationed because of inadequate stock, what do you know about this?
- f) What mechanisms do you have to ensure availability and sustainability of ARV supply?

**What do think the adherence levels of your patients' in terms of taking ARVs is?**

- a) What strategies have you in place to ensure patients receiving ARVs adhere well enough to their treatment?
- b) Do you have any reporting and monitoring system for this?

**Given your experience with your ARV programme is there any thing you would like to see done differently?**

- a) Do you think there are opportunities for improvement in your programme, if yes probe?

**The Botswana rollout programme has drawn attention from all over the world, what do you think other countries contemplating national rollout for ARVs can learn from you?**