

**“ BENEFIT INCIDENCE ANALYSIS OF ANTIRETROVIRAL DRUGS IN
UGANDA: A CASE STUDY OF KAMPALA AND MASAKA DISTRICTS ”.**

By:

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A mini dissertation submitted to the health economics unit, University of Cape Town, in partial fulfillment of the requirements for the Masters Degree in Public Health/ Health Economics.

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DECLARATION

This research paper is my original work and has not been submitted for any academic and/or examination purposes at any other university.

Signed by candidate

ROSETTE KYOMUHANGI

JUNE, 2005

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune- Deficiency Syndrome
ANC	Antenatal Clinic
ART	Anti-Retroviral Therapy
ARVs	Antiretroviral drugs
BIA	Benefit Incidence Analysis
CBO	Community Based Organisation
CDC	Centers for Disease Control and Prevention, Atlanta
CRS	Catholic Relief Services
DAI	Drug Access Initiative
DHS	Demographic Health Survey
FGDs	Focus Group Discussions
GDP	Gross Domestic Product
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GLIA	Great Lakes Initiative on AIDS
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IDC	Infectious Disease Clinic

IMR	Infant Mortality Rate
KCCC	Kamyokya Christian Caring Community
MAP	Multi-Country AIDS Programme in Africa (World Bank)
MIDC	Mild May Centre
MoH	Ministry of Health
MTCT	Mother to Child Transmission
NGO	Non- Governmental Organisation
NSF	National Strategic Framework
OI	Opportunistic Infections
PCA	Principal Component Analysis
PEPFAR	USA President's Emergency Plan for AIDS Relief
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child-Transmission
SSA	Sub-Saharan Africa
STD	Sexually Transmitted Disease
TB	Tuberculosis
UAC	Uganda AIDS Commission
UDHS	Uganda Demographic and Health Survey
UHSBS	Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS)

UNAIDS	Joint United Nations Programme on AIDS
UNAIDS_DAI	Joint United Nations Programme on HIV/ AIDS Drug Access Initiative
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organisation

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ABSTRACT

In the face of rising morbidity and mortality due to HIV/AIDS epidemic in Sub-Saharan Africa, there has been an increasing pressure to provide life sustaining antiretroviral drugs to countries in most urgent need of them.

Antiretroviral Therapy (ART) has been identified by policy-makers in Uganda as a potential programme aimed at mitigating the pervasive effect of HIV/AIDS on the social and economic life of the country. Since 2000, the country has shifted its focus from primarily HIV prevention to paying equal attention to care and treatment including ART. Provision of the ART programmes have been made possible through concerted efforts of international and national organizations such as the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), the World Bank, Multi-country AIDS Programme (MAP), Great Lakes Initiative on AIDS (GLIA), the USA President's Emergency Plan for AIDS Relief (PEPFAR), UN agencies, Bi-lateral and Government of Uganda inputs (UAC 2004).

New and increased funding notwithstanding, the Ugandan population has continued to grow exponentially at a rate of 3.5% and even though the economy has been growing at a rate of 6 % per annum, there is a widening disparity in incomes attributed largely to high levels of unemployment in the country (Ministry of Finance 2002). These income disparities have also greatly contributed to health inequities in Uganda, thus affecting the equitable allocation of the limited health resources including ART.

The main aim of the study was to establish the socioeconomic status of those individuals who benefit most from the provision of free ARV drugs and to explore factors that influence the distribution of such benefits.

The study was carried out in Kampala district (Uganda's capital city) and Masaka district. The study employed both qualitative and quantitative methods. Facility-exit interviews with patients accessing free ARVs formed the quantitative method, while

Focus Group discussions with community representatives and in-depth interviews with key informants formed the qualitative part of the study. Quantitative data was obtained by use of a questionnaire, which was structured to obtain information on socioeconomic characteristics, including asset possession as a measure of wealth. A principal component analysis was run for both the Uganda Demographic Health Survey (UDHS) and facility-exit asset data to determine utilization of ARV by wealth quintiles. A benefit incidence costing model was also employed to determine monetary benefit of free ARVs in Uganda.

Major findings from this study indicate that:

- Women utilize free ARVs more than their male counterparts
- Utilization of free ARVs is predominately among the productive age groups in Uganda. i.e. age groups 30-39 and 40-49
- Those who utilize free ARVs have attained a primary or secondary level education but the majority of those are unemployed. However, those with secondary level education and more have greater access to free ARVs in Uganda than other educational levels.
- On average, utilization of free ARVs is skewed mainly to the well off (those from the highest quintile) as compared to the rest of the quintiles. This pattern is more obvious in Masaka district than it is in Kampala district. In Kampala district, ARV utilization is skewed to the lowest and highest quintiles while in Masaka, utilization of ARVs increases with wealth, with more utilization concentrated in the two topmost quintiles (high and highest).
- The government ART subsidy is pro-rich. It is not well targeted to the poor. Indeed the ART subsidy favours the well -off in society and the poor seem to benefit only after the non-poor have benefited.
- Distribution of free ARV use is not well targeted according to need. The socioeconomic groups that bear a relatively heavy burden of HIV/AIDS do not access the drugs in relation to their need.

The study therefore concludes that based on vertical equity and the 'maximin' principle of social justice, distribution of free ARV is not equitable because it benefits the rich more than it does for poor, who are both financially and socially marginalized. Further, according to the "priority view" of the egalitarian approach and horizontal equity, provision of free ARVs in Uganda is judged unfair because these drugs do not equally benefit those in need of them. Therefore it is suggested that policy makers develop strategies that are aimed at targeting the ART subsidy to those who are more likely to suffer exclusion due to economic, social, geographical or other barriers as well as to those with the greatest need of the service.

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CHAPTER ONE: BACKGROUND TO THE STUDY

1.0 Overview

This study attempts to ascertain the socioeconomic status of individuals accessing free Antiretroviral drugs (ARVs) as well the socioeconomic correlates of HIV infection in Uganda. It focuses on establishing whether it is the poor or non-poor that benefit from the free ARV programme and whether distribution of this programme is targeted according to need. This evaluation is useful in assessing whether the distribution of such drugs has been equitable since the programme began. The study also seeks to establish reasons for any unusual distribution if any exists. This chapter will offer background information as well as an overview of the study. The research question will be defined, objectives will be highlighted and the justification of the study will be discussed. Finally, a brief description of the proceeding chapters will be outlined.

1.1 Introduction

Global HIV/AIDS prevalence rates have continued to escalate despite numerous efforts to combat the pandemic. Globally, it is estimated that 42 million people are infected with HIV/AIDS. About 95% of these are in developing countries of which 70% are in Sub-Saharan Africa (SSA) (UNAIDS 2003). Sub-Saharan Africa (SAA) has the highest HIV prevalence across the globe. In this region alone, it was estimated that the number of people who were HIV positive was about 29.4 million in the year 2003 (UNAIDS 2003).

Uganda is one of the countries in Sub Saharan Africa that has been hit hardest by the HIV/AIDS epidemic. In 1992, HIV/AIDS national prevalence rates were as high as 30% (UNAIDS 2000), making Uganda the country with the highest HIV/AIDS prevalence rates at that time. However, these rates have declined over time due to an open policy approach of a prevention intervention. The AIDS epidemic has had devastating social and economic effects on Uganda's population. AIDS-related mortality has been high such that by 2000 AIDS was the fourth leading cause of death among those under-five in

Uganda (UNICEF 2000). It has also affected adults in their prime years that constitute the labour force as well as heads of households and leaders at large. This has had definite implications for natural life and development processes of the country. For instance, Uganda's health system has been affected in the sense that there is a lot of financial pressure in terms of providing health services and diversion of development resources into programmes aimed at mitigating the AIDS pandemic (Ministry of Health 2003).

1.2 Uganda's socio-economic indicators

Uganda is classified as one of the least developed country with a Gross Domestic Product (GDP) estimated at about USD \$ 6.2 billion in 2003 (Ministry of Finance 2003). The GDP per capita is estimated at US\$300-330 per annum and the average annual GDP growth is projected at 6% over the long term. Uganda's population at the last census was estimated at 24.7 million (Uganda Population and Housing Census, Ministry of Health 2003). The country has the highest population growth rate in the world of 3.5% per annum (WHO 1997). More than 80% of the people live in rural areas and predominately depend on subsistence farming for a living. According to the Ministry of Finance (2003), the majority of Ugandan people live below the poverty line and survive on less than a dollar per day.

The country has high mortality rates. The Infant Mortality Rate (IMR) is about 97 per 1000 live births, while the Maternal Mortality Rate (MMR) is about 506 Per 100,000 live births. Life expectancy has declined from 52 years during the 1990s to 42 years due to the HIV/AIDS epidemic (Ministry of Health 2003). Physical access to health facilities is still low due to poor infrastructure, insurgency in the Northern part of the country and also health care financing mechanisms, which are predominately out of pocket payments. Most of the health facilities lack storage facilities, laboratory and clinical equipment and are in need of physical rehabilitation. The Ugandan health system also lacks both financial and human resource management capacity with no quality assurance systems (Ministry of Health 2003).

The current health care funding is about US \$13 per capita per annum, of which US\$ 8 is provided out of pocket and US\$ 5 by the state (government, faith based mission services and donor funding consolidated) (Ministry of Health 2003). Uganda's health system is decentralized to 56 districts. There are two referral hospitals, eleven regional hospitals, a number of district hospitals and below that, health center fours (IV). The health centers IV are at the sub-district level and are the equivalent of a primary care health clinic (Ministry of health 2003).

1.3 HIV/AIDS and its impact in Uganda.

In Uganda, AIDS was first referred to as "SLIM" due to its physical wasting characteristics. The epidemic began to spread on the shores of lake Victoria in the late 1970's but the first AIDS case was diagnosed in 1982 (UNAIDS 2000). Around this time there was very little knowledge about the disease. Between 1982 and 1986, the AIDS epidemic spread quickly attacking a huge mass of Uganda's population. HIV/AIDS was declared an epidemic in the country in 1986 with adult seroprevalence rates estimated at 37% (USAID 2002). By that time Uganda had one of the highest HIV/AIDS rates in the world (Dyer 2004).

Due to the large impact of HIV/AIDS on the population and the economy of Uganda, the country became one of the first African countries to respond aggressively to the HIV/AIDS pandemic. The government together with international partners put in place strategic management systems, which were aimed mainly at prevention.

In 1986, when the National Resistance Movement (NRM) came into power, president Yoweri Kaguta Museveni realized that the AIDS scourge had not only affected a large number of civilians but his army too. He took it upon himself to address the problem by touring the whole country and telling people to avoid the disease. Museveni's approach of intervention against HIV/AIDS was mainly preventative. He taught the public about how to avoid catching AIDS and his message mainly emphasized three strategies known

as the ABC- the preventative approach that has been adopted by policy makers in Uganda. The president told the people that they should abstain from sex before they are married (A), Be faithful to one partner (B) and to always use a condom (C). This was the first major intervention in Uganda that helped in bringing down the HIV/AIDS prevalence in the country. National HIV/AIDS prevalence rates declined from higher than 30% in early 90's to about 8% in the late 90's in the adult age group (Dyer 2004).

At the end of 2003, the government and the UN say that only 4.1% of adults had the virus. The country is seen as having implemented a well timed and successful public education campaign against indulging in casual sex as well as significantly cutting the HIV prevalence rate (USAID 2002).

Despite the tremendous progress achieved in fighting the epidemic, Uganda still remained vulnerable to negative impacts of the HIV/AIDS pandemic. For instance, Uganda's population was estimated at about 21 million in 1999, of which an estimate of 8.34% was living with HIV/AIDS (UNAIDS 2000). According to the UNAIDS report, HIV/AIDS prevalence among young people aged 15-24 years was estimated to be 6.65%-8.99% for females and 2.56 - 5.12% for males. The 2000 HIV/AIDS surveillance report from the Ministry of Health also showed that an estimate of about 1,438,000 people were living with HIV/AIDS by the end of December 1999. Of these 1,294,200 were adults and 143,800 children aged 12 years and below. In the adult group 761,300 were female adults while 532,900 were male (Ministry of Health 2000).

Although, there has been a decline in the HIV /AIDS prevalence rates from 8.34% in 1999 to about 4.1% by the end of 2003 (USAID 2002), as well as decline in new infections (incidence rates), those already living with HIV and progressing to AIDS are still many. AIDS is still a major cause of death, currently responsible for 12% of the total annual deaths in the country and a leading cause of death among people aged 19-45 years (Ministry of Health 2003). According to the UNAIDS epidemiological fact sheet 2002 update, it is estimated that 230 people in Uganda die daily due to HIV/AIDS related illnesses (UNAIDS 2003). The Ministry of Health has estimated that there are about

120,000 patients in need of ARVs if such high mortality rates are to decline (Ministry of Health 2003).

1.4 The Antiretroviral Therapy (ART) programme in Uganda.

In order to mitigate the impact of the HIV/ AIDS epidemic in Uganda, there was a concerted effort to fight the scourge through an antiretroviral therapy programme. The UNAIDS / Ministry of Health HIV/ AIDS Drug Access Initiative (DAI) was launched as a pilot project in Uganda in November 1997 and became operational in June 1998. The goal of the initiative was to improve the quality of life of persons living with HIV/ AIDS by increasing access to HIV/ AIDS drugs.

Uganda was among the first countries to participate in the UNAIDS Access to Drugs Initiative. As a pilot country, Uganda benefited from negotiated prices for triple therapy with antiretroviral drugs (UNAIDS, 2003). However, this programme had been confined to Non- Governmental Organization (NGOs) as well as research and pilot projects, and had not been available to the wider public through the public health system (Ministry of Health 2003). Antiretroviral drugs (ARV drugs) from the UNAIDS_ DAI initiative were subsidized therefore patients met the cost of their medical care, which included consultation fees, laboratory tests, and cost of the drugs, although the latter were at a lower than normal cost. By the end of 2000, only about 1000 patients could access ART from the UNAIDS_ DAI initiative programme (Ochola et al 2000).

After this pilot phase, the MOH took over the coordination of the ART programme in April 2000. An expansion plan to increase access to ARVs was developed with support from WHO, which is referred to as the "National Strategic Framework for expansion of HIV/ AIDS care 2001/2002 to 2005/2006." The main focus of the new strategy was to provide free ARVs to the estimated 120,000 patients in urgent need of them, plus the costs of related services (Ministry of Health 2003). Since then, the government with the support of international partners has worked tirelessly to ensure that free ARVs are provided through the public health system. During Financial Year 2003/2004, 58 health

facilities in 20 districts from both public and private sectors were accredited to provide antiretroviral drugs. Forty-eight of these facilities are currently providing ART and an estimated 23,000 patients are currently accessing ART from the different public outlets (Ministry of Health 2004).

The public sector ART programme was officially launched in June 2004 with drugs for treating 2,700 adults that were procured under the World Bank funded Uganda AIDS Control Project. The drugs were distributed to 26 health facilities, including all the 11 Regional Referral Hospital (Ministry of Health 2004).

Some of the projects involved in providing free ARVs include: Medicine San Frontiers (MSF), Center for Disease Control and Prevention (CDC) and Uganda Business Coalition for HIV/AIDS. (Ministry of Health 2000). The Ministry of Health in Uganda also intends providing free drugs on a large scale by the year 2005 through the Global Fund to Fight AIDS, Tuberculosis and Malaria. Currently, the projects under Ministry of Health involved in the provision of free ARVs are Presidential Emergency Project Fund for AIDS Relief in Africa (PEPFAR) and Uganda AIDS control project (UACP) referred to as the Multicountry AIDS Programme in Africa (MAP) (Ministry of Health 2003).

Despite the tremendous efforts to expand provision of free ARVs in Uganda, the majority of the people in need of these drugs have not been able to access them.

1.5 Problem statement

Officially 120,000 people in Uganda are in need of ARVs. Currently, however only about 23,000 access the free drugs bought by the government through the Uganda AIDS Commission, the MAP (Multi-country AIDS programme in Africa) project funded by the World Bank, the French governments and from President Bush's grant for AIDS in Africa. The Global fund project is expected to procure more drugs and provision will be rolled out gradually on a universal basis (Ministry of Health 2003). It is not clear how many people access free ARVs from all NGOs consolidated.

While provision of free ARVs to those in need is still on a very small scale, the main question of who benefits from such an initiative in Uganda is still pending. The ART roll- out policy needs to address issues concerning the beneficiaries of the ARV drugs. The new health policy is that the government of Uganda provides free ARVs to all its population, however, the main problem that arises here is how to measure the benefit obtained by users of the service. Secondly, as the government of Uganda and some international projects have already started offering free ARVs to those in need, it is important to assess who currently benefits from the programme in terms of socio-economic status, gender, or age group. This is important to evaluate equity of the gradual roll-out and to identify obstacles to accessing ARVs for particularly vulnerable groups.

1.5.1: Research Question

The major question to be answered here is “ which groups of people in Uganda benefit from free ARV programmes in relation to socio-economic status, gender, age group and geographical location; what are the implications of such benefits; and is current provision of ARVs equitable?”

1.5.2 Rationale:

The purpose of the study is to establish who benefits from free ARV drugs particularly in relation to socio-economic status and also to establish reasons underlying any unusual distribution of ARVs, if it exists. These issues are important to understand because the ARV roll- out policy is increasingly considered as one of most important HIV/AIDS programmes aimed at mitigating the HIV/AIDS pandemic in Uganda. If access to free ARVs is skewed in favor of certain socio-economic groups, this will have implications for the equitable delivery of these services, a concern that policy makers should address.

1.5.3 Study objectives

AIM

The aim of the study is to establish which socio- economic groups benefit the most from provision of free ARV drugs in Uganda and to determine the factors that influence the distribution of such benefits.

Specific objectives include:

- To assess the participant's knowledge and attitude towards ARV drugs.
- To understand the objectives underlying the provision of free ARVs in Uganda.
- To establish the criteria considered for eligibility to access free ARV drugs.
- To identify the type of ARV drugs provided free of charge.
- To establish the socio-economic and demographic characteristics of those accessing free ARV drugs. *
- To compare utilization of the ARV programmes between groups with different socio-economic and demographic characteristics such as age, gender, occupational history, education and geographical location.
- To compare the socio-economic and demographic characteristics of those accessing ARV drugs to those of the HIV positive population as well as those for the entire population (Uganda Demographic Health Survey)
- To explore possible social, economic and supply factors that may be facilitating or constraining access for the disadvantaged groups.
- To estimate the value of benefit derived from ARVs in terms of costs of services
- To calculate the benefits (average) that accrue to various socio-economic groups.
- To suggest tools for constant monitoring of the programmes' benefit incidence
- To derive guidelines on how to reach disadvantaged groups more effectively.

1.5.4 Justification for the study

Efforts to expand provision of free ARVs in resource poor settings have greatly improved. The WHO 3x5 initiative, increased financing available from the Global Fund to fight AIDS, Malaria and Tuberculosis (GFATM), the Presidential Emergency Plan for AIDS Relief (PEPFAR) and national efforts to fight the AIDS scourge through a health policy known as the "National Strategic Framework for expansion of HIV/AIDS care 2001/2002 to 2005/2006" has made it possible for Uganda to provide free access to antiretroviral drugs in particular institutions and facilities. Pilot studies have demonstrated that highly active antiretroviral therapy (HAART) has been feasible and effective in reducing the viral load and increasing CD4 counts in limited resource settings including Uganda. As a result, occurrence of opportunistic diseases has reduced and hospitalization rates have declined, translating into decreased morbidity and mortality rates (UNAIDS 2002). However, there is consistent evidence throughout the world that people at a socio-economic disadvantage suffer a heavier burden of illness and have higher mortality rates than their better-off counterparts (Mackenbach & Kunst 1997). These socio-economic inequalities in health are a major challenge for health policy, not only because most of these inequalities can be considered unfair, but also because a reduction in the burden of health problems in disadvantaged groups offers great potential for improving the average health status of the population as a whole. In a limited resource setting like Uganda, where not everyone in need of ARVs can access them, provision of such services should be guided by equity and human rights principles of fair distribution. However, in Uganda, such policy decisions based on equity are just beginning to emerge and as a matter of fact no study on benefit incidence on subsidized public goods and services has been documented. Therefore, the motivation for undertaking this research is to assess which socio-economic groups benefit from free ARVs in Uganda and to what extent, in order to inform policy makers about equitable access in the ARV roll-out programme. This will help in looking for strategies to improve the system, not only for ARV programmes but also, for all HIV/AIDS related programmes as well other subsidized public goods and services.

1.6 Outline of the thesis structure

Chapter 2: Theoretical and Empirical Literature reviews. The empirical literature review provides information on implication of the disease and socioeconomic correlates of HIV/AIDS in most of the affected African countries. The chapter further goes on to discuss strategies that have been adopted to mitigate the pandemic, of which the antiretroviral therapy is one. It also looks at different literature on equity concepts and definitions, giving clear health equity judgments on which the study will be evaluated. The final section examines different approaches to benefit incidence studies of the health sector, emphasizing the micro benefit incidence study type.

Chapter 3: Methodology. This chapter describes study design, sampling strategy, data sources and nature, the benefit incidence methodology and the costing methodology.

Chapter 4: Key findings from quantitative and qualitative research are presented.

Chapter 5: Study results are analyzed and discussed in detail.

Chapter 6: The final chapter presents the policy implications, recommendations and conclusions.

CHAPTER TWO: LITERATURE REVIEW

2.0 Overview

This chapter provides a review of the extent of HIV/AIDS problem, the impact of the epidemic on Africa and the socioeconomic correlates of the disease. The chapter goes on to consider concepts on Antiretroviral drugs (ARVs) and debates pertaining to affordability and sustainability in the context of limited resource settings in Africa. Equity concepts as major indicators of benefit incidence are also explored. Finally the chapter gives a theoretical review on what benefit incidence is and the studies that have been done in this area.

2.1 Introduction

HIV/AIDS is considered one of the most threatening diseases in the world today (WHO 1997). Empirical evidence shows that during 1999, over 5 million people became newly infected with HIV-bringing to over 34 million the number of people living with HIV/AIDS in the whole of Africa (i.e. Sub-Saharan Africa and North Africa) (WHO 1997). Sub-Saharan Africa is one of the regions that has been hit hardest by the HIV/AIDS epidemic. In this region alone, about 29.4 million people are estimated to be living with HIV and in 2004, approximately about 3.1 million new infections were anticipated to occur in the same region (USAID 2004).

In many countries of Sub-Saharan Africa, HIV/AIDS is impeding efforts to extend life expectancy. It is argued that millions of adults in this region are dying young or in early middle age. Average life expectancy in Sub-Saharan Africa is now 47 years, when it could have been 62 without the AIDS pandemic (Avert 2004).

HIV/AIDS epidemic has claimed almost 19 million lives over the past two decades including 4 million children. The epidemic is one of the major contributing factors to orphaned children because studies indicate that HIV/AIDS has left over 13 million children orphaned in its wake (WHO 1997).

The disease is today having a major impact on social and economic development not only in health but also in education, agriculture, transport, industry, human resources and the economy in general.

AIDS is different from other diseases because it strikes people in the most productive age. Studies have revealed that a high proportion of people living with HIV/AIDS in Africa are in the 19 - 49 year age group, i.e. their prime working lives (World Bank 2002).

In specific terms, Stover and Bollinger (1999) argue that HIV/AIDS has severe economic impacts on agriculture, firms and households. The two major economic effects are a reduction in the labour supply and increased costs.

2.2 Economic Impact of AIDS on Agriculture

Agriculture is the largest sector in most African economies responsible for a big percentage of production and employment (Stover and Bollinger 1999). Studies done in Tanzania and other African countries have revealed that AIDS will have adverse effects on agriculture, including loss of labor supply and remittance income. The loss of a few workers at crucial stages of planting and harvesting can significantly reduce the size of harvest and in countries where food security is a continuous issue due to drought, any declines in food production will have adverse consequences for households. In addition, a loss of agricultural labor is likely to cause farmers to switch to less labor-intensive crops. In many instances, this will mean switching from export crops to food crops. Thus

AIDS could affect the production of cash crops as well as food crops (Ilinigumugabo 1996).

In Gwanda, a village in the Rakai district in Uganda, the FAO found that many previously cultivated areas were lying fallow due to labour shortages. Furthermore, within four years, the crops cultivated had changed entirely from coffee and bananas, two profitable crops, to cassava and sweet potato, which are subsistence crops. This switch was due to labor shortages as well. In addition, households had also switched from cattle raising to pig raising which is less labor-intensive (FAO 1997). Data collected in Uganda also indicate that agricultural tasks were frequently disrupted when women needed to care for household members ill with AIDS-related conditions (Taylor, Seeley and Kajura 1996).

Loss of labour in the agriculture sector not only erodes the livelihood of small-scale and subsistence farmers, it also has serious consequences for Uganda's economy since the agricultural sector accounts for 43 percent of GDP, 85 percent of export earnings and 80 percent of employment (UAC 2004). In addition, 85 percent of the total population of Uganda live in rural areas and depend mainly on agriculture for livelihood (Asingwire 2001)

2.3 Economic Impact of AIDS on Firms

Stover and Bollinger (1999) argue that AIDS may have a significant impact on firms, in the sense that AIDS-related illnesses and deaths to employees affect a firm by increasing expenditures and reducing revenues. Expenditures are increased for health care costs, burial fees and training and recruitment of replacement employees. Revenues may be decreased because of absenteeism due to illness, caregiver duties or attendance at funerals and time spent on training. Moreover labor turnover can lead to a less experienced labor force that is less productive.

The loss of professionals as well as managerial expertise and experienced workers due to HIV/AIDS has had a significant impact on businesses in Uganda. For instance, in one banking institution in Kampala, five senior staff died from AIDS in one year, and between 1989-93, out of 250 government officials sent abroad for further studies, 12 died. At least ten of these deaths were reported to have been AIDS-related (Nabalonzi, Kaddumukasa and Mulumba 1995). The Uganda Railway Corporation has been hard hit by AIDS among its employees, experiencing a labor turnover rate of 15 percent per year in recent years (Southern African Economist 1997). This represents a substantial loss of investment in human capital by the government.

2.4 Economic impact of AIDS on Households.

The household level impacts begin as soon as a member of the household starts to suffer from HIV-related illnesses. This results in loss of income particularly if the patient is the main breadwinner. Household expenditure substantially increases due to medical bills. There are also indirect costs due to time off work or absenteeism in school especially as women or daughters stay home to care for the sick. Death also results in permanent loss of income. This can contribute to a household declining into poverty because as savings go into funeral and mourning expenses. For instance, studies in Tanzania, Cote d'Ivoire, Uganda and Ethiopia have documented the tremendous burden of loss of income, large health care expenditures and consumption of savings to pay for funeral and mourning costs (Over 1992).

Permanent loss of income usually forces households to take children out of school to save on educational expenses. This perpetuates household labor, resulting in a severe loss of future earning potential. Studies in Tanzania by Over and Ainsworth (1996) and in Uganda by Topouzis (1994) reveal that increased expenditures and reductions in income led to withdrawal of children from school in order to reduce education-related expenditures and to have children help with household chores.

The effects of HIV/AIDS on households in Uganda have been severe. Financial costs of caring for patients with HIV/AIDS are enormous, relative to the household's total income. One study revealed that households in Rakai district, spent one third of their total annual income on medical care for one month or for one funeral in 1996 (UNAIDS 1996). Another survey found that burial expenses and expenditures on treatment for terminal AIDS patients were greater than average monthly income, causing many households to sell property in order to pay for these costs (Konde et.al 1996).

Women in informal sector business are unable to continue with their trading activities because of caregiver responsibilities. In some instances, businesses have collapsed due to the needs of the AIDS patients (ILO EAMAT 1995).

2.4.1 Coping with HIV and AIDS

From the above section, it is clear that individuals, families and communities are impoverished by their experience of HIV and AIDS. There is thus enormous strain on the capacity of families to cope with psycho-social and economic consequences of AIDS related illnesses. The magnitude of the HIV impact depends on the capacity to cope with the effects of the disease. Poor families have reduced capacity to deal with the effects of morbidity and mortality than do richer ones for very obvious reasons. The poor lack savings and other assets, which cushion the impact of illnesses and death as compared to their rich counterparts. As Cohen (1996) argues the poor are already on the margins of survival and thus unable to deal with consequent health and other costs. In fact many poor families never recover to their initial standard of living, especially when productive household members fall sick or die and when assets once possessed are sold to meet health related expenses and funeral costs.

Policy makers should thus understand the relationship between poverty and HIV infection in order to put in place programmes that assist the poor to cope with the AIDS epidemic.

2. 5 Socio economic correlates of HIV/AIDS

Studies in industrialized countries have revealed that poverty and illiteracy raise the probability of HIV infection. This is due to the fact that people with low income and little education are less able to afford condoms and may also have less access to information about dangers of high-risk behaviour (Cowan et.al 1994; Krueger et.al 1990; McCoy et.al 1996) However, at least in the first decade of the HIV/AIDS epidemic in Africa, HIV infection did not follow this pattern (Ainsworth and Semali 1998).

Many studies that have analysed the socioeconomic correlates of HIV infection in the general population of many developing countries tend to support the hypothesis that HIV infection tends to be associated with higher socioeconomic status for both men and women. (Barongo et.al 1992; Gross Kurth et.al 1995; Serwadda et.al 1992; Menon et.al 1998). For instance, a study of urban areas of Butare, Rwanda, found that HIV incidence is lower among women in low-income households (Burtely et. al 1994). This argument is reinforced by results from the DHS of early 1990s and surveys of sexual behaviour which revealed that the probability of having a non regular sexual partner (or commercial partner) rises with education, potentially raising their exposure to contracting STDs, including HIV (Filmer 1998; Deheneffe et.al 1998). Further, men and women with more education are probably more likely to travel and thus have more opportunities for casual sexual contacts (Ainsworth and Semali 1998). Although none of the surveys measured income, it is reasonable to expect that demand for commercial sex and/or the ability to support multiple partners would rise with income.

The probable explanation to the above arguments is that, early in the HIV epidemic, it was not known how HIV was spread. The knowledge of and access to means of prevention such as condoms was low. Thus a disproportionate share of people infected early in the epidemic had higher education and income. Since HIV has a long asymptomatic period and cannot be cured, current patterns of infection are likely to reflect the correlates of new infections in the past (Ainsworth and Semali 1998).

However, as HIV/AIDS becomes an endemic disease in many African countries, the positive relationship between economic status and HIV infection may disappear. This will mean that the more educated may have greater access to information on how HIV is spread and may be able to act on this information. The DHS and WHO/GPA data show for example that in virtually every country studied, those with more education are more likely to use a condom in casual and commercial sex (Filmer 1998; Deheneffe et.al 1998). Limited evidence on the characteristics of those with new HIV infection (incidence) indicate that a shift in the pattern of infection to those with lower socioeconomic status is already under way in some countries (Ainsworth and Semali 1998). Consistent to this argument is personal communication from Uganda AIDS Commission public relations officer who said that "HIV infection was associated with higher socioeconomic group at the start of the epidemic. Today HIV infection has cut across all socioeconomic groups" (Mr. James Kigozi, UAC 2005). This pattern is confirmed by the experience of Brazil, where there has been a shift in the socioeconomic distribution of AIDS cases. In the early 1980's, three quarters of those newly diagnosed with AIDS had a secondary or university education; by early 1990s this share had fallen to a third (Parker 1996).

Thus, there is not clear evidence on the distribution of HIV/AIDS across socioeconomic groups at present. However, the evidence suggests that it may be more evenly distributed now than the initial concentration among higher income groups. In view of this, provision of antiretroviral therapy should be guided by fair distribution especially in a limited-resource country like Uganda.

2.6 What is HIV antiretroviral drug treatment?

Antiretroviral drugs (ARVs) have been defined as the main treatment, but are not a cure, for HIV/AIDS. ARVs have the capacity to suppress the virus in the body, hence preventing its reproduction. ARVs therefore reduce the rate of occurrence of opportunistic infections thereby enabling people to live longer. The treatment consists of drugs that have to be taken every day for the rest of someone's life (Avert 2004).

The World Health Organization (WHO) recommends that a particular combination of drugs be provided for everyone to take when they start treatment. This is sometimes called the " first line regimen". These include four possible combinations listed below.

d4T+3TC+NVP

ZDV+3TC+NVP

d4T+ 3TC+ EFZ

ZDV+3TC+EFZ

The alternative names for the components in the drug combinations listed above are :

d4T - Stavudine,

NVP- Nevirapine,

ZDV- Zidovudine or AZT,

3TC- Lamivudine

EFZ - Efavirenz

If treatment failure has occurred then WHO recommends that the entire drug combination is changed from first to a second line regimen. WHO recommends switching from first line regimens to second line regimens as follows:

Failure on:	Change to:
d4t or ZDV+	TDF or ABC
3TC+	ddI
NVP or EFV	LPV or SQV

The alternative names for the drug components listed above are:

TDF- Tenofovir LPV - Lopinavir

SQV- Saquinavir

ABC - Abacavir

ddI - Didanosine

WHO recommends that if one needs to change from second line, they should then be referred to a specialist physician for individualized care (WHO 2000).

2.6.1 Key issues on ARVs and their impact

The prospects for expanded access to antiretroviral therapy (ART) in resource-poor settings have greatly improved as a result of global and national efforts to reduce the cost of antiretroviral (ARV) drugs, growing availability of cheaper generics, and increased financing available from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), private foundations, corporate initiatives, government budgetary resources, and multilateral and bilateral donors. In addition, there is the prospect of additional financing for ARVs through the US Millennium Challenge Account.

The increase in the affordability of, and financing for, ARVs has resulted in a rapid expansion of programmes providing ARVs and of countries planning to introduce or scale-up access to ART (Picazo 2003). Whilst global organizations, such as World Health organization (WHO) and the International Human Immunodeficiency Virus (HIV) Treatment Access Coalition are supporting country efforts to increase access to treatment through a series of regional consultations exploring opportunities for scale-up and lessons learned from pilot initiatives (Kapp 2002), there is a lack of clear evidence-based information to guide policy makers and planners in resource-poor countries.

Pilot studies have demonstrated the clinical feasibility and effectiveness of highly active antiretroviral therapy (HAART) in a range of resource-poor settings, including Cameroon, Cote d'Ivoire, India, Kenya, Malawi, Senegal, South Africa and Uganda (Attawell and Mundy 2003). These pilots have achieved positive outcomes for patients that compare with those found in patients in rich countries, in terms of decrease in viral load, increase in CD4 cell count, decrease in morbidity associated with opportunistic infections (OIs), and similar rates of side effects, thus prolonging lives. Patients have demonstrated good adherence, and there is limited evidence of the development of resistance (Attawell and Mundy 2003). Mascoloni (2002), in an article summarizing findings presented at the Barcelona Conference, identified factors contributing to

effectiveness as careful preparation and counseling of patients prior to starting treatment, training family members to support patients, local government and community support, and recovery from AIDS illnesses, which strengthens patient commitment (Mascoloni 2002).

2.6.2 Health Systems and other impacts of ARV programmes

Universal provision of ART in Brazil has had a positive impact on health service expenditure. An estimated 358,000 hospital admissions were avoided between 1996 and 2002, saving \$2.2 billion (Attawell and Mundy 2003). Private sector companies, such as the Electricity Company of Cote d'Ivoire (CIE), have reported both health benefits and cost savings as a result of providing ART to employees. In the 2 years following the introduction of comprehensive HIV/AIDS care with ART there was a five-fold increase in company based voluntary counseling and testing (VCT), 94 percent decrease in absenteeism, 81 percent decrease in HIV-related hospitalizations, 78 percent decrease in new AIDS cases, and a 58 percent decrease in HIV-related mortality. During this period, the company saved \$287,000 from reduced absenteeism, \$294,000 in health care costs and \$194,000 in funeral costs (Eholie 2002; Eholie et al 2002). Evidence is also emerging of the positive social and economic impact of ART on households and communities.

2.7 Equity and priority target groups

Scale-up of ART programmes should be informed by equity issues. Policy decisions around equity are just starting to emerge in countries currently planning for scale-up. When not all persons in need of HIV treatment can be served, distribution of HIV treatment services should be guided by principles of equity or fair distribution and consideration of human rights, including the right of everyone to the enjoyment of the highest standard of physical and mental health (Universal declaration of human rights; Article 25). Ideally the WHO principle of reaching 3 billion people by the end of 2005 (3x5 initiative) would provide free ARVs to all in need through public health care institutions. This would ensure that not only will the poor not be excluded from scaling

up of ART but also priority will be given to the large numbers of people in developing countries for whom existing health care services have not been affordable and who would continue to be excluded if they were to pay for ART treatment (Macklin 2004).

Consideration needs to be given to coverage of the poor, of different geographical areas, of rural versus urban populations, and of specific population groups (Attawell and Mundy 2003). More attention also needs to be paid to gender, to ensure that clinical or socio-economic criteria do not for example disproportionately exclude women with HIV who are not pregnant from accessing treatment. In addition, WHO has expressed concerns at the exclusion of children from many ARV access programmes (WHO 1997).

Socio-economic criteria for determining which patients receive free or subsidized ARVs need to be carefully defined, to ensure equitable access. Even at subsidized cost, treatment may not be affordable for the poorest. Experience outside of large-scale national programmes indicates that the poor are the least likely to access ART (Attawell and Mundy 2003). For example, in the Drug Access Initiative (DAI) in Cote d'Ivoire, despite efforts to ensure equitable access, poorer people were less likely to access treatment than those who were better off (Attawell and Mundy 2003).

The design of a fair system for ARV distribution might be very difficult to define but the underlying assumption is that, every country and community should ensure that high priority to access free or subsidized ART is given to lowest socioeconomic classes and the poorest individuals, in conjunction with other eligibility criteria for treatment. This is because these groups of people are disadvantaged both in terms of health status and socio-economic status and they are also least able to pay for ARVs and other health services. This idea is in accordance with the guiding principle of equity as stipulated in the 3x5 initiative: " The initiative will make special efforts to ensure access to antiretroviral therapy for people who risk exclusion because of economic, social, geographical or other barriers" (WHO/UNAIDS 2005 pg 10)

2.7.1 Equity concepts and definitions

Equity is a broad concept that captures the notion of fairness. It is also related in some way to the idea of a fair distribution of something or the other across different individuals and/or groups in society (Mooney 1983). The two concepts that need to be distinguished and clearly clarified are "equity and equality". It is important to note therefore that "equity and equality" are not always interchangeable. The dictionary definitions of both terms are: equity is "a system of justice based on conscience and fairness" while equality is "the state of being equal" (Longman New Universal Dictionary 1982). Equality is, thus, a particular interpretation of equity. It is concerned only with equal shares. Donaldson and Gerald (1993), argue that equity, however, is about fairness, and it may be judged fair to be unequal in some instances. For example, in health care it may be judged equitable to have unequal access to services in a sense that groups who are more likely to be ill should perhaps be given greater access. Thus, equity can only be achieved if resources are allocated in a fair/just way within each society (Wagstaff and Van Doorslaer 1993). However, it should be noted that fairness is a value judgment issue. This therefore implies that an equity goal adopted in one health system may not necessarily be the same in another health system.

Another question that is posed here is whether equity sets out to achieve fair health or fair health care. Realistically, equality of health is not viable considering the fact that there are so many factors that influence health. For example genetically inherited conditions, natural deterioration in health over time, age, gender and the ability to ensure that individuals adhere to principles of "good health". These factors make it impossible to have equal health for all. Moreover it is not known exactly what is meant by "good health". Donaldson & Gerald (1993) argue that attempting to achieve good health may be seen as elitist in the sense that informed individuals are prevented from choosing their own level of health which may be somewhere below "good health". For example a person may choose not to give up smoking. Such a goal would necessarily impose a level of quality of life on a community. The objective for equity should be provision of opportunity, which is about health care rather than health itself.

Equity in health care can be evaluated in two dimensions: Horizontal equity and Vertical equity. Horizontal equity is concerned with equal treatment of equals. Following the explanations of Mooney (1983), equal treatment for equals is about equal treatment for equal need. This term would therefore imply that those with similar health conditions get the same treatment in all aspects.

In terms of ART treatment this could mean that those patients with a CD4 below a certain threshold be given the same equal opportunity to access similar health care. This can be evaluated in terms of equal expenditure for equal need; such as equal nurse cost per patient or equity can be evaluated according to equal utilization for equal need. For example this may require that individuals living in different geographical areas of the country receive the same treatment regimes for the ART programmes and also use the same services equally. Horizontal equity can also be evaluated according to equal access for equal need. In terms of ART programmes, this would provide individuals an opportunity to use needed health services in a fair way. For example equal waiting time for distribution of ARVs to patients with a particular CD4 count (Donaldson & Gerald 1993).

Vertical equity is defined as unequal treatment for unequals (Mooney 1983). Vertical equity can be evaluated as unequal treatment for unequal need. In terms of HIV/AIDS this principle would mean that patients who are in stage 1 of their disease would not be given the same measure of treatment and care as those ones in stage 4 of AIDS disease as long as they have different symptoms of the disease. The second concept of vertical equity is based on progressive financing according to ability to pay. If ART was funded by the government through taxation, this would imply that the rich pay a high proportion of their income in order to cross-subsidize the poor. This would enable the government to buy the ARV drugs and provide them free to the poor through public funded institutions. Vertical equity also implies taking additional measures to promote use by the worst off. For instance if two individuals both in stage 4 of HIV/AIDS

presented themselves for treatment, priority to access free ARVs should be based on the severity of the condition as well as ability to pay issues.

Equity requires that " equals be treated equally and unequals be treated unequally". Barry (1990) identifies two fundamental types of judgments to identify what is equitable. The first is to identify existing standards of distribution, which define in what ways people should be viewed as equals or unequals, and then analyze whether these standards are applied consistently. The second encompasses the development of standards where none exist. Addressing the first scenario, if for example the standard is universal provision of ARVs to all people with CD4 below 200, then inequity exists if certain groups with that criteria are not receiving the drugs. Similarly, standards for equity may involve identifying a minimum or basic level of health attainment, for example, all regions of a country achieve a life expectancy at birth of at least 65 years. Equity is achieved if all regions get to this minimum.

Often, however, there are no clear standards against which to assess equity. In most comparisons of social groups (rural Vs urban, men Vs women, rich Vs poor) there may not be an obvious criterion for when and how people count as equal and what inequalities are appropriate and/or required. The standards themselves need to be developed first. For example in comparing men and women, one may question how to weigh the fact that women often tend to have longer life expectancy but higher morbidity. Furthermore, even if standards exist, one may still argue that the norms of health that were developed for men do not apply to women (Evans et.al 2001) . In the assessment of health equity of this second type, broader considerations of social justice and of the social good have to be taken into account so that the judgments of equity become interlinked with judgments of social justice and fairness.

2.7.2 Equity principles for fair distribution of ART

As indicated previously, one of the guiding principles of the 3x5 initiative is equity (WHO/UNAIDS 2005). Several general ethical principles in addition to specific equity principles can potentially guide decisions in choosing one or another scheme for fair access to ART. However, these principles can conflict, therefore there is concern to balance competing issues to ensure that a fair decision is reached. For these reasons, leading commentators have urged that emphasis be placed on fair processes (Daniels and Sabin 2002). To the extent that decision makers in each country can agree on principled ways to set priorities among the various individuals and groups eligible for ART, the following principles of social justice can be used to justify their decisions.

2.7.2.1 Utilitarian ethical principle

The utilitarian principle calls for maximizing overall societal benefits. Applied specifically to health policy, the utilitarian principle aims at maximizing the overall health benefits of the society as a whole. This will therefore embrace a mix of health services that produces the greatest overall health effects (Mill 1863). The philosophical doctrine of utilitarianism states that we should maximize the sum of individual well being. Under the assumption that everybody's capacity to achieve health is equal, maximizing population health entails bringing everybody up to the highest possible level of health. Although the utilitarian principle has been understood to embrace considerations of justice, it does not provide a basis for choosing among the eligible groups in the most equitable manner. A common critique of utilitarianism is its inability to address issues of distributive justice (McGuire, Henderson & Mooney 1988). Utilitarianism is much more related to efficiency as opposed to equity. Efficiency deals with the optimum allocation of resources so as to maximize utility, while equity is about a fair distribution of resources and not necessarily maximization of utility. For instance, in the context of scaling up ART, a utilitarian approach could call for treating those patients where health improvement/ benefits would be maximized. This notion can therefore be more widely accepted and interpreted as giving priority to people whose

medical condition is such that they respond better to treatment and have greater chances to survive and live longest. Adhering to this interpretation would mean excluding patients who have advanced stage of HIV disease and whose benefit from ART treatment would only be minimal. This is the best example of “fair chances versus best outcome” problem (Brock 2002). Yet many people would argue that equity requires giving a fair chance of treatment to everyone regardless of the overall health outcome.

Although the utilitarian principle of equity is widely accepted in the public health literature, there are disagreements and uncertainties that need to be addressed. Such controversies could have implications for policy issues. For instance, one may question what benefits are to be considered? Is it only the medical benefits to the individual or other benefits as well? For example, treating health care personnel and teachers has the additional benefit of ensuring that needed personnel are available to administer treatment and health promotion and this would have additional health benefits to the society as a whole. Similarly treating factory workers rather than the children or the unemployed would have economic benefits to the country, which would in turn be used to increase treatment access (Macklin 2004). However, giving priority to the more productive members of society would perpetuate exclusion of those individuals in society who have lacked access to health care - a principle that would contradict the guiding principle of equity in the 3x5 initiative. According to ethical principles, social worth measured in terms of financial wealth should not be an acceptable criterion in giving priority to individuals or groups; instead if certain groups are to be given priority of treatment, it should be based on the anticipated secondary health or social health goods that are produced, and not the inherent worth of the chosen groups (UN 2002). Implications of the utilitarian principle of equity could be that exclusive use of this principle could result in ignoring specific claims for priority of access on the part of vulnerable or marginalized groups (Macklin 2004).

2.7.2.2 Egalitarian principle of equity

Egalitarian theories take different forms of interpretations depending on what egalitarian is perceived to entail. Some egalitarian theories emphasize equality of outcomes, which in the context of health would translate into equality of health status (Evans et.al 2001). An application to this interpretation would be to argue that it is more just if everyone in a population has a life expectancy of 60 years rather than having an average life expectancy of 70 years but when half the population can only expect to live to 50 years while the others half can expect to live to 90 years. Veatch (1991) argues that egalitarianism in the context of health requires that persons be given an opportunity to have equal health status. Thus he stresses the equality of opportunities, which entail equal access to health care. Dworkin (1993) yet argues that justice in health requires equality of health care resources. This would call for distributing resources equally among persons or distributing goods, such as health care services, equally among different groups. The principle underlying this theory is one that emphasizes health equity over health maximization.

Within this approach, there are also disagreements and controversial issues. For instance one may ask, what should be equalized? Resources for health, health care or access to health services. This theory would apply only if people had the same health needs. In reality however, giving everyone the same resources will produce different health outcomes because health needs vary. This may thus result in inequitable provision of health services. For example, groups that have TB or malaria in addition to HIV/AIDS have greater health needs than people living with HIV/AIDS (PLWHAs) without other diseases.

Aiming at equalizing health care would potentially divert resources to interventions that produce very small benefits for people who require enormous resources to obtain any benefit at all (Macklin 2004).

Partif (1997) also criticizes egalitarian theories described above, arguing that it is misleading to treat equality as in itself valuable. He stresses the fact that, it is need that matters most and not equality, thus this view termed as "priority view" constitutes a third approach to egalitarianism. This requires that health benefits be allocated according to need. Put another way, such an approach emphasizes those with the poorest health who have enormous need for health care. This view corresponds with arguments being put forward by the World Health Organization for an inter- individual assessment of health distribution that is independent of social groups (Gakidou et.al 2000).

Since the "priority view" emphasizes those with the poorest health and not necessarily the health status of the poorest, it may have more relevance within the health care system than a broader " society and health" perspective but considered exclusively, it does not clearly spell out which groups of people should have priority over the others. This is because everyone who needs ARVs should have equal access to them but they should not have priority over those with the same medical needs. Additional considerations are needed to make the case for determining priority of access.

2.7.2.3 The Maximin principle (concern for the worst off or the least advantaged)

This theory calls for giving preference to those who are worst off in some sense (Marchand, Wilker and Landesman 1998). However this principle is open to debate as far as the term "worst off" is conceptualized. In the context of health care delivery, this is usually understood to refer to those who are worst off in terms of health status, but it could also apply to a) the poorest in terms of income and consumption; b) the lowest socioeconomic class in terms of wealth or asset possessions; c) the most vulnerable (for example, children especially orphans); d) groups that are marginalized or most discriminated against or e) those who live in remote areas with poor access to any type of health services or f) even the sickest (Macklin 2004). In general terms, highest priority should be given to the least economically advantaged individuals and groups because

they are more likely to have poor health status and yet they are the same group of people who cannot afford access to health care services.

Under one interpretation, one can consider the least advantaged to be those who are the sickest, irrespective of how much they would benefit from the ART. This would mean that if people in their clinically advanced stage can benefit from ART, they should be given priority. The disadvantage with this interpretation would be to divert resources from those patients who could potentially benefit more from the treatment. This would thus conflict with the health maximization principle of utilitarianism.

Under another interpretation, concern for the “worst off” could mean giving priority to those most in need, where need is understood as how badly off people would be if not treated (urgent need). According to this view, priority should be given to those patients who are in urgent need of ART. This has the disadvantage of treating comparatively fewer patients who may even be the better off in financial terms in the society.

As seen from the above theories, it is now clear that a health care equity goal adopted by a particular health care system is dependent on an ideology. It is highly unlikely to find only one theory of social justice prevailing in one particular health care system in a particular country.

It is not clear which ethical and equity principles govern the distribution of free ARVs in Uganda, however the health minister in Uganda was quoted as saying that priority of the first batch of medicines would be given to the poor as well as some civil servants (<http://allafrica.com/stories/200405170504.html>). Such a statement however, does not give a clear indication of whether access to free ARVs is equitable or not. The gap to assess who benefits from such services still remains and the question posed here is: Do the poor benefit more or less than the non-poor from provision of free ARV drugs in Uganda?

2.8 An overview of equity in practice

In practice, equity takes two forms; namely equity in financing and equity in the delivery of health services (Wagstaff and Doorslaer 1993). According to Wagstaff and Van Doorslaer (1993), financing of health care should be a function of the ability to pay i.e. vertical equity; and that persons of families of the same ability to pay, should make the same contributions i.e. horizontal equity.

Equity in health service provision can be evaluated on a geographic and socioeconomic basis. Equity on a geographic basis implies that people with equal capacity to benefit from health care should receive equal treatment despite personal characteristics such as their place of residence that are not related to capacity to benefit, and equity on a socioeconomic basis implies that citizens from different socioeconomic status when ill, should receive the same treatment regardless of their influence in society or access to resources (Wagstaff and Doorslaer 1993).

2.8.1 Basis for equity evaluation in the study

This study will examine equity in terms of delivery of ARV drugs and equity in financing will be left out because the study is concerned with distribution of free ARVs, therefore ability to pay may not necessarily be applicable to this kind of study. In terms of health service delivery, the study will focus on evaluating equity on a geographical and socioeconomic basis.

Equity in the delivery of free ARV will be evaluated in terms of vertical and horizontal equity. Evaluation of vertical equity will require that persons with unequal need be treated in an appropriately dissimilar way. For example it could be judged to be fair if groups which are more socio-economically vulnerable and have ill health to have greater access than their counter parts. Evaluation of horizontal equity will be based on the notion that persons with equal need be treated equally. Equal need will be evaluated against a standard measure for eligibility of free ARVs. Horizontal equity will be evaluated according to equal utilization for equal need. Equal expenditure for equal

need, equal access for equal need and equality of health will be left out as they require that medical practice and compliance be standardized, a situation which may not be viable (Donaldson and Gerald 1993). They also involve a lot of data and value judgments.

Considering the principles of social justice given above, my evaluation of health equity will be based on theories that emphasize distributive considerations independently of aggregate population health. In this case, the utilitarianism approach will be left out as it ignores distributional aspects and instead focuses on efficiency aspects. As much as other theories should not be used exclusively in making clear judgments about health equity, in my view, they are better suited and they could have more relevance in informing health policy about equity than the utilitarianism, particularly, the "priority view" of egalitarianism and the maximin principle of social justice. This is because both theories are concerned with equity as opposed to efficiency. They also lay a firm foundation based on fairness that one can use to make sound judgments about distribution of a commodity or service. The main challenge is "how can one ascertain the extent to which the existing allocation of free ARVs in Uganda is reaching the poor and the most disadvantaged?" Benefit incidence is a tool that addresses this question.

2.9 Benefit incidence: What it is and why it is important

Benefit Incidence analysis has been defined as analysis that estimates the impact of public transfers, taxes, subsidies, or policy changes that affect prices (World Bank 2004). Benefit Incidence Analysis (BIA) measures the distributional incidence of benefits for different groups of interest, for instance households at different income levels or in different geographical locations. BIA can measure average/ aggregate benefit or marginal benefit-the incidence of the last (or next) unit of benefit (World Bank 2004). It brings together elements of the supply of and demand for public services and can provide valuable information on inefficiencies and inequities in government allocation of resources for social services and on the public utilization of these services.

Benefit incidence analysis is most commonly used to examine the impact of public expenditures and public expenditure reforms. It is also applicable to other policy reforms, including reforms affecting prices that change household income or expenditure and tax reforms. BIA studies can be applied to direct transfers as well as to transfers obtained by subsidized goods or services (World Bank 2004).

Three kinds of information are needed for the calculation of the incidence of government spending on the service it provides: Government spending on a service, public utilization of the service and the socioeconomic characteristics of the population using the service (Davoodi, Tiongson & Asawanuchit 2003).

BIA involves a five-step process methodology and these are:

1. Obtain the average unit cost of providing a public service by dividing government spending on the service by the total number of users of the service.
2. Define the average benefit from government spending on a service as the average unit cost of providing the service.
3. Rank the population of users from the poorest to richest using a welfare measure and aggregate them into groups with equal number of potential users.
4. Derive the distribution of benefits by multiplying the average benefit by the number of users of the service in each income or consumption group.
5. Compare the resulting distribution of benefits with a number of benchmark distributions.

Benefit Incidence is important because it tells us who benefits from services, transfers or price changes. BIA tells us who is benefiting from public services, and it also describes the welfare impact on different groups of people or individual households of government spending. This is done by combining information about the unit costs of providing those services (usually obtained from government or service provider data) with information on the use of these services (usually obtained from the households themselves through a sample survey) (Demery 2000).

While BIA is widely used and very useful in evaluating public subsidies, it suffers from a number of limitations. Firstly, a BIA has a weak conceptual framework, due to the fact that it represents an "equilibrium" outcome of government and household decisions (Davoodi, Tiongson & Asawanuchit 2003). Put differently, BIA does not specify a model underlying the behavior of either government or households. BIA studies do not give specific reasons as to whether an inequitable health system is due to government's failure to distribute health services in an equitable manner or whether it is due to the public's negative response to health services. By contrast, studies of demand functions for public services (especially micro studies such as one by Thiede, Palmer & Mbatsha 2002) address this shortcoming. However, these studies are rare and methods used to obtain information on barriers to access are not one of the usual components for BIA. Secondly, BIA uses the cost of providing public services as a measure of the value attributed to such services. BIA thus makes an assumption that the costs of provision are a good approximation of the benefit that users attach to government services. As usually implemented, BIA does not cover the entire cost of providing public services. For example it does not cover tax administration including pecuniary and nonpecuniary costs (Davoodi, Tiongson & Asawanuchit 2003). Thirdly, BIA captures at best benefit incidence of government spending at a point in time. To get a dynamic picture, BIA has to be conducted for different years. Lastly, estimates of benefit incidence often represent average incidence. This means that BIA does not typically provide information on who benefits from an expansion or contraction in government spending which are important issues to policymakers (Davoodi, Tiongson & Asawanuchit 2003).

2.9.1 Types of Benefit Incidence Studies and what they have shown

Most of the studies on benefit incidence have been done at a macro level and the main emphasis has been placed on the benefit incidence of spending of the social sector including health, education and basic infrastructure. BIA has been carried out for a number of countries: Some transition economies, middle-income countries and even some advanced economies (Davoodi, Tiongson & Asawanuchit 2003). However, within the scope of this paper, a few countries will be considered.

Some of the studies done on benefit incidence at a macro level include: benefit incidence of education in Indonesia, and health in Ghana by Demery (2000), effectiveness of public spending on education and health in Cote d'Ivoire, Kenya, Madagascar, South Africa and Tanzania by Castro-Leal et al (1999), benefit incidence of education and health spending in eight countries in Africa by Sahn and Younger (1992, 2000) and a general benefit incidence of public services as a whole including education, health and access to basic infrastructure such as roads and sanitation facilities in Bolivia and Paraguay by Ajwad and Wodon (2002).

Results from all of these studies revealed similar patterns, which were that government resource allocation is presently pro-rich. Results suggested that government / public subsidies of the social sector were not well targeted to the poor and indeed favoured those who were better off. Based on the Maximin principle of social justice, these results suggest that the distribution of public goods and services in most of these health systems are not equitable because the worst-off in society are not given priority and in fact are disadvantaged in accessing them. This is not a good sign because if such a pattern is not altered, then those who risk exclusion from accessing public subsidies and who are mainly the poor will continue being excluded. This is a violation of human rights principles, which emphasize the right of everyone to enjoyment of the highest standard of physical and mental health.

Whereas macro benefit incidence studies give a wide overview of the country's distributional aspects of public subsidies, they use aggregate data that is often crude and thus not very accurate. Government spending data are typically obtained from budget execution data as reported by the Ministry of Finance, the relevant line ministry, or the central statistical agency. The data used in macro benefit incidence analyses are typically reported on an aggregate basis. As such, the analyses cannot reflect the variation in the quality of services provided to different groups of users. For instance, health clinics in rural or low-income areas may not be as well staffed or equipped as clinics in urban or high-income areas. Lacking information on such quality variation, macro benefit

incidence studies are forced to maintain the hypothesis that quality is invariant (Davoodi, Tiongson & Asawanuchit 2003). Furthermore, because macro benefit incidence studies deal with aggregate data on public subsidies in general, they cannot inform policy makers about specific programmes that a country may be interested in evaluating. For instance studies on benefit incidence of health services as a whole do not specifically indicate how public funds are spent on different health services, for example, immunization programmes or HIV/AIDS programmes independently. As a result aggregate data on health will give a misleading picture on the distribution of government spending on particular programmes.

Another point to consider, is that macro benefit incidence studies will just inform policy makers that there is a problem with the distribution of the public subsidy but does not tell you specifically how to address such a problem. This is because these studies do not deal directly with the users of the service. For instance there are no focus group discussions conducted to ascertain factors that might influence or constrain accessibility of services, hence they cannot give a clear indication of what needs to be done to improve the situation.

It is important therefore to note that more studies on benefit incidence of specific health services are required to address such issues. Unfortunately, studies in this area have not yet been greatly explored. Having said that, below is an example on benefit incidence of a specific health service.

A study on the benefit incidence of a specific health service was done by Thiede, Palmer and Mbatsha (2002). The study covered three public clinics in the township areas of Cape Town, South Africa. The study was specifically addressing the question of 'who goes to the public sector for voluntary counseling and testing (VCT) for HIV/AIDS in South Africa'. A comparative benefit incidence analysis of VCT programmes was done in the light of two strategies to increase awareness - "ProTEST" and "LoveLife". The objective of the study was to establish the socio-economic status of those accessing VCT

at the public sector clinics in South Africa as well as to establish the reasons that could have influenced distribution or accessibility of such services.

The methods employed followed this approach: Facility-based exit interviews with patients were conducted to assess utilization of VCT services as well as general public clinic services by different socioeconomic groups. To establish socio-economic status of the respondents, the facility-based questionnaire asked a series of brief, closed-ended questions about gender, race, education, employment status, sanitary and living conditions and household assets. Many of the household asset questions were taken from the South African Demographic and Health Survey (DHS) in order to allow comparison with the DHS data set during the analysis phase of the study.

Data from the South African DHS on socioeconomic status of urban households was compared to data from the facility based questionnaire data to assess any differences in socioeconomic status between those attending the clinic and having VCT and those within the catchment area of the clinic. This was obtained by generating an asset index from South Africa's 1998 DHS for households in townships around Cape Town and Johannesburg using principal component analysis methods. Household characteristics and assets included in the generation of the index were household's main source of drinking water, type of toilet facility, flooring and wall material of the dwelling, access to electricity and a range of household valuables such as a radio, TV, car. The socioeconomic status of individuals attending services (including VCT) was then compared to the reference population of township households. This comparison group was ranked into quintiles based on the asset scores generated from the whole DHS urban sample. (Thiede, Palmer and Mbatsha 2002).

In-depth interviews and focus group discussions with staff, clinic users and local community groups were also conducted to explore barriers to access and attitudes to VCT. These interviews were taped, transcribed and analyzed for key themes, drawing

on fieldwork diaries as an additional source of information (Thiede, Palmer and Mbatsha 2002).

Findings about the use of clinics for general services as well as for VCT, showed that the two upper wealth quintiles were under represented and the second lowest was best represented. In specific terms, the low-income groups of people access more of the general services as well as go for VCT at public sector facilities than the well off. Overall, the findings showed that socioeconomic groups are not evenly represented in clinic attendance and more especially exaggerated when it comes to undergoing VCT. The least well-off quintiles among township population take up the services more than the others (Thiede, Palmer and Mbatsha 2002).

Compared to the macro studies discussed previously, results from this specific study, reveal that services are not skewed in favour of the well off. This is good because a large proportion of these services go to those people who are least able to afford them if they were provided for a fee. However, one cannot conclude absolutely that distribution of VCT and general clinic services at public sector facilities in township areas in Cape Town, South Africa is equitable because there are other factors that need to be considered in relation to horizontal and vertical equity before making any concrete decisions about whether a particular service is equitable or not.

Micro studies on benefit incidence have an added advantage over macro studies because they give the actual picture of what is happening specifically within a particular health programme, rather than giving an aggregate scenario of health services as whole. In addition to that, micro studies are better suited in informing policy makers on what needs to be done to improve the equitable distribution of specific programmes because interviews with service users and focus group discussions with representatives of the community highlight crucial issues that are useful in improvising strategies to deal with particular problems.

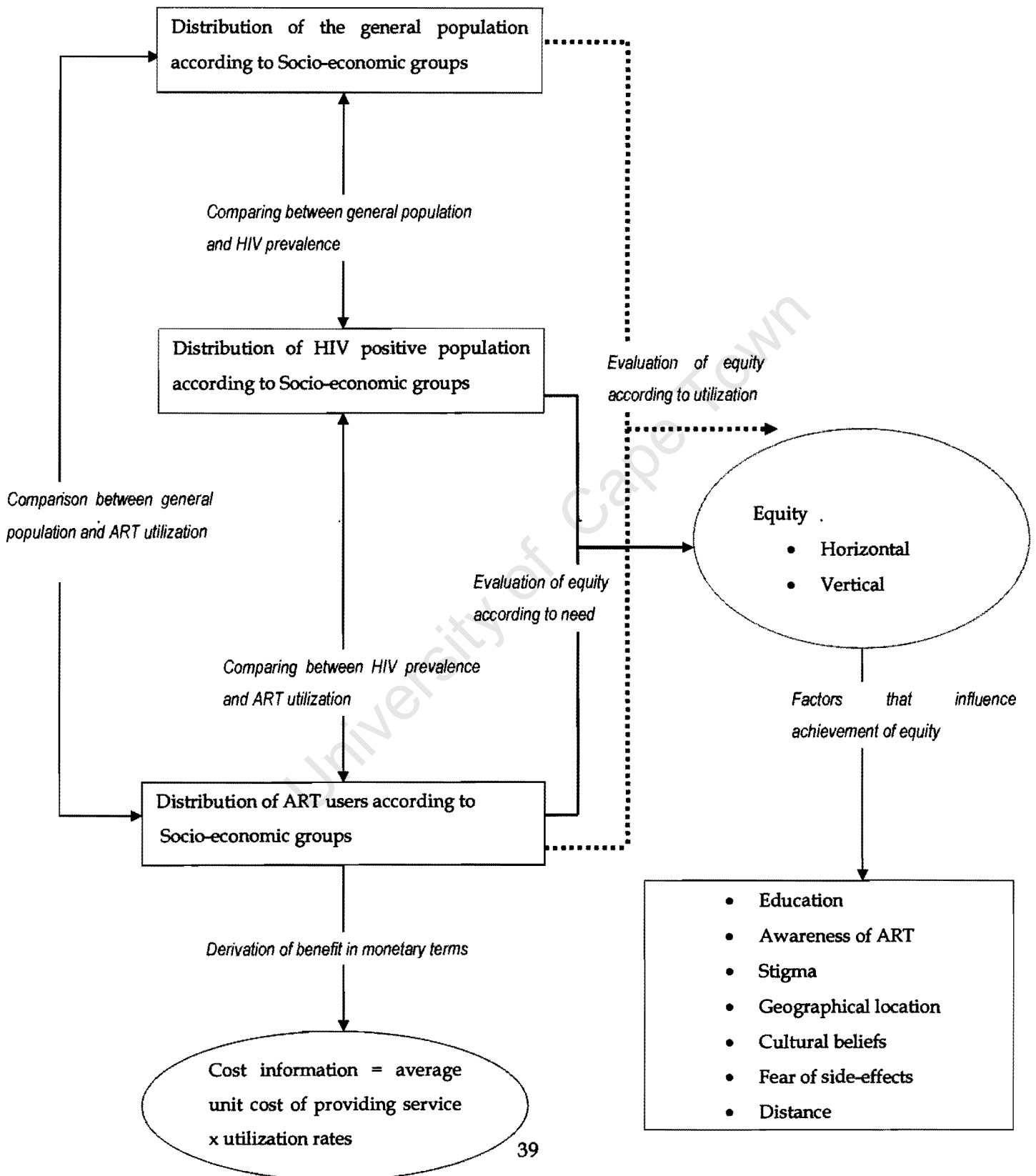
As my study will focus on benefit incidence of provision of free antiretroviral drugs in Uganda, it will more closely follow the approach of the study on a BIA of a specific type of health services than the macro level studies.

2.9 The Conceptual Framework of the study

Based on this review of the literature, the following conceptual framework was developed.

University of Cape Town

Conceptual Framework



The above diagram illustrates the following:

Comparison: - Comparison will be made between socioeconomic indicators of the general population, the HIV positive population and users of ART. This will be done in combination with geographical location (Rural Vs Urban). This will enable me to assess the socioeconomic status of those who access ART and to what extent. A comparison between socio-economic status distribution of HIV positive population and ART users will assist in evaluating equity according to need, while a comparison between socio-economic status distribution of the general population vis-a-vis ART users will assist in evaluating equity according to utilization.

Equity: - This will be evaluated in terms of horizontal equity and vertical equity
Horizontal equity- To evaluate whether those in need of ARVS (HIV positive patients) access them. Vertical equity- To evaluate whether priority is given to those who are HIV positive and who also are socioeconomically vulnerable.

Factors influencing achievement of equity- To understand supply and demand factors that affect the achievement of equity. Factors to be evaluated may include education, awareness of ART (sensitization), stigma, geographic location, distance, income, cultural factors and fear of side effects.

Cost information- In order to estimate the benefit derived from ARVs in monetary terms, the average unit cost of providing ART services will be obtained. This will be multiplied by the number of ARV users in each quintile in order to derive the distribution of benefits for each socioeconomic group. The costing perspective considered is the health system's perspective or provider's perspective. Costs accruing to patients will be excluded.

CHAPTER THREE: RESEARCH METHODOLOGY

3.0 Overview

This chapter provides a detailed description of the methodology used to collect both quantitative and qualitative data, the nature and sources of data and how such data will be integrated for later stages in the analysis. This chapter also describes the methodology used to evaluate information on the socioeconomic status of those receiving free ARVs in relation to the socioeconomic indicators from the Uganda Demographic Health Survey (UDHS). Finally, the methodology for costing of the benefit derived from accessing free ARVs is discussed.

3.1 Study design

A cross sectional study design was used to assess utilization of ARV drugs for the year 2004. Cross-sectional data included snapshot data of that year's utilization rates, socio-economic indicators and demographic characteristics of those patients receiving ARVs. Interviews administered in the waiting room of each facility were used to assess access to free ARVs by different socioeconomic groups. Information relating to knowledge, attitudes and barriers to access ARVs was obtained through focus group discussions, which were composed mainly of clinic users, staff and local community groups. Information regarding costs, criteria and eligibility of the ART programmes were obtained from key informants and these were mainly heads of ART programmes at selected facilities.

3.2 Study population

The study population included all adults accessing free ARV drugs in hospitals, primary health care facilities or local NGOs in Uganda. Owing to the limitations imposed by resources, the entire population could not be studied. A sample, therefore, had to be drawn from the study population. My purposive sample was Kampala and Masaka districts. (See map on the front page). These districts were chosen as areas of the study due to the following facts:

- The research was meant to compare the benefit incidence of ARVs in urban and rural areas in order to assess whether accessibility of ARVs was different in both settings.
- Kampala is the capital city of Uganda thus most of the well established health care facilities are situated there and Masaka is one of the first districts in the rural areas to have an ART programme.
- Both districts had well-established ART programmes that had been in place for the last two years. ¹
- These districts were accessible to the researcher within resource constraints.

The sample comprised of four facilities selected from Kampala and one facility selected from Masaka, which are discussed in detail later. One of the facilities in Kampala has two ART departments or subunits and the facility selected in Masaka serves patients from a hospital and an NGO. In total therefore patients from seven facilities were represented both in Kampala and Masaka. Not all facilities in one district were included. Due to resource constraints, only a few were purposively selected. These facilities were selected on the basis that they had in place a well-established ART programme.

The inclusion criteria were: Adults above 17 years of age, patients receiving free ARVs and must have been on these drugs for the past two months and patients had to be going to selected facilities to access the drugs. Exclusion criteria were: children, patients who had not yet started receiving ARVs and those patients who were visited at home by Community Based Organisations (CBOs). Put differently, the study was a facility-based interview; therefore it excluded household surveys of those patients served by CBOs- those patients who would not come to selected facilities.

¹ The ART programmes in Uganda were initially paid for. I.e patients met the cost of consultation fees, laboratory fees and the drugs. The free ART programmes were introduced in June 2004.

Sample size: It was estimated that people in need of ARV in Uganda was about 120,000 yet only 23,000 accessed free ARVs by the end of 2004. Therefore the study population was 120,000 adults in Uganda. A prevalence of 19 % of those accessing the drugs in relation to those in need was used as the estimate. A confidence interval of 95% and level of significance of 0.05 was used in this study. The required precision ± 5 (i.e. a range of 14% to 24%) was considered as an acceptable level for this study. Based on the above consideration, a minimum sample size of 400 patients was calculated using STATA. The intended sample size was thus ± 200 persons per district. The sample size for each facility was proportional to the size of the patient population as well as willingness to participate. Sampling was conducted over a time frame of three days per facility during morning and afternoon sessions. Calculation of sample size was based on the overall population of those in need of free ARV drugs in Uganda, irrespective of their geographical and physical addresses. Although the sample size was a representation of the entire group of those in need of ARVs in Uganda, an assumption was made that equal number of people would represent an urban and rural setting, hence results were presented separately by district.

3.3 Sampling strategy

A multi-stage sampling strategy was used. It involved many steps before getting to the sampling unit who was an individual at selected facilities. The sampling frame was a list of facilities in Uganda that offer free ARV programmes. The strategy involved the following steps: -

Firstly, the study population was stratified into rural and urban regions. Two districts were purposively selected, one from rural and one from urban areas. Kampala district was selected for the urban setting while Masaka was selected for the rural setting. Using the sampling frame, facilities within selected districts were also purposively selected because the process involved the deliberate selection based on certain predefined criterion (Depoy and Gitlin 1994). The criterion for choosing these specific districts and facilities was based upon well established ART Programmes with provision of free

ARVs. Out of the ten facility based ART facilities identified in Kampala, four facilities were purposively selected, and data was collected from a hospital which had two ART programmes, a primary health care facility and two local NGO AIDS support centers. In Masaka, out of three ART facilities identified, one large NGO known as Uganda Cares was purposively selected. This serves patients from both Masaka regional referral hospital and the Uganda Cares outpatient clinic. In each facility, a systematic sampling of people waiting in the queue to receive ARVs was used to conduct questionnaire interviews. Every third person waiting in the queue was approached and asked whether they would be willing to be interviewed. Sampling was conducted over a time frame of three days per facility during morning and afternoon sessions. The sample size for each facility was proportional to the size of patient population as well as willingness to participant. Purposive sampling was used to select focus group representatives and key informants.

3.4 Data collection sites

In Kampala the selected facilities included: Nsambya Hospital, Kamwokya Christian Caring Community (KCCC), Mulago Infectious Disease Clinic (MIDC) and MildMay Centre. In Masaka, Uganda Cares was selected.

- Nsambya hospital is one of the most well recognized hospitals in Uganda. It is a private hospital mainly funded by Catholic organizations one of which is Catholic Relief services (CRS). Nsambya hospital has had an HIV/AIDS treatment center that has been operational since the inception of the joint United Nations Programme on HIV/AIDS Drug Access Initiative (UNAIDS_DAI) in 1998 (Ministry of Health 2002). Thus it is one of the few treatment centers in Uganda with a long standing ART programme. It has two main ART programmes, namely Nsambya Home Care and Prevention of Mother To Child Transmission (PMTCT).

- Kamwokya Christian Caring Community is a local NGO located in one of Kampala's suburbs. Its ART programme just began in 2004. It is funded by PEPFAR and it gets its grants through CRS. It was formed with the main objective of providing free HIV/AIDS

treatment and care for the poorest of the poor in Kamwokya community and within a specified vicinity.

- An Infectious Diseases Clinic (IDC, MULAGO) was constructed in Uganda in 2001 at Mulago hospital in Kampala. It is mainly funded by Pfizer. The institute's main objective is to improve the quality of health care to adults and children living positively with HIV/AIDS, through the delivery of Antiretroviral therapy, clinical care, modern laboratory services, research, prevention programmes and training of African physicians and health care providers in HIV care and prevention (Infectious Disease Institute, News Update 2004).

- Mildmay center is an international non-governmental Christian organization. It was opened officially in 1998 on Entebbe Road, Lweza - Kampala's suburb. This center was developed with the aim of providing and demonstrating good quality holistic, comprehensive, outpatient care for patients with HIV/AIDS - related health problems. Since opening the center to patients with HIV/AIDS, around 75,000 patients attendances have been recorded. Mildmay International also runs a second project within Uganda, known as Jajja's Home. This is a day-care center and in-patient unit, which caters for seriously ill HIV-positive children. The center's major funder is CDC (Center for Disease Control and Prevention) (WHO 2001).

- Uganda Cares is a non-governmental organization funded by a health care foundation in the United States. Currently, it has 6 branches in Uganda and the Masaka branch was the first center to provide free ARVs in 2002. The main objective of setting up this organization was to evaluate whether it is possible to provide free ARVs in a resource constrained setting (personal communication with Dr. Penninah Jutung (medical officer- Uganda Cares- Masaka). Uganda Cares Masaka is responsible for patients from Masaka Regional Referral Hospital as well as the NGO's patients.

Although all the facilities mentioned above seem to be funded mainly by international organizations, some of the funds come from the government line ministry- Ministry of Health under the Multi-country AIDS Programme in Africa (MAP).

3.6 Data Collection instruments and methods

Instruments used to collect data included: Questionnaires, Focus Group discussion and key informant interview guidelines. To establish socioeconomic status of patients receiving free ARVs, facility based questionnaires asked a series of brief, closed-ended questions about gender, age, education, employment status, sanitary and living conditions and household assets. Many of these questions were taken from the Uganda Demographic and Health Survey (UDHS)- 2000-2001. This was to allow comparison of the data set from questionnaires to that from the UDHS for the analysis phase of the study. Some questions about knowledge around ARVs were also asked. The questionnaires were piloted in two centers in Kampala to check whether there were questions that needed to be phrased differently for easy understanding.

Questionnaires were developed in English and then translated to Luganda (main local language spoken both in Kampala and Masaka), for those persons who could not communicate in English and back translated to check the quality of translation. (See English version in appendix no.5). Interviews were administered by two fieldworkers whose choice was based on criteria that they must be university graduates and must have experience in data collection and research. The research assistants were trained prior to the commencement of the study. The training ensured that both research assistants understood the content of both the English and Luganda questionnaire and also practiced with each other in order to develop skills for time management for administering the questionnaire. Research assistants were also trained on ethical issues as discussed below in the proceeding section.

Qualitative methods were used for in-depth interviews with key informants and focus group discussions (FGDs) with community representatives. Five key informant interviews were conducted with heads of ART programmes at the selected facilities. The

interview guidelines for key informants consisted of about fifteen semi-structured questions (see appendix no.3), which were administered by the principal investigator. The interview guideline asked questions about criteria and eligibility as well as objectives underlying the provision of free ARVS. It also asked information of the general expenditure of the facility in question, total number of visits and costs on laboratory tests and provision of ARVs. Consent forms developed in English had to be signed prior to the interview (see appendix no.2).

Focus group discussions were very important on soliciting information on knowledge and attitude towards ARV drugs as well as to understand social, economic and supply factors that could have been facilitating or constraining access for disadvantaged groups.

The focus groups were divided in single sex groups. Females were interviewed independently from men. This was for the purposes of avoiding conformity because of the social interaction between males and females where both groups tend to "perform" for each other. For instance evidence shows greater diversity of ideas in single sex groups than in those of mixed sex (Stewart & Shamdasani, 1990). Four discussion groups were conducted, two groups (female and male) in each district. Each focus group consisted of 8-10 people, and these were people with common experiences or areas of interest. For instance the group consisted of patients who were on antiretroviral drugs (ARV's), community representatives (non- users) and some health workers administering the drugs. These were groups that were suggested by management of community-based organizations as representative. One major criterion was knowledge and experiences about ARV services. FGDs were conducted by the principal investigator with the help of two research assistants. Key informant interviews and FGDs were tape-recorded and field notes were written.

3.5 Ethical issues

Research assistants were trained to give a detailed explanation of the study to all respondents before their participation. Issues clarified included the following:

- The purpose of the study.
- That participation would be on a voluntary basis.
- That the participant is free to withdraw from the study at any time if they wish to.
- To give information about the use of data collection instruments and duration of each interview, Assurance of confidentiality via coded identity and other means.
- Advise on risk and harm, ensuring that the risk of harm is negligible
- To discuss potential benefits of the study outcomes.
- To obtain informed consent prior to the commencement of the interview.
- The main emphasis was placed on the points below:-

●Consent form

All participants (patients and key informants) were to be given consent forms, which they were free to accept or refuse to sign. There was no undue influence on the prospective participants. The subjects were notified of their right to refuse or withdraw from the study if they wished and that their treatment would not be jeopardized in any way. Participants were also informed of their right to ask any questions. Consent forms were developed in English and also translated to Luganda. They were given to respondents to sign before any interviews could be conducted. (See English version appendix no. 4)

●Confidentiality

Efforts were made to ensure total confidentiality. Personal information such as one's identity was not obtained. Measures were taken to ensure that individuals would not be linked to information provided by use of codes. The study also ensured anonymity by not reporting any private data that identified participants. Great care was exercised to protect privacy and maintain confidentiality by use of a coding system.

●Benefits versus risks

Potential physical, social and emotional risks to participants were minimized or eliminated by ensuring total confidentiality. The researchers also ensured that

questionnaires and interviews did not take a lot of participant's time off work. A minimum time of 10 minutes per participant was required which limited the cost of time that participants would invest in answering questionnaires.

The researchers explained to the participants that the study was not meant for only degree purposes but also would help to improve the equitable delivery of ARV programmes, which would benefit the participants and the society at large. In general, the study would ensure that the sum of potential benefits to the participant and the importance of the knowledge outweighed the risk of harm to the participants.

3.6 Nature and Sources of Data

- Facility-based exit interviews formed the utilization data and this was purely solicited from patients and was recorded by use of a questionnaire. Most of the data utilization data described socioeconomic status of those individuals accessing free ARVs. A total of 400 waiting room interviews were conducted, 218 in Kampala and 182 in Masaka. The researchers could not get equal number of participants from each district because Kampala has more ART centers compared to Masaka district. Therefore there were higher chances of getting more people in Kampala than it was in Masaka district. Patient populations in Kampala and Masaka were comparable as the investigator ensured uniform baseline characteristics such as age, gender, HIV prevalence, education and quality of care in the selected health services.

- There was need to collect data from the 2000/01 Ugandan Demographic health Survey (UDHS) on socioeconomic status of the entire population of Uganda. To assess which socioeconomic category each individual from the facility based questionnaires belonged, it was necessary to match all similar socioeconomic variables from facility based questionnaires with those from UDHS in order to generate an asset index - a concept which will be discussed later.

- Qualitative information from in-depth interviews and focus group discussions. FGDs and interviews were taped, transcribed and analyzed for key themes, drawing on fieldwork diaries as an additional source of information.

- Cost data- The cost data was collected mainly from key informants of the selected facilities and these were mainly heads of the ART department. Information collected comprised of: an estimate of the general total expenditure of each facility per year, total number of visits at each facility per year and annual estimate of total cost on ARV drugs for each facility. All selected facilities including hospitals have independently-run ART programmes, thus these facilities (or AIDS units within the facilities for which separate expenditure records were maintained) exclusively treat HIV/AIDS related illnesses. In view of this, total annual cost of expenditure on laboratory for each facility (or AIDS unit) was included in the general total expenditure. However, ARV drugs were not included in the general total expenditure because they were provided in kind. Therefore the information collected on ARV drugs in each facility, included number of patients on each drug combination and their market prices. These were multiplied to get estimates of total annual costs of ARV drugs in each facility. The costing was financial in the sense that it considered private costs incurred by the government. They did not reflect any opportunity cost of any resources, thus indirect costs were excluded. A provider's perspective was considered because the study aimed at establishing the amount of ART public subsidy that goes to each wealth quintile in monetary terms.

- Socioeconomic correlates of HIV infection in Uganda were obtained from literature as well from the Uganda Sero-behavioural Survey and the HIV/AIDS Surveillance Report. Data on asset index of HIV prevalence in Uganda was not available.

3.7 Data analysis

Entering, checking and cleaning of Data: Data was entered manually from questionnaires into a master spreadsheet. Data was checked and cleaned by a system of double entries into twin spreadsheets for each questionnaire by separate members of the

research team. After data entry completion these spreadsheets were compared and cross-checked.

Software used in analysis: STATA and EPIDATA software packages were used, in addition to standard Microsoft office packages (Microsoft Word and Microsoft Excel) to process and analyze the data. EPIDATA was used to enter the data while STATA was used to analyze the data.

Quality control (Validity and reliability of results)

The interview setting and conduct was comparable to avoid any differing responses. Fixed and closed rooms were used to avoid noise and other distractions and also to ensure privacy and confidentiality.

Face validity was assessed through the use of a mini-pilot study. Ten questionnaires were administered first in two facilities in Kampala before the main study began. Any problems with the draft questionnaire such as unclear questions were revised after the pilot. Content validity was accounted for by clarity of definition and terms.

Standardizing the questionnaire and other interview guidelines and ensuring that both questionnaires in local language and English had the same meaning accounted for reliability. All research assistants were trained to ensure that they were of the same mind and ways of administering the questionnaire and interviews were similar in all aspects. In addition, constant supervision was provided by the principal investigator.

3.8 Benefit incidence: Calculation of Asset index

A factor analysis to create an asset index for the benefit Incidence was used. The first step involved identifying socioeconomic variables that were similar from the exit-interview questionnaire and UDHS. Data was thus extracted from both sources. Household characteristics and asset variables used included main source of drinking water, the type of toilet facility, flooring, roofing and wall material, access to electricity and a range of household valuables such as radio, telephone, refrigerator, lantern and

cupboard. Other possessions such as car/truck, bicycle, motorcycle and boat or canoe were also matched.

The second step involved extracting data for Kampala district independently and for rural districts combined from the UDHS. This same procedure was repeated for data from facility-based questionnaires. The only difference was that rural districts in the UDHS were represented by Masaka district in the facility-based data. This was because the size of UDHS for Kampala was adequate enough to allow statistical analysis but UDHS data for Masaka was too small, so all rural districts in UDHS dataset were used.

A principal component analysis (PCA) was run for all identified variables of the two data sets (Kampala and rural areas) from the UDHS independently. This generated an unweighted mean, standard deviation and asset factor scores for all identified variables for both Kampala and the rural setting. In addition, each household asset was assigned a factor score generated through a PCA. These resulting asset scores were standardized and used to create the points that defined wealth quintiles. Five quintiles were generated for both the UDHS Kampala data set and rural data set. The quintiles were labeled in ascending order ranging from 1 to 5. These will be marked as: lowest, low, medium, high and highest for analysis purposes.

In order to get an individual asset index score for the facility based data for the two districts (Kampala and Masaka), so as to place these individuals in their respective quintiles generated earlier from the UDHS, the following formula was employed.

$$\text{Individual asset score} = \sum \left\{ \frac{\text{Value of asset variable} - \text{unweighted mean of asset}}{\text{unweighted standard deviation of asset variable}} \right\} \times \text{"raw" asset}$$

Where value of asset variable is value assigned to a particular asset variable such as electricity, unweighted mean of asset variable and unweighted standard deviation of asset variable for either Kampala or rural areas obtained from UDHS PCA. This depends on the area under consideration. " Raw" asset scores are the scoring coefficients generated by running the UDHS PCA. Results from this formula, generated asset index scores for facility-based data. Each individual was assigned a standardized score for each asset, where the score differed depending on whether or not the household owned that asset. Individuals were then ranked according to the total score of the geographical location in which they resided. Each individual was thus classified into appropriate quintiles accordingly.

3.9 Benefit incidence costing methodology.

- The total unit cost of providing ART service was obtained by adding unit cost of general expenditure to unit cost of ARVs. Unit cost of a visit at each facility was obtained by dividing the total expenditure of each facility (less drug expenditure) with total number of visits. Average unit cost of providing ARV drugs was obtained by estimating the total cost of ARV drugs and dividing by the number of people on ARVs in each facility. The annual estimate of ARV cost for each facility was obtained by multiplying the number of patients on each ARV regimen with market prices of those specified drug combinations.
- The average benefit from government spending on ART for each facility was defined as the average unit cost of providing the service at each facility.
- The distribution of benefits was derived by multiplying the average benefit by the number of users of the service in each quintile.
- The resulting distribution of benefits was compared across quintiles to assess which socioeconomic group benefited most from government spending on ART.

Limitations of the study

1. Owing to resource and time constraints, as well as the protocols put in place by various organizations, health workers and patients in the Focus Group Discussions could not be interviewed separately. The ideal would have been to interview them independently as these two different groups of people have power imbalances. This therefore could have introduced some sort of bias in the study because patients tend to shy away from voicing their ideas in fear that their treatment could be jeopardized.

2. Secondly, it was not possible to get asset data for HIV prevalence in Uganda. Education, HIV prevalence rates and literature on the correlates of socioeconomic characteristics and HIV infection were thus used as a proxy measure to estimate the socioeconomic group of those living with HIV/AIDS. If asset data for HIV infection was available, it would be compared with asset data from UDHS and facility based questionnaire asset data. This would have enabled one to clearly tell the correlation between HIV infection and socioeconomic status in Uganda, which would have thus helped in evaluating equity according to need.

3. A third concern is that the Demographic Health Survey in Uganda was last conducted in 2000/01, therefore the data are relatively old and asset ownership patterns in Uganda may have changed since that time.

CHAPTER FOUR : RESEARCH RESULTS

4.0 Introduction

This chapter presents the objectives of the ARV programme, the type and kind of ARV drugs provided to patients and the criteria for eligibility to benefit from the programme. Demographic and initial socioeconomic characteristics of the general population, people living with HIV/AIDS and of those in my study sample are analysed. The chapter further gives a description of each quintile or socioeconomic group in terms of household asset possession for both urban and rural settings. Findings about free ARV utilization by geographical location and by facility are presented. The chapter goes on to present the value of the benefit from ARVs in monetary terms. Finally factors that influence participation and those that prevent access to ARV programmes are discussed. This is integrated with knowledge and attitudes of users towards ARVs.

4.1 Objectives for the provision of free ARVs and types of ARVs

In order to understand the ARV-roll out policy in Uganda, it was important to find out the objectives pertaining to the provision of free ARVs. Interviews with key informants who were coordinators of government and NGO ART programmes, clearly pointed out that the main objective of providing free ARVs was to extend the years and improve the quality of life for those living with HIV/AIDS. In view of this, KI(A) said "yeah It is a WHO initiative to provide ARVs to all those who need them in order to improve their quality of life and survival rates." Although, there were differing responses, all of them were pointing in one direction, which was mainly to provide treatment to the infected. However KI(E) said that not only were they targeting the infected but they were also concerned about the affected. He further explained that providing ARVs to the head of the household would have an added benefit to his/her beneficiaries because he/she will live longer and thus be able to provide for his/her family. He argued that the objective of providing free ARV in their facility is "To improve the quality and quantity of life of HIV/AIDS infected and affected. i.e. the affected I mean that households could be affected if the bread winner is down and cannot provide for the family anymore."

Having established the objectives of the ARV programme in Uganda, the study went on to identify the type of ARV drugs offered free of charge. A question about type of ARV used in each programme was asked in the exit interviews with patients. About 10% of the respondents did not know what type of drugs they were on. Of those who knew, those on first line regimens and second line regimens were 75% and 15% respectively. The drugs were comprised of a three combination types. Of those patients on first line regimens, 20% were on AZT+3TC+NVP, 45% were on d4T+3TC+NVP and 10% on d4T+3TC+EFV. The patients on second line regimen seemed to be on the same drug combination which comprised of TDF+ ddI + Kaletra. Alternative names of the drugs mentioned above are as follows: -

AZT - Zidovudine or ZDV

3TC - Lamivudine

NVP - Nevirapine

EFV - Efavirenz

d4T - Stavudine

TDF - Tenofovir

ddI - Didanosine

Kaletra -Lopinavir

4.2 Criteria for eligibility to access free ARVs

It is of paramount importance to understand the criteria for eligibility to access free ARVs in Uganda because this forms the basis against which ARV programmes are judged fair or not, thus the criteria for eligibility were solicited from key informants. All of the interviewees (100%) said that they considered patients with a CD4 count of below 200 and patients who had WHO stage 4 disease or advanced WHO stage 3 disease as eligible. In addition to the medical criteria, facility E considered social aspects like disclosure of HIV status to family and friends, registration with the center and distance from the facility - KI(E). Consent for treatment -KI(D) and inability to pay-KI(F) were some of the other criteria considered by facility D and facility F as reflected in box 1 below.

Box 1: The criteria for eligibility of free ARVs in Uganda

KI(D): The main things we depend on are; of course you have to be HIV positive, then have a WHO clinical stage 3 & 4 and the third one is to have a CD4 count of less than 200. So those are the criteria we use! And then we want our patients to be able to come, to consent for treatment. We do not force them onto treatment, they have to consent themselves and we expect them to adhere to treatment.

KI(E): Here we look at the medical and social criteria. In the medical, we look at the stage of disease, we look at the CD4 count and where available we look at the viral load. I.e. we consider patients who are in WHO clinical stage 3&4 and who have a CD4 count of below 200. We also look at disclosure especially if one has disclosed to someone that implies that they will be able to get good social support. This is a very important in the management of HIV/ AIDS. We also look at the distance of where they stay. Initially we were looking at a radius of 3km from the center and we are increasing to 10 or 15 km. There are some exceptional cases where we go beyond 15km. Another criteria we look at is that you should be registered at this center.

KI(F): The very poor who cannot afford buying the drugs, those who have never had a chance to buy the drugs since they started in 1999. Those who were paying before are not considered. Also dependant on who registered first. Those who registered first get the opportunity. We also consider the scientific standard of WHO of CD4 count less than 200, stage 3&4 of the disease.

4.3 Demographic and initial review of socio-economic characteristics

This section presents demographic characteristics as well as initial socioeconomic characteristics of: the general population of Uganda; people living with HIV/AIDS in Uganda; and those of patients on ARV drugs that participated in the study. HIV/AIDS prevalence rates for urban and rural areas are presented as well. The demographic characteristics considered are age and gender and the initial socioeconomic indicators include: education, employment status, gender of head of household and average household size. Demographic characteristics and socio-economic indicators of those infected with HIV and those accessing ARVs are important to policy makers because they could help in developing programmes and policies that are aimed at targeting particular groups with the aim of mitigating the negative effects of HIV/AIDS.

4.3.1 Demographic and initial socioeconomic characteristics of Ugandan general population

Information on the demographic characteristics of the general population is obtained from the Uganda Demographic and Health Survey (UDHS 2000-2001). The 2000-2001 UDHS used a household questionnaire, which elicited information on the socioeconomic and demographic characteristics of usual residents. In terms of gender, the data showed that there are slightly more women than men, with women constituting 52 % of the population and men constituting 48%. Results revealed that the sex composition of the population does not show significant variation by urban-rural residence (UDHS 2001). In terms of age distribution, Uganda is depicted as a country with a young population, with a large proportion of the population being in the younger age groups. The population under age 15 constitutes 52 percent of the total population.

In regard to headship of households, nearly three in four households are headed by men, while one in four households are headed by women. The proportion of female-headed households is slightly higher in urban areas than rural areas (31 percent and 27 percent, respectively).

For household composition, it is reported that one in every nine households has only one member. However, very large households (nine persons or more) still exist in Uganda. Even in urban areas, which tend to have smaller household sizes than rural areas, 8 percent of the households have nine or more persons. In urban areas, 33 percent of the households have one or two members, compared with 21 percent in rural areas. The mean household size is larger in rural areas (4.9 persons) than in urban areas (4.2 persons).

As far as employment is concerned, data revealed that 73 percent of women and 63 percent of men were employed at the time of the survey and that the employment level for women was higher in rural areas than in urban areas, while the reverse was true for men. Employment in this survey is defined as any work that one is contracted to do for payment in cash or kind. Employment in this survey thus implies both formal and informal jobs. In specific terms, among women who were employed at the time of the survey, 77 percent were engaged in agriculture and 23 percent were involved in nonagricultural activities. The percentages for men are 54 percent and 46 percent, respectively. The strong involvement of the population in agriculture reflects the predominance of the agriculture sector in the Ugandan economy. The professional, technical and managerial occupations, which require more skill but have higher income-earning potential, employ only 3 percent of working women and 6 percent of working men.

In terms of educational attainment, the majority of the Ugandan population seems to have primary level education (59.8)%, while those who have no education at all are 21.8%. Those who have secondary level or more are the minority represented by only 18.4%. Rural people are less educated than their urban counterparts. The report revealed that one in four rural women do not have an education, compared with 7 percent of urban women. The corresponding figures for men are 7 percent and 2 percent for rural and urban men respectively. This pattern is reversed for secondary or higher education.

Whereas only 12 percent of rural women have attended secondary or higher education, 48 percent of urban women have at least some secondary education.

4.3.2 Demographic & initial socioeconomic characteristics of People living with HIV/AIDS (PLWHAs) in Uganda.

Information on the national HIV prevalence rates and demographic characteristics of PLWHAs is taken from the Uganda HIV/AIDS Surveillance report published in June 2003 by the STD/AIDS Control Programme of the Ministry of Health and the recent Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS) preliminary report. The HIV/AIDS Surveillance report is based on STD/HIV/AIDS programmatic data collected from surveillance activities for HIV infection, AIDS cases, STD/HIV/AIDS behavioural markers, sexually transmitted diseases and Tuberculosis.

Owing to the limitation of obtaining data on the socioeconomic characteristics (asset ownership) of PLWHAs in Uganda, this information will serve as a proxy to compare with socioeconomic characteristics of my study sample vis-a-vis those from UDHS in order to evaluate access of ARVs according to need.

HIV/AIDS prevalence rates in Uganda by geographical location

HIV/AIDS prevalence rates were determined for urban and rural areas. In general terms, the findings of the report were that HIV/AIDS prevalence rates in the rural areas were considerably lower than those in urban areas. For instance, the distribution of clinical AIDS cases by District of residence as of 31st December 2002 from 1998 showed that total adult cases were 11,370 and 10,507 for Kampala and Masaka districts respectively (Ministry of Health 2003). (Data on total population in each district was not available; therefore HIV prevalence per district could not be calculated). In addition, national HIV/AIDS estimates and projections developed by the UNAIDS reference group on estimates, models and projections correlated with the findings. The estimates for HIV/AIDS prevalence were 10.01% and 3.92% for the urban and rural population strata respectively (Ministry of Health 2003).

Further, the Ministry of Health on May 2nd 2005, released preliminary results of the Uganda HIV/AIDS Sero Behavioural Survey that indicated that 7 percent of adult men and women are infected with HIV in Uganda. Nationwide, prevalence is higher in urban areas at 10.7 percent than in rural areas at 6.4 percent (Ministry of Health 2005). The report further clarifies that adults living in urban areas are twice as likely to be infected with HIV as those in rural areas. The lowest infection rate at 2.5 percent is in the north west, while the highest levels are in Kampala, central and north central at about 9 percent each (Ministry Of Health 2005).

HIV/AIDS Prevalence rates stratified by gender and age group

A cumulative total of 56,451 adult AIDS cases are presented in the surveillance report. Of the 54,990 AIDS cases with sex recorded, 24,643 (44.8%) were males while 30,347 (55.2%) were females. This pattern was consistent with estimates of new HIV infections which are 28,890 and 26,650 for women and men respectively as of December 2002 (Ministry of Health 2003). The report also showed that age groups (25-29) and (30-34) were the most infected with HIV/AIDS with 15.4 and 21.1 HIV prevalence percentages respectively as of December 2002.

The recent Sero-Behavioural survey has also revealed that overall, 7.9 percent of women have HIV compared to 6 percent of men. For both sexes, infection levels are highest among those in the age groups of 30-40 and are lowest in the age group of 15-19 (Ministry Of Health 2005).

HIV/AIDS Prevalence rates by educational attainment

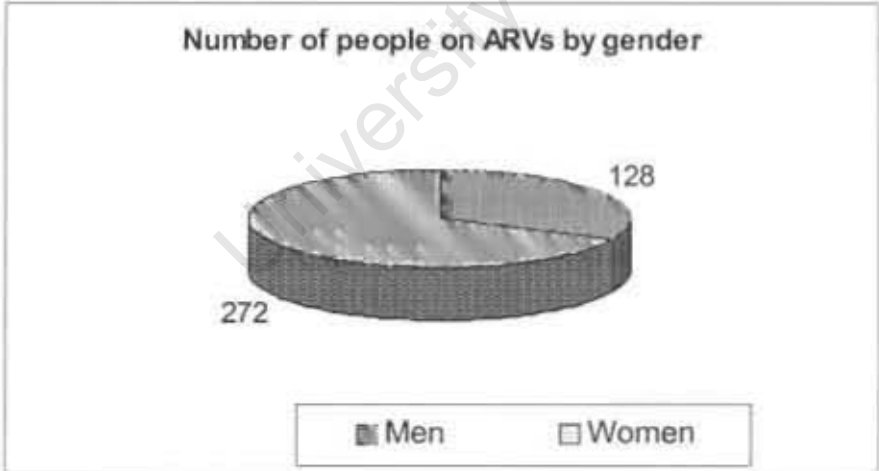
Preliminary results of the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS) revealed that there was no consistent pattern of HIV infection by education level. However, findings reveal that there is no major difference of HIV infection between those with secondary and tertiary education and those with no education at all but HIV infection is concentrated in those who have a primary level education. For both sexes,

the percentages of those who have primary education are 15.5%; those with secondary and tertiary education are 6.9% and those with no education are 6.7%. This report does not specify which socioeconomic class of people is greatly affected by HIV/AIDS, however the Uganda AIDS Commission spokesman clarified that initially, HIV infection was heavily concentrated in the upper socioeconomic groups due to their lifestyles. He further said that today, infection has cut across all groups of people irrespective of their wealth and education status (Personal communication; Mr. James Kigozi).

4.3.3 Demographic and initial socio-economic characteristics of participants

This section presents a comparison of utilization of the ARV programmes in the facility exit interviews between groups with different demographic characteristics such as age and gender as well as initial socioeconomic characteristics such as education, employment status, household composition and headship as well as geographical location. In total, 400 study participants were interviewed, 218 were from Kampala district and 182 from Masaka district. Of the 400 study participants, 272 were women and 128 were men as Figure 1 indicates below.

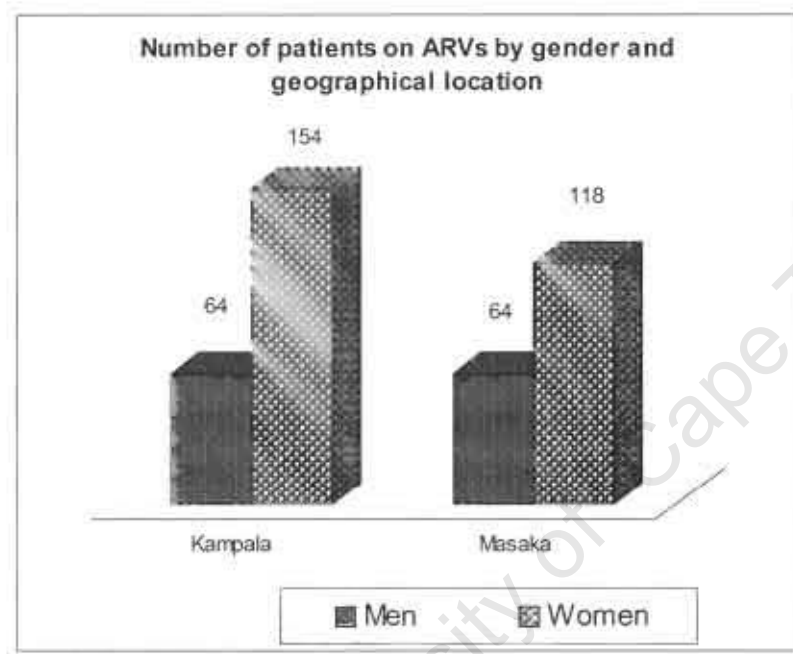
Figure 1: Number of participants on free ARVs by gender



The gender composition of participants

Figure 1 above, clearly indicates that more women (68%) than men (32%) access free ARVs. Stratified by geographical location, the same pattern is evident. Figure 2 below confirms that even in different geographical locations more women than men access free ARVs.

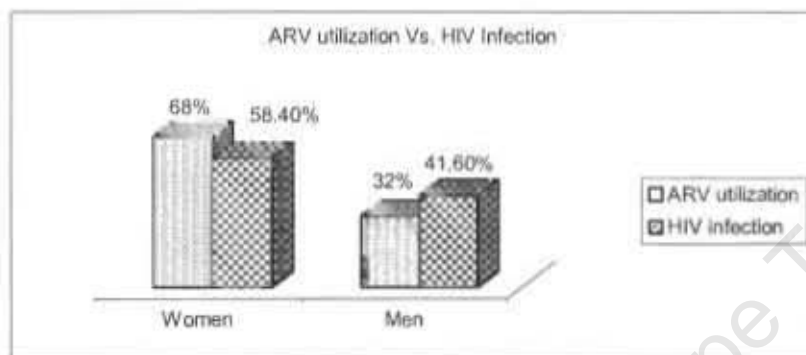
Figure 2: Number of participants on ARVs by gender and geographical location



This finding could be explained by the fact women in Uganda are more infected with the HIV virus as compared to men as clearly indicated in both the surveillance report and the Sero Behavioural Survey report. Figure 3 below however shows that if data from the Sero Behavioural Survey report is considered, the degree of free ARV use in the study sample and HIV infection in the Sero Behavioural survey is not the same for both sexes. For example, the recent Sero Behavioural report indicated that 58.4% of those infected with the virus were females while 68% of those in my study sample accessing free ARVs were females. On the other hand, 41.6% of those in the Sero behavioural report that were HIV positive were men but only 32% of those in my study sample accessing the drugs

were men. This clearly indicates that women are often more vulnerable and they respond positively to the call of ART treatment than men.

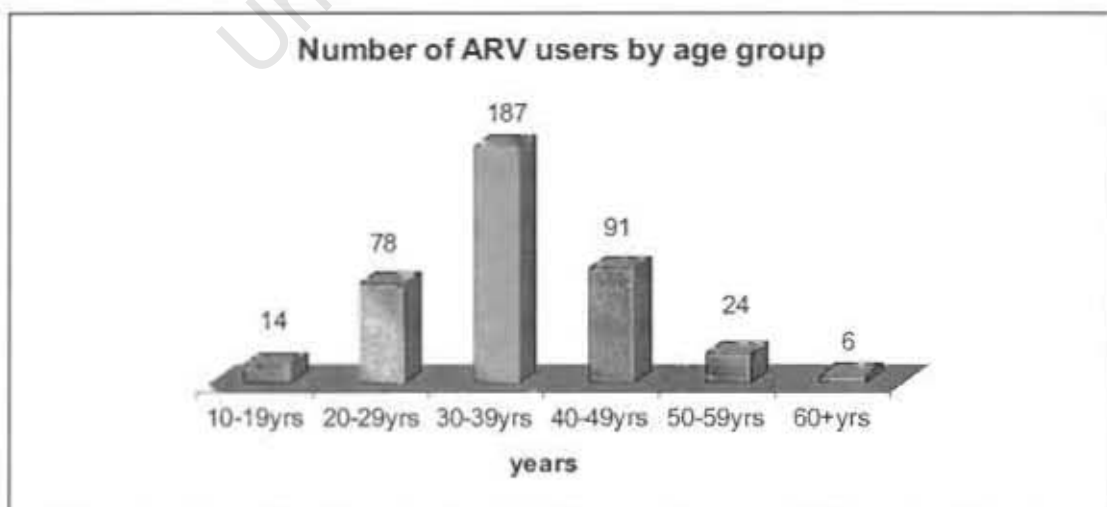
Figure 3: Percentage of ARV utilization and HIV Infection by gender



Age composition of participants

From Figure 4 below, one can argue that it is obvious that HIV/AIDS affects people in their most productive age. The 30-39 and the 40-49 age groups have greater access to free ARVs than the rest of the age groups with 46.75% and 22.75% respectively.

Figure 4: Number of participants on free ARVs by age group



This finding is clearly explained by results from the HIV/AIDS surveillance report and the HIV/AIDS Sero-Behavioural report which both confirm that the HIV infection levels are highest among the productive age groups. As indicated previously the surveillance report revealed that the overall mean age of adults with AIDS is 30.9 years (Ministry of Health 2003), while the HIV/AIDS Sero Behavioural Survey recently revealed that HIV infection levels are highest among those in the age group 30-40. However the degree of ARV use is not in proportion to need in the different age groups, with those in the 35-39 year age group being particularly disadvantaged. This argument is illustrated in figure 5 below.

Figure 5: Age distribution of HIV infection and ARV use.

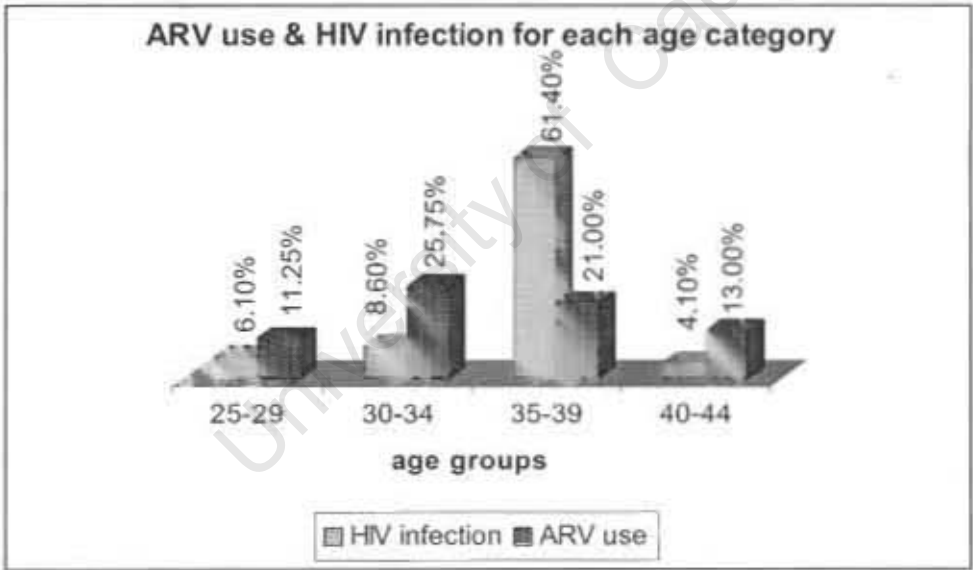


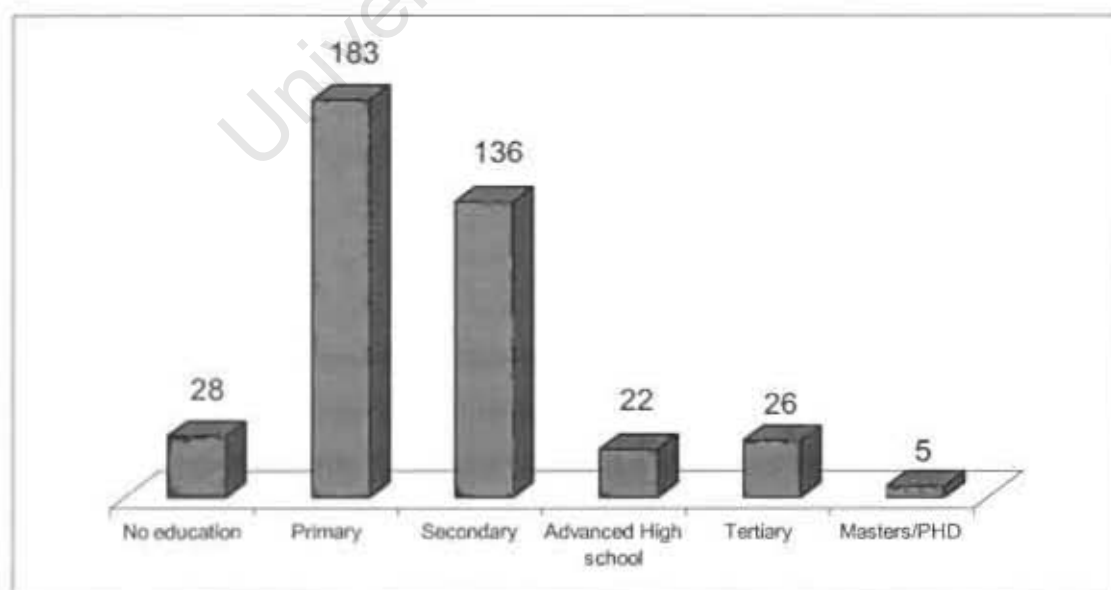
Figure 5 illustrates that HIV infection in Uganda is concentrated in the (35-39) age group at 61.4% (this being the estimate weighted against the entire population of Uganda). However, the (30-34) age group has greater access to free ARV than the age group that has the greatest HIV infection. The extent to which the (35-39) age group has access to free ARVs is much lower than the need. For instance in this age group alone, the

percentage of those infected with HIV infection is estimated at 61.4% and of those, only 21% have access to free ARVs. For the other age groups, access to ARV use is greater than the actual need. For instance as illustrated in Figure 5 above, age groups (25-29), (30-34) and (40-44) have greater access to free ARVs as compared to their relative need. In view of this, it is clear that in specific terms ARV use is not proportion to need. Even when the two age groups 30-34 and 35-39 are combined as in the case of Figure 4 above, it is still clear that HIV infection is concentrated in the 30-39 age group at 70% but access to free ARVs within this age group is only 46.75%. This implies that the majority of people infected with HIV in this age group are not accessing free ARVs in proportion to their need.

Educational attainment of participants

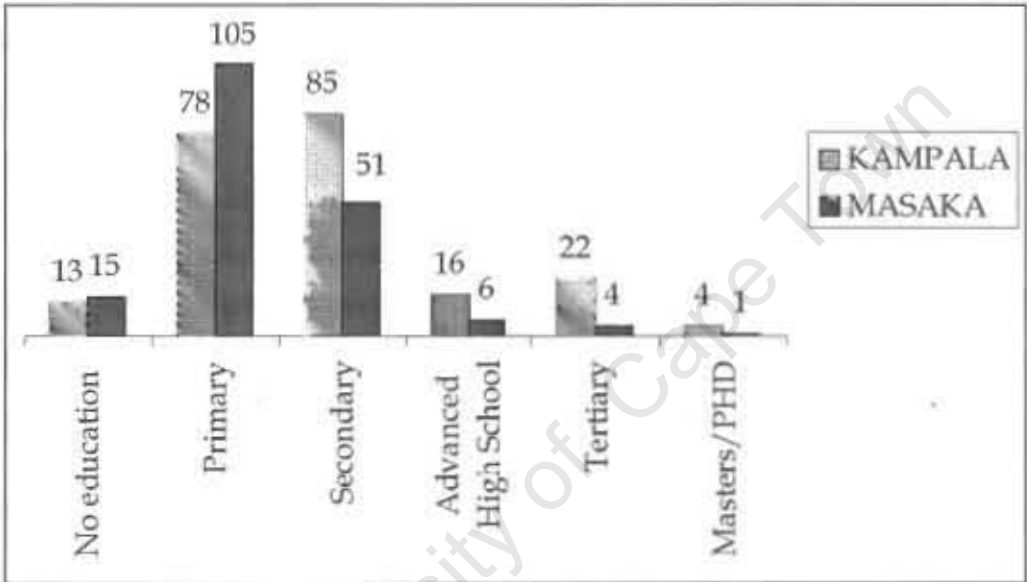
Six levels of educational attainment were considered. These were represented as follows:- never been in school at all (no education), primary level education, secondary level education, advanced high school, tertiary education, including undergraduate and diploma level , masters and PHD programmes. The frequencies are presented in Figure.6 below.

Figure 6: Number of participants on free ARVs by educational level



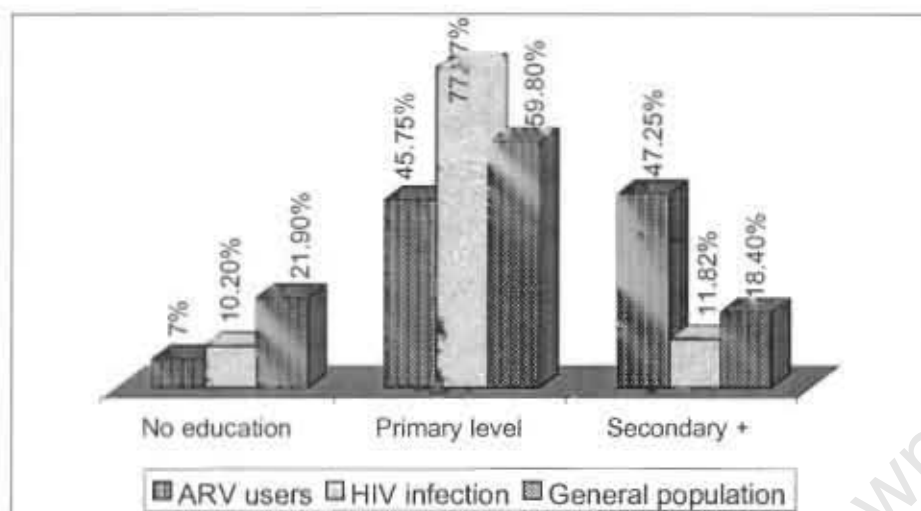
Considered as a whole, results from the sample revealed that individuals with primary level and secondary education have greater access to free ARV drugs in Uganda than the rest of groups with 45% and 34% respectively. Figure 6 also reveals that those without education, those with advanced high school level, those with tertiary, masters and PHD have the least access of the drugs.

Figure 7: Number of participants on free ARVs by educational level and geographical location



Stratified by geographical location, as in Figure 7 above, still those who have completed primary and secondary level have greater access to ARVs. However, the variation occurs in the extent to which those with primary level and secondary level education have access to free ARVs in different geographical locations. While the highest percentages of those who access free ARVs in Kampala have attained secondary level education, in Masaka it is those with primary education that have greater access.

Figure 8: Comparison of education status for UDHS, HIV infection and ARV utilization



Note: The Uganda Sero Behavioural Survey reported HIV prevalence rate by educational level i.e the percentage of people in each group infected. These data have been used to calculate the distribution of the HIV infected population between educational groups as reflected in Figure 8.

When the educational status of entire population is compared to that of ARV users and that of the HIV/AIDS infected population as indicated in Figure 8 above, it is clear that the group of people in Uganda that are actually greatly infected by HIV are those with primary education (77.97%). However access to ARV is greater among those individuals with secondary level education and more.

Educational attainment has been used as a proxy measure for socioeconomic status in many studies because they have shown a positive correlation between education and income (Ainsworth and Semali 1998; Filmer 1998; Deheneffe et.al 1998). As mentioned previously, owing to lack of asset data for HIV infection in Uganda, this study will use educational attainment for people living with HIV/AIDS as a proxy measure for their socioeconomic status. Using the UDHS data set Tables 1 and 2 below also reveal a positive correlation between educational attainment and wealth.

Table 1: Correlation between educational attainment and wealth quintiles in Kampala.

Quintiles	No education	Primary level	Secondary level& more
Q1	50%	34%	12%
Q2	25%	32%	16%
Q3	4%	16%	20%
Q4	17%	13%	24%
Q5	4%	5%	28%
Total	100%	100%	100%

Stata output 1.1 A stata output correlation between educational attainment and wealth quintiles in Kampala

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-----+-----
      | hv106_01 kam_quintiles
-----+-----
 hv106_01 | 1.0000
      |
      |
 kam_quintiles | 0.2308 1.0000
      | 0.0000

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Stata output 1.1 clearly indicates that there is a positive correlation between educational level and income. Although the correlation is not very strong, results show that the correlation is statistically significant because p-value is less than 0.05, thus it is justified to use education as a proxy measure for income. Results in Table 1 reveal that individuals with higher educational levels are more likely to come from the higher income groups and vice-versa. For instance, the majority of individuals with "secondary level education and more" are from the highest (Q5) and high (Q4) income groups with 28% and 24% respectively while the majority of those without education are from the lowest (Q1) and low (Q2) income groups with 50% and 25% respectively. Results further reveal that those with primary education in Kampala are more likely to come from the lowest and low-income groups as Table 1 clearly indicates that they are highly represented in those income groups at 34% and 32% respectively. Therefore one can

conclude that income increases with increasing education. This pattern is reinforced by Table 2 below, which reveals more or less the same general pattern in the rural setting.

Table 2: Correlation between educational attainment and wealth quintiles in a rural setting.

Quintiles	Secondary level		
	No education	Primary level	& more
Q1	29%	19%	7%
Q2	22%	22%	10%
Q3	23%	19%	15%
Q4	18%	21%	21%
Q5	8%	18%	47%
Total	100%	100%	100%

Stata output 2.1. A stata output correlation between educational attainment and wealth quintiles in a rural setting.

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      | hv106_01 rural_-s
-----+-----
  hv106_01 | 1.0000
          |
  rural_quin-s | 0.2467 1.0000
          | 0.0000
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Stata output 2.1 still confirms a positive correlation between education and income in the rural setting and results also reveal that the correlation is statistically significant because p-value is less than 0.05. Table 2 illustrates that in the rural setting, individuals with no education come from the lowest quintile (29%), the low quintile (22%) and middle quintile (23%) and they are least represented in the highest quintile (5%). Individuals with primary education are almost evenly distributed across all income groups but those with "secondary level education and more" are highly represented in the highest income group at 47% and in the high quintile at 21% and least represented in the lowest quintile at 7%.

Using information from Tables 1 and 2, one can conclude that individuals with the highest levels of HIV infections i.e those with primary level education are from the lowest and low income groups in Kampala while the same group of people is almost evenly distributed across all quintiles in rural areas.

Participant's household headship and composition

In the normal Ugandan setting as indicated from the UDHS, men have always headed households in all aspects. The proportion of female-headed households is small compared to male-headed households. This pattern is not true for study participants.

The headship of households of participants was different for different geographical locations. Whereas more of the participants' households were headed by men in Kampala (53.2%) than women (46.8%), the reverse was true for rural areas. In Masaka, 50.5 % of women compared to 49.5% of men headed the home. This therefore implies that households in the rural areas are in poor conditions as compared to those ones from urban areas as Cohen (1996) argues that the poorest households are often female headed.

In terms of household composition, results revealed that the household size of participants was large for both urban and rural areas. However, the average household size was larger in Masaka district (7.0 persons) as compared to (6.1 persons) in Kampala district.

Participant's employment status

Both in Kampala and Masaka the percentage of the ARV participants who were not employed were much higher than that of those who were employed. The employed in Kampala district, were only 30.2 % compared to 69.8% who were not employed. In Masaka district, only 13.2% were employed and 86.8% were not employed. It was interesting that in Kampala more women than men were employed. Of the 65 individuals who were employed at the time of the survey, 27 were men while 38 were women. The kinds of jobs of those employed in Kampala were mainly white collar jobs and these included: coordinator, investigator, land survey, manager, nurse, officer, revenue assistant, secretary, supervisor, teacher, advisor and business owners. Blue-

collar jobs included: shop attendant, carpenter, maid, laundry attendant, tailor, mechanic and driver. The white-collar jobs were mainly done by men while the non-white collar jobs were done by women. For instance, 74 % of men had white-collar jobs while only 24% had non-white collar jobs. On the other hand, 42% of women had white collar jobs compared to 58% with non-white collar jobs. In Masaka district, more men than women were employed. Out of the 24 employed, 14 participants were men and 10 were women. In Masaka district, the same percentage of men had equal chances of either doing a white-collar job or non-white collar job (50%). Those doing white-collar jobs were teachers, engineers, priests and army officers and those doing non-white collar jobs were mainly farmers, fishermen, cleaners and drivers. The women in Masaka mainly did informal work as compared to formal work. Of the 10 women employed only 2 (20%) had formal work. One was a cashier and the other one was a nurse. The rest 80% were farmers, vendors, shop attendants and waitresses. With this kind of data, one can argue that low employment rates could be either as a result of discrimination against those infected with HIV/AIDS or because the unemployed are more likely to attend public or NGO facilities. One other possible factor is that AIDS related illnesses affected people's ability to continue working due to physical weakness as evidenced from FGDs. Other evidence has shown that the epidemic has caused employment insecurities and discrimination in the labour force especially when organizations subject prospective employees to mandatory HIV screening tests before recruitment and those found to be infected with HIV are denied employment (UAC 2004).

4.4 Description of household asset ownership in urban/rural setting and by wealth quintiles.

Since this study sets out to judge equity on a socioeconomic and geographical basis, it is necessary to give a brief description of how household asset ownership differs in urban and rural setting and in terms of wealth quintiles. Data used is extracted from the Uganda Demographic Health Survey 2000/1.

It is clear that urban asset ownership is different from that one in the rural setting. From the data presented in Table 3 and Table 4 more than half of the households in Uganda own a radio; urban households are more likely than rural households to have a radio. Only about 6 percent of households own a television and about 4 percent own a telephone. Refrigerators are also uncommon. These assets are very common in the urban areas compared to the rural areas. Bicycles are more common in rural areas than in urban areas, while cars and motorcycles are almost exclusively owned by urban households. This therefore implies that urban households are more likely than rural households to have access to information and health care.

Information on housing characteristics including access to electricity, source of drinking water, type of sanitation facility and construction materials of dwelling reflects aspect of environmental health. According to UDHS 2000-2001, nine percent of households in Uganda have access to electricity. Access to electricity is much higher in urban areas (44 percent) than in rural areas (2 percent).

Data shows that open wells are still a major source of drinking water and only one in nine households has access to piped water, mainly from a public tap (UDHS 2000-2001). The percentage of households with access to piped water is much higher in the urban areas (63 percent) compared to the rural areas (2 percent).

Most households (79 percent) in Uganda, use traditional pit latrines; this is true in both urban and rural areas. Flush toilets are less common in the rural areas than in urban areas. The type of toilet facility has implications for the household's health status. For instance households without a proper toilet facility are exposed to the risk of diseases like dysentery, diarrhoea and typhoid fever.

The type of material used for the floors may be viewed as an indicator of the quality of housing (an income dimension) as well as indicator of health risk. Some floor materials like earth, sand and cow dung, pose a health problem since they can act as breeding grounds for pests and may be a source of dust. In general, rural households have poorer

quality floors than urban households. Ninety percent of rural households have earth or dung floors, while 73 percent of the urban areas have floors made from cement, tiles or polished wood (UDHS 2000-2001). This kind of information therefore has implications for the rural households, as it is clear that rural households are at a higher risk of poor health status as compared to urban households.

Table 3: Percentages of asset possession in different quintiles in an urban setting.

KAMPALA

Variable	Q1	Q2	Q3	Q4	Q5	Total
Have car/truck	0.0%	0.0%	1.9%	1.7%	33.0%	7.3%
Have motorcycle	0.9%	5.6%	5.7%	5.2%	13.0%	6.0%
Have bicycle	9.5%	7.1%	16.0%	6.0%	13.9%	10.4%
Have telephone	0.0%	0.8%	5.7%	26.7%	69.6%	20.4%
Have fridge	0.0%	0.8%	4.7%	20.7%	59.1%	16.9%
Have television	0.0%	2.4%	31.1%	66.4%	83.5%	36.1%
Have radio	56.9%	83.3%	91.5%	94.8%	98.3%	84.8%
Have electricity	6.9%	29.4%	62.3%	87.9%	93.9%	55.4%
Have piped water in residence	0.0%	0.0%	0.0%	0.0%	34.8%	6.9%
Have public stand piped water	77.6%	74.6%	77.4%	86.2%	51.3%	73.4%
Have flush toilet	0.0%	1.6%	1.9%	8.6%	47.8%	11.9%
Have traditional pit latrine	96.6%	96.8%	85.8%	75.0%	29.6%	77.0%
Have earth sand floor	50.9%	8.7%	4.7%	0.0%	0.0%	13.0%
Have cement floor	24.1%	54.0%	63.2%	79.0%	65.2%	54.7%
Have ceramic floor	0.0%	0.0%	0.0%	0.0%	1.7%	0.3%
Have cement block walls	1.7%	6.3%	4.7%	6.9%	16.5%	7.3%
Have mud-pole walls	50.9%	4.8%	0.9%	0.0%	0.0%	11.4%
Have burnt-mud walls	14.7%	10.3%	10.4%	5.2%	6.1%	9.3%
Have thatched roof	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Have iron sheet roof	99.1%	99.2%	99.1%	96.6%	70.4%	92.9%
Have tiled roof	0.0%	0.0%	0.0%	0.9%	14.8%	3.1%
Have asbestos roof	0.0%	0.0%	0.9%	1.7%	5.2%	1.6%

The five quintiles described below are labeled in ascending order from lowest to highest socioeconomic groups. These are represented as follows: Q1-lowest, Q2- low, Q3-

middle, Q4-high and Q5-highest. Below in Tables 3 and 4 a description of asset possession in terms of percentage ownership in different wealth quintiles is presented in an urban and rural setting respectively.

Table 3 above represents the percentage of those households in different wealth quintiles that possess the specified asset or item in Kampala district.

Data from table 3 indicates that on average in an urban setting, individuals/households from the highest quintiles possess more cars/trucks and motorcycles compared to the rest of the wealth quintiles. They also possess a good number of bicycles. Possession of telephones, refrigerators, televisions, radios and electricity is also highly associated with the highest income group. Piped water in residence, as a source of drinking water is exclusively associated with the highest socioeconomic group and public tap water is less common to this quintile compared to the rest of the income groups. The type of toilet facility is mainly flush toilet and houses from the highest quintile have cement floors, cement block walls and iron sheets, tiles or asbestos roofs.

On the other hand, none of the households from the lowest quintile possesses cars/trucks and only 0.9% of households in this quintile possess motorcycles. On average, at least 9.5% of households in the lowest income group use bicycles as a mode of transport. None of the households in the lowest income group owns a telephone, refrigerator or television, however, at least about 57% of households in this quintile own a radio. Households in this income group hardly have electricity and the main source of drinking water is a public tap. The toilet facility is mainly traditional pit latrine and the houses are mainly built with earth/sand floors with few exceptions of cement floors. The main wall materials are mud-pole and burnt-mud and the roofing materials are iron sheets.

Quintile groups low, middle and high mainly use motorcycles and bicycles as a means of transport. It is surprising that the low and middle-income groups have more motorcycles and bicycles than the high income group. However in terms of household

durable goods, ownership of a telephone, refrigerator, television and radio increases with increasing wealth. For instance the highest percentages of households from the high socioeconomic group own the above mentioned goods followed by the middle quintile and lastly the low quintile. Having electricity is more associated with high and middle-income groups (87.9% and 62.3%) than it is with the low-income group, which has only 29.4% households with electricity. The main source of drinking water for the three quintiles is a public tap. Traditional pit latrine is the main toilet facility but households with this facility decrease with increasing income. For instance, more households in low (96.8%) and middle-income groups (85.8%) compared to the high quintile (75%) have a traditional pit latrine. Housing characteristics of the three income groups are as follows:

The type of floor is mainly cement for all the three income groups but some houses in low and middle groups have earth/sand floors. Wall materials are mainly burnt-mud for low and middle quintiles and cement blocks for high-income group. Few households in low and middle-income groups have cement blocks while few households in high-income groups have burnt-mud walls. The main roofing material for all three income groups is iron sheets.

In conclusion therefore, data indicates that, in an urban setting, households from the highest socioeconomic group compared to other quintiles, are more advantaged in terms of access to information and health care because they have an efficient means of communication, transport as well as better standards of living. Higher ownership of household durable goods and assets also suggest that these households have better illness coping strategies than their other counterparts. On the other hand, the lowest socioeconomic group is more vulnerable than the rest of the income groups as far as health status is concerned.

Table 4: Percentages of asset possession in different quintiles in a rural setting.

RURAL

Variable	Q1	Q2	Q3	Q4	Q5	Total
Have car/truck	0.00%	0.00%	0.00%	0.00%	3.00%	0.60%
Have motorcycle	0.00%	0.00%	0.00%	0.65%	9.08%	1.95%
Have bicycle	15.90%	41.54%	31.46%	55.29%	62.17%	41.31%
Have telephone	0.00%	0.00%	0.00%	0.00%	2.81%	0.56%
Have fridge	0.00%	0.00%	0.00%	0.00%	1.69%	0.34%
Have television	0.00%	0.00%	0.10%	0.00%	8.61%	1.74%
Have radio	4.30%	39.71%	40.04%	65.95%	84.64%	46.92%
Have electricity	0.00%	0.00%	0.38%	1.12%	9.64%	2.23%
Have piped water in residence	0.00%	0.00%	0.00%	0.00%	0.56%	0.11%
Have piped public tap water	0.09%	0.64%	1.62%	1.68%	5.34%	1.87%
Have open well in residence.	0.00%	0.00%	0.00%	0.09%	0.09%	0.04%
Have open public well.	30.68%	22.06%	31.84%	31.15%	24.72%	28.06%
Have flush toilet	0.28%	0.55%	0.48%	0.47%	0.56%	0.47%
Have traditional pit latrine	57.06%	73.90%	86.08%	92.70%	92.98%	80.50%
Have earth sand floor	76.43%	57.72%	72.07%	69.13%	41.01%	63.22%
Have cement floor	0.00%	0.00%	0.00%	0.00%	32.02%	6.61%
Have ceramic floor	0.00%	0.00%	0.00%	0.00%	0.09%	0.02%
Have cement block walls	0.00%	0.00%	0.00%	0.09%	2.62%	0.54%
Have mud-pole walls	88.49%	61.95%	79.03%	70.63%	25.84%	65.13%
Have burnt-mud walls	0.56%	6.43%	6.39%	11.88%	12.45%	7.54%
Have thatched roof	99.81%	88.05%	27.93%	10.29%	0.94%	45.63%
Have iron sheet roof	0.00%	10.85%	71.31%	89.06%	97.94%	53.60%
Have tiled roof	0.00%	0.00%	0.00%	0.00%	0.37%	0.07%

In the rural setting, households in the lowest, low and middle quintiles have neither cars/trucks nor motorcycles. Of the households in the high quintile, only 0.65% of households have motorcycles. In rural areas, possession of cars/trucks and motorcycles are rare even in the highest quintile. Data in Table 4 above suggests that the major mode of transport in rural areas for all the income-groups is by bicycles. Possession of bicycles is more associated with low, high and highest quintiles as compared to lowest and middle-income groups.

In terms of household durables, possession of a telephone and refrigerator is exclusively associated with the highest socioeconomic group, although households with these items are very few (2.81% and 1.69%) respectively. Possession of television is also almost exclusive to the highest quintile (8.61%) with just an exception of one person in the middle quintile with a television. Possession of a radio applies to all income groups but the degree of possession increases with increasing wealth. For instance, households in the lowest quintile who have radios are only 4.3% compared to those in low quintile (39.71%), middle (40.04%), high (65.95%) and highest (84.64%). None of the households in the lowest and low-income groups have electricity. It is relatively uncommon in the middle and high quintiles but relatively high in the highest socioeconomic group.

The main source of drinking water in rural areas common to all quintiles is open public well although piped public tap water is common in the highest quintile. Traditional pit latrine is the most common toilet facility to all income groups. In addition, most households in all income groups have earth/sand floors but a significant number of houses in the highest quintile have cement floors (32%). Mud-pole is the main wall material in the lowest, low, middle and high-income groups but it is less common in the highest socioeconomic group.

Unlike in urban areas where none of the households is thatch-roofed, the majority of households in the lowest and low socioeconomic groups are thatch-roofed. As much as some households from middle, high and highest quintiles are thatch-roofed, the majority of these households have iron sheets as the main roofing material.

One can conclude therefore income groups in rural households differ from those in urban households in all aspects and households from the highest socioeconomic group still have an added advantage over other income groups in terms of health status. In addition, it is clear from both Tables 3 and 4 that households from the lowest socioeconomic group in the rural setting are much more disadvantaged than their urban counterparts in terms of asset possession and living conditions. This makes them a more vulnerable socioeconomic group in terms of health status as well as in access to health care.

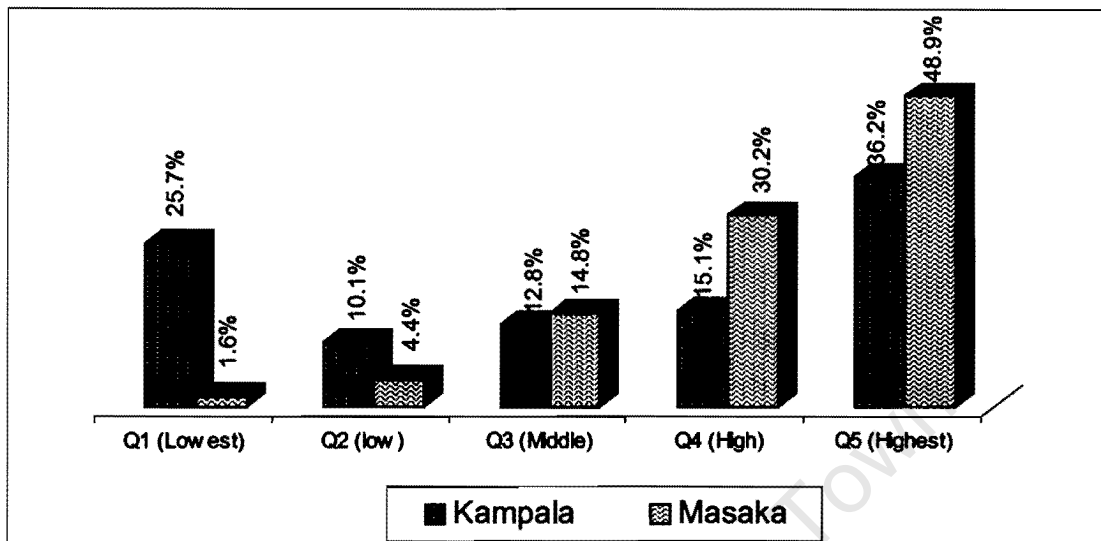
4.5 Asset Index results from Principal Component Analysis (PCA)

This section presents results of ARV utilization by different quintiles of socio-economic groups. Utilization is presented in terms of geographical location (Urban Vs Rural), gender and facility.

4.5.1 Utilization of ARV by Geographical location.

It is important to compare utilization of ARV programmes in different geographical locations and across wealth quintiles. This comparison forms part of the benefit incidence of ARVs in terms of urban and rural setting. Results from this comparison enables one to judge whether access in the two geographical locations is different and if so, it gives a clear foundation on which to judge equity on a geographical and socioeconomic basis.

Figure 9: Percentage distribution of people on ARVs by geographical location and wealth quintiles



As indicated in Figure 9 above, the distribution of ARV utilization is different in the two geographical locations. Overall, the findings show that socioeconomic groups are not evenly represented in free ARV utilization, and this pattern is exaggerated in Masaka district. Whereas distribution is concentrated in two extreme ends in Q1 and Q5 in Kampala with 25.7% and 36.2% respectively, ARV utilization in Masaka follows an ascending pattern from lowest to highest quintiles. Put differently, ARV utilization in Masaka increases with increasing wealth, however it is more skewed to the two topmost quintiles 4 and 5 with 30.2% and 48.9% respectively.

4.5.2 Utilization of free ARVs by gender and wealth quintiles

Table 5: Number (%) of patients on ARVs by gender and wealth quintiles

Quintiles	Kampala		Masaka	
	Female	Male	Female	Male
Q1 (Lowest asset score)	40 (25.9)	16(25.0)	3 (2.5)	-
Q2 (low asset score)	14 (9.1)	8 (12.5)	5 (4.3)	3 (4.7)
Q3 (Middle asset score)	20 (13.0)	8(12.5)	19 (16.1)	8 (12.5)
Q4 (High asset score)	28 (18.2)	5 (7.8)	32 (27.1)	23 (35.9)
Q5 (Highest asset score)	52 (33.8)	27(42.2)	59 (50)	30 (46.9)
Total	154 (100)	64 (100)	118 (100)	64 (100)

From Table 5 above, it is interesting to note that the pattern of ART utilization by gender is similar to that for the overall geographical location pattern. Both women and men in the lowest and highest quintiles (Q1 and Q5) in Kampala and both sexes in the middle, high and highest quintiles in Masaka have greater access to ARVs than those from the rest of the groups. The proportionality of ARV access however differs for different gender groups. In all instances utilization of ARVs is skewed in favour of women in both districts. Another point to note is that utilization of ARVs from the lowest and low quintiles is very low for both men and women in Masaka district. In fact, utilization of ARV for men in Masaka is nil in the lowest quintile.

4.5.3 Utilization by facility.

Table 6: Number (%) of patients on ARVs in different health facilities by wealth quintile.

	Kampala					Masaka	
	Facility A	Facility B	Facility C	Facility E	Facility F	Facility D	Facility G
Q1	23 (31.9)	4 (14.8)	8 (34.8)	14 (31.8)	7 (13.5)	2 (1.5)	1(2.0)
Q2	8 (11.1)	1(3.7)	2 (8.7)	5 (11.4)	6 (11.5)	6 (4.6)	2 (5.9)
Q3	10 (13.9)	2 (7.4)	4 (17.4)	3 (6.8)	9 (17.3)	20 (15.3)	7 (13.7)
Q4	10 (13.9)	5 (18.5)	3 (13.0)	11(25)	4 (7.7)	44 (33.6)	11(21.6)
Q5	21(29.2)	15 (55.6)	6 (26.1)	11(25)	26 (50)	59 (45)	30 (58.8)
Total	72 (100)	27 (100)	23 (100)	44 (100)	52 (100)	131 (100)	51 (100)

Table 6 above indicates that access to free ARVs in facilities A, C and E is skewed to the lowest and highest socioeconomic groups (Q1 and Q5) but more inclined to the lowest quintile, while in facility B, F, D and G distribution is skewed in favour of the highest socioeconomic group (Q5). It is interesting to note that in general, the socioeconomic group "low" (Q2) has the least utilization of ARV compared to the rest of the groups. It is important to note however, that in facilities D and G, distribution follows a particular pattern, with ascending frequencies from lowest to highest socioeconomic groups.

4.6 Cost and Benefit Incidence

In order to determine how much public subsidy is provided by either the government or donors for ART in each facility, total general expenditure (excluding medicines) for each facility was divided by the total number of visits to get general average unit cost per facility. This was added to the average unit cost of ARV drugs for each facility as shown in Table 7 below.

Table 7: Average unit cost of providing ART service in different facilities for the year 2004.

	Facility A	Facility B	Facility C	Facility E	Facility F	Facility D&G
Total Expenditure (USD)	2,976,000.00	172,414.00	342,618	499,435.20	3,000,000.00	611,871.89
No. of Visits	44,352	4,665	5,000	43,459	28,800	11,500
General average unit cost	67.10	36.96	68.52	11.49	104.17	53.21
Cost of ARV drugs	685,283.20	116,928	416,184.97	449,426.58	640,000	360,000
No. of patients	2,428	174	600	450	800	1200
Unit cost of ARVs	282.24	672.00	693.64	998.73	800.00	300.00
Total unit cost of providing ART	349.3	709.0	762.2	1010.2	904.2	353.2

As indicated in Table 7, there are diverse ranges of general expenditure unit costs as well as unit costs of ARV drugs for each facility. The variations in the unit cost of general expenditure are explained by the fact that different facilities have different general expenditure as well as number of visits. Some facilities are small NGOs and therefore have small expenditure while others are big NGOs and hospitals and thus have big expenditures. The differences in expenditure also reflect different staff mixes, as salaries are the largest component of health expenditure. Higher cost facilities are more likely to have larger numbers of doctors while low cost facilities have few doctors and a higher proportion of nurses. This influences quality of care and thus has a bearing on the general expenditure of different facilities. The variations are more distinct particularly for facilities E and F. Facility F is a large NGO with a wide range of different professionals i.e more doctors, physicians, specialists and nurses but Facility E is a small NGO with few health workers. Another point to note is that while Facility F has a big general expenditure it is not overcrowded, it is clear from Table 7 that this facility has fewer number of visits as compared to facility E and yet facility E has a much smaller

expenditure compared to facility F. This explains why there are distinct variations in the general average unit cost between the two facilities.

The variations in the unit cost of ARVs in different facilities are explained by the fact that different facilities have different numbers of people on different drug combinations and these drug combinations have different market prices. For instance some facilities have more people on first-line regimens while others have more people on second-line regimens. Second-line regimens are more expensive than first-line regimens. For example one drug combination on first line regimen i.e d4T+3TC+NVP goes for US\$15 per dose on the Ugandan market while a second line drug regimen i.e TDF+ddI+Kaletra goes for USD\$115.6 per dose. Facilities A and D&G have a higher proportion of patients on first line regimens. For instance, 94.7% of patients in Facility A are on first-line regimen while 86% of patients in Facilities D &G are on first line regimens and most of the drugs used in these facilities are generic drugs. On the other hand Facilities B, C, E and F have a relatively high proportion of their patients on second line regimens and those on first-line regimens are on branded drugs, which are equally expensive. For example 25% of patients in facility E are on second-line drugs and the majority of those on first-line drugs are on the branded drug combination d4T+3TC+EFV which is about US\$50 on the Ugandan market. The variations in unit cost of ARVs in different facilities are thus explained by these facts.

4.6.1: Benefit of ART users in different wealth quintiles.

The average unit cost of providing ART obtained in Table 7 was multiplied by utilization (number of ART users in each quintile for each facility) to obtain monetary benefit by each quintile (socioeconomic group) of the specified facility as indicated in Table 8 below. This is useful because values in monetary terms act as a measure of benefit that accrues to each socioeconomic group.

Table 8: Facility monetary benefit (USD) by wealth quintiles

Quintiles	A	B	C	E	F	D	G	Total benefit
Q1	8,034.85	2,835.84	6,097.32	14,143.05	6,329.17	706.41	353.21	38,499.85
Q2	2,794.73	708.96	1,524.33	5,051.09	5,425.00	2,119.24	706.41	18,329.76
Q3	3,493.41	1,417.92	3,048.66	3,030.65	8,137.50	7,064.13	2,472.44	28,664.72
Q4	3,493.41	3,544.80	2,286.50	11,112.40	3,616.67	15,541.08	3,885.27	43,480.11
Q5	7,336.17	10,634.39	4,572.99	11,112.40	23,508.33	20,839.17	10,596.19	88,599.63

In general terms, individuals from the highest quintile have the greatest benefit of ARVs as compared to other groups because from Table 8, this quintile alone has monetary benefit worth USD\$ 88,559.63. The second highest benefit (USD\$ 43,480.11) accrues to the high socioeconomic group and this is followed by the lowest quintile with benefit worth USD\$ 38,499.85. The low and middle quintiles have the least amount of benefit worth USD\$ 18,329.76 and USD\$ 28,664.72 respectively. In specific terms facilities B, F, D and G have the greatest benefit accruing to the highest socioeconomic groups while facilities A, C and E have the greatest benefit accruing to the lowest quintile. This implies that the ART public subsidy in facilities A, C and E are well targeted to poor while the reverse is true for facilities B, F, D and G. Findings from this model clearly indicate that in general, the ART public subsidy in Uganda is pro-rich. In other words, the ART programme in Uganda is not well targeted to the poor and indeed favours those who are better off. Although facilities A, C and E seem to target the lowest quintile, these facilities also have more benefit accruing to the highest socioeconomic than in any of the other quintiles, particularly the low and middle classes.

If monetary benefit per person on free ARV for each quintile is calculated the pattern of benefit is somewhat different as indicated in Table 9 below.

Table 9: ART monetary Benefit per person in each quintile

Quintiles	Total number of people	Total annual monetary benefit (USD)	Annual monetary benefit per person (USD)
Q1	59	38,499.85	652.54
Q2	30	18,329.76	610.99
Q3	55	28,664.72	521.18
Q4	88	43,480.11	494.09
Q5	168	88,599.63	527.38

Results from Table 9 indicate that when monetary benefit per person is calculated, the two lower quintiles have a larger public ART subsidy compared to the rest of the quintiles. The variations are not very distinct though. This information does not mean that the public subsidy is well targeted to the poor. There could be other factors that influenced such a distribution of the ART subsidy, which will be discussed later.

There are a range of factors that influence the pattern of free ARVs distribution, that is why it is important to understand supply and demand factors that affect the achievement of equity. In view of this, social, economic and supply factors that increase or constrain access for the disadvantaged groups were solicited from focus group discussions. It was also necessary to find out the knowledge and attitude that people had towards ARVs because this could have encouraged or constrained accessibility of ARVs.

4.7 Social, economic and supply factors that increase or constrain access for the disadvantaged groups.

In this section, knowledge and attitude towards ARVs, factors that encourage accessibility of ARVs and factors that constrain accessibility are presented.

4.7.1 Knowledge and attitude of ARVs

Firstly, the facility based questionnaire asked about the sources of information about provision of free ARV drugs. The majority of the participants responded that they heard

about it either from clinic personnel, community health workers or family and friends. These were represented by 29.2 %, 36 % and 22.8% respectively. Other media sources such as newspapers, leaflets and television were not a common source of information about ARVs. However, to some extent, radios played a role in conveying the message. One can therefore argue that either sensitization of ARVs through the media is still inadequate or that probably many people who need such information do not have access to the media due to financial constraints. It is evident however from the UDHS that the majority of Ugandans possess radios- one probable reason as to why radios played a major role in conveying the ARV messages.

In Focus Group Discussions (FGDs), respondents were asked to talk about what they knew about antiretroviral drugs for HIV/AIDS. In the female group in Kampala, all respondents acknowledged that ARVs are good and helpful. Most of the respondents said that the drugs are useful in prolonging life (**Respondent 1**) and giving people new hope to plan ahead (**Respondent 6**). Another major theme that emerged from the women's FGD discussions in Kampala was that ARVs restore energy and strength, hence people who had stopped working due to HIV/AIDS related illnesses are able to go back and do their usual work (**Respondent 8**). In other words, ARVs improve quality of life. Other issues raised were that ARVs give appetite, thus those who had suffered physical wasting as a result of the AIDS disease, gain weight and get back into shape and are no longer being stigmatized (**Respondent 9**). Below are some of the quotes supporting the above arguments.

Box 2: Knowledge and attitude towards ARV drugs

Respondent 1: "This drug is good because it helps in extending people's life, when people take them it increases energy because if someone was to die in one year, by taking the drug she can live for (*pauses a bit*) five or ten years depending on individuals. Kale (*okay*) these drugs do not heal completely but they give energy so that people can live longer."

Respondent 6: "Kale (*okay*) Me I would say that this drug help in giving people future plan ehh, if someone is taking this drug ehh., at first people did not have hope, they used to think about dying all the time but when one is on treatment , they have hope and are able to plan."

Respondent 8: "Me the good I know about this drug is that if one's baselikale (*White blood cells*) had been reduced by the virus, and she is being attacked by opportunistic diseases all the time, when she takes these drugs, the white blood cells are energized, the patient gets enough energy and also one of the drugs gives appetite like these ladies who take the drugs have testified, so you find that those who had lost weight, lost energy, it helps them regain their energy and go back to do his usual work and live longer."

Respondent 9: "This drug is good especially for women, not only women but men too (*Laughter in the background*) because people are no longer being stigmatized. Those who used to feel the stigma because their bodies looked horrible, after taking the drug, their bodies go back to shape, they are renewed so this reduces on the stigma. The drug has worked really well."

In the FGDs for male respondents in Kampala, like their female counterparts confirmed that ARV drugs were essential, particularly in improving people's quality of life. The

majority of the respondents reported that ARV had reduced the incidence of opportunistic infections and had thus enabled people to stay healthier and live longer. They emphasized the fact that ARVs reduce HIV viral load and increase CD4 count thus improving quality and quantity of life (Respondent 4). Other respondents said that ARVs help people to regain strength and also give people a new window of hope. In other words, those people who were bedridden as a result of HIV/AIDS related illnesses, go back to find jobs and sustain their families (Respondent 3). Below are responses illustrating these views.

A continuation of knowledge and attitude towards ARV drugs

Respondent 4: "what I know about this drug. When someone starts using the drug, it has many functions. It suppresses the virus, the virus is paralyzed and it can no longer multiply at the rate it used to before the antiretroviral drugs. Also the viral load decreases and with time the viral load decreases until the virus can hardly be detected in the body. Even the CD4, which had gone down, increase to the level of that of a normal person. This therefore reduces the opportunistic diseases that were so common and a person is able to live longer. This does not mean that the person is cured completely but their life expectancy is extended".

Respondent 3: "This drug is very useful because it has helped patients. I am one of the people who monitors patients in their homes. Ever since they started taking these drugs, there has been great improvement. Many people have gone back to look for work/jobs, others have regained strength and others look very good and feel good about themselves".

In Masaka, the women's group was mainly composed of ARV users. Like their Kampala counterparts, the ladies emphasized the fact that ARVs had improved their quality of life and restored them to their full capacity of going back to work and lead a normal life. For instance here are the words of **Respondent 4**: " This drug has helped us a lot because we were at the verge of death but now we have regained life. I never used to eat and walk, ever since I started on these drugs, I am able to eat well, I have energy and do my work properly and I also look good physically. In fact people ask me " ehh as you look different now". I am sure it is this drug that has made the difference." Most of them reported that before starting ARVs, they were very ill and could not plan for their children but with the use of ARVs, many of them have been able to educate their children and provide for their basic needs. Quoting from **Respondent 5**: " ... since I started on these drugs, ... I have also been able to work and pay for my children fees..."

Some other women also said that ARV reduce occurrence of opportunistic diseases and prolong life. For instance, **Respondent 5**: "I have no words I can use about this drug. I first of all thank all the health workers because I came here when one of my side was paralyzed, but ever since I started taking these drugs, now when you see me you can't believe that I had gotten paralyzed, so please go ahead and give us more drugs so that we stay alive longer and look after our children as Uganda Cares is helping us."

The FGD for men in Masaka reported that ARVs enhanced energy and restored people to their normal lives. **Respondent 2** stated, "This drug has helped us a lot because they have restored us to back to our original state. It has improved our quality of life and has given us the energy to go to our normal duties, which we used to fulfill before we were infected with the virus". They also emphasized that ARVs improved quantity and quality of life and appetite (**Respondent 1**) "Before these drugs, I never used to eat. I had no appetite, but since I started taking these drugs, now I have regained my appetite, I eat well. I even have strength and I can now ride a bicycle, something that I could not do when I was ill before taking this medicine." Another factor raised was that ARVs

increase CD4 count. **Respondent 6:** "It increases CD4 count; I came when my CD4 was 139 but now I am going to 250".

All in all, the major themes that emerged from all the four FGDS about knowledge and attitude towards ARV for both women and men were that ARVs:

- ◆ Extend life expectancy by reducing viral load and increasing CD4 count
- ◆ Improve quality of life by reducing opportunistic infections
- ◆ Give strength and energy
- ◆ Give hope and new plans to people living with HIV/AIDS
- ◆ increase productivity
- ◆ give appetite thus help in regaining weight.

4.7.2 Factors that promote accessibility of ARVs

Owing to the pattern of ARV utilization, it is necessary to discuss some of the factors that promote accessibility of ARV drugs. These factors emerged from focus group discussions held both in Kampala and Masaka as well as from exit interviews with patients. The major themes that emerged in the FGDs in both districts were "sensitization" and "testimonies." In Kampala in the women's group **respondent 7** said "The sensitization that we volunteers did, encouraged more people to come for ARVs. We also need to go on sensitizing the public because there are still people who believe that those drugs are not good. Another factor is testimonies. When people see that their colleagues have recovered well, they come and say "I also need to be tested and I would also need drugs". It is interesting that men respondents from Kampala also said that sensitization and testimonies were major contributing factors to accessing ARVs. Quoting **Respondent 3:** "Sensitization has played a big role, especially when people realize that there is hope to live longer. Every body is yearning for life, so many people are encouraged to come." In addition to sensitization and testimonies, some respondents in the men's group in Kampala said that personalized service also encouraged people to access ARVs. In this regard **Respondent 4** argued, "Clients on

drugs are witnesses to fellow patients. Also when we do home care visits, the way clients are handled, personal touch and confidentiality, has given people encouragement." In the men's group in Masaka Respondent 4 said "Also programmes on the radio have encouraged people to come for counseling and testing which has thus resulted in people accessing ARVs. More to that, testimonies of before and after the drugs have played a big role in encouraging people to come for drugs." In the women's group in Masaka the same themes emerged. However, in addition to sensitization and testimonies, Respondent 7 said that provision of food and transport by CBOs and also provision of free ARV drugs played a major role in increasing accessibility of ARVs: "First of all, community based organizations (CBOs) have helped a lot in transport costs and providing food. Sensitization have also helped a lot although it is still very low, but in villages where such sensitization has taken place, we see many people coming to get the drugs. Another factor is when people recover, they are testimonies to the rest of the society. Also the fact that these drugs are given free of charge, has encouraged many people to come to centers where such services are offered." It is interesting to note that patients from facility exit interviews generated more or less the same responses as FGDS.

The facility exit questionnaire asked respondents about the factors that could have facilitated them to be on the ARV programme. Only 138 out of 400 responded to the question. Of the 138, 40 people said that it was due to the testimonies from their colleagues, 54 said that counseling played a major role in encouraging them, 15 said that because the drugs were free, 20 said that their health status was very poor due to HIV/AIDS related illnesses and 9 said that it was due to the desire to live longer.

4.7.3 Factors that discourage accessibility of ARVs.

Questions about the factors that discourage accessibility of free ARVs were asked both in facility exit interviews and FGDS. The facility exit questionnaire asked about the factors that constrain some people from accessing the drugs. All 400 participants responded to the question. Of the 400, 28% responded that the major constraint was lack of money for transport costs and food, 16% said that the bureaucracy involved hindered people from accessing ARVs. The patients argued that there are many long processes

and procedures involved before one can actually access the drugs. Other factors raised were stigma (8%) and lack of sensitization (12%). In addition, many people (25%) argued that free drugs are still provided on a small scale in Uganda and therefore not everyone who needs ARVs has access to them. Some other people (11%) said that many patients are told that they are not yet eligible for the drugs. Put differently, these patients meant that some people who still had a high CD4 count could not access the drugs. It is interesting that some responses given in the facility based questionnaire tallied with those from FGDs.

The FGDs, asked respondents to give their views about factors they thought hindered accessibility of ARVs". The major responses that emerged were that: - many people lacked adequate sensitization. For example, some people were unaware that there are free ARVs being offered at particular facilities. Others feared side effects of the drug while other people still experienced stigma from the public. Some other factors that discouraged people from accessing ARVs were distance, for example some patients stayed far from the centers where such drugs were provided and in many centers one of the criteria for accessibility was that, patients had to be staying within a specified distance radius. Many respondents especially from Masaka districts reported that transport costs were a major hindrance. Some also said that ARVs give appetite and yet they lack the money to buy enough food. Other factors included cultural and religious beliefs and lack of disclosure to spouses.

It is interesting to note that both gender groups in the different geographical locations came up with similar responses. Below are some of the quotes for each factor mentioned above.

Sensitization

Women's group- Kampala

Respondent 1: "Kale (*okay*) many people would need the drug but the majority have not yet been sensitized or educated about ARVs. Some other people tell their colleagues that ahh that drug was brought to do what? To kill us! In other words, people would want to get the drug but they still lack being sensitized, about how this drug works and what

good things are in these drugs. Such kinds of things, kale (okay) even if they wanted it, they have not yet known it in detail”.

Men’s Group-Kampala

Respondent 1: “More to that we lack support from the government while sensitizing people. The media does not facilitate us in sensitizing the public. So many people do not know that even at this center we have free ARVS”.

Men’s Group- Masaka

Respondent 5: “Lack of sensitization in the villages.”

Women’s group -Masaka

Respondent 7: “Another factor is the belief about the ARVs in the village is still very bad. For reasons that people believe that these drugs kill, they burn. Many people will go and say the drug has terrible side effects, so if there is no sensitization going on, many people will get discouraged”.

Stigma

Men’s Group- Kampala

Respondent 6: “People are still ignorant, they get false information about the drugs. Another factor is stigma. Many people do not want to be seen here at the center because they do not want people to think that they have AIDS”.

Men’s Group-Masaka

Respondent 6: “ There is still stigma; people do not want others to know that they come to the center to access drugs, ... The most hindering factor however, is the stigma associated with HIV/AIDS”.

Women’s group- Masaka

Respondent 6: “Another factor is stigma. Many people do not want to be known that they come to centers to access drugs”.

Cultural and Religious beliefs

Respondent 1: (Man- Kampala) "Another major factor that has been a hindrance to some people are traditional healers. They tell our patients that " endagala elyo tilikola, elyaffe lyelikola nyo" meaning (That medicine (ARVs) does not work, ours is the best), Clients come and report! Saying " you people tell us that this drug works yet our traditional doctors tell us it does not work at all." So you can see the dilemma we are facing. The traditional healers of course want a market, so they will try to jeopardize our efforts , not all of them though but some."

Respondent 2: (Woman- Kampala) "Others would need them, but the majority of the people got saved meaning (Christian conversion), so when they go to their pastors, they tell them ' you are taking the drug for nothing, for we have prayed for you and laid hands on you for healing, you are healed!'. So this hinders them from taking the drugs believing that the way I have been prayed for, I am healed. They stop taking the drugs when in actual sense they need the drugs."

Side effects/ appetite

Respondent 5: (Woman- Kampala). "This drug, I am talking from experience as one who is on it, this drug brings a lot of appetite!(Stressing the point), you feel that you want to eat all the time. In fact I regret why I started it. (Laughter from background) in fact I am requesting the government to help everybody who is on these drugs. Me I usually disturb health workers even those who come home for monitoring, know me, I feel hungry all the time, I really need help!" (Stresses the point)

Respondent 5: (man-Kampala) "Our is society is still poor. People fear taking the drug especially when they know that ARVS give appetite, and yet they do not have enough money to buy all the food they would need. So poverty also hinders access to these drugs".

Lack of disclosure

Respondent 3: (Man- Kampala) "Disclosure is still a problem, especially women fear to disclose to their husbands and yet one of the criteria for couples to be on this drugs is that they have to disclose to their partners. Therefore you find that such a factor discourages people from accessing drugs".

Respondent 9: (Woman -Kampala) "some other people who have failed to access the drugs, okay, because in our secretariat, we usually advise patients that if both of you are sick, it is best that both wife and husband start on the drugs, but in most cases, women come and their husbands stay at home. Also with disclosing, some people do not like to do what? To show their wives or husbands that they are on these drugs. Therefore women fear that their husbands will chase them away from home especially when they refuse to fulfill their marital obligation because they are on drugs and their husbands are not. So you find that most women will say that " how will I take these drugs alone if my husband is not taking them, and yet you tell us that it is good that both of us need to be taking these drugs to be on the safe side".

Distance

Respondent 6: (Woman-Kampala) "Maybe among those who have not been able to access the drug, there is a fact that someone from Fort Portal (one of the districts in Uganda), who was being directed here by friend / relative that we at KCCC give free ARVS. We cannot give drugs to this person and he/she goes back to Fort Portal without any close monitoring, so those find that have not got the drugs. Also those who need them are still fearful about the drugs (Pauses abit) due to their side effects, especially when they see those who have developed side effects, or because of wrong rumors".

Transport Costs

Respondent 2: (Man -Masaka) "what discourages people from accessing these drugs are lack of ability to come to the centers due to transport costs".

Respondent 4: (Woman-Masaka) “Banage (my friends) I will also say that transport costs are a big problem. Some of us walk long distances due to lack of transport fees. This factor has hindered so many people from coming to the center to pick drugs. In fact today I do not have transport and I am worried on how I am going to go back”.

Having analysed information from FGDs, one can conclude that not only do supply factors influence the achievement of equity of free ARV drugs in Uganda but also demand factors play quite a big role in the distribution of these drugs. Therefore policy makers should look at both factors in order to formulate policies that are aimed at achieving equity in the distribution of health resources including ART.

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CHAPTER FIVE: DISCUSSION OF RESEARCH RESULTS

5.0 Introduction

This chapter will discuss results in a more integrated way. The main emphasis will be placed on the findings of socioeconomic status vis -a vis ARV utilization. It is also in this chapter that equity on a geographical and socioeconomic basis will be judged in relation to horizontal and vertical equity as well as according to the “priority view” of egalitarian and the maximin principle of social justice. Benefit in monetary terms will also be discussed on a socioeconomic basis and judged in the light of equity definitions and concepts.

5.1 The free ART policy in Uganda and what it involves

The main objective of providing free ARVs as elicited from key informant interviews is to improve the quality and length of lives for those living with HIV/AIDS and also those affected by the effects of HIV/AIDS. This is a “3x5” WHO initiative and it also consistent with goal 2a of The Revised National Strategic Framework (NSF) for HIV/AIDS Activities in Uganda. Goal 2a of NSF is to mitigate the health effects of HIV/AIDS and improve the quality of life of PLWHAs with the main objective of increasing and expanding access to ART and opportunistic infection care (UAC 2004).

Findings from the study reveal that the majority of the HIV positive Ugandans on free ARVs are on first line regimen. This is because the free ARV roll-out policy began only around June 2004 in Uganda and according to WHO recommendations, a standard combination of drugs known as first-line should be given to those who have just started on the ARV treatment. This explains the reason why the majority of ARV users are mainly on first line regimens.

It is also clear that the main criteria for eligibility to access the free ARVs in Uganda is based on the WHO recommendation guideline that in a resource-limited setting, starting treatment should depend on:

- ◆ WHO stage IV disease regardless of CD4 count
- ◆ WHO stage III disease taking into account if the person has a CD4 count less than 350
- ◆ WHO stage I or II disease with CD4 count less than 200

This medical eligibility is necessary but as Macklin (2004) argues it is not sufficient condition for ARV treatment. The threshold of CD4 count less than 200 in limited resource settings as set by WHO is just a condition that must be met before proceeding to other criteria for selecting individuals or groups to receive ARVs. Selecting individuals with social support as a basis of eligibility to access free ARVs and giving priority to those who registered first with particular centers could lead to discrimination against unmarried individuals or those who lack social support systems and those who are in most urgent of the drugs (the sickest) but who did not register with the specified centers early enough.

5.3 The Characteristics of those on ARV

5.3.1 Utilization by gender

Utilization of free ART by women has been considerable. Findings revealed that more women than men access ARVs both in an urban and rural setting. One reason for this finding is that, according to the Uganda HIV/AIDS surveillance report (Ministry of Health 2003) and the HIV/AIDS Sero Behavioural survey (Ministry of Health 2005), women are more infected by the virus than males. This finding is consistent with other studies in Central and East Africa that have found a higher percentage of women than men infected with HIV (Barongo et.al 1992; Berkley et.al 1990). However results reveal that the ratio of women to men on ARVs is much higher than the ratio of infection. In other words results revealed that 58.4% of women in Uganda are infected with HIV/AIDS but 68% of those who access free ARVs are women compared to 41.6% of men infected with only 32% of those accessing ARVs being men. The explanation to these findings can be obtained from FGDs which revealed that women are more likely to

go for voluntary counseling and testing and hence consent to ARV treatment than their male counterparts..

Based on the priority view of egalitarian and the maximin principle of social justice, one can argue that delivery of ART in Uganda is equitable from the perspective of gender because utilization according to need is addressed. A justification for this argument is that women who are more infected with HIV virus have greater access to the ART programme than men. In addition there are some factors, which make women a vulnerable group of people that must be considered as a priority for free ART rollout. For instance, literature has revealed that women usually bear the burden of caring for the sick and orphans to the extent that they usually forego productive activities including employment in order to fulfill these duties. Many other women are stripped of their property and discriminated against when they are widowed. Some surveys such as the HIV/AIDS Surveillance study in Uganda revealed that female children are more likely than male children to be taken out of school to care for the sick or dying parents and other relatives. Further, there is increased pressure among girls to engage in casual sex especially with older partners as a survival strategy (UAC 2004). Moreover some of these women are mothers who need to prevent HIV transmission to their unborn children and who need to live longer to care for their children.

5.3.2 Utilization by Age group

Results from the study also indicate that the age groups 30-39 and 40-49 have greater access to free ARVs than the rest of the age groups. This finding could be as a result of the much higher rates of HIV infection in the 30-39 age group. The recent Uganda HIV/AIDS Sero Behavioural survey report indicates that for both sexes, HIV infection is concentrated in the age group of 30-39 (Ministry of Health 2005). However if five interval age groups are considered, HIV infection is concentrated in the 35-39 age group at 61.4% but access to free ARVs in this age group is only 21%. If a ten-interval age group is considered i.e (30-39), 70% of individuals in this age group are infected but only 46.75% in the same group have access to the drugs. This age group constitutes the largest and most productive segment of the labour force and has the largest HIV

infection rates. Inadequate ARV access by this age group will therefore have implications for the labour force supply as well as the Ugandan economy in general. It could be considered unfair that the age group mostly infected by HIV/AIDS epidemic and which, constitutes the Ugandan labour force is not accessing free ARVs in proportion to their need. However priority should not be given to the more productive members of society purely due to their financial worth, rather, need should be considered as priority to access. Doing otherwise would violate ethical principles of human rights which emphasize that everyone is entitled to the enjoyment of the highest attainable standard of physical and mental health irrespective of their social worth (Article 25, paragraph 1, the Universal declaration of human rights). Furthermore, considering those members of society who constitute the labour force would lead to maximization of the overall societal monetary benefit (efficiency) but may ignore distributional goals of the egalitarian principle of social justice which emphasizes equal opportunities to access health care services. Policy makers should therefore prioritize access of free ARVs to the 30-39 age group not based on their financial worth but according to their need.

5.3.3 Utilization by educational level

As discussed previously, many of those accessing free ARVs currently in Uganda are not illiterate. Findings reveal that in both rural and urban areas, the majority of those accessing free ARVs have either attained a primary or secondary level education. In addition there are also those with advanced high school, tertiary education and even those with masters and PHD holders. In fact those without any education at all are an insignificant percentage (7%), compared to those with some education (93%). Although many studies, from Central and Eastern Africa in the late 1980s and early 1990's showed a positive correlation between HIV infection and socioeconomic status, as measured by schooling, this finding was not consistent with the recent survey done in Uganda. Findings from the recent Uganda HIV/AIDS Sero- behavioral survey revealed that the degree of HIV infection is higher among individuals with primary level education (15.5%) and almost similar among those with no education (6.7%) and those with secondary level education or more (6.9%). When HIV infection and ARV utilization are

compared in terms of educational status as indicated in Figure 8, it is concerning that individuals with “secondary level education and more” who have a much lower degree of HIV infection than those with primary education have greater access to free ARVs. In addition, although individuals with “no education” and “secondary level education and more” have more or less the same degree of HIV infection, the extent to which these two groups have access to ARVs is very unfair. Those with secondary level education are about 7 times more likely to access free ARVs in Uganda than those with no education and yet the degree of HIV infection in the two educational statuses is quite similar.

Based on horizontal and vertical equity, it is clear that free ARV distribution in Uganda is not equitable for the following reasons:

Firstly, if free ARV distribution is judged according to horizontal equity, it is clear that these drugs in Uganda are not distributed according to equal treatment for equal need. This is justified by the fact that individuals with “no education” have the same need as those with ‘secondary level and more’ education and yet they are not getting equal treatment in terms of free ARV utilization. In other words, the two groups are not getting equal opportunity to access the drugs.

Secondly, in terms of vertical equity, distribution of free ARV drugs in Uganda is not based on unequal treatment for unequal need. One would expect that individuals with primary level education who bear a heavier burden of HIV infection would have more access to the drugs than their counterparts. Instead it is those with a secondary level education with a lesser burden of HIV infection that have greater access. In addition, priority is not given to those who are equally in need (i.e those with no education) and those who are also socioeconomically vulnerable.

5.3.4 Household headship, composition and Employment status

The household composition of Kampala and Masaka sample of people who access free ARVs is much larger than the average household size of the general population of

Uganda. According to the 2000-01 UDHS, the mean household size for rural and urban areas are 4.9 and 4.2 persons respectively while the mean household size for ARV users is 6.1 persons for Kampala and 7.0 persons for Masaka. The fact that the mean household sizes for those accessing free ARVs are larger than the mean household sizes for both urban and rural areas in the general population may have implications on the living conditions and consumption levels of ARV users, which may transcend into poor health status.

As far as household headship is concerned, the UDHS revealed that on average, male-headed households are more than female-headed households and that the proportion of female-headed households is slightly higher in urban areas than rural areas. However, results from the study revealed that female-headed households among ARV users are more in rural areas than in urban areas. Since results revealed that women participants were more disadvantaged than men in terms of employment opportunities in rural areas, this composition will have implications for the income of these households and on their coping strategies. ART distribution in rural areas should be targeted to women who are the breadwinners in this community in order to enable them cope with the negative economic impact of HIV/AIDS. As evidenced in the Masaka FGDs, many women confirmed that ARVs had increased their productivity and has thus helped them to cater for their families. Respondent 6 (woman-Masaka) was quoted as saying "Me what I have seen is that we have been able to plan for our children. Before, when we were down with sickness, we had left them in a bad situation, but I have been able to build my house which had fallen down, I have also been able to work and pay for my children fees, I even have one who is going to Makerere! (meaning university) but if had not got this life back, I could not have been able to do all this. Okay the drug has helped us to live longer and plan for children".

Although the UDHS revealed that employment rates in Uganda were high at the time of the survey, it was evident that many of those accessing free ARVs were unemployed. Further, participants in Masaka were less employed than those in Kampala. Rural areas

should thus be considered as areas with people who are economically worse off and least disadvantaged.

Overall, most of the beneficiaries of the free ART programme have no steady income. On average, as far as employment is concerned, free ART distribution in Uganda is to some extent fair because it is targeted to the unemployed who do not have the ability to pay for the ARV drugs.

5.4 Benefit incidence analysis of ARVs

In this section, evaluation of the benefit incidence of free ARVs in Uganda will mainly focus on socioeconomic status highlighting a few differences about ARV utilization on a geographical and facility basis. Benefit in monetary value will also be discussed in the light of socioeconomic status.

5.4.1 Utilization of ARV by geographical location & socio-economic status

Both the Uganda HIV/AIDS Sero behavioural survey and the HIV/AIDS Surveillance reports reveal that urban residents bear a heavier burden of HIV infection than their rural counterparts. However, clear equity judgments cannot be made on a geographical basis based on my study sample because the total number of people in both districts who access free ARVs in relation to need is not known. In this case equity on a geographical basis will be judged from the perspective of wealth quintiles and only differences in the ARV utilization pattern in both districts will be discussed.

As previously mentioned, there is currently no asset data for HIV infection in Uganda. Therefore it is not possible to directly compare the general population with HIV infection and ARV utilization in terms of asset ownership. However a comparison between the general population and ART users revealed that ARV utilization in Kampala was high in the lowest and the highest quintiles while in Masaka it was

skewed to the topmost quintiles (the high and highest) socioeconomic groups. In both districts, the low and middle socioeconomic classes had the least utilization of ARVs. While the pattern of utilization is different in the two districts, it is evident that on average in both districts, the free ARVs are mainly accessed by the individuals from the highest socioeconomic group. The variation exists in the extent to which accessibility accrues to the highest socioeconomic groups. While ARV utilization in Masaka increases with increasing wealth, in Kampala, at least the lowest socioeconomic group is also catered for. Without HIV infection asset data, exact "need" in each quintile is not known.

Literature shows that initially HIV infection was concentrated amongst richer groups but it now cuts across all socioeconomic groups (Burtely et al 1994; Carr et al 1994; Parker 1996). This line of argument is supported by Uganda AIDS commission's public-relations officer who said that HIV infection in Uganda was initially higher among the richer groups due to their lifestyles but today it cuts across all socioeconomic groups.

Further, the recent Sero Behavioural Survey in Uganda has revealed that HIV infection is higher among individuals with a primary level education and almost similar among individuals with "no education" and those with "secondary level education and more". Since data on educational status of HIV infection is available, it is correlated with asset quintiles in order to determine HIV infection by socioeconomic groups as indicated in Table 1 and Table 2 of the results chapter.

Based on the notion that education is a proxy measure for socioeconomic status, it is clear that in Kampala, individuals with the highest levels of HIV infection and who also have primary level education are from the lowest and low-income groups. However access to free ARVs in Kampala is not proportional to need. This is because individuals in the highest quintile have greater access to the drugs (36.2%) and only 25.7% and 10.1% of individuals from the lowest and low quintiles respectively who have the greatest need, have access to free ARVs. This implies that distribution of free ARVs is not according to equal treatment for equal need thus horizontal equity is still not

achieved in Kampala district. On one hand one can argue that in Kampala district there is some equity as far as the maximin principle of social justice and vertical equity are concerned. This is because the most financially disadvantaged (the lowest quintile) are served. However, the degree to which these individuals and those from the low-income group are served is not relative to their need. If need was to be addressed in Kampala, one would expect the pattern of ARV utilization to decrease with increasing wealth as indicated in the primary level education column in Table 1. Instead free ARV utilization in Kampala is skewed to the highest and lowest quintiles but follow an ascending order across the low, middle and high quintiles. Vertical equity in Kampala is also not achieved because those who are more socio-economically vulnerable (lowest and low) quintiles and who also have enormous need of free ARVs do not have greater access to them.

In Masaka, HIV infection is likely to be evenly distributed across all socioeconomic groups as suggested in Table 2. Therefore for need to be addressed, one would have expected the pattern of ARV utilization to follow the same trend. It is surprising though that it is not the case. As discussed previously, ARV utilization follows an ascending pattern across wealth quintiles, increasing with increasing wealth. In view of this, distribution of ARV use in Masaka is judged inequitable for the following reasons.

Firstly, distribution of ARV use is not proportional to relative need instead it is skewed to the high and highest quintiles and not across quintiles, as it should be. Thus horizontal equity is not being achieved in Masaka because current distribution of ARV use is not according to equal treatment for equal need.

Secondly, it is clear from the results section in Tables 3 and 4 that individuals from the lowest socioeconomic group are both economically disadvantaged and vulnerable in terms of health status. Moreover individuals from the lowest quintile in rural areas are much more disadvantaged than their urban counterparts in terms of asset possession and living conditions that influence health status. Yet individuals from this group in Masaka who are least able to afford ARV drugs and able to cope with the HIV/AIDS

effects are the ones that are underserved. In terms of vertical equity, distribution of ARV use in Masaka is not equitable because there is no additional measure to promote use of those who are HIV infected and who are also socioeconomically vulnerable. In addition, priority is not given to the least financially advantaged individuals from the lowest quintile thus ART distribution is judged unfair according to the maximin principle of social justice.

In general terms, current distribution of ARV use is inequitable in both Kampala and Masaka districts because not only do the highest quintile benefit more than other income-groups but also individuals who bear the heavier burden of HIV infection are not served in proportion to their relative need in both districts, particularly in Masaka district. In view of this and according to the "priority view" of egalitarian, it is clear that distribution of ARV use is not according to need, thus it is judged inequitable.

5.4.2 ART Utilization by Facility

Facilities A, C and E seem to target the poorest in the community. This explains why the distribution of ARVs is skewed to the lowest socioeconomic groups in these facilities. However, in the same facilities, the richest quintile also benefit from the distribution of free ARVs, while individuals from low, middle and high socioeconomic classes are underserved. Basing on vertical equity, facilities A, C and E are judged to achieve some equity because distribution of free ARV use is more skewed to those unable to pay for the drugs and who have a similar need as individuals from the high and highest quintiles. However these facilities suffer the weakness of not targeting individuals from the low who bear a heavy burden of HIV infection and middle-income groups who have about the same need. (See earlier discussion on the correlation between education and asset quintiles).

Distribution of free ARV use in facilities B, F, D and G is judged inequitable for the following reasons:

Firstly, in these facilities, free ARV distribution is skewed to the better-off quintiles (high and highest) than to the rest of the income groups. Yet HIV infection is concentrated amongst individuals with primary education who are represented more in the low quintile and about the same in the lowest, middle and high quintiles. Individuals from the highest quintile do not bear as much burden as individuals from the low, lowest and middle income-groups yet they have greater access to free ARVs than the rest of the groups. In this case facilities B, F, D and G are judged unfair as far as horizontal equity and the priority view of egalitarian are concerned.

Secondly, facilities B, F, D and G do not promote free ARV use by the socio-economically vulnerable (individuals from the lowest and low quintiles) who are least able to pay for the drugs and who have more need of the free ARV drugs than their better-off counterparts. Therefore, in view of vertical equity and maximin principle of social justice, these facilities are judged unfair.

5.4.4 Benefit Incidence Analysis of ART users in different wealth quintiles

Overall, average government spending on ART in Uganda favors those who are better off in terms of wealth and asset endowment as compared to their worse-off counterparts. Findings from the study clearly indicate that individuals from the highest and high socioeconomic groups get a larger proportion of government's ART subsidy than the rest of the socioeconomic groups. This finding is consistent with many macro BIA studies of the social sector spending including health, education and basic infrastructure, which, revealed that government subsidies were not well targeted to the poor but favoured those who were better off (Demery 2000; Castro-Leal et.al 1999; Sahn and Younger 1992,2000; Ajwad and Wodon 2002). On the other hand, results from my study contradict those of a micro BIA study done by Thiede, Palmer and Mbatsha (2002) in South Africa, which revealed that it is the least well off who actually have greater access to government VCT subsidy and other general services at the public facilities. This finding could have been as a result of the fact that in South Africa, the richest

groups prefer private care as opposed to public care (Castro-Leal et al 1999). As far as findings of my study are concerned, ARV distribution in Uganda is not equitable because those who are more likely to suffer exclusion of access to health care and who are the poor are continually being excluded from accessing life sustaining ARV drugs. It is also clear that HIV infection is currently relatively high among individuals from the low socioeconomic group. Yet this groups with the greatest need is underserved in terms of total public ART subsidy. Therefore it is obvious that distribution of free ARV use in Uganda is currently inequitable because not only is the public subsidy not well targeted to the financially worse off and most disadvantaged but it is also not well targeted to those who bear the heavier burden of the HIV infection. For example the total benefit to the highest quintile (Q5) is more than double (USD\$ 88,599) compared to the total benefit that accrues to the lowest quintile (Q1), which is worth (USD\$ 38,499). It is also about five times more than benefit that accrues to the low-income group (Q2-USD\$ 18,329.76) and three times more than the benefit that accrues to the middle-income group (Q3-USD\$ 28,664.72). Although monetary benefit per person reveals that two lower quintiles have a larger public ART subsidy in Table 9 of the results chapter, this information does not indicate that the poor get a large share of the subsidy. For instance the high monetary benefit per person in the two lower income groups could be that the majority of the people in the lowest (Q1) and low (Q2) are on second-line drug regimens, which may be related to compliance issues. In other words the poor could have failed to comply with first-line drugs due to difficulties in regular accessing their monthly supply of ARVs and could have thus developed resistance to them. As a result they could have been put on the high cost second-line regimens. Another possible reason could be that higher cost facilities are the ones targeting the poorest of the poor, thus influencing the monetary benefit per person. This is an area that needs to be further investigated. It is still clear however, that people from the highest quintile (Q5) benefit most from the ART public subsidy in terms of total ART resource allocation and in the number of people that have access to free ARVs in Uganda.

According to the Maximin principle of social justice and vertical equity, one would argue that in general terms, ARV distribution in Uganda is not equitable because there is no evidence of additional measures taken to promote use of free ARV by the worst off in terms of wealth endowments as well as the severity of need except for a few facilities. Indeed, the poor who are least able to cope with social and economic consequences of HIV/AIDS are the ones not actually being targeted in this case. It is unfair to note that poor households, which have few, if any financial or other assets, are being socially and politically marginalized. As much as the non-poor also find their resources diminished by their experience of HIV infection, they stand a better chance of coping with the epidemic because of their initial asset endowments as compared to the poor. Studies by Ainsworth and Semali (1998) also reveal that adult members of poor households are more likely than those in better-off households to die from causes other than AIDS, while AIDS death occur across economic spectrum. This means that in Uganda, as in other low-income countries, in order to make the largest contribution to mitigating the impact of AIDS, programmes should focus on helping households with the fewest resources.

According to horizontal equity and the "priority view" of the egalitarian principle of social justice, it is still arguable that the ART public subsidy is unfair because it not well targeted to those in most need of them. For instance on average, distribution of free ARV use is not proportional to relative need. It is clear that HIV infection occurs across all socioeconomic groups in Uganda but free ARV use is skewed to particular income groups.

Although results revealed that in specific terms ART monetary benefit per person is higher among individuals from the two lower quintiles, there could be other factors influencing the results, which need to be further investigated. It is clear that in absolute terms individuals from the higher quintiles benefit most from the ART public subsidy in terms of total resources and in number of people.

CHAPTER SIX: CONCLUSIONS AND POLICY RECOMMENDATIONS.

6.0 Conclusions

This paper set out to answer the question: “ Which groups of people in Uganda benefit from the provision of free ARV programmes in relation to socioeconomic status, gender and geographical location; what are the implications of such benefits; and is current provision of ARVs equitable?”

The investigation has established that women have substantial benefit of free ART relative to men and the age groups 30-39 and 40-49 have the greatest access to ART although access of these drugs is not proportion to relative need in both perspectives. In addition, those with primary and secondary level education, the unemployed and from large household size have greater access to ARVs. It was clear that HIV infection in Uganda is greater among individuals with primary education but those with secondary level education and more have greater access to free ARVs. Further, results indicate that on average, the non-poor or the highest socioeconomic group has the greatest access to free ARVs in Uganda compared to the rest of the groups. This finding is more exaggerated in the rural areas compared to urban areas. In urban areas, the lowest socioeconomic group benefits after the highest socioeconomic group has benefited.

Further, based on the correlates between education and wealth quintiles the investigation established that the distribution of free ARV use in Uganda is not in line with need both in Kampala and Masaka. The degree to which individuals from different socioeconomic groups access free ARVs is not in proportion to the need. The benefit incidence analysis model confirmed that the government ART subsidy is pro-rich. It is not well targeted to the poor and indeed favours the better off in society. The poor only benefit after the non-poor have benefited. In addition, the public subsidy is not well targeted according to need. In this regard, free ART distribution in Uganda is judged unfair from the perspective of vertical and horizontal equity as well as in the light of the maximin principle of social justice and the “priority view” of the egalitarian approach because the financially worst-off and least disadvantaged are being excluded from

accessing free ARVs and these drugs are not well targeted according to the severity of need.

In summary therefore, this investigation has established that:

- There is need for improving vertical and horizontal equity in ARV targeting and provision in Uganda.
- There is need for improving resource distribution in favour of the poor, the less educated and least advantaged both socially and economically as well as according to need.
- There is need for carrying out research to more clearly establish the socioeconomic characteristics e.g. in terms of asset possession of those who are infected with HIV/AIDS. Further investigation needs to be carried out in this area to enable a proper asset index comparison with the UDHS and ART users, on which clearer equity judgments can be based.

6.1 Policy Recommendations

In the face of limited resources to provide free ARVs to all those who need them in Uganda, the quality and length of lives of PLWHAs could be improved through a more equitable allocation of the limited ARVs. This should be in line with human rights, laws and ethical principles, which provide guidance on expanding access to ART in a just and equitable manner. The human right to life, health, equality and non-discrimination obliges states to provide HIV-related treatment and care without discrimination to all those who need it (WHO/UN 2004). Towards this goal therefore, governments and donors should develop practical and sustainable strategies and plans that include timetables and benchmarks as part of their commitment to the progressive realization of the right to health, including the right to ART and other aspects of care for people with HIV/AIDS. The goal of universal access means that cost and or socioeconomic status must not be a barrier to accessing treatment and care, and particular efforts should be made to enable the poor to gain access to treatment. Strategies should be developed to provide ART free mainly to those who cannot afford it and those who are in greater need of it. In the light of this study, the following issues need to be addressed in order to at least achieve a fair distribution of ART in Uganda.

Firstly, analysts and policy makers need to establish the socioeconomic characteristics of those mostly infected with HIV in terms of asset endowment. These are important because:

- Information on the socioeconomic characteristics of those most likely to be infected can improve the targeting and effectiveness of programmes aimed at prevention as well as care and treatment of HIV/AIDS.
- The characteristics of those infected with HIV affect the economic impact of AIDS epidemic on households and the economy, including the distribution of skills in the labour force and the demand and ability to pay for curative medical care.

- The socioeconomic characteristics of individuals infected with HIV and who die from AIDS are also important in developing programmes to assist households and communities in coping with the epidemic.

After establishing the socioeconomic characteristics, policy makers should develop a standard against which to measure accessibility of ARVs according to ability to pay as well as according to need. As much as it is quite difficult to have clear standards against which equity is accessed, efforts should be directed to ensure access to ART for people who risk exclusion because of economic, social, geographical or other barriers as stipulated in the "3x5" WHO initiatives. In this regard, policy makers should improvise strategies that will address issues pertaining to social, economic and supply factors that constrain accessibility of the socially and financially least advantaged in society. This can be achieved by doing the following:

- ◆ Firstly, government should increase availability of more free ARVs as findings from the service users indicated that lack of enough drugs hindered many from accessing them. The government should also shorten the bureaucracy involved in accessing these drugs. HIV patients are already psychologically affected by the epidemic; subjecting them to long processes and procedures make many people shun the ARV drugs.

- ◆ The government should expand the availability of ARVs by taking these services to the rural settings and nearer to the people. In fact, efforts to provide free ARVs in rural communities should be prioritized especially towards the poorest of the poor. Put differently, the government can facilitate those hindered by transport costs by building more centers at grass root levels, or they could employ, train and facilitate more community based volunteers to go deep in the communities and reach those who are not able to come to the few scattered ART centers.

◆ The government should also widely sensitize the public about ARV programmes by increasing awareness of these programmes in the mass media as findings in this study reveal that currently, mass media is not one of the major ways contributing to the ART awareness in Uganda. For example the government should create awareness about availability of free ARVs and at which centers they are provided as well the good aspects of these drugs. The government should for example educate the public that ARVs improve quality of life and extend life of people living with HIV/AIDS. Further, given that most Ugandans have access to radios (as opposed to TVs and newspapers), this method of communication should be prioritized.

◆ National campaigns aimed at mitigating HIV stigma should be staged in all sub-counties and at grass-root community levels. This can be achieved by improving the mechanism of spreading the gospel of the good about ART (Testimonies). People on these drugs who have experienced positive outcomes from ART should be given a platform on which to voice their views.

◆ The government should not only offer ARV treatment but it should provide basic care, such as food to those who cannot afford to buy it. This will reduce discouragement of people who fear to take the drugs due to their side effect of increasing appetite.

◆ Lessons can be learnt from facilities that have managed to achieve some degree of equity and these can be applied in other settings. For instance, looking in detail at the facilities that are explicitly targeting the poorest and identifying what is making them successful can help in deriving guidelines on how to reach disadvantaged groups more effectively.

◆ The government should ensure that the ART public subsidy is targeted to groups who are least able to afford ARV drugs as well those who have greater need of them. This can be achieved through designing a resource allocation

process in such a way that distributes health care resources in a fair/just way within each society. Targeting of the public subsidy according to need will only be successful if stakeholders in the ART programme in Uganda first establish the HIV/AIDS socioeconomic correlates in terms of asset ownership and in relation to the UDHS. However, according to this study, I would recommend that ART stakeholders in Uganda should target or prioritize the following groups in order to achieve some equity in relation to need:

- Target individuals from the 30-39 age groups where HIV infection is mostly concentrated.
 - Target more people in the lowest and low quintiles in Kampala but have an even distribution of ARV drugs in rural areas.
 - Target individuals who have attained primary level education
 - Encourage more men to go for Voluntary Counseling and Testing and thus to consent to ARV drugs.
- ◆ The government should develop tools for constantly monitoring the programme's public subsidy to ensure that it is well targeted according to the set priorities and groups. This can be achieved by use of anonymous score asset cards, which can be assessed biannually or annually. i.e these cards can be designed in such a way as to assess the socioeconomic status (in terms of asset ownership) of those accessing free ARVs. There is a need to indicate to patients that the information they provide will not affect their continued access to ARVs so as to increase the likelihood of obtaining accurate information.

As long as provision of free ARVs is still on a small scale in Uganda, there is a need to set priorities for accessibility of these drugs and to target them in such a way that they will reach the least advantaged groups and those in need of them if equity is to be achieved. The rationale for choices of target groups and other priorities should be "reasonable" in the sense that it appeals to reasons and principles that are accepted as relevant by the stakeholders (Daniels and Sabin 2002). Whatever options are selected for setting priorities and whichever ethical

principles are chosen as most equitable for Uganda, those responsible for making decisions should take into consideration all relevant ethical and equity principles to ensure that all human rights obligations are respected, protected and fulfilled (Macklin 2004).

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Appendix 1: Letter of request to stakeholders

Heads of Institutions where facility-based interviews will be conducted

(Note: Each letter will be headed individually, not collectively as appears below)

The medical Superintendent/ Head of Aids support organization, Uganda / Ministry of Health-Uganda

Dear Sir/ madam,

RE: REQUEST TO CONDUCT A STUDY ON BENEFIT INCIDENCE OF FREE/ SUDSIDIZED ARV DRUGS IN UGANDA

My name is Rosette Kyomuhangi, a student at the University of Cape Town in South Africa. I am pursuing a master's programme in Public health, concentrating in health economics.

I wish to conduct a study on the benefit incidence of free provision of antiretroviral drugs in Uganda. This is in fulfillment of the requirements contributing toward the award of Master of Public Health. However, the study will have the added advantage of informing policy makers about key issues regarding the equitable distribution of the programme.

This letter therefore seeks your permission to let me access your facility as well as the patients that access the drugs from your facility.

You are assured that the information solicited for will be on voluntary basis and will be treated with complete confidentiality. Persons responsible for the study will only access completed questionnaires. Protection of identity, no names or personal information will

be obtained from the participants. Participants also have the right to withdraw from the study whenever they wish to.

The study findings will be made available to you on completion of the research.

Attached, please find the study protocol.

Thanking you in advance.

Yours faithfully,

Rosette Kyomuhangi

University of Cape Town

Appendix 2: A letter of consent for key informants

This study, which you are being requested to participate in, is about who benefits from free/ subsidized antiretroviral drugs in Uganda. The information being volunteered will be treated as confidential. Your participation is entirely voluntary and you have the right to withdraw from the process of the interview whenever you wish to. The information provided will only be accessible to the researchers and no personal information will be required from you.

The study is for purposes of my masters programme but it will contribute to the generation of knowledge base for policy makers by suggesting tools for constant monitoring the programmes' benefit incidence as well as to derive guidelines on how to reach disadvantaged groups more effectively.

Declaration

I have read and understood the nature of the study in which I am participating. I therefore agree/ do not agree to participate. I also give / not give permission for this interview to be taped by the interviewer

Signature of respondent: _____

Date: _____

Appendix 3 :Key informant interview schedule

- 1.Please describe the ARV programmes you are involved in?
- 2.Are the ARV drugs provided free or on a subsidized basis?
- 3.When were each of these programmes initiated?
- 4.What are the objectives underlying the provision of free or subsidized ARV drugs?
- 5.What are the criteria for eligibility to access free ARVs?
- 6.Are these ARV programmes aimed at individuals or households?
- 7.What groups of people are these ARV programmes mainly targeting?
- 8.What is the monthly cost of ARV drugs per patient to your organization and if not made available free of charge 9.what is the monthly cost to patients?
- 10.Do you believe those eligible for free /subsidized ARVs are accessing them?
If not, what are the barriers?
- 11.How do you monitor who is accessing the drugs and if you are meeting the target group?
- 12.Can you give me an estimate of the general total expenditure of your facility per year?
- 13.What would you consider to be the total number of visits per year?
- 14.What is the estimate of total expenditure on ARV drugs per year ?
- 15.What are the total cost of expenditure on laboratory test per year?

Appendix 4: Informed consent form for study participants

I am a student at the University of Cape Town (UCT) in South Africa. I am conducting a study to evaluate who benefits from free antiretroviral drugs in Uganda. This is in fulfillment of the requirements contributing toward the award of Masters of Public Health. However, the study will have the added advantage of contributing to the generation of knowledge to policy makers who may in turn improve the health services you are receiving. A feed back of research findings will also be provided to you.

You are assured that the information to be volunteered will be treated as confidential and will in no way impact on the treatment you receive at this facility. Completed questionnaires will only be accessible to persons responsible for the study and they will be destroyed immediately after data analysis. No names or any other personal information will be requested of you. You have the right to choose or choose not to participate in the study, and as a participant, you have the right to withdraw from the process of the study whenever you wish to.

Verbal consent: Would you like to participate in this study? Yes / No

Signature of participant: _____

Date: _____

Appendix 5: Questionnaire

SECTION A

Reference Number: _____

Name of facility: _____

Location: (Area, town) _____

PLEASE INDICATE BY TICKING THE APPROPRIATE ANSWER WHERE APPLICABLE.

Socio- economic and demographic characteristics of respondents

Gender

MALE	1
FEMALE	2

What is your age? _____

3a) What is the highest level of school you completed? Please tick appropriate box

00= never been in school (no education)

01-07= primary level education

S1-S4= Secondary level education

S5-S6= Advanced high school level

Above S6= Tertiary education, including undergraduate and diploma level

Higher advanced learning = masters and PHD programmes

3b) if aged less than 25 years: Are you still in school?

YES	
NO	

4. Where do you live? _____

5. How long do you travel to reach this clinic/ hospital /facility?

Less than 15 min	1
15-30 minutes	2
30 mins to one hour	3
Over one hour	4

Do you travel by public or private means?

Private	1
Public	2

If public how much does it cost you to travel here? _____

6. For the last 6 months, how many times have you utilized this programme? _____

7a. Are you employed?

Yes	1	Go to questions 7b and 7c
No	2	Go to question 8

7b. If yes, where do you work? _____

7c. What is your position there? _____ Go to question 11

8. In the past 7 days have you had any work for pay?

Yes	1	Go to question 8
No	2	Skip to question 9

9. What type of work was it? _____ go to 12

10. When was the last time that you worked for money?

Within the last month	1
Within the last 3 months	2
Over six months ago	3

11. In the past 7 days have you had money available from other sources than work?

Yes	1	Go to question 13
No	2	Skip to question 14

12. What were the sources _____

13. What is the number of people living in the household? _____

14. Who heads the household? Male or female _____

15. What is the main source of drinking water for members of your household?

Piped	1	→		Outside		Public tap	
		→	In residence	1	residence	2	3
Open well	2	→	In yard/plot	1	Outside yard	2	
Protected well	3	→	In yard/plot	1	Outside yard	2	
Borehole	4		In yard/plot	1	Outside yard	2	
Spring water	5						
Rain water	6						
Tanker truck water	7						
River, canal or surface water	8						
Bottled water	9						
Water from gravity flow scheme	10						

16. What kind of toilet facility does your household have?

Flush toilet (own)	1
Flush toilet (shared with other household)	2
Traditional pit toilet/ latrine	3
Ventilated improved pit latrine	4
No facility/ Bush/ Field	5
Other: Please specify _____	6

17. Please indicate by ticking if your household has:

Electricity	EL
Radio	RD
Television	TV
Telephone (fixed) / (mobile)	PH
Refrigerator	FR
Lantern	LN
Cupboard	CB

18. What is the principal flooring material in your house?

Earth/ dirt/sand/dung	1
Cement	2
Vinyl or asphalt tile	3
Ceramic tiles	4
Parquet or polished wood	5
Other, please specify _____	6

19. What is the main material in the walls?

Thatched	1
Mud and pole	2
Un burnt bricks	3
Burnt bricks with mud	4
Burnt bricks with cement	5
Timber	6
Cement blocks, bricks, concrete walls	7
Stone	8
Other, please specify _____	9

20. What is the principal roofing material in your house?

Thatched	1
Iron sheets	2
Asbestos	3
Tiles	4
Tin	5
Cement	6
Other, please specify _____	7

21. Does any member of your household own...

A bicycle	BK
A motorcycle or motor scooter	MB
A car or truck	CA
A boat or canoe	BO
A donkey	DK

22. What do you use for lighting?

Electricity	EL
Biogas	BIO
Kerosene	KR
Charcoal	CH
Dung	DG
Others please specify _____	

23. Now let us talk about the household and what it can afford. Would you say that people in your household often, sometimes, seldom or never go hungry?

Often	1
Sometimes	2
Seldom	3
Never	4

University of Cape Town

SECTION B

ANTIRETROVIRAL DRUGS

24. From what sources did you know about provision of free ARVs?

Friends/family	FF
Posters at clinic	PC
Newspapers	NP
Leaflets	LL
Clinic personnel	HW
Community health worker/health educator	CHW
Radio	RP
TV	TV
Other, please specify _____	

25. How did you qualify to be on this programme? _____

26. When did you start receiving ARV drugs on this programme? _____

27. Which drugs are you receiving? _____

28. How many times in a month are you entitled to the drugs?

Once a week	1
Once in a fortnight	2
Once a month	3

29. Are you the only person in your household accessing the drugs?

Yes	1	Skip to qn 31
No	2	Go to qn 30

30. How many other people are accessing free ARVs? _____

31. Are you the only one who needs these drugs in the household?

Yes	1	Skip to 33
No	2	Go to Qn 32

32. What are the factors that could be constraining accessibility of these drugs for members of your household that need them _____?

33. What benefits do you get from these programmes? _____

34. Do you incur any costs in accessing these drugs?

Yes	1	Go to qn 35
No	2	Skip to 36

35. What are the costs?

Consultation fee	CF
Payment for drugs	DG
Laboratory test fees	LT
Other costs, please specify _____	

36. What factors would you consider to have facilitated you to be on this programme?

37. Do you think every body that needs these drugs gets access to them?

Yes	1	End
No	2	Go to Qn 38

38. What factors do you think constrain some people from accessing the drugs?

Appendix 6: Focus Group discussion Guidelines (community)

Representative community within selected area will participate in focus group discussions, which will be conducted in single-sex groups. To ensure, representation 2 groups in each region will be selected, one will comprise only males and the other will comprise females. The reason for such a separation of gender is that, females may not feel free to discuss some issues in presence of males and vice-versa.

I will give a brief introduction about the research project, and myself then obtain verbal consent from all participants.

Questions

- 1.Can you tell me what you know about antiretroviral drugs for HIV/AIDS?
- 2.What benefits do you think are derived from antiretroviral drugs?
- 3.Do you know whether ARVs are provided free or at a low cost in any facility in your community?
- 4.Do you know who is eligible to access free or low cost ARVs?
- 5.Which groups of people would you think benefit more from such health services?
Why?
- 6.Do you think everyone who needs to use these ARVs get access to them?
- 7.What factors would encourage or discourage people from accessing antiretroviral drugs?
- 8.How do you think provision of ARVs should be made more accessible to ordinary people?

Appendix 7: Extra notes for Literature review

2.2 How different countries in Africa are affected by the HIV/AIDS scourge

National HIV prevalence rates vary greatly between individual countries. There is empirical evidence that in some African countries, the epidemic is still growing while others face an increasing danger of explosive growth. For instance, literature states that there was a sharp rise in HIV prevalence among pregnant women in Cameroon (more than doubling to over 11%) among those aged 20-24 between 1998 and 2000. In Somalia and Gambia, the prevalence is estimated to be under 2% of the adult population while in South Africa and Zambia around 20% of the adult population is infected (Avert 2004).

In four Southern African countries, evidence clearly shows that the national adult HIV prevalence rates have risen more than was expected and now exceed 24% in some of these countries like Botswana (37.3%), Swaziland (38.8%), Lesotho (28.9%) and Zimbabwe (24.6%) (USAID 2002).

West Africa on the other hand is relatively less infected although in some countries the prevalence rates are creeping up. In West and Central Africa HIV prevalence is estimated to exceed 5% in a number of countries including Cameroon (6.9%), Central African Republic (13.5%), Cote d'Ivoire (7.0%) and Nigeria (5.4%) (USAID 2002).

HIV infection in East Africa varies between adult prevalence rates of 2.7% in Eritrea to 8.8% in Tanzania. In Uganda the countrywide prevalence among the adult population has declined and is estimated at 4.1% (Avert 2004).

Over and above personal suffering of those infected with HIV/AIDS in Sub-Saharan Africa, HIV threatens to devastate whole communities, impeding progress towards a healthier and more productive future of the citizens of the most affected countries.

A general overview of the impact of HIV & AIDS in Africa

In addition, the effect of HIV/ AIDS on households is very severe. Many families have lost income earners and families of those that die have to find money to pay for their funerals. Many of those who die have surviving partners who are infected and in need of care. As a result HIV/AIDS strips family assets, further impoverishing those at the margins of existence. As parents die, they leave behind children who struggle to survive without parental care. This scourge of HIV/AIDS eventually dissolves households as parents die and children are sent to relatives for care and upbringing. Countries that are heavily affected by the HIV epidemic are facing increasing health care expenditure, which is far beyond what their economies can sustain. This is due to the fact that as the epidemic matures so does the demand for care of those living with HIV/AIDS.

HIV/AIDS has the potential to create severe economic impacts in many African countries. In terms of labour supply, the loss of young adults in their most productive years affects overall economic output. In addition, if AIDS is more prevalent among the economic elite, then the impact is even larger than the absolute number of the AIDS deaths (Stover and Bollinger 1999). In terms of costs, the direct costs include expenditure on medical care, drugs and funeral expenses and indirect costs include lost time due to illnesses, recruitment and training costs to replace workers and care of orphans. If such costs are financed out of savings, a reduction in investment could lead to a significant reduction in economic growth. The economic effects of AIDS are first felt by individuals and their families and then it spills over to the firms and businesses and eventually to the macro-economy. In fact, a World Bank study of the economic impacts of AIDS in Africa concluded that the macroeconomic effects could be significant (Over 1992).

2.5.1 When to start treatment

WHO recommends that before anyone starts treatment in a resource-limited setting, a basic clinical assessment should be carried out. This should include: documentation of past medical history, identification of current and past HIV-related illnesses, identification of other medical conditions that might influence the timing and choice of ART and current symptoms and physical signs of other medical conditions such as TB and pregnancy (Avert 2005). Once this assessment has been carried out, it will be known which stage of HIV disease the person has. WHO has a method of describing people with HIV as being at different stages of HIV infection, according to the different clinical symptoms they may have.

WHO recommends that all people who have WHO stage IV disease, should start treatment. However, making a decision on whether other people should start depends on what laboratory tests are available and in particular whether the person's CD4 cell count is known. A CD4 test measures the number of CD4 or T-helper cells in a person's blood. The more CD4 cells there are per millimeter of blood, the stronger is the immune system, and the stronger the immune system, the better the body can fight illnesses (WHO 2003). WHO recommends that a person should start treatment when one is in WHO stage IV disease regardless of CD4 count, WHO stage III disease taking into account if the person has a CD4 count less than 350 and WHO stage I and II disease with a CD4 count less than 200 (WHO 2003).

Antiretroviral therapy needs to be changed for two main reasons, namely side effects and treatment failure. The drug combinations are known to often cause side effects. It is reported that some people only experience mild side effects and find them easily manageable but for some people the side effects are so severe that they have to consider alternative drugs. The second reason for changing treatment is when the drugs have failed to work and are not slowing down the reproduction of the virus in the body. The WHO definition of treatment failure depends on whether a CD4 test is available. If a CD4 test is available, then treatment failure is said to occur if CD4 count has returned to

the level that it was before treatment started, or if there has been a 50% fall of CD4 count while the person has been on therapy.

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