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**Evaluation of the Antiretroviral Community Education and Referral (ACER)
Project – *Ng'ombe project site***

Dissertation submitted in partial fulfilment of a Masters of Arts Degree in Gender Studies

By

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Approval

This dissertation of **Joseph Simbaya** has been approved as fulfilling part of the requirements for the award of Master of Arts degree in Gender Studies of the University of Zambia.

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Acronyms

ACER	Anti-Retroviral Treatment Community Education and Referral project
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy or treatment
ARV	Antiretroviral
BCC	Behaviour Change Communication
CBO	Community-Based Organisation
CBoH	Central Board of Health
CHAZ	Churches Health Association of Zambia
CHW	Community Health Worker
CM	Community Mobilizer
CSG	Community Support Group
DHS	Demographic Health Survey
ZDHS	Zambia Demographic and Health Survey
FBO	Faith Based Organisation
FGD	Focus Group Discussion
GFATM	Global Fund against AIDS, TB and Malaria
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
IHA	International HIV/ AIDS Alliance
INESOR	Institute of Economic and Social Research
KAPB	Knowledge, Attitudes, Practices and Behaviour
MoH	Ministry of Health
M & E	Monitoring and Evaluation
MTCT	Mother to Child Transmission
NAC	National Aids Council
NGO	Non Governmental Organisation
NZP+	Network of Zambian People Living with HIV
PLWH	People or Person Living with HIV
PMTCT	Prevention of Mother to Child Transmission
STI	Sexually Transmitted Infection
TB	Tuberculosis
TH	Traditional Healer
THPAZ	Traditional Health Practitioners Association of Zambia
TM	Treatment Mobilizer
TSW	Treatment Support Worker
UNAIDS	United Nations Joint Program on AIDS
UNZA	University of Zambia
ZNAN	Zambia National AIDS Network

Abstract

In Zambia, the prevalence of HIV is estimated to be 16% among individuals 15-49 years old. Among 15-24 year olds, women (12.7%) are four times more likely to be infected by HIV than men (3.8%) (ZDHS, 2002).

The Antiretroviral Community Education and Referral (ACER) project was conceptually designed on the basis of the findings from the community consultations, to improve health seeking behaviour, equity of access, adherence to Anti-Retroviral Treatment, prevention for people living with HIV and how to decrease stigma and discrimination.

This evaluation assesses the role of the project in supporting access and adherence to ART so as to recommend ways of enhancing community access and adherence to ART. The specific objectives are: (i) To assess the adequacy of project design and implementation strategies and the extent to which gender issues were taken into consideration; (ii) To assess the contribution of the ACER project to the people's access and adherence to ART and recommend ways of enhancing community access and adherence to ART. The researcher questions are: (i) Were the project design and strategies adequate to take into account gender dimensions of ART access and adherence? (ii) What has been the contribution of the ACER project to community access and adherence to ART and how could it be enhanced and sustained?

The first strength of the project has been the development of partnerships between organisations in the communities which has extended the reach of the project. However, specific strategies aimed at closing the gender gap in HIV infection and ART access were not included in the design of the project. The project put more emphasis on mobilising people for ART without adequate strategies aimed at prevention of infection, especially among women. The other strength in the design has been the involvement of people living with HIV/AIDS (PLWHA). The study findings suggest that stigma has reduced, indicated by the increase in the number of people seeking VCT services and those joining support groups and a reduction in incidents of experienced stigma.

The study has recorded an increase in the number of people on ART from 11 to over 400 people over a 2 year period. Adherence data from the project shows high levels of self-reported adherence (about 99%). The potential for the activities to be sustainable are high.

Based on the findings, it is recommended: (i) that a strategy must be developed to ensure that uptake for testing and ART is improved among men. (ii) that targeted efforts aimed at reducing infection levels among women must be adopted (iii) that the project must mainstream gender into all project activities.

1.0 BACKGROUND

The Human Immunodeficiency Virus (HIV) has taken a catastrophic toll in Africa with sub-Saharan Africa being by far the worst affected region in the world. At the end of 2000 over 36 million people worldwide were living with HIV and AIDS, two-thirds of them in sub-Saharan Africa. The year 2001 recorded 3.4 million new HIV infections in sub-Saharan Africa alone (UNAIDS, 2002). By 2005, a total of 40.3 million people were living with HIV. Since 1981, 25 million people worldwide have died of AIDS-related illnesses. (UNDP 2007 p.39)

Zambia is one of the countries hardest hit by the HIV epidemic with a national prevalence of 16 percent among the 15-49 year age group (Zambia Demographic Health Survey, 2002). With first cases reported in the early 1980s, HIV/AIDS has not only compounded the country's health problems, but has had far-reaching socio-economic consequences. The increasing poverty levels have fuelled the spread of the epidemic especially among women. The HIV prevalence for women and men between the ages 15 and 45 in Zambia are 18 percent and 13 percent respectively (UNDP 2007). The rates in urban areas are 23 percent as compared to 11 percent in rural areas. Forty percent of all babies born to HIV positive mothers are infected (GRZ/MoH 2004). The 2004 estimates put the current number of people living with HIV in Zambia at 920,000 with about 94,000 deaths as a result of AIDS per year (UNAIDS 2004).

Antiretrovirals (ARVs) are known to immensely prolong lives of HIV-infected persons. By tackling the virus itself, this treatment can revive a person's immune system and give them more years of a healthy life. The WHO estimates that at the end of 2004, 149,000 people living with HIV in Zambia were in immediate need of Anti-Retroviral Therapy. The limitation, however, is that their accessibility is constrained by, among other factors, inadequate information of where and how to get them (MoH 2005).

Recognizing the urgent need for antiretroviral therapy (ART), the Government of the Republic of Zambia (GRZ) allocated funds in 2002 to purchase drugs to treat 10,000 people. By August 2005, treatment and laboratory services at public institutions became free (GRZ, 2005), thus facilitating access to ART by a greater number of people. However, the patients still needed to meet the costs of investigations. Though nominal, these costs are too high in view of the poverty levels in the country. By September 2005, close to 110 sites were providing ART across the country. The number of people receiving antiretroviral therapy increased from 8,500 in June 2004 to more than 43,000 in November 2005 through the public sector and an additional 2,000 people through private facilities. By October 2007, there were about 69,580 people on ART nationwide (MoH ART Department).

Zambia's treatment programme has only been made possible by an unprecedented amount of funding from the Global Fund, the US Presidential Emergency Plan for AIDS Relief (PEPFAR) and other sources. The WHO's 3 by 5 initiative and PEPFAR set their own targets for the end of 2005 and were determined to achieve them. The delivery of the programme relies on the involvement of many NGOs, churches and communities.

In the absence of a cure, the solace for people living with HIV has been found in Antiretroviral Therapy (ART). Antiretroviral Therapy is an essential component of care for people with HIV. In Zambia however, issues of access and adherence are still of concern. With the toll HIV has taken on the already ravaged health system, the Zambian government is only able to provide ART in a limited number of clinics. To supplement government efforts, non-governmental and community-based organizations are carrying out community projects aimed at increasing community awareness about ART and influencing access and adherence to treatment. One of these projects is the ART Community Education and Referral (ACER) implemented by International AIDS Alliance.

According to the Zambia National HIV/AIDS/STI/TB Policy, all sectors of the Zambian society continue to feel the negative impact of HIV/AIDS (GRZ 2005). It is in recognition of this situation that a multi-sectoral approach to addressing the HIV pandemic has been adopted by the Zambian Government. The Government approach has been to involve all stakeholders and partners in the fight against the epidemic. The multi-sectoral approach also means that the realities of individuals and communities affected by the pandemic are critical in the design of interventions to reflect the realities of the affected and infected. Through a community consultation process in 2002, involving major stakeholders at community level, the International AIDS Alliance identified factors that are critical to understanding issues around HIV/AIDS among community members. This led to the design of an intervention by the International HIV/AIDS Alliance called Anti-Retroviral Treatment Community Education and Referral (ACER) project in 2004.

This report is an evaluation of the ACER project intervention activities carried out from inception in 2004 to 2007 and it focuses on Ng'ombe, the Lusaka-based intervention site. Ng'ombe is a peri-urban settlement situated in the North-eastern side of the business district of Lusaka. It has a presence of all the project partners; home-based care, Network of Zambian People Living with HIV (NZP+), Traditional Health Practitioners Association of Zambia (THPAZ) and Africa Directions

1.1 The ACER Project

1.1.1 *Background to the project*

During November 2002 and May 2003, the International HIV/AIDS Alliance (the Alliance), the Network of Zambian People living with HIV/AIDS (NZP+), the Catholic Diocese of Ndola and the Churches Health Association of Zambia (CHAZ) carried out two formative assessments known as 'community consultations' (IHA 2004) in peri-urban and rural Zambia to learn about individual and community perceptions, knowledge and experiences of HIV/AIDS and its related treatment.

The first community consultation was carried out in Lusaka and Ndola. The second consultation took place in four rural villages in the Southern Province.

The following were some of the findings from the community consultations:

- a) Communities are keen to be involved in HIV prevention as well as supporting the safe and effective delivery and use of ARV treatment. They can provide treatment support and help to reduce stigma and discrimination;
- b) Mobilising and building on existing community structures including traditional healers and increasing community involvement would reduce the burden on the fragile and over-stretched health system;
- c) People living with HIV have a key role to play in community education on ARV treatment;
- d) Making ARV treatment information available in simple, accessible language and ways (especially in local languages) is key to fostering community involvement in ARV treatment.

Building on the findings of the community consultations, the Alliance in partnership with the Horizons Program and key stakeholders in Zambia embarked on a two year intervention initiative to implement models of community education and involvement in Anti-Retroviral Treatment (ART) and HIV prevention in Zambia. The project was officially launched in June 2004.

The Anti-Retroviral Treatment Community Education and Referral (ACER) project, started as a two-year pilot project intended to provide evidence and examples for developing similar larger-scale interventions in the future. ACER is now in its third year of implementation and project activities are being implemented by partners in two sites: Nkwazi in the northern part of Ndola and Ng'ombe in the north-eastern part of Lusaka. The project is managed by the Alliance Zambia Country Office.

Funding for ACER has come predominantly from the European Union with additional funds from USAID for the costs of accessing ARV therapy and from the Friend For Life programme of Aids Funds, a Dutch NGO. Locally, ACER has been able to access funds from the Global Fund against AIDS, TB and Malaria (GFATM) through the Zambia National AIDS Network (ZANAN)

1.1.2 Goal and Objectives of the ACER Project

The goal of the project is to improve health seeking behaviour, equity of access, adherence to Anti-Retroviral Treatment and prevention for people living with HIV.

The specific objectives of the project are:

- a) To increase understanding of how to expand health literacy on Anti-Retroviral Treatment (ART);
- b) To document approaches for mobilising and building on existing community structures and engaging people living with HIV to support adherence and prevention;
- c) To explore strategies that can decrease stigma and discrimination through efforts targeted at different stakeholders in the community.

1.1.3 Areas of Implementation

The main strategies for the project are:

- a) Educate and mobilise the community for ARV treatment using existing community structures;
- b) Support adherence for ARV treatment;
- c) Enhance prevention for people living with HIV;
- d) Develop and strengthen a two-way referral system between health services and the community;

1.1.4 Engagement of the community

The strategy of engaging the community is through working with partners who are in direct contact with community members. The project works with two groups of partners: the civil society partners and Government.

The civil society partners are:

- (a) Network of Zambian People living with HIV/AIDS (the projects works with the Lusaka and Ndola Networks)

- (b) Traditional health Practitioners Association of Zambia (The project works with the Lusaka and Ndola branches)
- (c) The Catholic Church, through the Home Based Care programmes in Lusaka and Ndola
- (d) African Direction, a local NGO focusing on the Youth, based in Lusaka

The Government partners are:

- (a) The ART Clinics at the University of Zambia and Ndola Central Hospital
- (b) The local Clinics at Ng'ombe and Nkwazi.
- (c) At policy level the project collaborates with the District Health Management Teams of Lusaka and Ndola. It started with the Central Board of Health (CBoH) and currently collaborates with the Ministry of Health.

The strategy of working with civil society is to support the organisations in their activities and build their capacity to effectively undertake activities. Capacity building activities are based on the needs identified through joint assessment. The other strategy of supporting the organisation is through promotion of linkages and networking among the partners.

Collaboration with government has been through supporting the activities in the ART clinics through placement of Treatment Support Workers at the clinic and setting up the community referral system linking the community with local clinics, ART clinics and other sources of support for individuals in need. It also includes close liaison with District Health Management Teams and the Central Board of Health so as to share information, solicit for support and feedback on project activities.

Another strategy the project is using is a form of behaviour change communication. Behaviour change communication is a process by which information and skills are shared and disseminated to people in a specific target audience with the intention of influencing them to adopt sustainable changes in sexual behaviour or attitudes or to engage in other health seeking behaviour. The elements of this strategy include knowledge, approval, intention, practise and advocacy. Behaviour change communication needs to be more closely linked to service (e.g. condom, VCT, ART etc). This enables the audiences to know what concrete steps they can take to respond to the behaviour change communication messages. The process and the learning that can be derived from the process are perceived as very critical.

1.1.5 Targets

The first target group for the project were individual community members in the project area (Ng'ombe). Individual community members were targeted with HIV awareness and treatment literacy messages in order to mobilize them for VCT and ART.

Community members were generally targeted to reduce stigma and increase support for those with HIV while family members of those infected were particularly targeted to increase support for people with HIV and reduce stigma.

The second target group was the people on with HIV. These were targeted to mobilize them for treatment, promote adherence and improve treatment outcomes. They were also targeted for positive prevention (prevention of re-infection) among people on treatment.

2.0 EVALUATION

Following the completion of the initial phase of the intervention in 2006 in Ng'ombe, and request to evaluate the project, the project management agreed that this evaluation be conducted and submitted as a Masters dissertation. The ACER project was designed as a pilot project to document lessons in the role of community education and referral in the support of ART. It was therefore, imperative to evaluate the project and assess its contribution to people's access and adherence to ART. The evaluation would also feed into the design/redesign of other similar projects. There was also need to review the gender gaps and make recommendations of how to effectively increase access and adherence to ART for both men and women.

2.1 Objectives of the Evaluation

2.1.1 Main Objective

The overall goal of the evaluation is to assess the role the project has played in supporting access and adherence to ART so as to recommend ways of enhancing community access and adherence to ART.

2.1.2 Specific Objectives

The specific objectives are;

- i) To assess the adequacy of project design and implementation strategies;
- ii) To assess the extent to which gender issues have been taken into consideration;
- iii) To assess the contribution of the ACER project to the people's access and adherence to ART;

- iv) To recommend ways of enhancing community access and adherence to ART and ensuring sustainability.

2.2 Research Questions

The study aimed at answering the following questions:

- i) Were the project design and strategies adequate?
- ii) Did the project design and implementation strategies take into account gender dimensions of ART access and adherence?
- iii) What has been the contribution of the ACER project to community access and adherence to ART?
- iv) What could be done to enhance and sustain community access and adherence to ART?

3.0 LITERATURE REVIEW

3.1 Global HIV/AIDS Context

The Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) have for the past two decades continued to spread across all continents killing millions of adults in their prime, disrupting and depriving families, turning millions of children into orphans, weakening the workforce and threatening the social and economic fabric of communities. A World Health Organisation-United Nations Programme on AIDS (WHO-UNAIDS) report showed that by December 2001, a total of 40 million people around the world were living with HIV/AIDS. Of these, 37.1 million were adults, (18.5 million women) and three million children below 15 years of age. By the end of 2005, a total of 40.3 million people were living with HIV. In 2005 alone, 3.1 million people died of AIDS, out of which 570,000 were children. By 2007, more than 25 million people had died of AIDS-related illnesses. About five million people were also newly infected with the virus that causes AIDS (UNDP 2007, p39).

In Sub-Saharan Africa, more than 28.5 million people were living with HIV/AIDS in 2005 (UNAIDS 2005). According to the 2007 Human Development Report (UNDP 2007 p 41), Southern Africa has the highest prevalence ranging from 15% to 35% compared to West Africa (1-5%), North Africa (0-1%) and East Africa (3-7%). The biggest tragedy is the growing number of orphans estimated at 14 million worldwide of which 11 million are in Africa. The arrival of the HIV/AIDS pandemic has caused a re-emergence of TB epidemics throughout Southern Africa. As many as two-thirds of TB patients may be HIV positive. Many adults in Southern Africa carry a latent TB infection, which is suppressed by a healthy immune system. When HIV weakens the immune system, overt TB disease develops.

3.2 National HIV Context

The population of Zambia stands at 10.3 million people with an annual growth rate of 2.9 per cent (CSO 2000). More than 50 per cent of the population is less than 20 years of age and constitutes the most vulnerable group to HIV infection. Currently, 16 per cent of the adult population aged 15-49 is living with HIV. By June 2000 there were 830,000 people over the age of 15 reported to be living with AIDS. Of these, 450,000 were women while 380,000 were men. The peak ages for HIV among females are 20 to 29 years while that for males is 30 to 39 years. Young women aged 15-19 are five times more likely to be infected, compared to males in the same age group. It is estimated that 25 per cent of pregnant women are HIV positive. Approximately 39.5 per cent of babies born to HIV positive mothers are infected with the virus. HIV/AIDS is contributing to

the most profound reversal of development gains made in Zambia over the past 37 years. HIV/AIDS is the most critical development and humanitarian crisis Zambia faces today. Some of the social and economic reversals due to the HIV/AIDS epidemic include:

- i. Decimating the active age group required for economic growth in the country. This has led to loss of productivity.
Life expectancy without HIV/AIDS was projected to be 60 years at birth, but it is now projected at only 37 years due to HIV/AIDS.
- iii. The increasing number of orphans due to AIDS-related deaths.
- iv. The high burden of disease, which has overwhelmed the health care delivery system.

There are, however, some hopeful indications. The prevalence of HIV positive results among 15-19 year-old youths indicated a drop over most of the country between 1994 and 1998. In Lusaka, the rate was 28 percent in 1993; by 1998, it had dropped to 15 percent. The overall prevalence of positive tests in the country appears to be stable and is not increasing, though doing so at a high prevalence level. This has been attributed to behavioural changes. However, the current burden of infection will continue to impact Zambia negatively, especially women, for many years to come (UNDP 2007).

3.3 Factors that perpetuate the transmission of HIV

a) Social-cultural beliefs and practices

Social cultural beliefs, which subordinate women in society, can make them more vulnerable to HIV infection. Difficult socio-economic conditions compel women to exchange sex for money or gifts. Other cultural practices such as dry sex and the traditional practice of widow/widower cleansing also facilitate the transmission of HIV. (Mena 1992)

b) Mobility of Groups

Specific groups such as refugees, long distance truckers, migrant workers, cross-border traders, fish traders and uniformed security personnel are more susceptible due to their mobility.

c) Prison confinement

There are approximately 13,000 men and women in Zambia's prisons. Their vulnerability to HIV stems from unprotected sex frequently in the form of rape, high prevalence of STDs, and very low and inconsistent use of condoms. The law currently

prohibits condom distribution in prisons. Unprotected, penetrative anal intercourse is common. In many instances, prisoners delay in accessing medical services, thus delaying the timely diagnosis and treatment of STDs.

d) Poverty

The inter-relationships between HIV/AIDS and poverty are complex. The manifestations of HIV/AIDS lead to poverty, and the state of poverty directly or indirectly creates vulnerability to HIV/AIDS. HIV/AIDS leads to poverty by eliminating the productive sector of society, the 15 - 45 year age group. More than 70 per cent of the population falls below the poverty level and of these 90 per cent are women. (UNDP 2007 p54)

e) Inadequate and inappropriate Information, Education and Communication (IEC)

Increased levels of HIV are because in most cases the information disseminated is not audience specific and not based on evidence. In addition, the communication methods used are usually directive. People with different levels of understanding of HIV/AIDS are not catered for.

f) Gender Perceptions

Women lack control over their lives and are taught from early childhood to be obedient and submissive to males, particularly males who command power such as a father, uncle, husband, elder brother or guardian (Mena, 1992). In sexual relations, a woman is expected to please her male partner, even at the expense of her own pleasure and well being. Dominance of male interests and lack of self-assertiveness on the part of women puts them at risk. Women are taught to never refuse having sex with their husbands, regardless of the number of partners he may have or his non-willingness to use condoms, even if he is suspected of having HIV or another STI (Mena, 1992). A number of women continue to practice dry sex, which increases vulnerability to infection through the bruising and laceration of genital organs of both partners. Women have limited access to productive resources such as land, credit, skills, capital, technology and information. Because of this, most women are economically dependent on a man, which contributes to their inability to negotiate for safer sex and in some cases, leads to their engagement in commercial sex in order to survive (Mena, 1992). There are inadequate organised services to deal with people involved in sex work. Girls from poor families are sometimes forced into early marriages, sexual arrangements in exchange for money, or school requisites and thus become vulnerable to HIV (Ibid).

3.4 Factors putting women at greater risk of HIV infection and AIDS impacts

A variety of factors have been known to significantly increase the vulnerability of women and girls to HIV infection. These include:

- i) Their limited access to economic and education opportunities. According to the 2004 Living Conditions Monitoring Survey (p.114), extreme poverty is more prevalent among female-headed households than poor male headed households. This fuels the infection of HIV among women of reproductive age.
- ii) The numerous and multiple household and community roles they are responsible for,
- iii) Social norms that deny women sexual health knowledge,
- iv) Practices that prevent them from controlling their bodies,
- v) There is growing evidence that a large share of new cases of HIV infection is due to gender-based violence in homes, schools, the workplace and other social spheres.
- vi) Not all young people have sex because they want to. For example a nationwide study of women 12 to 24 years old in Kenya, 25% said they lost their virginity because they had been forced to, a recent study in Nairobi indicated that 4% of HIV infections in the adolescent 13-19 year age group were consequence of rape (Goodridge & Lamprey, 1999).
- vii) Unwilling sex with an infected partner carries a higher risk of infection, especially for girls. Since force is used, abrasion and cuts are more likely and the virus can more easily find its way into the blood stream. What is more, condom use is unlikely in such situations (Ibid).
- viii) Research has also shown that in up to 80% of cases where women in long-term stable relationships are HIV positive, they acquire the virus from their partners (who had become infected through their sexual activities outside the relationship or through drug use) (Ibid).
- ix) In a variety of contexts, research shows that women’s attitudes towards sex and sexual behaviour differ considerably from those of men. According to Long & Ankrah, 1996, women reported a preference for sexual relations based on mutual fidelity, intimacy and open communication.
- x) Studies have shown that, when women do express a desire for safer sex, men are often obstructive. Perhaps not surprisingly, therefore, the major HIV risk for women is their regular sexual partner or husband (Goodridge & Lamptey, 1999). On the other hand, dominant ideologies of masculinity promote the display of sexual prowess, and encourage men to have multiple partners (Rivers and Eggleton, 1999).
- xi) It is also true that many existing HIV prevention programmes fail to take adequate account of the social vulnerability of women or the unequal power relations between men and women in many, if not all Zambian communities. These inequitable relations make it difficult for women to influence decision-making in their sexual relationships as well as in the creation of equal socio-economic opportunities (Mena, 1992).

- xii) According to Goodridge, (Goodridge & Lamprey, 1999), the key elements of many HIV/AIDS programmes, including: - partner reduction, condom use and STI treatment - are not necessarily appropriate for women, who do not have multiple partners, cannot always influence the decision to use condoms, and may be asymptomatic for STIs.

In a nutshell, women are biologically more vulnerable than men to HIV infection, their subordinate position to men can make it difficult to protect themselves and certain cultural and economic practices can increase the risk of transmission. In addition the burden of care in AIDS-infected households falls on women and female children. (UNDP 2007p 56)

All the above gender imbalances factors have implication for both infection and impact of HIV as reflected below. For example, tables 1 and 2 below shows that men are more knowledgeable in HIV/AIDS issues. They are thus more likely to protect themselves from infection than women

The above gender issues have not only made it difficult for women to gain HIV-related knowledge, but have resulted in more women being infected and disproportionately suffering the impacts of the epidemic as shown from the ZDHS (2001-2002) data below. Table 1 shows the percentage of women and men who spontaneously mentioned ways to avoid HIV/AIDS;

Table 1: HIV prevention knowledge among men and women

Ways to Avoid HIV	Women	Men
Does not know of AIDS or if AIDS can be avoided	8.6	3.3
Believes no way to avoid AIDS	6.1	4.2
Does not know specific way to avoid AIDS ¹	0.8	0.5
Ways to Avoid AIDS		
Abstain from sex	43.7	52.9
Use condoms	48.1	61.9
Limit number of sexual partners	8.1	4.8
Limit sex to one partner/stay faithful to one partner	45.9	33.4
Avoid sex with prostitutes	1.5	6.3
Avoid sex with persons who have many partners	1.2	2.0
Avoid sex with homosexuals	0.1	0.1
Avoid sex with persons who inject drugs intravenously	0.2	0.8
Avoid blood transfusions	1.5	2.5
Avoid injections	2.0	4.1
Avoid sharing razors/blades	5.2	6.7
Avoid kissing	0.1	0.7
Avoid mosquito bites	0.1	0.1
Seek protection from a traditional practitioner	0.1	0.2
Other	1.8	2.1
Number of women	7,658	2,145

Source: ZDHS 2001-2002 p.196

The Zambia sexual and behaviour survey (2003) also revealed that men’s knowledge about HIV is slightly higher than that of men as shown on table 2 below.

Table 2: Knowledge, Attitudes and Behaviour around HIV for men and women

KAB around HIV	Female (%)	Male (%)
Heard of HIV/AIDS	98	99
HIV can be avoided	81	89
A healthy-looking person can have HIV	86	90
HIV can be transmitted through a mosquito	24	21
Reported that they knew at least one way in which HIV could be avoided	74	80
Spontaneously mentioned condom use as a means of protecting oneself	71	77
A woman can insist on using a condom if she suspects her husband is infected	49	61
A woman can refuse sex if she suspects her husband is infected	66	62

Source: The Zambia Sexual Behaviour Survey (ZSBS) 2003

3.5 HIV Prevalence among men and women in Zambia

According to the ZDHS 2001/2002, 15 percent of women aged between 15 and 19 had been forced by a man to have sexual intercourse at some point in their lives while

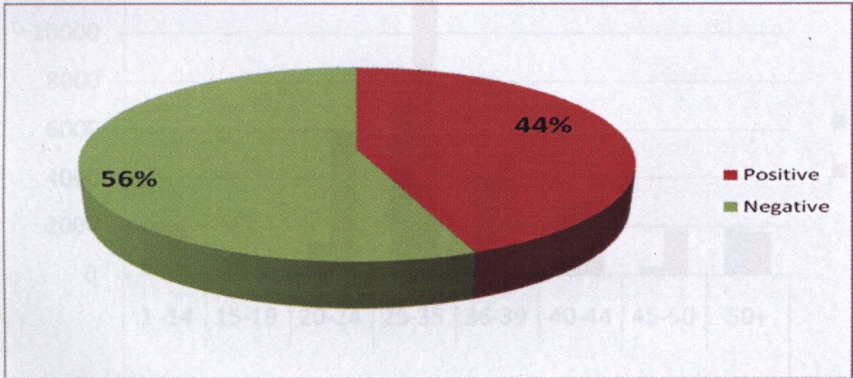
¹ Believes there is something a person can do to avoid AIDS, but cannot spontaneously mention any specific way.

nearly 8 percent had been forced to have sexual intercourse in the 12 months prior to the survey.

According to ZDHS 16 percent of the individuals tested were found to be HIV positive. Women are more likely to be HIV positive than men (18 percent versus 13 percent). Overall, the proportion HIV positive rises with age from 5 percent among those 15-19 to 25 percent in the 30-34 age group, before falling to 17 percent among those 45-49. Among women, the proportion found to be HIV positive rises abruptly with age, from 7 percent among the 15-19 cohort to 29 percent in the 30-34 age group and then drops off to 14 percent in the 45-49 cohort. Among men, HIV prevalence is below 5 percent among those under age 25, rises to 15 percent in the 25-29 age group, peaks at 22 percent in the 35-39 age group and stays around 20 percent in the 40-49 age group. HIV prevalence is higher in the 55-59 cohort (12 percent) than in the 50- 54 cohort (7 percent). (ZDHS 2002)

Findings from the ZDHS reflected above have also been echoed by the Zambia VCT Services, which show that there are more women infected than men. The figures 1, 2 and 3 below show the national VCT results in 2005. Figure 1 shows the number of people who tested positive and those who tested negative:

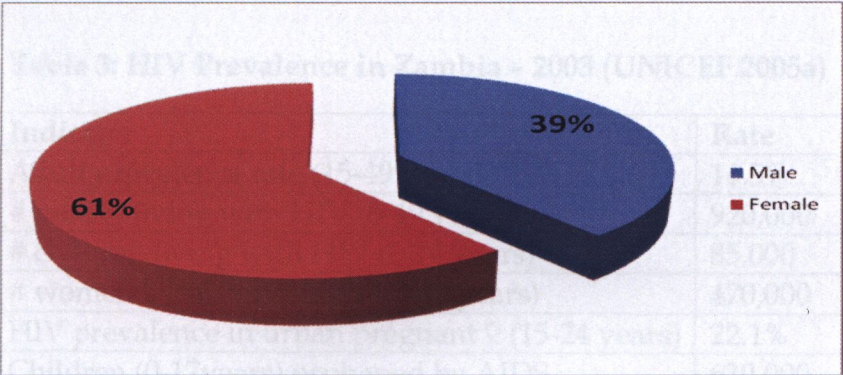
Figure 1: Zambia VCT results, 2005



Source: ZVCT Service Activity Annual Report, 2005

As figure 2 below shows, there are more women than men who tested positive to HIV. This may be attributed to the unequal power relationship between men and women resulting in women’s vulnerability to HIV infection.

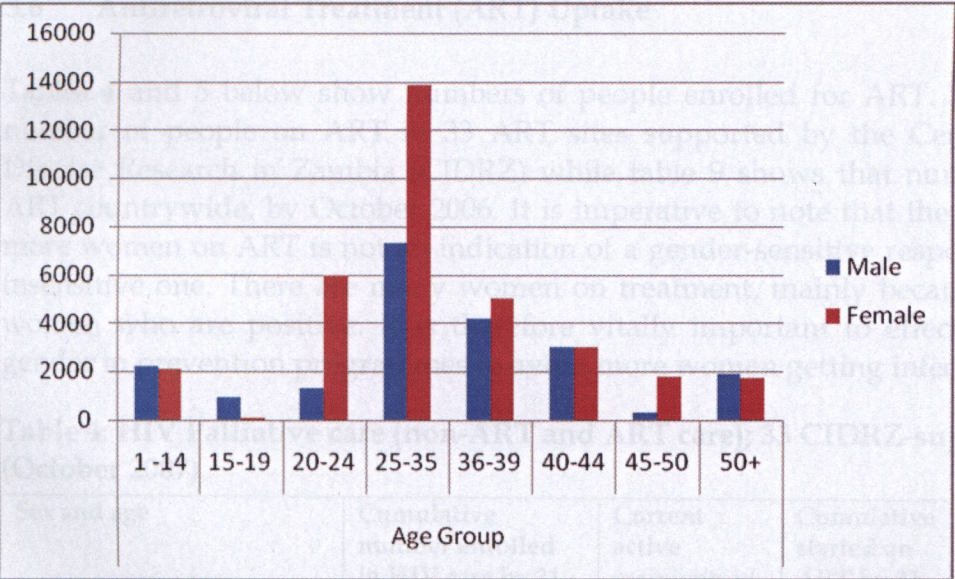
Figure 2: Zambia VCT results by sex



Source: ZVCT Service Activity Annual Report, 2005

Compared to males, more women are infected between 15 and 39 years of age. The distribution is changes with age. Among the clients who are 50 years and above, there are more men who are infected with HIV than women as figure three below shows:

Figure 3: VCT results by age group and sex



Source: ZVCT Service Activity Annual Report, 2005

According to UNICEF (2005a), by 2003 more women than men were living with HIV as shown in table 3 below;

	2003	2004	2005	2006
Total	68,660	67,809	42,695	35,477
Totals by Sex on ART				
Male	23,983 (34.9%)	21,983 (32.4%)	13,983 (32.7%)	11,983 (33.8%)
Female	44,677 (65.1%)	45,826 (67.6%)	28,712 (67.3%)	23,494 (66.2%)

Source: CIDRZ, Oct. 2007

Table 3: HIV Prevalence in Zambia - 2003 (UNICEF 2005a)

Indicator	Rate
Adult prevalence rate (15-49 years)	16.5%
# people living with HIV (0-49 years)	920,000
# children living with HIV (0-14 years)	85,000
# women living with HIV (15-49 years)	470,000
HIV prevalence in urban pregnant ♀ (15-24 years)	22.1%
Children (0-17years) orphaned by AIDS	630,000
Children (0-17 years) orphaned due to all causes	1,000,000

With HIV infection rates currently estimated at 16% of people aged 15 - 49, it is clear that many more children may lose their parents. Zambia's orphan's crisis is growing. By 2003, these

figures had risen to almost 1 million children. This suggests that Zambia has among the highest proportion of orphans in Sub-Saharan Africa and a much higher proportion than any other country in Asia, Latin America or the Caribbean (UNAIDS/UNICEF 2002).

3.6 Antiretroviral Treatment (ART) Uptake

Tables 4 and 5 below show numbers of people enrolled for ART. Table 8 shows the number of people on ART in 33 ART sites supported by the Center for Infectious Disease Research in Zambia (CIDRZ) while table 9 shows that number of people on ART countrywide, by October 2006. It is imperative to note that the fact that there are more women on ART is not an indication of a gender-sensitive response, but rather an insensitive one. There are many women on treatment, mainly because there are more women who are positive. It is therefore vitally important to effectively mainstream gender in prevention programmes to avoid more women getting infected.

Table 4: HIV Palliative care (non-ART and ART care); 33 CIDRZ-supported sites (October 2007)

Sex and age	Cumulative number enrolled in HIV care by 31 October 2006	Current active recipients of HIV care	Cumulative started on ART by 31 October 2006	Current number actively on ART by 31 October 2006
Males (0-14 years)	2,386	2,050	1,584	1,390
Males (15 or more years)	23,872	19,618	15,515	12,593
Females(0-14 years)	2,399	2,048	1,468	1,277
Females (15 or more years)	40,003	34,089	24,091	20,211
<i>Total</i>	<i>68,660</i>	<i>57,809</i>	<i>42,658</i>	<i>35,471</i>
<i>Totals by Sex on ART</i>	<i>Male</i>	<i>13,983(39.4%)</i>		
	<i>Female</i>	<i>21,488(60.6%)</i>		

Source: CIDRZ, Oct. 2007

Table 5: National ART uptake by sex by October 2006

Total number enrolled on ART	69 580
Total number of males	27,832 (40%)
Total number of females	41,748 (60%)

Source: Ministry of Health; ART department

3.7 HIV/AIDS Intervention Design

Zambia's health care system is being ravaged by rising numbers of HIV/AIDS related morbidity and mortality from the general population, while at the same time health care workers are ill, dying and otherwise overtaxed by the epidemic in their personal capacities. Nurses in Lusaka reported feeling burned out and hopeless from treating those with HIV/AIDS (International HIV/AIDS Alliance, 2002). Most of Zambia's medical institutions provide only clinical care and counselling, while organizations based in the community tend to provide more holistic care which includes clinical management, home-based and palliative care, and counselling, social and spiritual support. The shortage of trained healthcare workers is severe in many high-prevalence settings such as Zambia. As this situation is likely to persist in the near future and scaling up access to antiretroviral (ARV) treatment remains a priority, a public health approach to HIV/AIDS treatment must include strategies that reduce the burden on highly skilled physicians and other professional health providers.

In order to ensure a continuum of comprehensive care for people living with HIV/AIDS, there needs to be a more efficient coordination among the hospitals, clinics and the community-based services and support (National AIDS Council, Government of Zambia, 2002). Many respondents from a community consultation on ARV treatment in Zambia in November 2002 made it clear that communities already play a significant role in the provision of health care but this has not been sufficiently recognized or utilized. Additionally they stated that communities are willing and able to be involved in many different ways in order to support hard-pressed health care providers in doing their jobs (International HIV/AIDS Alliance, 2002).

It is now accepted that ARV treatment is an essential component of care and support for people with HIV (WHO, 2001). Additionally, access to ARV treatment offers powerful support for HIV/AIDS prevention (International HIV/AIDS Alliance, 2002). Although it cannot cure HIV/AIDS, ARV treatment has dramatically reduced the morbidity and mortality, prolonged lives and improved the quality of life of many people with HIV (WHO, 2001). Increased political will for improving access to ARV treatment and dramatic price reductions of ARVs have made it possible for developing country governments such as the Zambian government to begin planning and implementing national ARV treatment programs. ARV treatment in Zambia is currently available through two government pilot ARV treatment programs in Lusaka and Ndola,

prevention of mother-to-child transmission programs, and in the private sector through private clinics and workplace programs such as the police and the military ARV treatment programs for their staff and dependants. With support from the Global Fund to fight AIDS, TB and Malaria, the Government of Zambia plans to eventually scale up their ARV treatment program to each of the country's nine provincial hospitals, and initial sensitizations for health care staff from all nine provinces have already taken place.

Recent data suggests that people with HIV taking ARVs must take their medicines on time at least 95 percent of the time (Low-Beer et al., 2000; Patterson et al., 2000). In order to achieve long-term viral suppression, strict adherence is essential (Carpenter et al., 1997). This means taking the correct dose at the correct times, in the correct way for as long as prescribed. Non-adherence can compromise the health of an HIV positive individual by enabling a rapid increase in viral load and development of drug resistant virus. Patients who miss even a few doses of their ARV medication demonstrate significant increase of circulating virus (Ho et al., 1995; Kastrissios et al., 1998). This may have personal and public health consequences.

Increasingly, it is accepted that adherence to ARV treatment has medical, psychological, social and financial dimensions and is an important public health priority. Additionally, it is also now understood that supporting adherence requires a multifaceted, dynamic, socially and culturally specific approach. Researchers (e.g. Ickovics and Mead, 2002) have identified variables associated with adherence and classified them into several types – medical regimen variables, patient variables, provider variables and support variables (Broadhead, 2002). Medical regimen variables include numbers of pills and complexity of administration of medication. Patient factors include beliefs about their illness and effectiveness of medication, fear of and actual side-effects, presence of severe anxiety and/or depression, poor social relationships and social support, substance use and fear of stigma and discrimination (Ickovics and Meade, 2002; Gordillo et al., 1999). Provider variables include lack of knowledge and skill, lack of time, provider beliefs and provider-patient collaboration (Williams and Friedland, 1997; Noring et al., 2001; Ickovics and Meade, 2002). Support strategies include peer support groups, outreach education, buddy systems (also known as treatment mentor systems) and provider supports (Broadhead, 2002). Evidence to date from the developed world has largely documented factors associated with and affecting adherence. However, what remains lacking is evidence on practical, relevant strategies for supporting adherence in resource-limited settings such as Zambia.

With the advent of antiretroviral therapy, concerns have been raised about its impact on HIV/AIDS-related behaviours. There is a growing body of evidence that 'treatment optimism' and perceived reductions in infectivity and acceptability of HIV/AIDS due to ARVs may lead to increased sexual risk taking behaviour (Remien, 2000). In a high-prevalence setting such as Zambia, with the introduction of ARV treatment, there will

be more people living longer and healthier lives with HIV. These people represent a key population for prevention efforts since increasing their engagement in HIV/STI related protective behaviours can a) reduce their own vulnerability to STIs and/or re-infection with HIV, and b) reduce the possibility of transmission to non-infected individuals (Brewer, 2002; Schlitz and Sandfort, 2000). Evidence has shown that preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, and resources, than preventive interventions focused on negative individuals (International HIV/AIDS Alliance, 2003). A change in the risky behaviour of an HIV positive person will, on average and in almost all affected populations, have a much bigger effect on the spread of the virus than an equivalent change in the behaviour of a negative person (King-Spooner, 1999; Vernazza et al, 1999). There is an increasing understanding that ARV treatment and prevention for people with HIV have a symbiotic relationship, i.e. efforts to scale up access to ARV treatment must go hand in hand with specific prevention efforts targeting people with HIV. Furthermore, providing ARVs offers opportunities for delivering secondary prevention interventions and ongoing chronic health management.

3.8 Community Engagement in HIV/AIDS Interventions/Responses

As the availability of ARVs increases through new efforts such as the United States President's Emergency Plan for AIDS Relief (PEPFAR) and WHO's '3 x 5 initiative' (3 million people on ARVs by 2005), there is concurrent recognition by USAID and others of the need to understand ways of linking with, preparing and engaging communities. Health experts working on ARV access acknowledge that the success of these programs will require much more than the reliable provision of ARV medication and related monitoring and laboratory tests by well-trained and qualified clinical staff, but must also include effective community education about ARVs, how they must be taken and adhered to, side effects, and enrolment criteria, and also two-way referral between clinic and community services. Without effective community preparedness and mobilization efforts, and the establishment of efficient referral systems, the full potential of ARVs is not likely to be fully realized.

Involvement of communities that are the most affected has also been a critical factor in many of the most successful responses to HIV/AIDS. This notion is widely accepted in HIV/AIDS prevention but is equally true in respect of HIV treatment, where partnerships with affected communities, including people with HIV themselves, will determine health-seeking behaviour, the acceptance of ARV treatment and the extent to which barriers to care, for example stigma and discrimination, are reduced or eliminated. Community preparedness includes consumer education on ARV treatment, working with health care providers, involving people with HIV, and strengthening community mechanisms to promote treatment adherence and prevention (International

HIV/AIDS Alliance, 2002). Such an approach would aim to support adherence and prevention for people with HIV through improving knowledge and support and would result in building social capital² among people with HIV and the wider community.

Community education and referral provides an opportunity for community members and health care workers to become active partners in addressing health needs. It brings community members and other stakeholders together to identify and link health needs and resources in a way that helps people to help themselves. It is also well established that community education contributes to the reduction of stigma and can enhance positive living, which in turn can encourage people to come forward for testing and treatment (Mills, 2002). Evidence from a number of disease areas indicates that education involving and focusing on families, peers and communities is critical for large-scale rollout and increased coverage of health related programs. Evidence also indicates that community structures or institutions can be effectively mobilized to reach the general public with HIV/AIDS education. Lessons from efforts to treat tuberculosis show that systematic and coordinated engagement of community groups can improve treatment and prevention outcomes as well as generate more effective local responses (Maher, 2003).

It is imperative however, that community interventions are appropriate to the community's cultural context. They must deal with the real and practical issues and decisions that face men and women, young and old, relating to sexuality (Drinkwater et al. 2006)

One of the approaches to behaviour change communication is audience-centered communication. Audience-centered communication is an approach to BCC based on a model of dialogue between those who wish to promote behaviour change and a participating audience. It is essentially a consultative partnership, focusing on interaction at every stage between the communicating institution and the public. While a number of methodological tools are available (focus groups, key informant interviews, and various participatory learning and action [PLA] techniques, among others), no technique will be truly effective unless it is imbued with an attitude of respect for the target audience and a determination to understand the audience's point of view and address the audience's central concerns throughout the BCC campaign, culminating in its evaluation (FHI, 2001).

Audience-centered communication has three stages. The first stage determines the parameters for effective BCC through a series of research and planning activities. The

² Although there are various definitions of social capital, one of the most frequently used is that developed by the World Bank in which social capital is defined as consisting of processes between people that establish networks, norms and social trust, and facilitate co-ordination and co-operation for mutual benefit (World Bank, 2002).

second stage involves developing a communication concept and messages based on the formative research findings, drafting materials, and pretesting them with the target audience. The third stage involves implementing BCC activities, and includes monitoring communication activities, checking comprehension, and assessing communication effects (FHI, 2001).

The following have been identified as important standards in the development and implementation of a successful behaviour change communication;

- i) Interventions should focus on well characterized, specific target audiences.
- ii) HIV/AIDS prevention interventions and messages must be crafted to motivate and appeal to the specific target audience's perceived needs, beliefs, concerns, attitudes, present practices, and readiness to change.
- iii) At-risk individuals must be provided with both skills and supplies to prevent HIV.
- iv) A supportive environment needs to be created for HIV prevention and for the protection of those infected with HIV.
- v) Mechanisms need to be created to maintain and sustain HIV prevention behaviours and activities over time.
- vi) BCC planners should identify and use opportunities to work collaboratively and in different sectors of the community/country.
- vii) A monitoring plan is essential to guide the adequate implementation of behaviour change communication projects (FHI 2001).

There are different types of evaluations. These include formative, process and effectiveness evaluation. As a first step in the program development cycle, formative evaluation seeks to collect information in order to describe the current situation, identify needs, and orient an effective response. Process evaluation gives attention to service delivery through monitoring program inputs and outputs, including service quality and coverage, and is crucial for program management. It monitors and evaluates inputs and outputs. Effectiveness evaluation focuses on outcomes and impacts and evaluating the effectiveness of a program and usually involves estimating the impact of programs on the system and behaviour change. For an HIV program it involves estimating the impact of an intervention on prevalence and incidence of HIV and HIV-related behaviours, including treatment seeking behaviours, condom use and sexual behaviours (Ibid).

3.9 Emerging issues from the literature review

- i) It is clear from the literature reviewed that;

- ii) HIV is a global crisis with its prevalence and impacts highest in sub-Saharan Africa
- iii) Zambia is one of the most affected countries with a high prevalence
- iv) The HIV policy in Zambia operates in a poverty environment, which fuels the increase of the epidemic in terms of both infection and impacts.
- v) The policy makers do not adequately take gender issues into considerations when making and implementing policies related to HIV prevention, treatment and care.
- vi) The HIV/AIDS problems have gender dimensions of both prevention and care
- vii) There are more women suffering from the epidemic as both infected and affected, as such there are also more women on treatment than men.
- viii) In Zambia, women are more vulnerable to HIV infection due to multiple factors and thus most infected and affected than men.
- ix) Successful responses to HIV are those that genuinely involve people living with HIV.
- x) Although there are some barriers to accessing treatment, more women are testing and subsequently accessing treatment. As such gender-sensitive prevention interventions must be paced up to reduce the number of infections, especially among women.
- xi) Holistic approaches to fighting HIV must be adopted that are designed to prevent HIV infection, provide affordable and accessible treatment and care and fight stigma and other barriers to care access.
- xii) Involvement of communities in design and implementation of HIV initiatives is critical to success.
- xiii) Taking into consideration gender dimensions of infection, treatment and care is critical in the design of successful interventions

4.0 METHODOLOGY

4.1 Research Design

This study was an end of project evaluation that focused on assessing the processes and how these affected the project outcomes such as community access and adherence to ART.

4.2 Study Setting and Population

The evaluation was carried out in Ng'ombe, a peri-urban settlement of Lusaka where the intervention was conducted. The intervention targeted the general community in an effort to increase literacy about VCT and ART. People with HIV were specifically targeted to mobilize them for treatment. This was done through community partners.

Interviews with members of the community and project partners were done in Ng'ombe, a peri-urban settlement of Lusaka, where project activities were implemented. The project identified community-based organizations in Ng'ombe who were trained to implement intervention activities. In addition to community-based partners, the project recruited and trained treatment and community mobilizers. The community mobilizers are based in the community while treatment mobilizers (treatment support workers) are based at the University of Zambia (UNZA) clinic, being the nearest clinic where people on ART from Ng'ombe receive their medication. Community Mobilizers were interviewed in Ng'ombe while TSW were interviewed at UNZA clinic. People on treatment were recruited to the study at two points, namely UNZA clinic and the home-based care offices in Ng'ombe. Health and HBC worker at the clinic and HBC offices, respectively, assisted in accessing consenting people on ART.

Interviews with other project staff and IHA management were done at Alliance country office. Other stakeholders within Lusaka were also interviewed. These include the Sister-charge and the ART manager at UNZA clinic and the VCT coordinator at Ng'ombe clinic.

4.3 Selection Procedures

The study made use of non-probability sampling techniques. All respondents were purposefully selected. Community members were recruited through the Residents Development Committee and included both men and women. People on ART were recruited for in-depth interviews at the clinics through health care providers and at

Ng'ombe HBC through HBC workers. Project staff from different levels were interviewed and included treatment support workers, community mobilizers and project management.

Two focus group discussions from the community were conducted, with each group comprising 7 to 11 discussants. One group was gender-balanced while the other had more women than men. To adequately inform the evaluation, a purposive sample of 5 people on ART were interviewed comprising 3 women and 2 men. This ratio of men to women was arrived at from the baseline data of the project, which revealed that the ratio of men to women on treatment was 2:3 (ACER, 2005). Two treatment support workers based at the clinic and two community-based treatment mobilizers were recruited to the study and interviewed. Other project staff interviewed include the ACER project manager and Alliance Programmes Director. One Focus Group Discussion was conducted with each community-based partner (i.e., Africa Directions, THPAZ, NZP+ and HBC). For secondary data, a record review was done on all records, services statistics and quarterly reports for IHA and the partners.

Additionally, three health staff were interviewed at UNZA clinic; the sister in charge, the ART Manager and a VCT Counsellor. To triangulate data from VCT records, the VCT Counsellor from Ng'ombe clinic was also interviewed. One representative from the Lusaka DHMT was also interviewed.

4.4 Data Collection Tools

Qualitative methods of data collection were used. These enabled the collection of in-depth information on stakeholders' views and perceptions about the intervention's contribution to community access and adherence to ART. Baseline and process data from the project were used for reference and triangulation. A desk review of quarterly and other reports from the project and its partners was done.

Both primary and secondary data were collected. Primary qualitative data were obtained mainly through unstructured interviews with people on ART, implementing partners and project staff. Implementing partners of the project are community-based organisations, which are trained by the project to carry out community activities and these include staff from NZP+, the Home-Based Care of the Lusaka Archdiocese, THPAZ and Africa Directions. In-depth Interview (IDI) guides were used to conduct interviews. Community members were interviewed using Focus Group Discussions (FGDs) guides. Refer to Annex 2 for the tools.

4.5 Data Analysis

Taking into account the fairly large sample and amount of data envisaged, the computer was used to analyse some of the qualitative data. Atlas.ti, computer software for processing and analysing qualitative data was used. Typed transcripts from audiotapes were assigned to Atlas.ti and coded. In addition to pre-determined, instrument-based codes, all transcripts were read thoroughly in order to tease out emerging themes and allow for generation of new codes for data sorting. After generating code-based outputs from Atlas.ti, a further systematic analysis was done, making use of content analytic summary tables. These helped present data on codes from different respondents on the same matrix to allow for effective comparison and holistic analysis of the data. Thematic conceptual matrices were also used to analyze data under different themes. Secondary data fed into the discussion of findings and served to triangulate the data. Some data were analyzed manually as some respondents did not want to have their voices recorded and only notes were taken.

Assessment Criteria

Adequacy of project design and strategies was assessed in terms of how comprehensive the approach was and the extent to which project design standards were adhered to. These include involvement and participation of target groups, use of community-based organisations and structures and the project's potential for sustainability.

Gender issues were assessed by reviewing the extent to which design took into consideration the gendered factors outlined in the literature review that might affect both access and adherence and examining the number of males and females on ART, and ART adherence levels between men and women. The project and partner organizations were also assessed in terms of how many men and women were recruited to work on the project.

The project's implementation and achievement of its objectives were assessed by focusing on the project areas as stated in the objectives. These are number of people being referred for and access VCT and ART, ART adherence levels and stigma levels.

4.6 Ethical Considerations

The study adhered to research ethics. Ethical clearance was given by the University of Zambia Research Ethics Committee.

Only consenting adults on ART aged between 18 and 55 on ART were interviewed. The researcher considered confidentiality and anonymity as major concerns and ensured that they were protected as a way of minimising the risk of the study to the respondents. Respondents were assured of full confidentiality of the information provided. Names of respondents were not recorded on any written or electronic materials. All data have been stored in a locked file box and password-protected computer account and are only accessed by the researcher.

4.6 Limitations of the study

The major limitation of the study is that some information was missed as some of the staff who were originally involved in the study were not available for interviews. These included the first ACER manager who was no longer with the project and out of the country at the time of the interviews and her successor who died. However, this limitation was offset by an extensive review of project documents and reports.

Furthermore, the absence of ART at Ng'ombe clinic meant that eligible residents of Ng'ombe took their ARVs from any nearby clinic. As a result some people were accessing ART from Chelstone, Kalingalinga and University clinics. This made it very difficult to assess the number of people that the project had mobilized for ART as the treatment support workers were only based at the University clinic and could only capture a limited number of people.

The evaluation was also done at the time when not many project activities were going on as the initial funding ended and some partners were no longer active with project activities. The researcher however, endeavoured to interview who project partner members who were actively involved in project implementation.

The rate at which people on ART were recruited to the study was slow and took longer than anticipated. This was due to the fact that people on ART were collecting ARVs for longer periods and it took long for them to return and others were sending their treatment supporters (*Buddies*) to collect drugs for them. A remedial measure had to be put in place and this involved recruiting some people through the HBC in the community.

5.0 FINDINGS

The study focused on three areas, namely (i) the adequacy of project design and implementation strategies, (ii) the extent to which gender issues were taken into consideration in the project design and implementation and (iii) the project's achievement of its objectives; its contribution to community VCT and ART uptake; adherence to ART and prevention and support for people with HIV; stigma reduction; involvement of people living with HIV and development of a referral system.

5.1 Adequacy of Project Design and Strategies

Adequacy of project design is assessed by evaluating the extent to which the project design and strategies adhere to standards of design such as i) involvement of the target groups ii) comprehensiveness of the partners, iii) use of existing community structures, iv) building-in sustainability measures from the start, v) easy access of the project services by all in the target group and vi) putting in place an M & E system.

5.1.1 Involvement of the target groups

The rationale for ACER is based on the assumption that “community education, referral and support for ART improves uptake of VCT, PMTC, uptake of and adherence to ART, emotional and social well-being”.

The ACER project has three direct targets for its interventions; a) individual members of the community, b) families of people living with HIV, and c) people living with HIV. Individual community members in the project area (Ng'ombe) were targeted with HIV awareness and treatment literacy messages in order to mobilize them for VCT and ART. Increased awareness and literacy among individual community members also aimed to reduce stigma and increase support for those with HIV. Family members of those infected were particularly targeted to increase support for them and reduce stigma. People living with HIV were targeted to mobilize them for treatment, promote adherence and improve treatment outcomes. They were also targeted for positive prevention (prevention of re-infection) among people on treatment.

While the main target groups were included in the project, the project would have benefited from active involvement of the target groups in the running of the project. The communities were mainly involved in community meetings with community-based. However, this could have been enhanced by inviting selected community members to planning meetings for community activities. This was not usually the case as only partners were represented during such meeting.

The use of the strategy to include treatment supporters ensured that families and friends of those infected were adequately involved in the care of the infected. However, the project could have benefitted from increased participation of families and friend of the infected beyond care-giving.

People living with HIV were involved either as individuals or through the Network for Zambian People living with HIV (NZP+). They actively participated in the decision making, planning and running of the project as reflected in the quarterly reports and minutes of meetings held during the lifespan of the project.

Involvement of PLWH is strength in the design of the ACER. The involvement of PLWH is at two levels; at the partner level and at the level of project implementation. At partner level the involvement of the Network of Zambian People living with HIV/ AIDS ensures that the personal and organizational experiences of the members of the organizations are pooled to enrich the strategies being used to increase the uptake of HIV testing and ART. It also brings in the beneficial aspect of reducing stigma, especially self-stigmatization, as it gives a human face to the messages being propagated.

According to the THPAZ, most of their members in Lusaka have undergone VCT and this has helped in increasing the understanding among traditional health practitioners of the importance of working with clinics in the fight against HIV.

The second level of involvement is at the level of project implementation. The strategy has been to encourage PLWHA to join the project. All the treatment mobilizers and treatment support workers are living openly with HIV/AIDS. The members of staff provide counselling from a personal perspective. They provide role models of positive living and help patients overcome helplessness in face of sickness and fear. This also helps in reducing stigma and discrimination that has been associated with HIV/ AIDS.

Because the members of staff are openly living positively, the demand for their services has increased beyond the confines of the project. According to staff in the project, they are often called upon to give talks to other organizations as they embark on or want to improve the support to their staff in HIV/AIDS. For example they have been called upon to give talks to the Business Coalition on HIV/AIDS. Most people living with HIV, including health staff, prefer to be counselled by someone who is in their situation;

“Clients as well as medical staff would rather talk to us than other health care workers”“We are a visible example of what people living with HIV look like, this is the best way to educate people about HIV and AIDS”“People on ARVs need to be involved at all levels – even at Government level” (TSW)

5.1.2 Comprehensiveness of the partners

The ACER strategy is based on the involvement of already-established partners with permanent structures that are closely associated with and provide support to people affected and infected by HIV. The community approach in this case starts with partners that can ultimately reach the wider members of the community. Through building the capacity of partners by increasing their knowledge and skills and providing them with materials (where necessary), the partners are able to provide information, referral and other support services. This contributes to the increase in the demand for VCT services and ARV treatment.

According to a member of the Catholic Diocese Home based Care,

“....the greatest achievement of this project has been the bringing together of organisations that would normally not have worked together.”

The bringing on board of traditional healers is an innovative aspect of the project. The project was designed to enable traditional healers refer patients for ART, home-based care services and support networks. The linkages created have improved services offered by the individual organisations and minimised duplication of efforts in the same areas. One good example of the improvement in linkages has been the ability of the organisations to work together through partners meetings and joint programme development. This is very significant in that, for example, faith based organisations have traditionally not worked together with traditional healers and in general traditional healers do not work with other organisations.

The partnership builds on the cooperative strength of each of the organisations. By and large, most potential partners were included. In the relationship between the organisations participating in the ACER, the comparative strengths are indicated in Table 6 below:

Table 6: Organisational Comparative Strength

Organisation	Comparative strength
Network of People of Living with HIV/AIDS	With their slogan of “nothing about us without us”, This organisation has the advantage of being able to share individual and group experiences, giving a human face to the fight against HIV and showing that stigma can be reduced.
Traditional Health Practitioners Association of Zambia	Culture and tradition play a critical role in Zambian society. Traditional medicine is often used as the first line in treatment seeking behaviour. The influence of the members of THPAZ is wide, with over 40,000 members in all parts of the country.
The Home Based Care programmes under the Catholic Church	With over fifteen years of experience in providing palliative services to sick people in low-income areas of Zambia, the Church has a wealth of experiences and innovation that have been successful in providing specialised services. The Church also has permanent structures and support services that provide additional support to the home based care services
ART Clinic and Clinics located in the project sites	The ART clinics have been established as a response to the wider availability of ARV. They provide free ARVs and are open to all members of the public. Their advantage is the availability of services and linkages to other specialised services through existing referral system
District Health Management Teams	They are the policy and implementation arm of Government. Their advantage is that they are a permanent arm of Government and they have a district-wide mandate of overseeing health activities. They are also critical in linking learning from the project into policy and implementation aspects of health services
Africa Direction	Focusing on youth, this is the only partner in the project that has extensive experience in working with youth. Their location within the community also makes it relatively easy for them to reach their intended targets

The comparative strengths of these organisations are further supplemented by the partnerships that have been forged partly as a result of working on the ACER project and partly through implementing their other activities.

The partnership approach has brought together the comparative strengths of each of the organisations to provide more comprehensive services. It has increased the reach of the organisations in both coverage and the range of services that a person can access through the ACER partner organisations. This has also enabled the organisations to learn from the strategy and forge beneficial relations with other organisations.

The project included all relevant partners essential not only to increase the reach of the project and increase the range and volume of the services, but ensure continuity of the projects benefits beyond the lifespan of the project.

5.1.3 Use of existing Institutions and organisations

The ACER project partnered with institutions that were present in the communities. After selecting partners based on their comparative strengths as shown in Table 6 above, the intervention sites were selected on the basis of the presence of all the partners. Ng'ombe enjoys the physical presence of all the ACER partners. Thus, instead of developing new institutions and structures, the project exploited existing structures.

5.1.4 Sustainability

Use of existing institutions and organisations is key to sustainability of project activities and benefits go beyond the lifespan of the project. The project has high potential for sustainability as partners will continue to exist beyond the existence of the project.

Another step toward sustainability is the project's ability to access support from both local and international sources. Following the completion of the initial phase, the project accessed funding from the Global Fund through Zambia National AIDS Network. Continued efforts in this direction together with other strategies aimed at promoting self-sufficiency and less reliance on external funding will enable the project to be sustained.

5.1.5 Access to intervention services by the target groups

The physical presence of the different organisations in Ng'ombe made it easy for project target to easily access the services. VCT services were supported at Ng'ombe clinic and support services such as food supplements for people with HIV were available at the Home-Based Care office within Ng'ombe. Due to circumstances beyond the control of the project, ART could not be provided at Ng'ombe clinic during the lifespan of the project. However, arrangements were made by the project for people in need of treatment to receive transport money to access treatment and other support services at the University Clinic where ART was being provided. Treatment support workers employed by the project were also based at the university clinic to provide counselling and adherence support services. Before the presidential pronouncement of free ART, the project also managed a scheme to pay for ART including laboratory for about 200 people from the intervention site.

All the services however were designed for adults and children could not easily access treatment due to a combination of factors. First, the national ART programme framework, within which the project operated, had overlooked paediatric ART provision and as such more clinical staff were not able to provide such services. Drugs for paediatric

were also not easily available. Secondly, the project did not have adequate skills to handle paediatric ART services.

In the design of the project, children's access to ART was ignored. Apart from the clinic at Ng'ombe, whose Family Support Unit has a special focus on providing VCT services for children, none of the partners are targeting children aged 0-14 years. The need for ACER to incorporate children as one of its strategic programmatic areas was identified by all partners. Many of the children encountered by partners are either orphans being cared for by relatives or children of people on ART. However, because of the special and different skills required to work with children on ART and their care givers, almost all partners would require training before starting work in this area. The partners also alluded to the difficulties of targeting children who cannot make decisions for themselves.

When asked to identify training needs, many of the partners mentioned the need for capacity building in providing support to families of children on ART. Treatment Support Workers commented that the development of a paediatric ART manual as well as sharing lessons learned on working with children on ART and their care givers would support and further develop work in this area. Treatment Support Workers are often called upon by clinic staff to advice children and youth up to the age of 18 that have started on ARV treatment.

Generally however, the information is easily accessed by the people in the community. In order to effectively influence behaviour, the project is using behaviour change communication strategies to increase VCT and ART uptake. Through 'theatre for development' (drama targeted at disseminating HIV/AIDS information), project partners disseminate information to the community. In addition to mobilizing people for VCT and ART, drama is used to fight stigma and discrimination. This has been effective as evidenced by the number of people going for VCT and receiving ART.

5.1.6 Monitoring and Evaluation System

In the design of any project, a coherent information system is essential for tracking progress made toward the attainment of project objectives. While data on referrals was being compiled by each partner, the project would have benefited from a monitoring and evaluation system institutionalised by the partners and coordinated by the project.

Review of the records showed that the data being submitted by the partners were not being entered and partners had to count figures manually and feed into the quarterly reports. In addition, carbon copies of the referral forms were sent to Alliance leaving partners with no records. This makes it difficult to promote ownership of the monitoring and evaluation system. Records also revealed inconsistent figures of people

attending community mobilization meetings. Evidently, adequate attention was not given to monitoring and evaluation during the design of the project.

There is no clear link between the project and the M & E function at the Alliance country office. It was assumed that the Operations Research (OR) component would provide sufficient data for decision making and assessing progress. However, the OR only has data collection points at two intervals, mainly baseline and end line. This was not sufficient to generate data for day-to-day management of the project. As a result, a lot of process data was missed. The project would have benefited from a coherent information system to generate timely information for decision making.

5.2 Gender Dimension of HIV Testing and ART Uptake

Assessing gender dimensions will focus on the extent to which the project design and implementation strategies took into account the gender dimension of access and adherence. The focus is on b) what was deliberately done either by design or in the implementation to ensure that both men and women have equal access to ART, a) how gender-balanced the project team is.

5.2.1 Measures taken to promote equal access to ART by women and men

There are more women accessing treatment from the project site than men. However, most of those accessing treatment are above the age of 25. It is evident that the project has equally reached more women than men as men are most of the time out working or looking for work. However, to ensure that both men and women have access to prevention and other messages, the project made arrangement to carry out some activities on weekends (Saturdays). Data from the baseline and end line community surveys show that women are less knowledgeable about ways of preventing themselves from HIV. This could explain why there are more infections among women and subsequently more women on ART not only in the project intervention site, but nationwide. Young girls especially, have less access to information than boys. This evidently makes them more vulnerable to infection than boys. The project did not have any deliberate effort aimed at addressing the gender differentials in access information on HIV services especially among the youth. Bringing in the project a youth organisation was not adequate in itself, but adequate strategies needed to be designed and implemented to address the knowledge gaps between men and women especially that these were identified from the baseline data. Interviews with the community members show that the intervention was targeted at everyone and no special groups were targeted by the intervention;

‘They were reaching anyone who was in the community and was willing to listen to them. Our young girls usually have no time for such things. It is usually us older ones who listen to them...they must find ways of making sure that the young listen to them since the children are the future and a lot of them are getting sick’ (*Female community member*)

This is also evident in the activities of one of the partners. Africa Directions in Lusaka specifically targets youth. However, their activities have drawn male youth more than female youth. This is because most of their activities are perceived to be more “boys’ kind of activities.” No special attention has been given to deliberately bring in the girls. According to the staff at the centre, because it is boys that mostly frequent the centre, very few girls come to the centre. They believe that the reason is that the girls are not allowed to come to the centre by their parents and guardians as they have a care giving role to play. It was also evident from the evaluation that many girls from the community did not consider the centre as providing ‘safe spaces’ for girls.

To counter the notion of ‘boys-only’ centre, the organisation is pursuing ways of increasing girls’ access to the information they are disseminating. They are doing this through the use of two methods:

- (a) Deliberately providing spaces for the girls to participate. This has been through creation of girls clubs, special girls’ days to create activities specifically targeted at girls such as modelling and dancing.
- (b) Conducting activities outside the centre where girls are able to attend. For example, drama sessions in open spaces and within the compound where girls are able to attend because the activities are close to their homes.

Participants from the Home Based Care programmes in Lusaka reported that more women than men access their services. According to the staff this is because women have less financial resources than men and therefore the Home Based Care programme is a more feasible option for them. As a result, more women than men are being referred by them for VCT. Of the more than 300 Lusaka Home Based Care clients that have been referred for VCT since ACER started, only about 92 (about 30%) are men. Men often opt for private care but tend to do so when they are already very ill. Staff at the Home Based Care programme reported that women in general seek care when they are in the first or second clinical stages of HIV infection; men frequently wait until clinical stage 4 before seeking treatment. As men have witnessed the positive effects of ART in the communities, more are gradually seeking treatment at an earlier stage. Reaching men in the early stages of HIV infection through the Home Based Care programmes, however, remains a challenge.

The fact that there are more women accessing ART than men raises gender concern. The implication could be that more women are being exposed to HIV than men. There are no deliberate efforts being done by the project to reduce infections among women as a

targeted group. It is imperative that deliberate effort be made to fight HIV among women as well as reduce the burden of care on women.

5.2.2 Gender Balance in the ACER project team

The ACER project team is gender balanced, with slightly more women than men. Among the partners, there are more women than men at the HBC and about the same number of women and men among members of NZP+ and Africa Directions. There are however, more male than female members at THPAZ. However, it should be noted that while the project could determine the number of male and female employees, it could not do so with the partners.

The design of the ACER project was based on the assumption that community education, referral and support for ART improves uptake of VCT and PMTCT, adherence to ART, emotional and socio-economic wellbeing of all, but overlooked gendered factors.

5.3 Project Implementation and Achievement of Objectives

In evaluating the extent to which the project achieved its objectives, the focus is on; i) the extent to which the project increased access to and utilization of VCT and ART services, ii) the role the project played in increasing and maintaining adherence levels, iii) presence of an effective referral system, iv) reduction in stigma, and v) promotion of positive living for people with HIV. These were assessed by review of records and interviewing stakeholders.

5.3.1 Uptake of HIV Testing and ART

The first major achievement of the ACER project has been the marked increase in the number of people undergoing voluntary HIV counselling and testing and receiving ARVs in the project site. It was not possible to assess the actual numbers of people testing for HIV and enrolling for ART as community members were being referred to more than one place. Even if the project's VCT centre was the university clinic, where treatment support workers were based, community members were free to go to Ng'ombe, Chelstone or Kalingalinga clinics. Only the University clinic kept these referral slips. Records at these clinics did not indicate the referring agent as the referral slips developed by the project were not being filed.

Before the advent of ARVs, the question that people faced was "what next after I undergo VCT?" According to observations by partners as well as ACER project staff, the visible effect of ARVs on people on ART has been the single most effective tool in

demonstrating the benefits of going for VCT and starting antiretroviral treatment. Partners reported that people who were extremely sick and bed-ridden were once again visible in the community and able to go about their daily lives. Those who were retired on medical grounds from their jobs were now looking for work. This phenomenon is evident in the project site.

ACER partners attribute the increase in the number of people seeking VCT and ART to a variety of reasons. Among these are:

- (a) the availability of information disseminated through various media such as IEC materials and radio programmes;
- (b) The visual effect of community members observing a person who was very sick and has improved and is able to lead a normal life;
- (c) The project allowing some level of flexibility enabling partners to respond to needs as they arise on the ground. For example, partners have been able to budget and utilise ACER funds for transport in order to ensure people can access ART at the clinics and get their CD4 count levels. Transport money is also provided to ensure that they access their medication at regular intervals.

Staff at the Catholic Home Based Care programme in Lusaka reported an increase from 20 patient referrals for ART in January 2005 to 300 patients by December 2005, significantly exceeding their target of 100 referrals:

“within a short period we were suffused with people wanting to know their HIV status and wanting to be referred” (*HBC*)

It is evident from the findings that more people are accessing VCT and subsequent ART services as echoed by the respondents below;

“People were starving for information, you can see it in the response to our outreach activities, people are now seeking VCT” (*Community Mobilizer*)

“Before ACER we would record 7 deaths every week, since ACER this figure has dropped to only 34 deaths in one year” (*HBC, Ng’ombe*)

“Traditional healers are now flocking to the centre, they want to know more about HIV and AIDS, many have gone for VCT and some are even on ARVs” (*THPAZ, Ng’ombe*)

In addition to couples going for testing, they are also taking their children for testing as the following quotes show:

“I didn’t experience any difficulties (in having an HIV test) because transport was provided by the home based care. We were encouraged to go to Kalingalinga for CD4 count. I and my husband went for it but as for the baby; we were told to wait until it was 1½ years old” (*Female, Ng’ombe*).

“.. And at this house, we are a positive family, my wife and I including our daughter who is at college are all positive” (*Male, Ng’ombe*)

5.3.2 Adherence support

ART is a lifelong therapy and patients must be prepared adequately for the life-long journey that they are about to embark upon. It is emphasized that this is their journey and their life. Because it is a life-long treatment, the potential for drug resistance due to poor compliance and long term use is high. Adherence is a very crucial issue in ART. To promote adherence the project uses three strategies:

- (a) The buddy system where the patient identifies a friend or relative who assist them to maintain the schedule for the medication, including collection for them at the clinic when they are unable to;
- (b) Support group strategy where people who have undergone VCT form groups to support and encourage one another;
- (c) Through the support provided at clinic level from Treatment Support Workers (TSWs). This may also include facilities to support adherence such as stop watches, alarms, books, or other item to remind them to take their medication.

The TSWs prepare clients for starting ARV treatment and provide ongoing adherence support and information about ART. They also ensure the referral of clients back to the community support structures. This relationship is reported to be working extremely well in the project site. Clinic staff reported that the TSWs have now become indispensable members of the VCT centre and clients have responded well to them as suggested by the quotes below:

“It is easier for them to talk with someone who is going through similar experiences” (*Sister in Charge, UNZA clinic*).

“When they are away we really feel it. We would appreciate two more treatment support workers; they have contributed a lot on adherence.” (*ART Manager*)

The TSWs are very much appreciated partly due to the important role they are playing in supporting people on ART, but mainly due to the acute shortage of clinic staff as they assist in all aspects of the clinic’s work. The TSWs provide adherence counselling for all of the clinic’s clients, not just those referred from ACER.

Review of baseline and end line data from the project shows adherence levels of above 90%.³ Mean 4-day self-reported adherence was reported to be over 99% in the project site at both baseline and end line. Adherence decreased over longer periods of recall and over the project period. The proportion of respondents who reported never missing any doses decreased significantly between baseline and end line from 94% to 85% ($p=0.004$). These data reveal that adherence levels are slightly decreasing with the length of the time on ART. However, there was no difference in adherence between men and women.

High adherence levels reported from the project data were triangulated with field data, with the same results, as the following narratives with a man and women on ART from Ng'ombe show;

“Moderator (M): Have you ever missed taking medicine for any period of time?

Respondent (R): No, I have not missed any single day.

M: Out of the two times in which you take your medicine which time is not convenient?

R: The morning time of 08:00hours to me is the one that troubles me especially when I go out for piece work I have to ask people to tell me the time. In this case I miss the time but not a failure to take the pill” (*Man, Ng'ombe*)

“M: when did you ever miss taking the pills?

R: I have never missed any

M: which dosage gives you problems in taking?

R: if I were taking many pills it would be difficult but I take only one pill in the morning and one in the evening so I do not face problems.” (*Woman, Ng'ombe*)

It is evident from the above that in spite of the difficulties encountered, adherence is high and will need to be maintained.

The support group system has been used by all organization. These are groups by people who have undergone VCT or are on ART or have similar issues bringing them together. The HBC and NZP+ both have support groups, while the THPAZ and Africa Directions refer clients in need of support to the two organisations with support groups.

³ Calculation of adherence was based on patient self report and a 4-day recall was used as the main measure of adherence. Mean 4-day adherence was calculated by dividing the number of doses actually taken by the number of doses that needed to be taken for 4 days x 100. For assessment of adherence over longer periods, the following additional self-reported measures of adherence were done: (i) the total number of missed doses over the last week (7 days), (ii) the last time the patient missed any dose, (iii) the last time the patient missed a full day's medications since starting ART, (iv) the number of times treatment was stopped for more than 1 week since starting ART, (v) how closely the patient followed the medication dosage schedule as prescribed by the physician.

AT the time of the evaluation, the HBC under the Arch Diocese of Lusaka had 8 support groups and NZP+ had 4 support groups.

The size of the support group can range from 10 to about 50 members. Each partner organization is still working out issues of the size of the support groups. These groups share information and personal experiences as part of the process of supporting one another. In addition, some of them have been trained in project proposal writing to enable them to source financing to assist themselves. The support groups are an important strategy in promoting adherence through sharing and encouragement among people living with HIV (PLWH). The groups also give PLWH a voice and is an indicator of the reduction in stigma (especially self-stigmatization).

Poverty is reported by partner organizations to be one of the greatest barriers to adherence among those on ART. The medication is usually blamed for acute hunger in people who lack food and this can affect adherence. Inability to cover transport costs to and from the health facilities and fees for ongoing HIV monitoring (CD4 and viral load counts) also present serious challenges to adherence to ARV drugs. ARV supplies are initially given by the ART clinics for short periods during which side effects are monitored, and clients are required to make several follow up visits to the clinics during this time. It was reported that some people stop taking their ARVs when food is not available as the following quote shows;

“I had no food to accompany the pills so I was feeling very bad whenever I took the pills. I cannot hide I even stopped taking the medicine for one month. The HBC came back to me and took me to the clinic. I was asked to state reason why I stopped taking the pills. I told them that I was feeling bad whenever I took the medicine because I did not have food to eat before the pill.....I missed for one month because I was not feeling well after taking the medicine. I was experiencing a lot of pain in the stomach. It was a result of taking of ARVs...” (Male, Ng’ombe)

Some ACER partners are able to provide nutritional support for people on ART⁴. Funds for this, however, are mobilized from other sources.

The TSWs pointed out that there is lack of sufficient information among ART patients on what happens when a patient does not adhere to the treatment schedule. Adherence data from the study shows adherence levels above 95%⁵ in the project catchment area.

⁴ The Catholic Diocese in Lusaka has been able to mobilise funds from its mother body and is providing high-energy protein supplements to people on ART.

⁵ This is reported adherence, the calculation based on number of missed pills and not pill counts. It was calculated as the number of pills actually take in the 7 days prior to the interview as a percentage of the total number of pill which were suppose to be taken in the 7 days.

Another important issue affecting adherence to ART is the improvement in health of the clients. When people start to feel better they sometimes stop adhering as strictly to their ARV medication as they did before. This is reported as an ongoing challenge by all the partner organizations. Treatment Support Workers and Treatment Mobilizers, in collaboration with the partners, play a crucial role in monitoring clients on ART and providing ongoing adherence counselling. A member of staff at UNZA clinic commented that community involvement is crucial in the follow-up of clients on antiretroviral treatment:

“As a Government institution we are unable to follow up with patients, this is why collaboration with NZP+, THPAZ and the other ACER partners is so important”.

5.3.3 The Referral System

The community referral system has become an important indicator of acceptance of the HIV/AIDS message disseminated through the various methods that each of the organisations is using. When a person seeks a referral the action is a product of having understood the message, internalised it and decided to take positive steps to have questions answered. One of the objectives of the project was to develop and strengthen the referral systems between the community (community and community-based partners) and the health facility and among the partners.

Through ACER, a referral system has been established between the partners in the community (NZP+, Catholic home based care, THPAZ and Africa Directions), the local clinics and the ART clinics. The clinics also respond to the referral by providing feedback on the forms provided. It works as a two-way system to enable community organisations to keep track of referrals and to enable the clinics also to refer patients back to the community when necessary. Patients were being referred back to community mainly to NZP+ and HBC for continued care and support. Whenever a person is referred, feedback from the referral is almost nonexistent, except in few cases where the referrer makes a follow-up.

Between January 2005 and December 2006, the following were the referrals made by the four partners obtained from partner records;

Table 7: Number of referrals made by project partners

Referred from;	Number referred
NZP+	512
THPAZ	774
HBC	323
Africa Directions	188

The majority of people were referred for VCT/Testing (60%) followed by ART access which accounted for 27% including 8% who were specifically referred for the Alliance ART Scheme.⁶ CD4 counts accounted for 9% and counselling 1%. The rest (3%) were referred for other reasons. Of the total number referred, 44% were male and 56% were female. Generally, there are more women than men being referred for services. The majority of the people being referred are adults above the age of 20 with the median and mean ages being 30 and 32.3 respectively. Prior to the establishment of the referral system by ACER, a limited number of referral were being made mainly from NZP+, Africa Directions and the home-based care to the clinics⁷. No referrals were reported from THPAZ prior to the start of the ACER project.

All the partners expressed happiness with the referral system and that they are using the system. The organisations that have up-to-date records show high numbers of referrals since the system was introduced at the start of the project. However record keeping is not consistent as some of the organisations were unable to provide up-to-date statistics.

All respondents reported the referral system to be working well. At the UNZA clinic, staff reported that three quarters of the clients they receive are being referred from the Ng'ombe clinic and the partner organisations carrying out activities in the Ng'ombe compound. As the project gained momentum, so too did the rate at which people were being referred. Africa Directions reported that at the beginning of the project numbers of referrals stood at 11 people. By the end of December 2006, more than 188 people had been referred and attributed this to the ACER project.

Clinic staff reported significant changes in how clients arrive at the clinics since the start of the ACER project:

"Before ACER people would come through haphazardly without any referral note or documentation, there was a repetition of VCT – clients would already have been for VCT in another clinic - the referral system eliminates duplication". (Ng'ombe Clinic VCT Counsellor)

It was reported that the first client to be referred to access ARV treatment through ACER was referred by THPAZ. This is of particular significance as THPAZ had historically been isolated as a community based organisation with little interaction and dialogue with more formal local health care facilities. Before ACER started, THPAZ would hold on to their clients, now the organisation is referring people to Government clinics.

⁶ Before ART became free, the project had put aside funds to cater for about 200 patients.

⁷ The project partners had no records of referral made before the ACER project

5.3.4 Stigma

NZP+ described themselves as the most stigmatized group. According to them, the stigma attached to HIV/AIDS is changing. The evidence of this change is that they are receiving a lot of people enquiring about their activities and HIV/AIDS. They attribute this to the public acknowledgement that they are living with HIV and the fact that people can see them as visible examples of people with HIV/AIDS. Availability of treatment and better treatment outcomes were also said to have contributed to the reduction in stigma. All partners asserted that stigma was reducing, but still there;

“To mark World AIDS Day, we held an event in the compound. Two support groups got up and sang about the importance of ARVs in front of a huge crowd. A year ago they would have been afraid to say they were positive, now they are going public - AIDS related stigma is being broken down” (NZP+)

“When we started work at the clinic clients would ask to wait in closed rooms, now people wait in the corridor, they are talking about their experiences, sharing with others while waiting in the clinic” (TSW, UNZA Clinic)

In addition to partners' views, people on ART also asserted that stigma was reducing as the following quote shows;

“In some families people with AIDS were not allowed to eat food together with other members of the family. This kind of discrimination is reduced because of good understanding of how the virus can be transmitted”. (Male, Ng'ombe)

But many respondents also said that stigma is still there and spoke about how stigma is changing now as people start putting on weight with ARVs, as one man on ARVs commented:

“There is no change, they still laugh at us”; “(stigma) cannot go down as we are all different personalities”.“They (people) have observed a change, since I was very thin, now I am growing fat, so they have changed their remarks, ‘namutendeka ukubiluda’ (you have started building up...) (and asking) are you swallowing beans?” - Beans in this context is the nickname for pills.

In general the strategy of bringing the issues of HIV/AIDS into the open by involving people with HIV/AIDS in the campaign is one of the most effective strategies in fighting the stigma associated with HIV/AIDS.

The second strategy against stigma is the formation of support groups. This provides an avenue for people to liaise and have their problems and issues addressed and answered by people with similar conditions.

The third strategy that has been effective is in getting the traditional healers to acknowledge the fact that this is a condition that requires team work between themselves and the clinic. This is manifested through THPAZ referring people to the clinics which they previously were not doing. According to all the partners, this has contributed to removing the stigma and the myths around HIV/AIDS.

5.3.5 Positive Prevention for People on ART

During the counselling before ART, patients are informed about the need to use a condom for their own protection as well as the protection of their partner. The strategy is to make condom always available within the community. The IEC 'Stand' for both THPAZ and the drop in centres for NZP+, and African Directions maintain condoms all the time. This is achieved through working with the clinics where Government free condoms are distributed.

Other methods of preventing HIV are the promotion of safe methods among traditional healers and traditional birth attendants. This is through training in the hygienic use of razor blades. The razor blades are also distributed by the project. The traditional birth attendants are also trained in the safe handling of deliveries and handling of body fluids. They are given gloves by the project in order for them to practice what they learn. In addition, support groups of birth attendants have been formed which meet twice a month to share experiences and support each other.

"Members of support groups are now getting married. They are contemplating having children, and ask about how to go about having one if they are using condoms, this is an indication they are using condoms"
(CM, Ng'ombe)

"before the coming of the ACER we were using one razor blade on many patients, but now, through workshops we have been taught to use one razor per client and we advise our clients to bring their own razors to our surgeries" (THPAZ, Ng'ombe)

One of the difficulties in the promotion of the use of condoms is the non availability of female condoms. In view of the gender issues around power relations and the capacities of females to negotiate for safe sex, the female condom is an important weapon in fighting the spread of HIV. Its absence in all the project sites reduces the power of women to control their exposure to unsafe sex.

Interviews with people on ARVs revealed that they had been taught about safe sex and re-infection. When asked: What is wrong with having sexual relations without the use of condoms, a woman in Ng'ombe answered the following:

“The problem maybe that a partner with a high load of the virus can pass onto another and increase the other person’s load, the result is reduced immunityWe were taught that people on ARVs need to use condoms because these two people have different strains of HIV virus so to avoid infecting each other they need to protect themselves”.

People are even talking about using condoms with their spouses as another woman from Ng’ombe reports:

“Yes, there is a change because this time we use condoms.”

All the respondents interviewed, except for one demonstrated correct knowledge about ART and reproductive health as reflected from the following quotes;

... “Yes, we have been taught by the sisters that if I am pregnant I have to see the doctor for advice and even before delivery I have to consult the doctor. I went through the same process for my last child. There are other women here who are on ARVs who have babies without HIV”.

“They teach us that a person on ARVs can be pregnant and continue taking ARVs until a day of delivery when she can be given Nevirapine to prevent a baby from contracting a virus. Some of the women they are giving birth to babies without even going to the hospital and they breast feed their babies without protection. May be they are ill informed or they distort the information from the way it is given”

“...Because we are HIV+ so the child will be born with it so it’s not good to have children”.

6.0 DISCUSSION OF FINDINGS

6.1 Adequacy of Project Design and Strategies

The ACER project was designed to:

- i) Improve treatment literacy within communities,
- ii) Increase uptake of health systems and other forms of support,
- iii) Provide support for individuals to start and continue with treatment and prevention behaviour; and
- iv) Promote strong partnerships and linkages between health services and community organisations, especially people with HIV. The model also includes a two way referral system to facilitate service uptake, follow-ups and on-going support and community education on the availability of services and how to access them.

The project design stage benefited from the community consultations. Thus it was based on evidence and addressed the real need of the people. This ensured involvement of the target communities in the design of the intervention. Partners were also involved in the design of the project during the consultative meeting that was held in June 2004 to solicit partners' ideas and choose the sites.

Involvement of different partners with different competencies is also another important factor that has contributed to scores of success recorded by the project. Involvement of community based partners also enhance the performance as they were already rooted in the communities and thus achieved more than could have been possible by a single principal. Different partners also have different competencies. Government partners are strategic for advocating for policies that are evidence-based on the experiences of the project. Faith-based organisations were also crucial in ensuring not only acceptability of the intervention by the general community, but also their wide membership. The HBC also has a comparative strength of community based home care for people on ART. Providing food supplementation to people on ART, which should be prescribed as part of treatment, is easily done by the HBC because of the vast experience in home-based care. Traditional healers also have a clientele that need to be reached. In addition to their clients, traditional healers also need accurate knowledge of HIV for them not only to practice, but also communicate it to their clients in order to prevent infections. All partners are trained by the project to carry out the intervention. Africa Directions is also strategic in ensuring that the youth are catered for. Involvement of all these partners strengthens the design.

Strength of the design is the genuine and greater involvement of people on ART in the running of the project and providing services. The TSW model of recruiting people with HIV to be involved in providing HIV services is an innovative aspect of the project that

has recorded successes. It has also eased the pressure on the few health workers at the clinic.

In addition to involvement of people with HIV, another innovative aspect of the design is the component of prevention for people on treatment. This unique focus of the project is not provided by many organisations, and yet is a very important aspect in the life of people on treatment.

Using community mobilizers as focal point persons to mobilize communities for VCT and ART and provide support to partners is also an important element. The project also planned to provide ART to about 200 people. It thus had not only the awareness component, but also provision of treatment through the clinics and care through the HBC. Prevention efforts, especially for people on treatment, were done through awareness campaigns carried out in the community and during counselling sessions with people on ART. It can be argued therefore that the project had a holistic approach of prevention, treatment and care.

However, more emphasis was put on mobilizing people for ART than prevention of infection. It is imperative that there be a balance between prevent, treatment and care efforts. The project concentrates on raising awareness about VCT and ART uptake without must emphasis on prevention. In addition, children were not initially included in the design of the intervention package. There is need to adequately meet the needs of the children in the provision of services as children are equally affected by the epidemic.

Although the project was designed within the parameters of operations research (OR), it was necessary for it to have a monitoring and evaluation (M & E) system that would ensure the collection of process data and link with and feed into the OR whose research activities were periodical (baseline and end line). The absence of a strong M & E system at the Alliance meant that a lot of valuable data were not captured. These data are very useful in feeding into evaluations and management decisions on a daily basis. A system would have been put in place to capture referral data and truck referrals. The OR team had to rely on exit interviews and partner records to capture referral. This did not provide an accurate way of capturing referrals and some clients referred could not have effected the referral by taking action. In addition, the fact that the OR team could only be at the referral points for limited number of days meant that referrals were missed.

It can therefore be said that the system for monitoring changes in the numbers of people going for VCT and receiving ART, so far, has not been thoroughly developed within the project and this is an area that would benefit from strengthening in the next phase of ACER. The ART manager at UNZA clinic commented that a computer for ACER staff based in the ART clinic would assist significantly in reporting on ACER progress and analysing project related data such as referrals and adherence to ART.

The project document does not reflect elaborate monitoring and mid-term evaluation systems. It however highlights specific, measurable, attainable and realistic indicators, placing the M & E function within the OR. Project partners are expected to submit quarterly report on the progress in the achievement of objectives. The OR is expected to give feedback to the intervention on the extent of progress. However, the OR is scheduled to collect data at baseline and end line. This is not sufficient to provide adequate feedback to the intervention partners on their performance.

To improve on the monitoring and evaluation systems, there is need to have regular monitoring activities that routinely gather data that not only feeds into management decisions, but also helps the OR in refining their tools and strategies for impact assessment.

It is imperative to put in place a comprehensive M & E strategy to:

- i) Involve those persons participating in the provision of service (i.e. partners, individuals and their families, Community-based care providers and volunteers and other organizations);
- ii) Ensure ongoing monitoring is adequately implemented;
- iii) Ensure ongoing needs assessment and adjustment of all plans;
- iv) Monitor the evaluation process to ensure the quality, appropriateness and effectiveness of all services;
- v) Determine if the service is meeting the outcome expectations; and
- vi) Establish a dissemination, follow-up and feedback system for information.

In addition to the indicators that are stated in the project document there is need to develop indicators to measure:

- i) Professional conduct
- ii) Minimum service standards
- iii) Structure standards
- iv) Process and outcome standards (value added)
- v) Appropriateness: does the project as a whole respond to the health needs of the target population?
- vi) Acceptability: are the services provided in a manner that is acceptable to the target population and encourages their appropriate utilization?
- vii) Accessibility: are the services provided so that the problems of access to information, health professional, drugs and supplies, assistive devices are minimized and the equity promoted?
- viii) Effectiveness: Do services provide satisfactory outcomes both from the clinician's/health care provider's point of view and that of the users and their families?

- ix) Efficiency: are the elements of the project provided so that the maximum output is obtained from the resources expended and does the mix of the services represent the best value for money with regard to the health needs of the community?
- x) Equity: are the needs of the different sections of the target population met in a fair and just fashion?

6.2 Gender Dimension of Access and Adherence

Young women aged 15-19 are five times more likely to be infected compared to males in the same age group (ZDHS 2002). Overall, the HIV prevalence rate among women is estimated at 18% as compared to 13% for men. The high prevalence rate among women, and the cultural belief that a girl as a care giver is expected to undertake activities that contribute to the productive needs of a family much earlier than a boy, places girls in the 15-19 age group at a disadvantage in terms of their access to information critical to reducing the HIV infection. The cultural role, on the other hand, predisposes the girl child to the effect of the pandemic much earlier. The limitation to the knowledge is due to the culture belief that limits the girl's activities to those around the home.

It is evident from the data that there are more women than men accessing treatment. This is consistent with national data on the number of men and women who are living with HIV. The ratio of men to women who are living with HIV stand at 2:3 (National VCT Services 2005). Therefore, the fact that there are more women than men on ART from the project site is indicative of the fact there is equity of access between men and women. However, there is need for the project to focus more on the gendered nature of HIV infection.

Special effort need to be made by the project to ensure that women and young girls are targeted with prevention messages. However, men and boys must not be left out, but adequately sensitized and mobilized for VCT and ART for those eligible. The fact that there are more women than men on ART indicates that there are gender gaps in the prevention efforts and could indicate that either more women are getting infected or less men are accessing VCT. The project lacks a coherent gender policy. Gender must be mainstreamed in all the activities to ensure that the infection levels and impacts of HIV are equally felt by both men and women. Through the process of gender analysis, all factors that account for the differences between men and women in accessing VCT and ARV must be identified and measures taken to ensure gender sensitive programming.

6.3 Project Implementation and Achievement of Objectives

Overall knowledge around prevention and transmission of HIV and around ART is reported to be increasing. There is still, however, some misinformation and lack of clarity around a number of factors especially around condom use. Knowledge about ART has been spreading quickly and most people now know about its' availability and how it works. As in knowledge about HIV prevention and transmission, there are still

people who are not clear about some aspects of it, e.g. the issue of side-effects and the necessity of still using condoms. For people on ART, generally knowledge about HIV and ART is very high with people knowing how ARVs work, the importance of taking them at the same time each day every day.

Despite relatively high levels of knowledge, continued work on raising awareness is required to ensure that people have complete information and that false rumors and misrepresentation of information about ART are not circulated and believed. Information around condom use in particular must be continued to be emphasized and the characteristic of HIV being a chronic disease with people able to manage it now with ARVs like any other chronic disease also needs to be continued to be stressed.

In general, all the respondents and informants said that stigma was decreasing, increased education and the effects of ARVs being the cause of this. ARVs are playing a vital role in reducing stigma as people become well again, as they are able to resume normal life and as this encourage self-esteem and confidence.

Despite the above, stigma continues in the project site. Although it is decreasing as shown both from the records and interviews, it is still there. Some people continue to stigmatize others, with some respondents saying it is “just their nature” or it is “the ignorant” who continue to stigmatize. Some respondents pointed out the need for continued education and awareness raising for health workers. Stigma was also in evidence as people mentioned that they have not been stigmatized as members of the community think they had TB and not HIV, thus emphasizing that people with HIV are still stigmatized. Whilst on the one hand ART has decreased stigma levels as described above, stigma is also changing as now people who are getting fat are singled out with others commenting that they must be HIV+ and on ART. Similarly, when someone is seen to be well again, others reject or deny that the person is HIV+ saying that they were merely bewitched.

The above all points for the need for further awareness raising and sensitization around stigma. Perhaps stigma interventions need to be re-thought in light of ART. An important aspect of stigma raised in a few of the in-depth interviews was the fact that the people were never stigmatized since they never looked ill.

Careful targeting of different population groups, in different settings and with different priorities would need to be considered. Although this was not planned in the interventions, for future activities a suggestion could be to target women (and their partners if they bring them) at antenatal and under 5 clinics; similarly, perhaps there is more work to be done around PMTCT and reproductive health. In order to target youth and adolescents perhaps work in schools could be carried out or working with partners who target youths in particular, e.g. musicians, theatre groups, etc.

There is no doubt that over the life-time of ACER technical support and funds have been intensive and perhaps the focus has been on too small an area, effecting change, increasing awareness and in general having a positive effect on various outcomes in this area and perhaps not saturating the site as had originally been envisaged as the overall aim of the interventions. The challenge is now, therefore, to explore how such an in-depth and intensive intervention can be scaled-up, keeping the positive and successful attributes but also adding breadth to the approach. Similarly, whilst the activities and interventions are clear to the intervention partners, there is need to package the interventions in such a way that they become easy to adapt and scale-up in different settings and by different kinds of institutions. This approach is also key to sustainability.

Sustainability can be defined as durability of positive project results after the termination of the project and can be defined in terms of two broad categories namely; static sustainability - the continuous flow of the same benefits, set in motion by the completed project, to the same target groups and dynamic sustainability - the use or adaptation of project results to a different context or changing environment by the original target groups and/or other groups (UNDP 2000). The target group thus, plays a major role in project sustainability. Yet decades of experience in implementing primary health care have shown that meaningful community involvement in health services is not easy to develop and sustain, and is especially hard to institutionalize on a wide scale. Communities are often assumed to be homogenous and unproblematic entities and little thought is given to the tasks involved in mobilizing them. In poverty-stricken areas, problems of mobilizing the community are even on a larger scale. This is especially so in Ng'ombe where poverty levels may be high. Worse still, community mobilization programmes are often perceived as easy to develop. However, they are a time consuming endeavour requiring specific skills in the areas of motivating and sustaining community involvement, developing partnerships and linkages, and creating opportunities where all participants feel equally respected and able to make a valued contribution.

There is growing awareness that most conventional methods used in identifying problems and solutions of resource -poor people have failed largely because they have ignored beneficiary participation. Participation techniques as a result put a lot of emphasis on participation, recognizing that the failure of projects has been due to people not being genuinely involved in their identification and planning. And if people do not consider an activity or project to be theirs, they have no incentive to ensure its sustainability. Advocates of the participatory approach argue that the production of knowledge and the generation of potential solutions should be devolved on to those whose livelihood strategies form the subject for such a service. Beneficiary participation should therefore be looked at as the cheapest and most efficient way of empowering the marginalized people in society and in this contest should include enhancing beneficiaries' capacity to manage their own problems and any projects being

undertaken in the community. There is therefore, need to institutionalize beneficiary participation in the decision making process at all levels of the project. Currently, this is not the case. The Alliance office takes a leading role. It is also evident that while the project has potential for dynamic sustainability, there is need to ensure that strategies are put in place to ensure sustainability. Project partners were quite inactive in implementing ACER activities when the ACER funding temporarily came to an end in 2006. This is evident that there need for more institutionalization of the programmes by the partners that reduces reliance on ACER funding and enhances ownership of the initiatives and activities

The critical activities of all the partners focus firstly on providing information in such a way that it encourages people to go for VCT. This includes dissemination of information through printed materials, drama, radio programs, and other activities at compound level. The second focus is the provision of support services after VCT to enable a person access ART and be able to live positively. This includes the referral system, support at clinic level through the treatment support workers, and follow-up in the community, coordinated by the treatment mobilisers. Support group formation and activities also provide a most significant sustainability angle for the psychosocial support of people living with HIV/AIDS. The groups form a structure through which any organisation can channel assistance to PLWH.

Within these activities is the importance of the linkages created by the project and those that have been created by the partners themselves as a result of the visibility of their activities. The partnerships are very important in that they have made co-operation possible for organisations which traditionally never interacted with one another. These organisations (THPAZ and the Catholic Church) have a very profound influence in society. Their coming together will continue to be a strong force in dispelling myths and misinformation that have predisposed people to contracting HIV.

Challenges to sustaining these activities include reliance on the referral system that is driven by the Alliance in the sense that the referral forms bear Alliance letter heads and the cost of printing is the responsibility of the Alliance. The question is; to what extent do the partner organisations view the referral system as their own, which they can continue to use beyond the life of the project? The second challenge will be in maintaining the momentum of the partnerships when the ACER project comes to an end and there is a reduction in project coordinating activities in the management of the partnership.

7.0 CONCLUSIONS AND RECOMMENDATIONS

Generally, the project has demonstrated that community support and involvement of non medical staff in the provision of HIV services in a health care setting improves

health worker morale and improves access of services by both the community and health workers. In addition, involvement of traditional healers has increased community participation. The use of TSWs openly living with HIV, working in ART clinic, has helped increase treatment literacy, reduce stigma and the impact of staff shortages at health facilities. Treatment adherence has also increased with increased community participation and support.

The ACER project has the potential for increasing the uptake of HIV testing and ART due to its strategy of utilising partner organisations that are operating within the target communities. The potential for the activities to be sustainable is high. In addition, because of the participatory nature of the process undertaken in the development of the project strategy, the project is addressing the felt needs of the people and this also ensures that it is relevant and can continue beyond the life span of the project. However, more testing and uptake of ART is being recorded among women than men. Current strategies are not adequate in ensuring a reduction in infection levels among women and increasing the numbers of men testing. Children were also left out in the design of the project.

The project has had impact in influencing policy and policy implementation through its working with the Ministry of Health and the organs within the ministry (CBOH and DHMTs).

On the basis of the findings from the study, the following recommendations are being made for the next phase of the project:

Design and Strategies

- a) That the next phase of the project should distribute IEC materials in both English and local languages. The production of these materials should be coordinated with the National HIV/ AIDS/STI/TB Council and other relevant organisations.
- b) That documentation of experiences by the project should be a major focus. This will enable the replication of the project with minimal cost and will also increase the reach and impact of the project.
- c) That the project should have a deliberate focus on children between the ages 0-14. This should be in addition to the above 15 years that it is currently focusing on.
- d) That one of the key project components should be a strategy to address livelihood issues of people on ART. This needs to be explored to take into account available support services through organisations that have a comparative strength of handling livelihood issues, and taking into account sustainability issues.

- e) *That a phase out strategy should be developed at the beginning of the next phase of ACER. This will allow for the building of sustainability activities from the beginning of this phase.*

Gender Dimensions

- f) *That a strategy must be developed to ensure that more uptake for testing and ART is improved among men.*
- g) *That targeted efforts aimed at reducing infection levels among women must be adopted.*
- h) *That the project must mainstream gender into all project activities.*

Project implementation and performance

- i) *That there is significant need for information about treatment management for children on ART. This should also be complemented with a deliberate focus on building the capacity of partners to deal with issues of children on ART. This capacity should include providing skills, and space at clinics for working with children.*
- j) *That more targeted support in building the capacity of partners should be undertaken. This will enable effective use of time and resources of the project. This could take into account a participatory process where the partners also identify their needs and strengthen on the basis of their requirement as an organisation*
- k) *That support should be provided in the training for clinic-based staff and home based care givers on ART adherence counselling to ensure effective treatment.*
- l) *That targeted efforts must be made to ensure that adherence is maintained for people who have stayed long on treatment.*
- m) *That staff workload should be monitored in view of the demand for staff services by other organisations outside working hours. Additionally, ACER staff in Lusaka suggested they would benefit greatly from getting together and sharing lessons learned about their work on a regular basis and/or having exchange visits of project staff between the two project sites.*

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Annex 1: List of Documents Consulted

- Quarterly Reports- NZP+
- Quarterly Reports - THAPAZ
- Quarterly Reports - Arch Diocese of Lusaka - Home Based Care Program
- ACER baseline and end line Reports

Annex 2: Data Collection Tools

Evaluation of the Antiretroviral Treatment Community Education and Referral (ACER) Project

In-depth Interview guide ACER Staff/Other Stakeholders

Project Staff: Management

1) Design: *Was the design adequate?*

Probe for;

- i) How adequate was the project design in terms of inputs/ strategies
- ii) Are inputs being made available as planned?
- iii) Are activities being carried out as planned?
- iv) Are outputs being produced as scheduled?
- v) What changes have taken places (additions or deletions)?
- vi) What problems or difficulties have been encountered?
- vii) What remedial actions have been taken or planned?
- viii) Adequacy of the problem analysis; Socio-economic and gender context
- ix) Adequacy and coherence of development and immediate objectives
- x) Overall validity of design
- xi) To what extent was gender analysis done to ensure that all gender dimensions of access and adherence to ART were taken into account
- xii) To what extent were ACER’s founding assumptions valid, namely that “community education, referral and support for ART improves uptake of VCT, PMTCT, uptake/adherence of ART, emotional and socio-economic wellbeing.”
- xiii) What criteria were used to select the community-based partners?
- xiv) What competencies did they bring to the project?
- xv) To what extent did you include all the essential partners?
- xvi) What were the major contributions of each partner to the project?

2) Implementation: How were activities implemented?

Probe for;

- i) Do you think the inputs into the project are adequate?
- ii) Do you feel they activities are adequately designed?
- iii) Are they being adequately carried out?
- iv) Are the outputs adequate vis-à-vis inputs?

- v) Are there any problems which in your view act as an obstacle to the efficient implementation of the project?
- vi) What are these problems and how best do you think they can be solved?
- vii) In your opinion what action should management take in order to address the problems stated above?
- viii) Did the project provide any treatment to HIV-positive people?
- ix) Degree of interaction between project and policy levels

3) Performance: *Effectiveness: To what extent has the project achieved its objectives*

Probe for;

- i) Contributions of ACER to generating greater knowledge and understanding around issues of community involvement in ART
- ii) The extent to which ACER has responded strategically and effectively to supporting the Zambian Government ARV programme i.e. how has the project evolved in response to policy and the external environment over the period in question?
- iii) The initial perceived impact of ACER on partners, communities and other key stakeholders, and documentation of any unexpected impacts.
- iv) Positive results/impacts that ACER has achieved as well as key weaknesses and challenges of the programme
- v) What specific recommendations can be made to ACER staff and its partners to improve the appropriateness and effectiveness of the project?
- vi) To what extent has it reached its target group(s)?
- vii) *Efficiency:* Do the project results continue to justify the costs incurred?
- viii) *Relevance:* Does the project continue to make sense
- ix) *Validity of Design:* Is the design Logical and coherent?
- x) *Causality:* What specific factors have affected the project results
- xi) *Unanticipated effects:* Is the project having any significant (+ve or -ve) effects which were not foreseen?
- xii) *Alternative Strategies:* Is there, or would there have been, a more effective way to address the problem(s) and achieve the objectives?
- xiii) How did the project fare in ensuring that the services adequately meet the needs of both men and women?

4) Gender Dimensions: *To what extent where gender consideration taken into account during the implementation of the project?*

Probe for;

- i) Between men and women, who is more likely to access the services you provide?
- ii) Why the difference?
- iii) Were any adjustments made to ensure that the services are reaching both men and women?
- iv) What gender concerns arose during implementation?
- v) Among men and women, who received the services more and why was this the case? What did you do to ensure that both men and women were reached with information?
- vi) *Currently there are more women on ART than men. This could suggest that more women are infected than men.* What did the project do to ensure that the burden of the diseases is lessened on women, both as the infected and affected group?

5) M & E: Does the project have an M & E system,

Probe for;

- i) when in the project cycle was it formulated
- ii) How effective has it been in generating data/information for timely decision making?
- iii) Has it been engendered? Does it collect gender-disaggregated data
- iv) Type of information being collected, who collects data, how often, what tools are used and how effective are they?

6) Sustainability: What is the likelihood of continuity for the services being offered by the project?

Probe for;

- i) What is the likelihood that project benefits will be sustained after the withdrawal of external support?
- ii) What support do you get from beneficiaries?
- iii) What are your long-term plans?
- iv) Ownership of benefits
- v) Are you a member of any network?
- vi) Information sharing
- vii) Linkages with international organizations
- viii) Capacity to respond to changes in the environment
- ix) Fundraising strategies
- x) Capacity to implement
- xi) Ability to access diversified sources of funding
- xii) Capacity to respond to calls for proposals

- xiii) Resource diversification
- xiv) Multiple funders
- xv) Can the community based partners continue with the activities after you pull out?

Project Staff: Treatment Support Workers and Community Mobilizers

Role of treatment support workers and Treatment Mobilizers

7) Uptake of HIV testing and ART:

- i) Have you noticed a difference in the uptake of HIV testing and ART? (Numbers)
What do you attribute this to?

8) Adherence to ART:

- i) Are you noticing a difference in rates of adherence to ART among the clients you see? What do you attribute this to?
- ii) How has the treatment schedule been working?
- iii) Are people missing doses? What are the main reasons for this?
- iv) How can adherence to ART be improved through? And what role can ACER play in this improvement?

9) Stigma and Discrimination:

- i) Since ACER started, have you seen a change in levels of stigma and discrimination among: clients on ART, those supporting them, partners of clients on ART, and the staff at the clinics, at community level? What do you attribute this to?

10) PLHA involvement:

- i) As people living with HIV, how important do you think your HIV status has been in carrying out your role?)

11) Referral System:

- i) How well has the two-way referral system worked? How can it be improved upon?

12) Knowledge about ART and support:

- i) Considering your knowledge and understanding of ARV treatment and support before the project started, how much do you think your knowledge/ the knowledge of the partners/ clients/ and community has changed? Why?

13) Capacity building:

- i) To what degree has the training you have received been relevant to your work?
- ii) Are there any areas of training that you feel you require/ would improve your work?

14) **ACER achievements:**

- i) What do you consider have been the key achievements of the ACER project so far?

15) **Challenges:**

- i) What have been the challenges in fulfilling your role as Treatment Support Workers?
- ii) How could your job be made easier?
- iii) What have been the challenges in general for the ACER project?
- iv) Are there any groups you feel ACER is not managing to reach? If so, how do you think they could be reached?

16) **Recommendations:**

- i) Are there any recommendations you would make for future ACER activities?

Evaluation of the Antiretroviral Treatment Community Education and Referral (ACER) Project

In-depth interview with people on ARVs

1. Demographics

- i) Residential area
- ii) Marital status
- iii) Sex
- iv) Age
- v) Educational levels
- vi) Number of children
- vii) Occupation
- viii) Work status
- ix) Intervention/comparison site

2. HIV Treatment-related knowledge and exposure to the project activities; I would like you to give me details about ARV treatment

Probe for:

- a. When did you start ARVs?
- b. What type of information (e.g. written, verbal, etc.) were you given about taking ARVs? Was it helpful/easy to understand? Who gave it to you?
- ii) Do you understand what ARVs do/how they work/what benefits they have?
- iii) Were you explained the reasons for taking these medications? What are these?
- iv) Do you think you have enough information about these treatments?
- v) Are you satisfied with the care you are getting? Is it confidential? Are the TSWs helpful?
- vi) Was adherence to ARVs discussed? What is your understanding of adherence?
- vii) Do you know what a CD4 count/a viral load test is? Have you had either of these done?
- viii) Are you aware of the ACER project?
- ix) What role has it played in supporting your access to HIV-related services?
- x) What role has it played in helping you adhere to treatment?
- xi) What other help have you received from the project in accessing and adhering to treatment?
- xii) What could be improved about the way the project delivers its services to people on ART?
- xiii) Are you aware about TSW? What do they do? Are they helpful to people on ART? How?
- xiv) How did you know about the program and how were you recruited into it?
- xv) What are your needs; what kind of support do you need?
- xvi) Type and Adequacy of support; what kind of support and how much of it do you receive?

- xvii) Magnitude and level of satisfaction of the support received
- xviii) Which of your needs are being met and which ones are not
- xix) What is 'best' about the program?
- xx) What is not good about the help and support you receive; what do you want changed?
- xxi) What would you like to be done in order to meet your needs
- xxii) Level of involvement/consultation in the running of the programme.
- xxiii) Sustainability: How could the project benefits continue to flow; what should be put in place to ensure sustainability.

3. Access to ARV treatment, adherence and follow-up; Would you relate to me how people in Ng'ombe access ARVs and what challenges they face?

Probe for:

- i) Can anyone in the community access HIV treatment?
- ii) Who is unlikely to receive treatment? Why
- iii) What are the barriers to treatment in Ng'ombe?
- iv) What ARV pills are you taking? (names)
- v) How many do you take? How often? Do you have to take them with food/drink?
- vi) Have you ever missed taking your pills? (Why, when, for how long, etc.)
- vii) What is the most difficult dose to take (morning, afternoon, evening)?
- viii) Have you ever stopped taking your pills? If yes, for how long?
- ix) Is there anything specifically you do to help you take these medications?
- x) What do you think is helpful/and what is still missing in services?
- xi) Between men and women, who is likely to receive treatment and care? Why
- xii) How does ACER work in ensuring that the services are equally accessed by both men and women?
- xiii) Do you think the project has contributed to more people in Ng'ombe accessing HIV services? How and to what extent?
- xiv) What is lacking about the project in terms of the services they offer and how they offer them?

4. Stigma and Discrimination; Would you describe to me how people with HIV in this compound are perceived and treated?

Probe for:

- i) What is the general feeling in your community towards HIV+ people and those on treatment?
- ii) What personal experiences of stigma and discrimination do you have as a person on treatment?
- iii) Do you see yourself differently now that you are taking ARVs? Do you think other people see you differently?
- iv) What are your experiences with health care workers and employers? (Issue of stigma from health workers by health workers...)
- v) Do their attitudes affect your access to treatment?

- vi) Who discriminates?
- vii) Is there stigma and discrimination amongst people living with HIV/ AIDS?
- viii) How do you feel when confronted with a situation dominated by stigma and discrimination?
- ix) What strategies do you use when confronting or reducing the effect of stigma and discrimination?
- x) Have you noticed changes in levels in stigma and discrimination in the last few years? What do you attribute this to? Why?
- xi) What role has the ACER project played in fighting stigma?
- xii) To what extent have they succeeded in fighting stigma?

5. Experience of the interview...

- i) Was it comfortable?
- ii) Do you have any questions for me?
- iii) Was anything of importance missed out?

6. Social Context: describe environment under which interview was conducted.

Thank you for taking the time to have this interview. The information is going to be used to help make programmes for people taking HIV medications better.

Evaluation of the Antiretroviral Treatment Community Education and Referral (ACER) Project

FGD with ACER Project Community-based Partners

1. Number disaggregated by sex, age-range, type/category of group
2. What group of people are more at risk of HIV infection in your community?
Probe for;
 - i) Sex most at risk; Why at risk
 - ii) Age group most at risk, Why at risk,
3. What do you know about condoms?
Probe for;
 - i) View on condom use and their effectiveness
4. Can AIDS be cured (and if it cannot why not?)
Probe for;
 - i) Knowledge about ARVS (Have you heard about ARVs?)
 - ii) Attitudes to ARVs (What do you generally think about ARVs?
 - iii) Knowledge about ARVs and sexual intercourse. (Should people on ARVs have sex?), ARVs and pregnancy? ARVs and children.
 - iv) Do you think you have enough information about these treatments?
5. What is the importance of adherence to ART?
6. Do people on ARVs in your community (where you are operating) generally adhere?
Probe for;
 - i) What strategies is the ACER project employing to promote adherence among people on ARVs
 - ii) What more could they do? What is lacking in the intervention to effectively enhance adherence?
7. What do you understand by 'prevention for people with HIV'?
Probe for;
 - i) What are the basic guidelines for prevention for people with HIV?
 - ii) Why Necessary
 - iii) How it is done; How could prevention for people with HIV be done?/In which ways could people with HIV prevent re-infection?
8. What do you think is helpful now/and what is still missing in HIV/ AIDS-related services being provided?
Probe for;
 - i) Describe your activities as an organization.

- ii) What type of support do you receive from the ACER project? Describe the difference ACER has made to the activities within your organization. What have been the positive aspects of this support? How can ACER improve its support to you?
 - iii) What activities do you undertake within the community that promote the uptake of HIV testing and ART.
 - iv) What activities do you perform among community members that help reduce the spread of HIV/ AIDS?
 - v) What activities do you perform among community members that help in supporting persons on ARVs?
 - vi) How have your activities in general contributed to knowledge and uptake of ART within the community? Can you support your answer with specific examples?
 - vii) What have been the results of the above activities? Can you describe the results? Is it possible to show these results in terms of numbers of persons (segregated into male, female, youth, and children?)
 - viii) What have been the challenges in performing the above activities?
 - ix) Describe your linkages to the ACER Project
9. Is there stigma and discrimination against people living with HIV/ AIDS in your community?

Probe for;

- i) What strategies do you use when confronting or reducing the effect of stigma and discrimination?
- ii) Have you noticed changes in stigma and discrimination in the last few years? What do you attribute this to? Why?
- iii) What role has the ACER project played in fighting stigma?
- iv) What is lacking in the fight against stigma?

10. Do you have the capacity to provide services?

Probe for;

- i) Do you have the capacity (both human and financial resources) to provide these services?
- ii) What challenges are you facing in delivering these needs?
- iii) How could these challenges be met?
- iv) What role had the ACER project played to build your capacity?

11. What do you think about the intervention; its design and implementation?

Probe for

- i) What do you know about the project/intervention?
- ii) What do you think about the project?
- iii) Looking at the way the project has been designed, would you say it is adequate to meet the needs of the clients as well as your needs to provide good services? Please give reasons why you so answer.

- iv) What else do you think could have been done to make the intervention more effective and efficient?
- 12. Does the project adequately meet the needs of both men and women in providing HIV/ AIDS services?

Probe for

- i) Have you noticed any differences in the uptake of services between men and women?
- ii) What are these differences?
- iii) Who accesses more of your services between men and women
- iv) What accounts for the differences
- v) What is being done by the project to ensure that these differences are mitigated?
- vi) How can prevention, treatment and care strategies ensure that the needs of both men and women are taken into account so that the burden of the disease does not fall disproportionately on one sex?
- 13. How are you involved in the intervention?

Probe for

- i) At what level are you involved in intervention activities (i.e. planning, implementation, review etc.)?
- ii) What do you hope to gain as a result of the intervention?
- 14. How would you rate the quality of services being offered (poor, fair, good, very good) so far. Give reasons for your rating
- 15. What changes have you observed as a result of the project?

Probe for

- i) What services are offered?
- ii) Volume of services offered
- iii) Quality of services (poor, fair, good, very good).
- iv) Quality of health of clients
- v) What other factors apart from the intervention activities can you attribute these changes to?
- 16. What role has the ACER project played in bringing about this change?
- 17. Are the changes brought about by the project sustainable?
- 18. What do you think should be done to sustain these good changes you have observed that are as a result of the project intervention.

Evaluation of the Antiretroviral Treatment Community Education and Referral (ACER) Project

Focus Group Discussion – Community Members

1. How has the problem of HIV AIDS affected your community?

Probe for

- i) Who is affected most (men and women) and why?
- ii) What has been the impact of the disease on women?
- iii) What is being done in the community to help the women?

2. Have you ever heard of stigma?

Probe for

- i) Is there stigma against people with HIV in this community?
- ii) Which sex is most stigmatized? Why
- iii) Do you think people's perceptions with regard to stigma towards people living with HIV/ AIDS have changed in the last few years?
- iv) What has brought about the change?

3. Have you ever heard of adherence to ARVs?

Probe for

- i) What is adherence?
- ii) Do people adhere to ARVs in this community?
- iii) Between men and women, who adhere more closely to treatment? And why?
- iv) What support is provided to people on ART to help them adhere to treatment?

4. Have you ever heard of the ACER project? (if no, probe for partners and their activities which are related to the ACER)

Probe for

- i) What does the project do in this community?
- ii) Do you think that it has been of benefit to the community at large?
- iii) In what areas and to what extent?
- iv) Who is more likely to access services provided by the project and its partners between men and women?
- v) What has the project done to ensure that services are equally accessed by both men and women?
- vi) What unique aspect has the ACER project brought to the community?
- vii) What changes has the ACER project brought about?

- viii) How can their activities together with the benefits be sustained?
- ix) What role has the ACER project played in mobilizing the community for VCT and ARV treatment?
- x) What role has the project played in your community in fighting stigma?
- xi) What role has the project played in promoting adherence to ARVs for people with HIV?

Annex 3: Informed Consent Forms

Informed Consent Form: In-depth interview with Project Staff/Stakeholders

Evaluation of ART Community Education and Referral (ACER) Project

Introduction

My name is Joseph Simbaya, and I am evaluating efforts to educate people about treatment and other services for HIV and AIDS.

Purpose of the study

I am conducting the study evaluate the effectiveness of community efforts aimed at increasing access adherence to ART and to learn how to improve the medical and health education services received by people in the community. Specifically, I would like to know about your experiences of/what you know about providing education on ARVs, and about referrals for HIV/ AIDS services. The findings from this study are expected to help improve access to services and care for people in the community and for people with HIV.

Procedures to be followed

You are being asked to participate in an interview which will last about 60 minutes.

If you agree to participate, I will lead the discussion and take notes. An audiocassette will be used to record the discussion. The cassette will not have your name or the names of any other participants written on it anywhere. After the discussion, the cassette will be stored in a locked file cabinet. Later I will transcribe (write) on a computer what we have said during the discussion, so that I can better review the responses of the participants. The only person who will have access to this cassette is I and the person who will transcribe the cassette. No other person or institution will listen to this cassette. Once we have finished transcribing, the cassette will be destroyed.

You will be asked questions about your experiences of providing information about HIV prevention and other services, and about treatment for people with HIV, along with your observations and opinions about these services. You will be free not to answer questions or to stop the interview at any time, without giving any reason.

The risks to you as a participant in this study are minimal. Please note that you may skip any questions that you do not wish to answer or stop the interview at any time, without giving any reasons.

Agreement to participate and right to refuse or withdraw

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future, if it helps to increase our understanding about ways to provide better health education and care and treatment for people with HIV.

You understand that your participation in this study is voluntary. You will be free to decline if you wish.

You understand that you are free to ask questions before signing this form and that if you have further questions during the course of the study, you may contact Dr. Phillimon Ndubani, my supervisor, at the University of Zambia, PO Box 30900, Lusaka, telephone 294131, or Mr. Christopher Kangale, the Director of International HIV/AIDS Alliance, Woodlands Shopping Complex, Woodlands. Telephone; 0211 260818

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction. I agree to participate in this study.

Signature of Respondent:

Signature of Interviewer:

Date:..... Place:.....

Informed Consent Form: In-depth Interview with people taking ARVs

Evaluation of ART Community Education and Referral (ACER) Project

Introduction

My name is Joseph Simbaya, and I am evaluating efforts to educate people about treatment and other services for HIV and AIDS.

Purpose of the study

I am conducting the study evaluate the effectiveness of community efforts aimed at increasing access adherence to ART and to learn how to improve the medical and health education services received by people in the community. Specifically, I would like to know about your knowledge and use of HIV/ AIDS services and treatment, and about your HIV prevention behaviors. I would also like to know about your adherence to antiretroviral medication, and about your experiences of taking these medications. The findings from this evaluation are expected to help improve access to services and care for people in the community and for people with HIV.

Procedures to be followed

You are being asked to participate in an interview that will take between 45-60 minutes. If you agree to participate, we will ask you questions from a printed checklist/guide and will note your answers.

The risks to you as a participant in this study are minimal. During the interview you may decide to share information that is personal in nature. This could be stressful to you. Please note that you may skip any questions that you do not wish to answer or stop the interview at any time, without giving any reasons.

Your responses will be kept confidential. Your name will not appear on the interview record. No identifying information will be reported with your response. Your responses will be seen only by the researcher and all interview transcripts and other records will be stored in a locked and secured place, under the control of researcher and will be destroyed after the evaluation has been successfully completed.

I will not provide any money for your participation in this study. However, I can provide you with information about HIV/ AIDS and about where to find HIV testing and counseling and other health services in your area. I will offer you a nutritious drink after the interview has finished.

Agreement to participate and right to refuse or withdraw

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future, if it helps to increase our understanding about ways to provide better health education and care and treatment for people with HIV.

You understand that your participation in this study is voluntary. You will be free to decline if you wish. If you agree to participate, you can decide not to answer certain questions and can stop the interview at any time.

Your decision about whether or not to participate in this study or to answer any specific questions will in no way affect any services that you receive.

If you do participate, you understand that a representative of the researchers may contact you to ensure that you have consented to do so.

You understand that you are free to ask questions before signing this form and that if you have further questions during the course of the study, you may contact my Supervisor, Dr. Phillimon Ndubani, at the University of Zambia, PO Box 30900, Lusaka, telephone 294131, or Mr. Christopher Kangale, Director of the Alliance Zambia, Woodlands Shopping complex, Woodlands, PO Box 33796, Lusaka, telephone 260818.

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction. I agree to participate in this study.

Signature or thumb print of Respondent:

Signature of Interviewer:

Date:..... Place:.....

Informed Consent Form: FGD with Partners

Evaluation of ART Community Education and Referral (ACER) Project

Introduction

My name is Joseph Simbaya, and I am evaluating efforts to educate people about treatment and other services for HIV and AIDS.

Purpose of the study

I am conducting the study evaluate the effectiveness of community efforts aimed at increasing access adherence to ART and to learn how to improve the medical and health education services received by people in the community. Specifically, I would like to know about your experiences of providing education on ARVs, and about referrals for HIV/AIDS services. The findings from this study are expected to help improve access to services and care for people in the community and for people with HIV.

Procedures to be followed

You are being asked to participate in a group discussion with 8-10 other people that will last about 60 minutes.

If you agree to participate, I will lead the discussion and my colleague will take notes. An audiocassette will be used to record the discussion. The cassette will not have your name or the names of any other participants written on it anywhere. After the discussion, the cassette will be stored in a locked file cabinet. Later I will transcribe (write) on a computer what we have said during the discussion, so that I can better review the responses of the participants. The only person who will have access to this cassette is I and the person who will transcribe the cassette. No other person or institution will listen to this cassette. Once we are finished transcribing, the cassette will be destroyed.

You will be asked questions about your experiences of providing information about HIV prevention and other services, and about treatment for people with HIV, along with your observations and opinions about these services. There are no correct answers to the questions that will be asked. Some of the questions may embarrass you or make you feel uncomfortable. You will be free not to answer questions or to stop the interview at any time, without giving any reason.

Each one of the people in this group will be asked to keep what is said completely confidential. You may use a nickname for the purposes of conversation during the group if you like.

The risks to you as a participant in this study are minimal. During the interview you may decide to share information that is personal in nature. This could be stressful to you. Please note that you may skip any questions that you do not wish to answer or stop the interview at any time, without giving any reasons.

I will not provide any money for your participation in this study. However, I will offer you a nutritious drink after the group discussion has finished.

Agreement to participate and right to refuse or withdraw

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future, if it helps to increase our understanding about ways to provide better health education and care and treatment for people with HIV.

You understand that your participation in this study is voluntary. You will be free to decline if you wish. Your decision about whether or not to participate in this study or to answer any specific questions will in no way affect your employment or working relationship with others.

You understand that you are free to ask questions before signing this form and that if you have further questions during the course of the study, you may contact Dr. Phillimon Ndubani, my supervisor, at the University of Zambia, PO Box 30900, Lusaka, telephone 294131, or Mr. Christopher Kangale, the Director of International HIV/ AIDS Alliance, Woodlands Shopping Complex, Woodlands. Telephone; 0211 260818

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction. I agree to participate in this study.

Signature or thumb print of Respondent:

Signature of Interviewer 1:

Signature of Interviewer 2:

Date:..... Place:.....

Informed Consent Form: FGD with Community Members

Evaluation of ART Community Education and Referral (ACER) Project

Introduction

My name is Joseph Simbaya, and I am evaluating efforts to educate people about treatment and other services for HIV and AIDS.

Purpose of the study

I am conducting the study evaluate the effectiveness of community efforts aimed at increasing access adherence to ART and to learn how to improve the medical and health education services received by people in the community. Specifically, I would like to know about your knowledge of HIV/AIDS and on services and treatment relating to HIV/AIDS. I would also like to know your views and experiences of people with HIV and how the services are provided in this community. The findings from this study are expected to help improve access to services and care for people in the community and for people with HIV.

Procedures to be followed

You are being asked to participate in an interview that will take between 45-60 minutes. If you agree to participate, we will ask you questions from a printed checklist/guide and will note your answers.

The risks to you as a participant in this study are minimal. During the interview you may decide to share information that is personal in nature. This could be stressful to you. Please note that you may skip any questions that you do not wish to answer or stop the interview at any time, without giving any reasons.

Your responses will be kept confidential. Your name will not appear on the interview record. No identifying information will be reported with your response. Your responses will be seen only by the researcher and all interview transcripts and other records will be stored in a locked and secured place, under the control of researcher and will be destroyed after the evaluation has been successfully completed.

I will not provide any money for your participation in this study. However, I can provide you with information about HIV/AIDS and about where to find HIV testing and counseling and other health services in your area. I will offer you a nutritious drink after the interview has finished.

Agreement to participate and right to refuse or withdraw

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future, if it helps to increase our understanding about ways to provide better health education and care and treatment for people with HIV.

You understand that your participation in this study is voluntary. You will be free to decline if you wish. If you agree to participate, you can decide not to answer certain questions and can stop the interview at any time. Your decision about whether or not to participate in this study or to answer any specific questions will in no way affect any services that you receive.

If you do participate, you understand that a representative of the researchers may contact you to ensure that you have consented to do so.

You understand that you are free to ask questions before signing this form and that if you have further questions during the course of the study, you may contact my Supervisor, Dr. Phillimon Ndubani, at the University of Zambia, P.O. Box 30900, Lusaka, telephone 294131, or Mr. Christopher Kangale, Director of the Alliance Zambia, Woodlands Shopping complex, Woodlands, P.O. Box 33796, Lusaka, telephone 260818.

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction. I agree to participate in this study.

Signature or thumb print of Respondent:

Signature of Interviewer:

Date:..... Place:.....

