

The Costs of HIV Treatment, Care, and Support Services in Uganda



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BY

Scott Moreland

Futures Group/MEASURE Evaluation

Eve Namisango

African Palliative Care Association

Alexander Paxton

Futures Group/MEASURE Evaluation

Richard A. Powell

HealthCare Chaplaincy

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Executive Summary

The costs of HIV care services in 12 Ugandan public and non-public facilities that provide HIV care and support services were studied. The aims included: to determine the average annual unit cost per patient (adult and child) for specific HIV treatment, care and support services; to establish the key cost components or “drivers” of such HIV treatment, care and support services; to determine what costs are borne by patients (“out-of-pocket costs”) that are not incurred in a clinical facility; and to compare cost variation by level of service delivery. Data was collected at the facility level on major cost elements, staffing, patient loads and services provided. These were used to estimate the per-patient costs, including for both anti-retroviral therapy (ART) and non-ART patients. The study covered both adult and pediatric patients. Patient-level information was also gathered on services received, physical functionality, socio-economic background characteristics and costs incurred by patients in receiving care.

Results showed that the annual facility-level cost of providing HIV treatment, care and support to adult HIV patients ranges from UGX 254,000 to UGX 824,000 (\$116.28 to \$376.20) across the 12 sites, with a median cost of UGX 567,000 (\$258.78).¹ When restricted to adults on ART, annualized costs ranged from UGX 403,000 to UGX 1,330,000 (\$183.54 to \$606.48), with a median of UGX 734,000 (\$335.16). For children, we found that costs ranged from UGX 190,000 to UGX 1,869,000 (\$86.64 to \$852.72), with a median cost of UGX 630,000 (\$287.28).

The main cost drivers for both adults and children are ARVs and laboratory tests. Among all adults, ARVs account for some 51% of costs and for children ARVs account for 69%. For laboratory services the percentages are 21% and 16% respectively. First-line drugs account for the largest share of ARVs.

The study also found that among the facilities contacted, public hospitals had a higher cost per adult patient than did non-public, not-for-profit hospitals but only by around 12% (UGX 655,018 vs. UGX 582,894.) Public hospitals had lower staff costs per patient while laboratory costs were higher. By contrast public health centers have much lower per-patient costs than non-public health centers for adults (UGX 335,625 vs. UGX 512,073.) The major factor here was much cheaper staffing costs in public health centers (UGX 28,850 vs. UGX 168,845.) Similar patterns were found for children.

Regarding patients’ out-of-pocket expenses on transportation and the value of time lost in seeking and getting treatment for patients on ART, annualized adult costs were UGX 266,814 and for children UGX 174,090. The largest component of this cost was the value of time lost.

Septin/cotrimoxazole as a prophylaxis was the most frequent service and was received among 90% of adults and children in the sample. ART was received by 83% of adults and 73% of children. Adherence counseling was the top ranking service among children (91%) and was third in line for adults (78%). Pain control using non-opioids and pain assessment were in the top ten services received by adults (45% and 44% respectively), but did not rank in the top ten services for children. Lastly of interest was that among adult respondents, 42% had received family planning counseling.

¹ The exchange rate used was UGX 2,200 per US\$, the average during 2010.

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Section 1 Introduction and Objectives

MEASURE Evaluation and The African Palliative Care Association (APCA) conducted a follow-up study to the HIV care services costing study component of the public health evaluation (PHE) that was completed in 2009 with King's College London in association with APCA and MEASURE Evaluation [1]. This new study took place in selected public and private not-for-profit health facilities across Uganda. The study sought to provide a broader, more comprehensive insight into the costs of providing HIV care at differing levels of service delivery in Uganda. The specific objectives included:

- To determine the average annual unit cost per patient (adult and child) for specific HIV treatment, care and support services;
- To establish the key cost components or “drivers” of such HIV treatment, care and support services;
- To determine what costs are borne by patients (“out-of-pocket costs”) that are not incurred in a clinical facility, and;
- To compare cost variation by level of service delivery facility.

Section 2 Background and Rationale

Like many countries in sub-Saharan Africa, Uganda is being hit hard by the AIDS epidemic. Despite early success in reducing the HIV prevalence rate, recent evidence suggests that the prevalence rate has risen from 6.4% in 2005 to 7.3% in 2011. This implies an HIV-positive population of over 1.1 million in 2011 [2]. Moreover, it is estimated that the number of new infections is double the number of those newly enrolling in anti-retroviral treatment programs [3].

Globally, in 2008 alone over US\$16.8 billion was expended on HIV control [4]. Anti-retroviral therapy (ART) is central to HIV care, contributing significantly to the cost burden to treatment interventions (more specifically, the ART medicines) [5]. Currently, 54% of people eligible for ARVs globally and 56% of people in sub-Saharan Africa receive treatment [4]. Confronted by potentially diminished external donor funding in the current adverse financial climate, and the transitioning of HIV from an emergency to a chronic condition [6], many African countries will have to assume responsibility for the costs of HIV care in the future. Indeed, informed fiscal budgeting (including the extent to which programs can reduce per-patient costs) will increasingly be needed over the longer term to ensure that the goal of universal access to ART is realized.

Despite the importance of care and treatment in national responses to the HIV epidemic, estimating the costs of AIDS programs is a relatively recent development [7]. Moreover, differences in relative pricing structures, program protocols, what programs include in their definition of 'care and treatment' and costing methodologies render the comparison of study results problematic. Notable recent cost studies include those by McCoy, et.al. [8], Menzies, et.al. [9], Rosen, et.al. [10], Bikilla, et.al. [5], Martinson, et.al. [11], Koenig, et.al. [12], and Harling and Wood [13]. Moreover, very few studies have examined the costs for ART programs. Consequently, a costing study of HIV care and support services, that includes ART, could generate useful insights and reliable information for policymakers into the costing profile of different intervention components, as well as the amount of monetary resources required to sustain or expand HIV care and support programs, thereby enabling informed resource-allocation decisions.

The current study is a follow-on to a previous study in Uganda that was funded through MEASURE Evaluation [1] and that included a cost component. That study was part of a larger care and support public health evaluation that included the financial costs of service provision at 6 PEPFAR sites. However, there were only 6 sites surveyed by the study and it was felt that they were not representative of the profiles of the majority of the typical sites offering HIV care services across Uganda; they had been chosen because they were large clinical sites with the institutional capacity and patient throughput necessary to support the evaluation.

Consequently, this study sought to provide a broader, more accurate insight into the costs of HIV care at differing levels of service delivery in Uganda. The present study gathered data from 12 sites and included adult as well as pediatric patients.

While the vast majority of the HIV infected population in Africa is adult, pediatric HIV and AIDS care exists on the continent. For example, of the estimated 1.1 million HIV+ people in Uganda [14], 10% are calculated to be children, who also account for 22% of all new infections [15]. In terms of treatment, the country's Ministry of Health reports that of 248,222 clients on ART as of September 2010, 19,854 (8%) were children; similarly among the 18,314 newly enrolled patients during the June-September 2010 period, 2,000 (11%) were children. The Simms et.al. [1], study only considered adult patients; indeed, few costing studies investigate pediatric services. Since pediatric HIV care involves the use of unique staff cadres, (e.g., play therapists, child psychologists, pediatric nurses), costing profiles can differ from those for adult patients. Indeed, one recent study in Ghana conducted among a purposive sample of 15 clinical care sites found that the cost per year for a pediatric client was about 10% higher than that for an adult (i.e., US\$663.48 versus US\$608.76), with the greater expense attributable to providing ARVs to the children [16].

Section 3 Methods

3.1 STUDY DESIGN

This was a cross sectional study of service delivery sites with descriptive and analytical components. Cost data were collected directly from each site as well as from a sample of adult and pediatric patients presenting at HIV clinics.

3.2 PARTICIPATING FACILITIES

In order to be broadly reflective of current service provision across Uganda, participating sites are comprised of public and private not-for profit health facilities across Uganda providing comprehensive HIV clinical care, that includes ARVs. Additionally, sites were included if they were:

- Focused on the care and treatment of HIV-positive people;
- Provided services in a clinical setting;
- Already providing services widely in the clinical setting (i.e., they were not formative sites with fledgling care and treatment services), and;
- ART accredited centers.

3.3 SELECTION AND RECRUITMENT PROCESS

The study selected a purposive sample of 12 of Uganda's accredited ART centers.² The sites reflect key characteristics thought to influence unit cost, including: level of service delivery; major implementing partner; and type of ownership [16].

The main criterion for site selection for this study, however, was the level of facility service provision. According to a recent ART report published by the Ministry of Health, Uganda and the STD/AIDS Control Program, in September 2010 there were 419 health facilities providing adult ART services and 309 providing pediatric services (see Table 1) [17]. Of these, 306 (representing 74% of those providing adult services and 83% of those providing pediatric services), are at levels HC III and above.

² The study team considered using a random sample of sites instead of a non-random, purposive sampling approach. To ensure that the study was completed at relatively low cost, over a short period of time, with sites that were reflective of current service provision, a purposive sample was selected.

Table 1 Coverage of ART Services by Level, September 2010

Type of service	Providing adult ART			Providing pediatric ART		
	N	%	Cumulative %	N	%	Cumulative %
Regional referral hospitals	15	4	4	15	5	5
General hospitals	101	24	28	89	29	34
Health centre IV	139	33	61	117	38	72
Health centre III	55	13	74	37	12	83
Health centre II	3	1	75	2	1	84
Research and specialized clinics	36	9	83	31	10	94
Private, for-profit	70	17	100	18	6	100
Total	419	100		309	100	

Source: Ministry of Health, STD/AIDS Control Program (2010) The Status of Antiretroviral Therapy Service Delivery in Uganda. Kampala, Uganda: Ministry of Health, Table 3.1

The proportional distribution of these sites is shown in Table 2 in the middle column. We attempted to apply this percentage distribution to the target number of 12 sites for this study whilst bearing in mind the need to select at least two regional referral hospitals with different main donor partners to allow for a comparison of costs based on donor.

Table 2 Sampling Proportional to Size and Distribution of Sites Selected by Level

Level	Number of facilities providing ART	% total	Number of sites to sample
Regional referral hospitals	15	5	1
General hospitals	101	33	4
Health center IV	135	44	5
Health center III	55	18	2
Total	306	100	12

The final study sites selected are shown in Table 3 and their locations on the map in Figure 1.

Figure 1 Site Locations

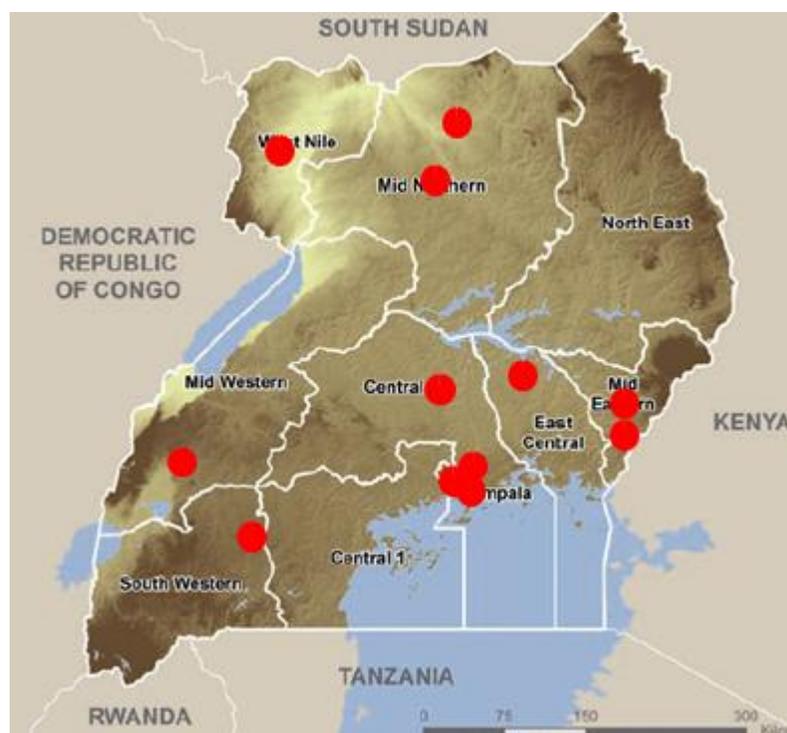


Table 3 Participating Sites by Type and Location

Site name	Level of service delivery	Type of ownership	District	Main implementing partner(s)
Gulu Regional Referral Hospital	Regional Referral Hospital	Public	Gulu	Infectious Diseases Institute, MOH
Mbarara Regional Referral Hospital	Regional Referral Hospital	Public	Mbarara	MJAP, MOH
Mbuya Reach Out	AIDS clinic	NGO	Kampala	PEPFAR
Mukuju Health Centre IV	Health Centre IV	Public	Kayunga	Baylor Uganda, MOH
Busiu H/CIV	Health Centre IV	Public	Mbale	STAR E/PIDC, MOH
Vikira Hospital	General Hospital	PNFP	Fort portal	AIDS RELIEF, MOH
Arua Regional Referral Hospital	General Hospital	Public	Arua	Medicins sans Frontiers, MOH
Kayunga Hospital	General Hospital	Public	Kayunga	Walter Reed, MOH
St Joseph's Hospital Kitgum	General Hospital	PNFP	Kitgum	Catholic Relief Services
Kawempe H/CIV	Health Centre IV	Public	Kampala	Infectious Diseases Institute, PEPFAR, MOH
Holy Cross Kikyusa	Health Centre III	Public	Luwero	Holy Cross / MOH
Kiswa H/C III	Health Centre III	Public	Kampala	Infectious Diseases Institute/ PEPFAR / MOH

3.4 PATIENT INTERVIEWS

3.4.1 Sample Size

The study aimed to conduct 600 interviews (an average of 50 per site) with adults and 200 (an average of approximately 16 per site) with children (or their care-givers.) The numbers constituting each sample were determined to ensure a reasonable representation of the site populations and to facilitate any required sub-group analysis, rather than to test a hypothesis. Sampling at the facility level was based on the sampling-by-size approach, using the formula below:

$$\frac{n}{N} \times n_i$$

n = the total number of HIV/AIDS clients at the specific facility;

N = the total number of HIV/AIDS for all participating facilities;

n_i = the total sample size required for the study for the specific target group (i.e., 600 adults and 200 pediatric)

Routine statistics on the total number of clients served in 2010 for each of the participating study sites were obtained from the Ministry of Health national HIV treatment, care and support records. This was used to calculate the number of patients to interview per site. Sample calculations for each site are found in Appendix 1. In those instances where the calculated sample size was less than five, we increased the target number of respondents to ten, especially for pediatric patients.

3.4.2 Inclusion criteria

The study focused on ambulatory HIV/AIDS only and patients were consecutively recruited if they fulfilled the following inclusion criteria:

Adults:

- Patients (male and female) aged 18 years or over;
- Patients diagnosed HIV positive;
- Patients know of their diagnosis;
- Patients with sufficient cognitive ability to answer the study questions, and;
- Patients who have been receiving HIV care and support services for at least one month.

Children:

- Care-givers (male or female) aged 18 years or over of child patients (aged 0–17 years) diagnosed HIV positive;
- Care-givers know of the child's diagnosis;
- Care-givers with sufficient cognitive ability to answer the study questions, and;
- Care-givers of child patients who have been receiving HIV care and support services for at least one month.

3.4.3 Recruitment procedure

Following the reading of an information sheet (see Appendix 2), participants were provided a written informed consent on a form (see Appendix 3) to participate in the study. These documents were translated into the relevant local languages (i.e. Runyakitara, Luganda, Luo and Lugisu), and were read aloud by the researchers if the participant was illiterate. Participants were given a small compensation (i.e., \$2.28) for their time in the form of refreshment.

3.4.4 Sampling procedure

Patients were consecutively recruited into the study if they fulfilled the above study inclusion criteria. Since ART is one of the primary cost drivers of HIV care, and based upon routine statistics findings for the Simms et. al., study [1], the proportion of pre-ART and on-ART patient sub-groups targeted for selection was 30% and 70%, respectively. While service utilization may be predicted by staging levels, the irregular recording of that data means patients were not stratified further by that variable; rather, selection was stratified by ART status and data was collected on WHO clinical staging. In those instances where this data was unavailable, patients were staged by facility health workers using Ministry of Health Uganda staging guidelines.

3.4.5 Conduct of patient interviews

Patient interviews were conducted in privacy and anonymously. The patient interview instruments are found in Appendices 4 and 5. Respondents were informed about the objectives of the study and that the data collected were treated confidentiality and only accessed by the investigators. Written informed consent was obtained from all respondents before the start of the interview, with interviews lasting approximately 15–20 minutes each.

3.5 KEY INFORMANT INTERVIEWS

The key informants who provided information on service costs data were purposively selected to ensure interviews with the most informed staff about the respective costing components. These key informants included: clinicians, nurses, social workers, pharmacists/dispensers, hospital administrators or managers, and accountants.

Section 4 Data Collection

4.1 TYPES OF COST DATA COLLECTED

The study captured data on both financial and economic costs. The data collection instruments for the costs are found in Appendix 6. Financial cost is a measure of the amount of money spent on a resource or on a health program. Economic cost refers to the entire cost borne by society and, as such, is based on the concept of opportunity cost, defined as the value of the next best forgone alternative use for a resource.

Costed inputs included direct and indirect costs.

4.1.1 Direct costs

Direct costs are costs of inputs used in service delivery that can be directly assigned to patients (e.g., the cost of staff servicing a patient, the cost of medicines and supplies used, and the cost of diagnostic and other tests performed). In this study, case-specific direct costs were collected based on the services received by the patient in the previous 30 days prior to the survey.

These included:

- staff time in caring for clients;
- drugs to prevent and treat opportunistic infections;
- ARV drugs;
- medical consumables and supplies used for clinic visits;
- laboratory testing;
- medical equipment;
- vehicles used directly for client care, and;
- physical infrastructure used for client care.

4.1.2 Indirect costs

Indirect costs cannot be directly identified with a service or product—rather, they are the costs of supporting direct cost activities. Indirect costs incurred by patients were calculated as the value of foregone productivity because of illness using the human capital approach, which uses lost earnings as a substitute for the impact that the illness or disability has on the individuals and society [18, 19]. Data were collected on costs to program clients (e.g., client time, transport, meals, out-of-pocket payments, user fees for services or drugs, and so forth).

Waiting time at the facility was also captured to provide an insight into lost working time. The opportunity cost of the lost working time in the respective settings was obtained in monetary terms to capture a wider component of patient costs. Major non-market resource inputs to the HIV treatment, care and support programs (e.g., patient/family leisure time) were documented alongside other costs when reporting the results [18].

At the facility level, indirect costs can be seen as costs of resources and inputs shared among all patients at the health facility. While it is impossible to assign these cost types to a specific patient, they nevertheless can be assigned to classes of patients. Indirect costs included the labor cost of administrative staff, overhead expenses (e.g., office supplies, travel expenses, communication, etc.), depreciation of equipment and assets (e.g., equipment and furniture in the clinical and diagnostic units) and equipment and building used generically at a facility.

4.2 PEDIATRIC PATIENTS

To estimate the costs of providing HIV care, treatment and support to children, the study used a similar approach that was used for the adults, with some minor adjustments to the data collection instruments. Also, children's care givers were interviewed, rather than the children themselves, when completing the services use tool and in answering questions about out-of-pocket costs incurred.

4.3 VALUATION OF INPUTS

As a general rule, the value of an input should reflect its economic (opportunity) cost [18]. In most cases, the economic cost is the same as the financial cost (i.e., the amount paid for the input). In other cases, the economic cost differs if the input was not purchased at the market price (e.g., donated drugs or volunteer labor).

This study aimed to identify both the financial and market costs of inputs (where a difference may exist). For donated or subsidized inputs, the study used market prices. The prices for medicines and medical supplies were obtained from either the National Medical Stores or Joint Medical Stores for the fiscal year 2009/10. If not available, the 2008/09 prices were used. For laboratory tests, the study used prices from the National Referral Hospital. For capital inputs, 2010 replacement prices from the market were considered.

4.4 PATIENT BACKGROUND DATA

In addition to out-of-pocket and service utilization data, we collected basic socio-demographic and clinical data (e.g., functionality) to profile the sample. Data collected included a patient's age, sex, level of education, socio-economic level and assets. Physical functionality was scored using the Eastern Cooperative Oncology Group (ECOG) scale [20].

4.5 STUDY LIMITATIONS

Like any study, the present study has limitations. First, while the study gathered cost information from 12 sites across the country that represent a cross-section of public and private sites at various levels, it cannot be considered as comprehensive and using the results to draw general conclusions, especially at the national level, should be approached with caution. Second, while the cost elements that were included are fairly exhaustive, we did not capture all of the costs. We had intended, for example, to capture "up-stream" costs incurred at central level by the Ministry of Health in overseeing

the national HIV/AIDS care program and similarly by donors and the INGOs that provide services, but these data are not included. Thirdly, we did not have information on the length of time HIV patients in the facilities had been diagnosed or how long they had been in treatment and been on ARVs. This could be important since it would influence the relative importance of ARVs as a cost driver.

Section 5 Results

5.1 SITE DESCRIPTIONS

This study incorporated 12 clinics that were purposefully chosen to represent a variety of geographic areas and facility types. In 2011, these sites cared for a total of 137,779 unique patients: 58,579 (43%) patients received some form of HIV-related care, and 33,019 (24%) were on antiretroviral therapy (ART) at some point in the year. Of the HIV patients, 14% were pediatric. The clinics ranged in size from 1,506 to 20,974 patients per year. All clinics have a significant portion of patients that are HIV-positive (see Table 4), and all see at least 750 HIV patients per year (Figure 2). Clinics 7 and 12 have the highest volumes of HIV patients and the highest HIV-related expenditures.

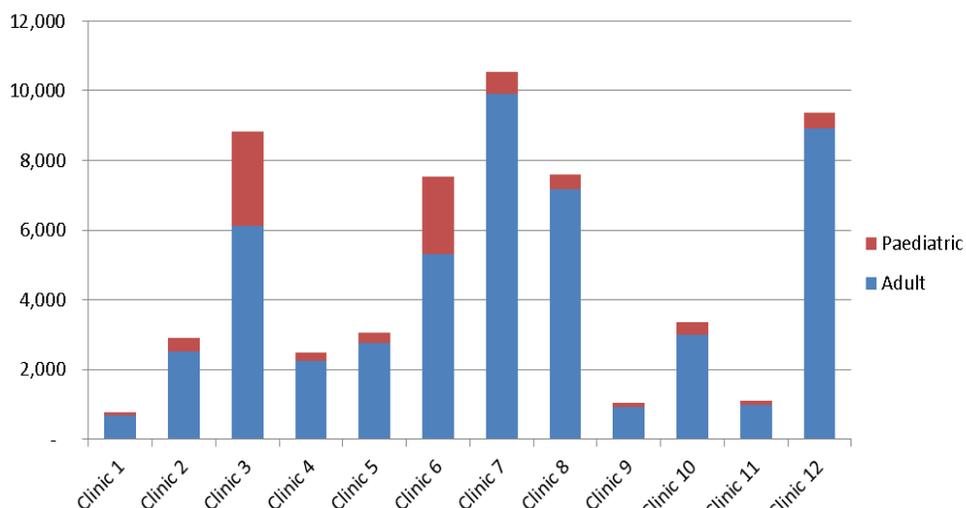
Table 4 Numbers and Percentages of HIV Patients at Each Site³

Site		HIV+ adults	Adult patients on ART	HIV+ pediatrics	Pediatric patients on ART	All HIV+ patients
Clinic 1	Total	677	246	100	40	777
	% of all patients	28	10	4	2	32
Clinic 2	Total	2,503	1,370	408	211	2,911
	% of all patients	43	23	7	4	50
Clinic 3	Total	6,115	2,300	2,700	1,500	8,815
	% of all patients	32	12	14	8	46
Clinic 4	Total	2,254	860	237	147	2,491
	% of all patients	17	7	2	1	19
Clinic 5	Total	2,757	1,492	309	188	3,066
	% of all patients	64	34	7	4	71
Clinic 6	Total	5,300	2,500	2,230	1,200	7,530
	% of all patients	38	18	16	9	54
Clinic 7	Total	9,893	7,931	650	485	10,543
	% of all patients	47	38	3	2	50
Clinic 8	Total	7,184	2,950	417	101	7,601
	% of all patients	95	39	5	1	100
Clinic 9	Total	918	652	112	72	1,030
	% of all patients	61	43	7	5	68
Clinic 10	Total	2,998	2,336	362	252	3,360
	% of all patients	51	40	6	4	57
Clinic 11	Total	976	300	118	26	1,094
	% of all patients	14	4	2	<1	16
Clinic 12	Total	8,905	5,460	456	400	9,361
	% of all patients	65	40	3	3	68

Source: Ministry of health, Uganda, Health Management Information System, Routine Statistics, 2012

³ Appendix 8 provides a list of clinic numbers and clinic names.

Figure 2 Annual HIV Patients: Adult and Paediatric



5.2 PER-PATIENT COST OF HIV CARE: ADULT PATIENTS

Figure 3 presents the estimated total expenditures on adult HIV care for each clinic. The cost of HIV care per adult patient varies greatly across the sites surveyed. Costs range from UGX 252,000 (\$114.54) to UGX 841,000 (\$383.04) (see Table 5 and Figure 4), with a median cost of UGX 568,000 (\$258.78). The survey sites were purposefully selected, so we cannot assume that the sites are statistically representative. However, for illustrative purposes we provide summary statistics of the study population. Across the 50,480 adult HIV patients in the study, the mean annual cost of care per patient is UGX 536,000 (\$243.64). The biggest drivers of the annual cost per patient of adult HIV care are antiretroviral medications (ARVs) at UGX 273,000 (\$124.26) per person and lab tests at UGX 111,000 (\$50.16) per person. On average for all 12 clinics, ARVs constituted 51% of costs and labs 21% of costs. See Figure 6.

The higher average costs seen at Clinics 2 and 9 are primarily due to higher ARV costs per patient than at other sites (see Table 5). The relatively low per-patient cost at Clinics 6 is due to low expenditure on ARVs. Figure 5 presents the percentage cost breakdown for each clinic.

Table 5 Adult Patients: Total and Per-Patient Annual Costs of HIV Care (in Thousands of UGX)

Site		Staff	ARVs	Other drugs	Lab cost	Building, utilities, rental	Total
Clinic 1	Total cost	36,097	73,958	5,363	61,480	64,830	241,728
	Per patient	53	109	8	91	96	357
Clinic 2	Total cost	241,688	1,231,600	138,475	198,400	252,339	2,062,503
	Per patient	97	492	55	79	101	824
Clinic 3	Total cost	149,167	1,264,083	50,037	595,660	29,785	2,088,733
	Per patient	24	207	8	97	5	342
Clinic 4	Total cost	46,136	794,715	44,981	688,280	135,608	1,709,720
	Per patient	20	353	20	305	60	759
Clinic 5	Total cost	245,784	745,128	62,052	260,600	358,073	1,671,637
	Per patient	89	270	23	95	130	606
Clinic 6	Total cost	145,028	705,466	57,071	397,840	40,385	1,345,791
	Per patient	27	133	11	75	8	254
Clinic 7	Total cost	200,614	3,283,487	40,150	2,392,210	524,449	6,440,910
	Per patient	20	332	4	242	53	651
Clinic 8	Total cost	1,212,979	1,455,749	69,016	477,740	463,250	3,678,734
	Per patient	169	203	10	67	64	512
Clinic 9	Total cost	60,003	615,602	18,047	58,460	19,750	771,862
	Per patient	65	671	20	64	22	841
Clinic 10	Total cost	149,184	1,159,026	33,423	136,920	204,367	1,682,919
	Per patient	50	387	11	46	68	561
Clinic 11	Total cost	3,105	190,192	7,591	32,900	485	234,274
	Per patient	14	195	8	34	2	252
Clinic 12	Total cost	306,621	2,264,159	41,048	292,020	2,213,169	5,117,017
	Per patient	34	254	5	33	249	575
Weighted mean*	Per patient	55	273	11	111	85	536

* weighted by adult HIV patients at each clinic

Figure 3 Total Annual Cost of HIV Care (Millions of UGX)

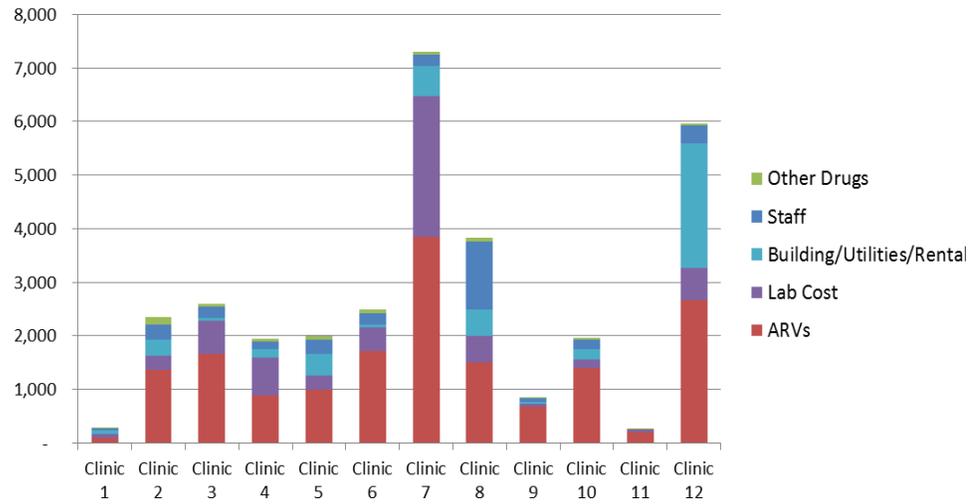


Figure 4 Annual Cost Per Adult HIV Patient (UGX)

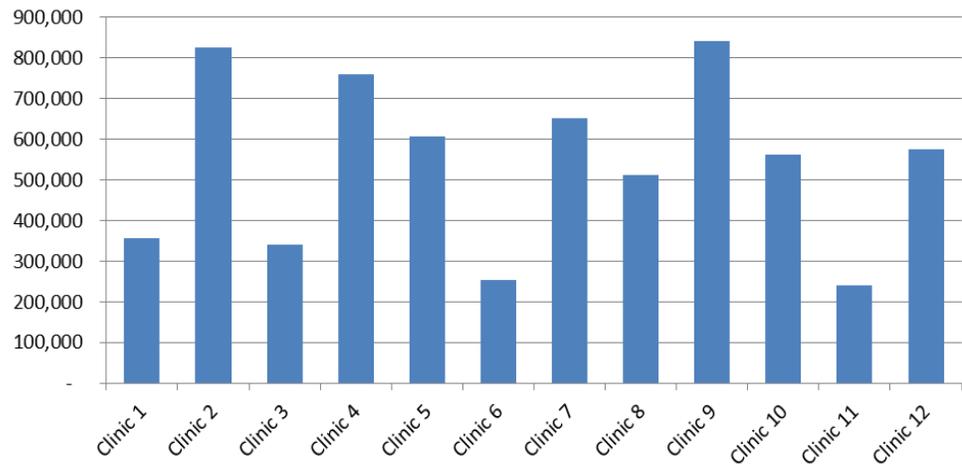


Figure 5 Adult HIV Cost Distribution

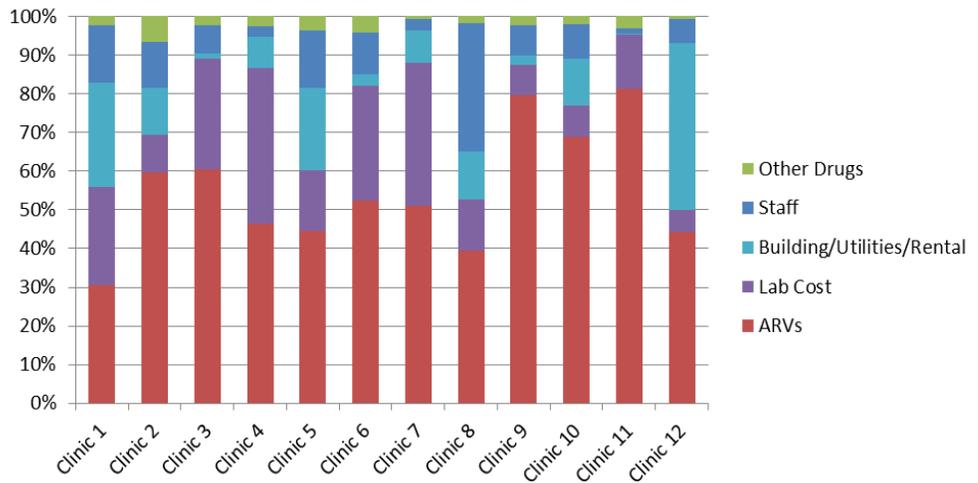
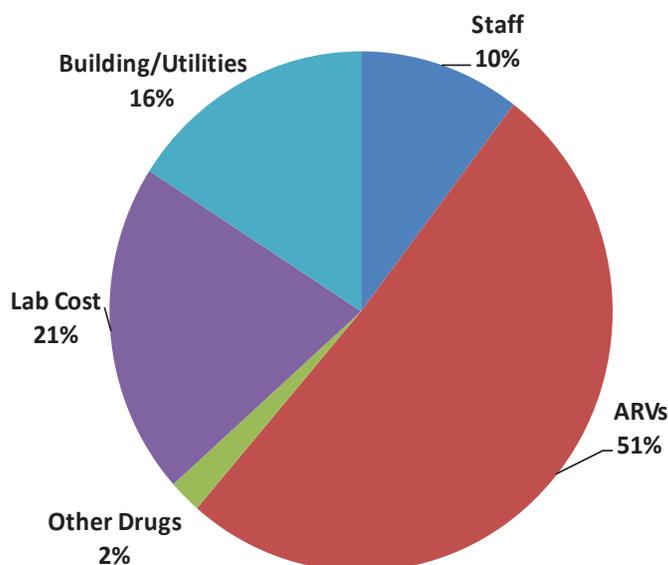


Figure 6 Distribution of Cost Elements Adults—12 Sites



5.3 PER-PATIENT COST OF HIV CARE: PEDIATRIC PATIENTS

It is useful to examine pediatric patients separately due to their unique treatment regimens. For this population, annual per-patient costs range from UGX 190,000 (\$86.64) to UGX 1,869,000 (\$852.72) (see Table 6 and Figure 7). The median cost of annual pediatric HIV care is UGX 631,000 (\$286.82). The mean annual cost of care for the 8,099 pediatric HIV patients is UGX 584,000 (\$265.45). As with adult HIV care, the biggest drivers of cost are ARVs and lab tests at UGX 402,000 (\$183.54) and UGX 94,000 (\$43.32) per person per year, respectively, constituting 69% and 16% of costs respectively.

Per-patient costs vary greatly between clinics. Clinic 12's high cost per pediatric patient is largely due to very high expenditures on ARVs, lab tests, and buildings/utilities/rental (Table 6). Conversely, Clinic 3 has very low expenditures per patient in all cost categories.

The data show that for children, on average 69% of costs are going for ARVs and 16% for lab costs (Figures 8 and 9.) This is a higher proportion than we found for adults.

Table 6 Pediatric Patients: Total and Per-Patient Annual Costs of HIV Care (in Thousands of UGX)

Site		Staff	ARVs	Other drugs	Lab cost	Building/ utilities/ rental	Total
Clinic 1	Total cost	5,332	21,408	1,264	3,210	9,576	40,790
	Per patient	53	214	13	32	96	408
Clinic 2	Total cost	39,396	137,827	15,540	64,020	41,132	297,915
	Per patient	97	338	38	157	101	730
Clinic 3	Total cost	65,863	392,063	6,935	34,960	13,151	512,973
	Per patient	24	145	3	13	5	190
Clinic 4	Total cost	4,851	97,113	5,799	17,620	14,259	139,641
	Per patient	20	410	24	74	60	589
Clinic 5	Total cost	27,547	247,395	3,263	7,860	40,132	326,197
	Per patient	89	801	11	25	130	1,056
Clinic 6	Total cost	64,414	1,007,165	7,189	46,040	16,992	1,141,800
	Per patient	29	452	3	21	8	512
Clinic 7	Total cost	13,181	563,902	11,005	239,710	34,458	862,256
	Per patient	20	868	17	369	53	1,327
Clinic 8	Total cost	70,408	54,446	990	8,820	26,890	161,554
	Per patient	169	131	2	21	64	387
Clinic 9	Total cost	7,321	61,941	697	2,890	2,410	75,259
	Per patient	65	553	6	26	22	672
Clinic 10	Total cost	18,013	239,093	2,510	19,840	1,999	281,456
	Per patient	50	660	7	55	6	778
Clinic 11	Total cost	375	19,816	5,634	11,140	59	37,025
	Per patient	14	168	48	94	2	314
Clinic 12	Total cost	15,701	410,749	6,718	305,890	113,330	852,388
	Per patient	34	901	15	671	249	1,869
Weighted mean*	Per patient	41	402	8	94	39	584

* weighted by pediatric HIV patients at each clinic

Figure 7 Total Cost Per Pediatric HIV Patient (UGX)

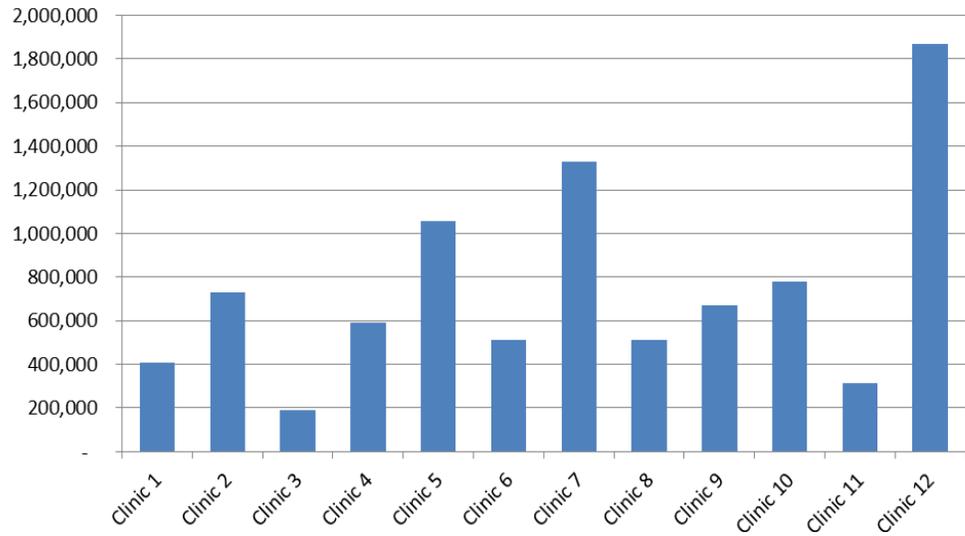


Figure 8 Pediatric HIV Cost Distribution

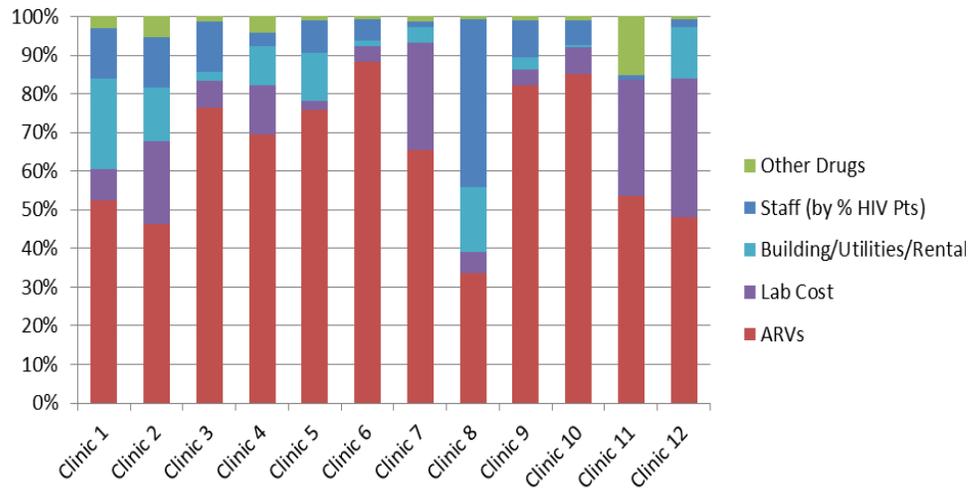
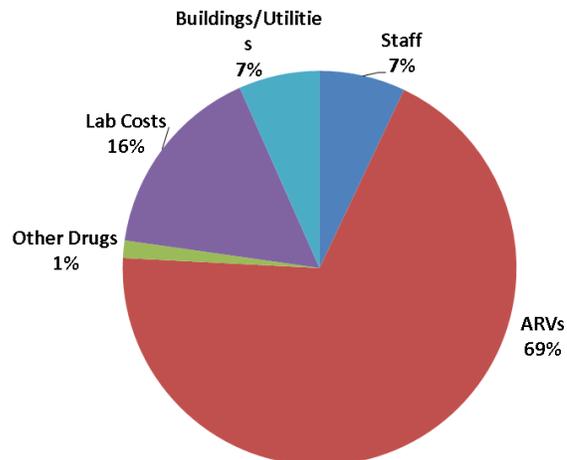


Figure 9 Distribution of Cost Elements Pediatric Patients—12 Sites



5.4 COSTS FOR PATIENTS ON ART

The figures reported above are averaged across all HIV patients in the study; however, the cost of care for HIV patients on ART is much greater than the cost of care for HIV patients who are not on an ART regimen. It is logical to examine these groups separately, as the proportion of patients on ART may differ from site to site. Moreover, the proportion of HIV patients in the study population that are on ART is 56%, which is twice the reported national average of 28%. This may be due to the fact that we purposely selected ART-accredited facilities. Therefore, the average per-patient cost of HIV care in the study population is likely considerably greater than the true national average. In order to separate the confounding effects of the number of patients on ART, we estimated the per-patient costs at each clinic for both ART and non-ART patients with HIV. The cost of antiretroviral medications was applied only to those patients on ART, and other costs were split proportionally between ART and non-ART patients.

As can be seen in Table 7, per-patient annual costs for adult patients on ART range from UGX 403,000 to 1,330,000 (\$183.54 to \$606.48). In contrast, HIV-positive adult patients who are not on ART incur annual costs ranging from UGX 57,000 to 406,000 (\$26.22 to \$184.68). Figure 10 graphically displays these results for adults, and Figure 11 displays the same results for pediatric patients.

Adults on antiretrovirals (ARVs) incurred an average annual per-patient cost of UGX 757,000 (\$345.42). HIV-positive, non-ART adults incurred a cost of UGX 252,000 (\$115.14). Pediatric patients on ART have an annual cost of UGX 916,000 (\$418.38). HIV-positive pediatric patients who are not on ART incur an average annual cost of UGX 142,000 (\$64.98). The average annual cost of ARVs per patient on ART is UGX 485,000 (\$221.16) for adults and UGX 704,000 (\$321.48) for pediatric patients.

Table 7 Annual Per-Patient Costs of HIV Care for ART and Non-ART Patients (in Thousands of UGX)

Site	Adults		Paediatrics	
	ART	Non-ART	ART	Non-ART
Clinic 1	548	248	729	194
Clinic 2	1,231	332	1,046	392
Clinic 3	684	135	306	45
Clinic 4	1,330	406	840	179
Clinic 5	835	336	1,571	255
Clinic 6	403	121	900	60
Clinic 7	733	319	1,622	459
Clinic 8	803	309	796	257
Clinic 9	1,114	170	979	119
Clinic 10	671	175	1,066	117
Clinic 11	691	57	920	158
Clinic 12	735	320	1,995	969
Minimum	403	57	306	45
Maximum	1,330	406	1,995	969
Median	734	279	950	187
Mean	815	244	1,064	267
Weighted mean*	757	252	916	142

* weighted by number of patients of that category at each clinic

Figure 10 Cost Per Adult HIV Patient: ART vs. non-ART (UGX)

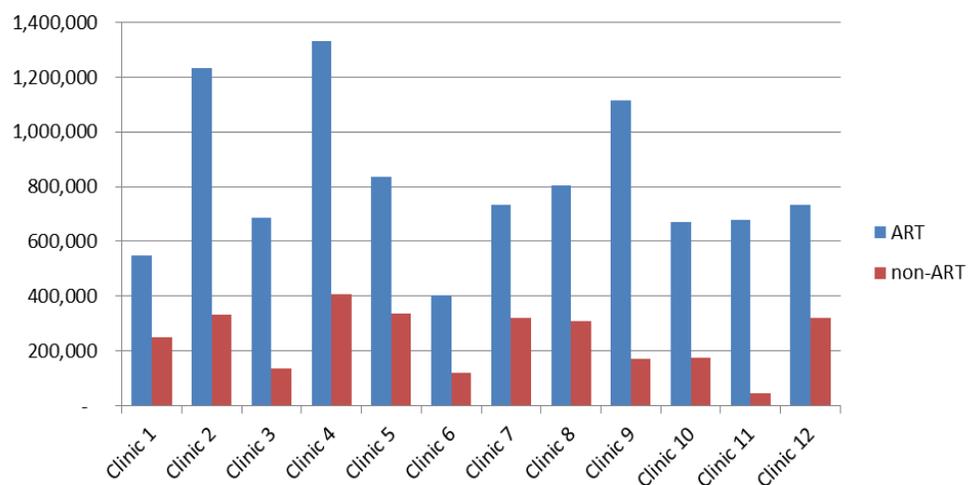
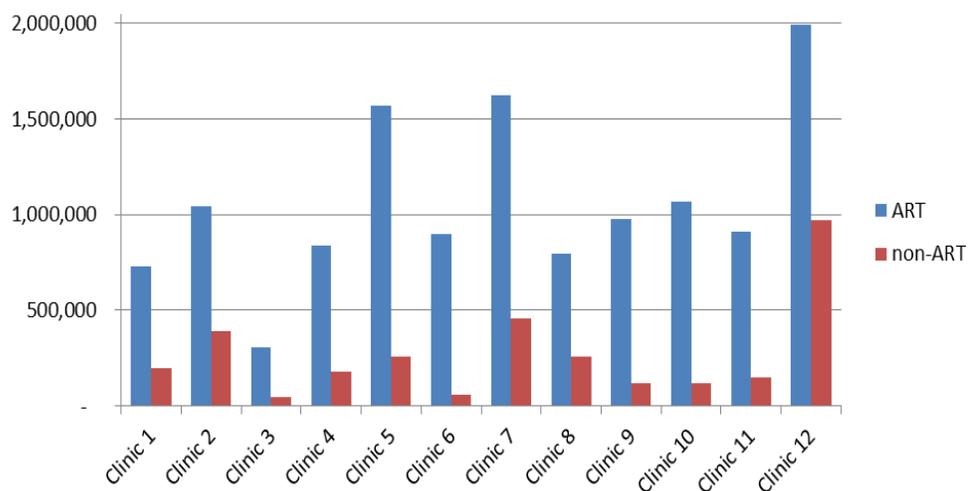


Figure 11 Cost Per Pediatric HIV Patient: ART vs. non-ART (UGX)



5.5 FIRST- AND SECOND-LINE ARVS

In order to better understand the disparities in per-patient ARV costs, ARVs were classified into first- and second-line drugs for analysis. Figures 12 and 13 reveal that for adult and pediatric patients, first-line drug costs varied considerably between clinics. Second-line drug costs made up a relatively small proportion of expenditures at most clinics. For adult patients, Clinics 9 and 11 had almost no second-line drug expenses at all. However, Clinic 5 had an especially large expenditure on second-line drugs when compared to first-line. For pediatric patients, Clinics 4, 11, and 12 had no second-line drug expenses, and Clinics 3 and 6 had greater expenditures on second-line drugs than first-line.

These results should be interpreted with caution. Differences between clinics do not necessarily reflect efficiency or quality of care because they may be attributable to variance in patient populations, case mix, resource restrictions, or preferred drug regimens at each clinic, among other causes. Furthermore, some ARVs can be used as first and second line drugs. Precise data was not available on the number of doses of each ARV that were used for first- or second-line therapy. Our analysis is based on the most common use of each ARV, as provided by local physicians.

Figure 12 ARV Costs Per Adult Patient: First- and Second-Line Drugs (UGX)

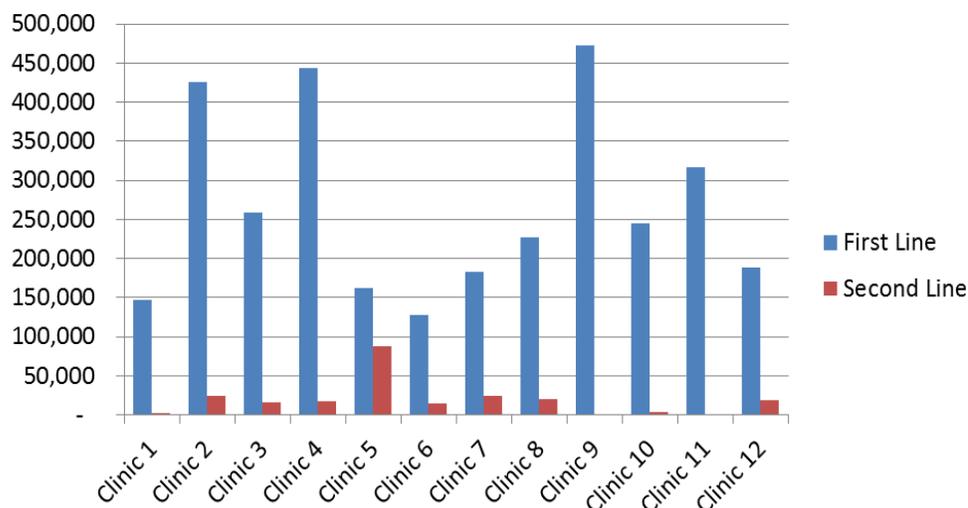
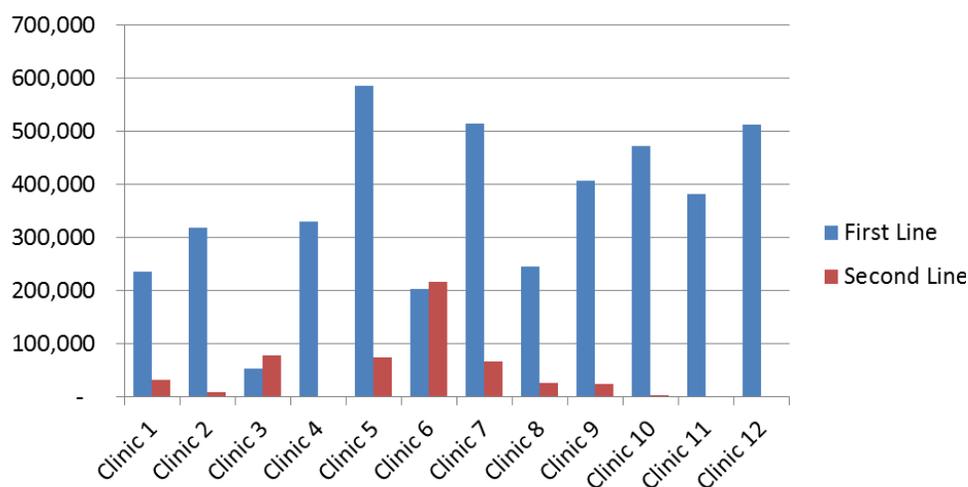


Figure 13 ARV Costs Per Pediatric Patient: First- and Second-Line Drugs (UGX)

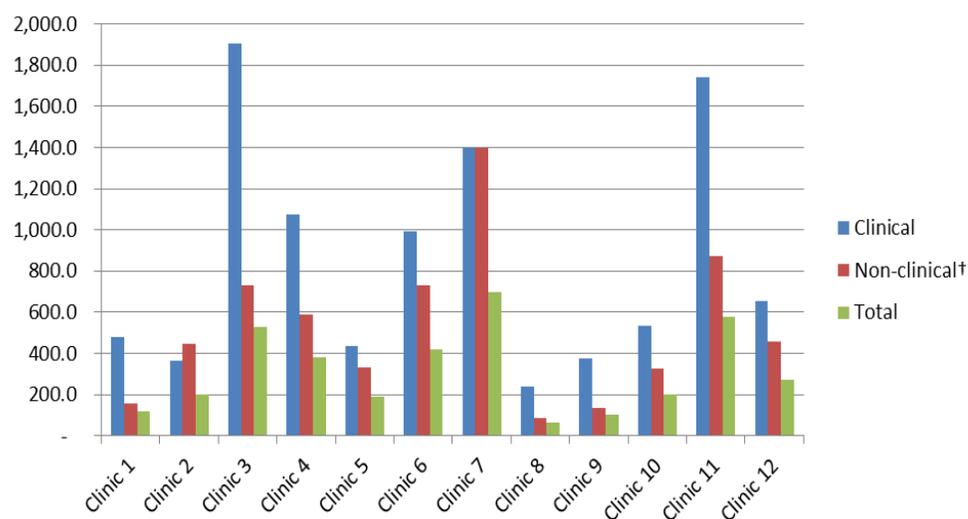


5.6 STAFF COSTS

While staffing is not the primary driver of costs at most of the clinics, patient to staff ratios reveal much about the use of resources and provide clues about the resources available to each clinic. A clinic with exceptionally low staff costs per patient may suffer from a large patient burden. Therefore, patient-staff ratios may be an indirect indicator of quality of care. Here, we examine staffing levels for clinical, non-clinical, and all staff (Figure 14). All types of patients (not just HIV) are considered. Administrative staff is not included.

Significant disparities in patient burden are immediately apparent. Clinics 3 and 11 have the highest patient-staff ratios for clinical staff at 1902 and 1741 annual patients per staff member, respectively. This is consistent with the low staff costs per patient in Tables 5 and 6. Clinic 8 had the highest staff cost per patient and, expectedly, the lowest patient to staff ratios (Clinical: 237.5, Non-clinical: 84.5, and Total: 62.3).

Figure 14 Patient-Staff Ratios



† does NOT include administrative staff

5.6 COSTS PER PATIENT BY LEVEL AND OWNERSHIP

We grouped the clinic-level cost data by level (hospital and health center) and by ownership (public and non-public) and we calculated the average costs per patient in each of these four categories for adults and for children. The results are shown in Tables 8 and 9 for adults and children respectively. It can be seen that per patient costs in public hospitals are higher than in non-public for both adults and children but the reverse is true in the health centers.

Table 8 Cost Per Adult HIV Patient by Level and Ownership

Type of cost	Public hospitals	Non-public hospitals	Public health centers	Non-public health centers
Staff	37,948	68,630	28,850	168,845
ARVs	321,544	330,870	203,725	202,638
Other drugs	11,236	16,590	9,875	9,607
Lab cost	151,599	69,074	81,963	66,501
Building, utilities, rental	132,692	97,731	11,212	64,484
Total	655,018	582,894	335,625	512,073

Table 9 Cost Per Pediatric HIV Patient by Level and Ownership

Type of cost	Public hospitals	Non-public hospitals	Public health centers	Non-public health centers
Staff	41,764	67,900	27,276	168,845
ARVs	690,800	725,019	285,626	130,566
Other drugs	22,308	8,603	4,129	2,375
Lab cost	358,218	41,282	18,677	21,151
Building, utilities, rental	116,036	62,789	8,057	64,484
Total	1,229,127	905,593	343,965	387,421

Looking first at the differences in cost by ownership for hospitals it is notable that cost per patient for labs are significantly higher in the public sector compared to the non-public sector. The same is true for the costs attributed to buildings/utilities/rentals. These differences more than compensate for the lower staff costs per patient in public hospitals.

As regards health centers where the public sector per patient cost is lower, we can see that staff costs are significantly higher per patient for both adults and children as are the estimated costs for buildings, utilities, and rentals. These differences more than cancel out the lower ARV costs in the non-public clinics.

5.7 EXTRAPOLATING TO A NATIONAL ESTIMATE

As mentioned previously, study sites were not randomly selected, and therefore are not nationally representative. Data were collected from ART-accredited centers where treatment is emphasized. This is evidenced by the large disparity between the study population and the national population with regards to the percentage of HIV patients on ART. However, it may be useful to use our estimates of the costs of HIV care to provide a preliminary estimate of national costs. Directly scaling the per-patient costs of HIV care to the national number of HIV patients is likely to over-inflate the costs of care due to the difference in ART prevalence between the study population and the national population. Instead, scaling the per-patient costs of ART and non-ART patients to the national numbers for both adult and pediatric patients will result in a more accurate estimate of the national cost of HIV care. The Ministry of Health, Uganda's HIV Surveillance Report 2011 estimates that there are 1,042,711 adult and 149,661 pediatric HIV patients. Of these, 302,361 adults and 26,699 pediatric patients are on ART therapy. Applying our per-patient ART and non-ART cost estimates to these patient numbers we arrive at an estimate of UGX 457,421,125,491 (\$208,584,033) for national HIV spending each year (Table 10). Although we account for differences in ART coverage, this estimate does not model the myriad other likely differences between the study population and the national population that would affect the cost of HIV care.

Table 10 Estimate of National Annual Cost of HIV Care

Type of care	National patients	% of national sampled	Per-patient cost	National cost estimate
Adult ART	302,361	9	756,814	228,830,925,560
Adult non-ART HIV care	740,350	3	252,061	186,613,293,448
Pediatric ART	26,699	17	916,383	24,466,511,609
Pediatric non-ART care	122,962	3	142,405	17,510,394,874
Total	1,192,372	5	542,655	457,421,125,491

5.8 RESULTS AT THE PATIENT LEVEL

There were some 637 adult patients and 208 pediatric patients that were recruited at the 12 sites. Table 11 shows their demographic characteristics. Among both male and female adults the largest portion of the sample was in the 25–34 age-bracket with more females than males. Among pediatric patients the 6–10 age range had the most patients for both girls and boys. In terms of education, a higher proportion of males completed secondary than females. Among the pediatric patients' care-givers, around 60% of both males and females had completed primary and 20% had completed secondary.

Table 11 Demographic Characteristics of the Participants

Adult patients N = 637	Male n (%)	Female n (%)	Both sexes n (%)
Age group			
18–24	80 (31.62)	90 (25.78)	179 (28.10)
25–34	115 (45.45)	157 (40.89)	272 (42.7)
35–44	53 (20.95)	114 (29.69)	167 (26.22)
45+	5 (19.8)	14 (3.65)	19 (2.98)
Education			
No education	33 (13.04)	70 (18.23)	103 (16.17)
Completed primary	98 (38.74)	206 (53.65)	304 (47.72)
Completed secondary	92 (36.36)	93 (24.22)	185 (29.04)
Diploma	18 (7.11)	15 (3.91)	33 (5.18)
Degree	12 (4.74)	0 (0)	12 (1.88)
Other			
Mean number of dependents (sd)	6.0 (3.4)	5.2 (2.5)	
Mean distance to facility (sd)			13.83 (1.16)

Pediatric patients N = 208	Male n (%)	Female n (%)	Both sexes n (%)
Age group			
0–5	17 (19.32)	39 (32.50)	56 (29.62)
6–10	44 (50.0)	53 (44.17)	97 (46.63)
11–17	27 (30.68)	28 (23.33)	55 (26.44)
Education			
No education	12 (13.64)	20 (16.67)	32 (15.38)
Completed primary	52 (59.09)	72 (60.00)	124 (59.62)
Completed secondary	18 (20.45)	22 (18.33)	40 (19.23)
Diploma	5 (5.68)	3 (2.5)	8 (3.85)
Degree	1 (1.14)	3 (2.5)	4 (1.92)
Other			
Mean number of dependents (sd)	5.3 (2.5)	5.6 (2.5)	
Mean distance to facility (sd)			9.91 (2.3)

Note also that adult patients lived on average almost 14 kms from the facility and children lived nearly 10 kms from the facility.

Table 12 shows the clinical stage of patients. We note that for both age groups and sexes the largest percentage were in ECOG 1, “fully active”, and WHO stage I

Table 12 Clinical Characteristics of Patients Interviewed

Variable	Adult patients N=637			Pediatric patients N=208		
	Male n (%)	Female n (%)	Both sexes n (%)	Male n (%)	Female n (%)	Both sexes n (%)
Functional performance (ECOG)						
Fully active	151 (59.68)	226 (58.85)	377 (59.18)	56 (63.64)	89 (74.17)	145 (69.71)
Restricted	90 (35.57)	147 (38.28)	237 (37.21)	28 (31.82)	31 (25.83)	59 (28.7)
Ambulatory	12 (4.74)	10 (2.60)	22 (3.45)	4 (4.55)	0(0.00)	4 (1.92)
Limited self-care	0 (00)	1 (0.26)	1 (0.16)	0 (0.00)	0(0.00)	0 (0.00)
WHO clinical stage						
1	104 (41.11)	152 (39.58)	256 (40.19)	31 (35.23)	56 (46.67)	87 (41.83)
2	86 (33.99)	122 (31.77)	208 (32.65)	29 (32.95)	30 (25.00)	59 (28.37)
3	32 (12.65)	56 (14.58)	88 (13.81)	16 (18.18)	17 (14.17)	33 (15.87)
4	4 (1.58)	19 (4.95)	23 (3.61)	2 (2.27)	1 (0.83)	3 (1.44)
Missing	27 (10.67)	35 (9.11)	62 (9.73)	10 (11.36)	16 (13.33)	26 (12.50)

Table 13 shows some results from patient interviews that attempted to ascertain the private financial burden on patients of their HIV status. Adults claimed to spend UGX 7,069 on transport and care-givers of pediatric patients UGX 6,779. We also asked them to estimate the value of time lost due to the illness and we see that among adults this came to UGX 18,700 for the last 30 days and UGX 11,118 for care-givers of child patients.

Table 13 Private Cost of illness

Cost category	Adult patients	Paediatric patients
Mean amount commonly spent on transport for a single visit (UGX)	7,069	6,779
Mean value of time lost due to illness in the last 30 days (UGX)	18,701	11,118
Mean days lost due to illness in the last 30 days	4.07	2.45
Mean school days lost due to illness in the last 30 days	2.46	

Using the data in Table 13 we extrapolated these to an annual basis in Table 14 where we present the average annual private burden on patients and/or their care-givers. As expected, adult annual out-of-pocket and opportunity costs were higher than those for children and the private costs to patients on ART were higher.

Table 14 Estimated Annual Private Costs Per Patient

Private costs	Adults		Pediatric Patients	
	ART	Non-ART	ART	Non-ART
Transport Costs	42,414	28,276	40,674	27,116
Value of Time Lost	224,400	224,400	133,416	133,416
Total Cost per Patient	266,814	252,676	174,090	160,532

5.9 SERVICES RECEIVED

We used the Client Services Receipt Inventory (CSRI) to ascertain the kinds of services that were being provided to patients (Appendix 5). The CSRI lists some 54 services that could be received. In Tables 15 and 16 we present the most often received services defined by a cut-off of 40% or more of patients. We note that there is considerable overlap between the services received by adults and children, with ART and related services topping the list. This is consistent with the cost distribution results seen earlier. It is also interesting and encouraging to see that 42% of adults received family planning services.

Table 15 Most Often Received Services Among Adult Patients—All Clinics

Question	N	%	
C43	septrin/cotrimoxazole to take every day	575	90.27
C13	ART/ARV (n = 617)	511	82.82
C5	adherence counseling	496	77.86
C14	assess ART treatment	470	73.78
C39	nutritional advice	439	68.92
C10	prevention with positives	415	65.15
C30	treatment for malaria	311	48.82
C18	non-opioids(e.g., paracetamol)	287	45.05
C15	assessment of pain	279	43.87
C54	infection control training	275	43.17
C6	family planning counseling	267	41.92

Table 16 Most Often Received Services Among Pediatric Patients—All Clinics

Question	N	%	
C5	adherence counseling	186	90.73
C43	septrin/cotrimoxazole to take every day	184	89.76
C13	ART/ARV	149	72.68
C39	nutritional advice	142	69.27
C14	assess ART treatment	136	66.34
C10	prevention with positives	130	63.41
C30	treatment for malaria	104	50.73
C38	Multivitamins	99	48.29
C54	infection control training	95	46.34
C40	malnutrition assessment	84	40.98

The services distribution by clinic is shown in Tables 17 and 18 for adults and for children. These largely mirror the aggregate results in Tables 12 and 13.

Table 17 Most Often Received Services Among Adult Patients (% of HIV Patients)

Services	Clinic											
	1	2	3	4	5	6	7	8	9	10	11	12
Patients interviewed	39	51	18	21	55	16	145	84	40	54	17	97
Septin/cotrimoxazole daily	98	86	94	100	95	63	92	98	95	98	95	74
ART/ARV	75	60	61	77	82	63	83	81	80	94	55	91
Adherence counselling	98	68	67	92	93	81	63	99	68	87	70	68
Assess ART treatment	73	50	56	77	84	50	82	61	78	85	45	83
Nutritional advice	88	76	89	92	71	88	52	94	63	96	90	31
Prevention with positives	78	68	83	92	82	100	23	96	63	96	80	49
Treatment for malaria	35	52	44	80	51	44	50	45	58	52	30	56
Non-opioids like paracetamol	43	32	6	46	55	6	40	33	60	67	35	62
Assessment of pain	48	34	17	54	49	13	60	29	58	48	20	37
Family planning counselling	43	32	11	23	53	6	24	63	23	83	20	31

Table 18 Most Often Received Services Among Pediatric Patients (% of HIV Patients)

Services	Clinic											
	1	2	3	4	5	6	7	8	9	10	11	12
Patients interviewed		22	17	10	16	12	32	26	10	27	6	21
Adherence counseling	78	86	100	89	100	87	87	93	78	96	100	90
Septin/cotrimoxazole daily	89	81	94	100	100	60	97	89	100	93	50	90
ART/ARV	33	52	65	89	80	60	87	63	89	78	100	95
Nutritional advice	78	86	94	56	60	60	39	93	67	89	100	30
Assess ART treatment	33	52	59	89	80	27	81	59	67	74	100	90
Prevention with positives	67		82		53	75		96	70	74	100	
Treatment for malaria	44	43	47	44	40	60	48	52	67	56	100	70
Multivitamins	22	43	82	67	27	80	42	70	11	59	50	5
Infection control training	78	38	59	33	47	40	16	56	67	67	50	35
Malnutrition assessment	33	100	18	100	7	27	19	15	44	96	50	100

Section 6 Discussion and Summary Results

This study found that the annual facility-level cost of providing HIV care and support to adult HIV patients ranges from UGX 254,000 to UGX 824,000 (\$116.28 to \$376.20) across the 12 sites, with a median cost of 567,000 UGX (\$258.78). This range is consistent with a 2011 report funded by the USAID Health Initiatives for the Private Sector (HIPS) Project that examined a total of six HIV treatment sites from Uganda's public and private sectors and from a variety of geographic settings [8]. The HIPS study found that annual costs ranged from \$226.86 to \$539.22 per adult patient on ART. This is similar to our results for adult ART patients of between \$182.40 and \$606.48 per patient per year (Table 4). The study by Menzies, et.al., estimated that adult annual ART treatment costs are much higher at between \$1,079.58 and \$1,102.38 [9].

However, as reported above there have been a few other studies from the last 10 years that estimate ART costs in sub-Saharan Africa (see Appendix 7), but many of them utilize cost data that were collected 5–10 years ago. The scale of ART therapy rollout and increased availability of generic ARVs in recent years make it likely that these older estimates are no longer reliable.

For children, we found that costs ranged from UGX 190,000 to UGX 1,869,000 (\$86.64 to \$852.72), with a median cost of UGX 630,000 (\$287.28). At sites where per-patient pediatric HIV care costs were the greatest, above-average ARV costs were the primary causes. The data show, then, that HIV care costs for children are higher than for adults. Few studies have examined the cost of HIV care for pediatric patients specifically. The Menzies, et.al., data for Uganda show a lower pediatric care cost compared to adults of between \$395.58 and \$517.56 per year.

The WHO estimates per capita health expenditures in Uganda in 2010 (\$141.36) which translates into annual expenditures of UGX 10.7 trillion for the 2011 population [21]. Using the estimated average costs of care found in this study and using the actual numbers of reported HIV adult and pediatric patients in 2011 we estimated a total care and support burden of UGX 447 billion. Using the WHO figure as an estimate of total health care expenditures and our figures for HIV care and support translates into a care and support burden of HIV/AIDS of 4.2% of total health care expenditures in the country.

The main cost drivers for both adults and children are ARVs and laboratory tests. Among all adults, ARVs account for some 51% of costs and for children ARVs account for 69%. For laboratory services the percentages are 21% and 16% respectively. So the main costs per patient are accounted for by direct services to the patients. Regarding ARVs we also looked at the distribution of costs between first and second line drugs. At this point, for the sample of clinics we visited (with one exception: Clinic 6) first line drugs account for the largest share of ARVs. As the HIV-population ages and when and if resistance to first line drugs builds, this situation may dramatically

change in the future resulting in an increase in costs since second line drugs are more expensive. Also, given the large proportion of total costs that is comprised of ARV cost, the trend of per patient cost over time is likely to closely mimic the price trends of these pharmaceuticals. Moreover, sites may benefit from some standardization of drug regimens to avoid unnecessary expenditures on more expensive drugs.

The study also found that among the facilities contacted, public hospitals had a higher cost per adult patient than did non-public hospitals but only by around 12% (UGX 655,018 vs. UGX 582,894.) Public hospitals had lower staff costs per patient while laboratory costs were higher. By contrast public health centers have much lower non-public health centers for adults (UGX 335,625 vs. UGX 512, 073.) The major factor here was much cheaper staffing costs in public health centers (UGX 28,850 vs. UGX 168,845.) Similar patterns were found for children.

We collected information from patients about some of their out-of-pocket expenses on transportation, and the value of time lost in seeking and getting treatment. For those patients on ART, annualized adult costs were UGX 266,814 and for children UGX 174,090. The largest component of this cost was the value of time lost. These out-of-pocket costs amount to a high burden for individuals when compared to per capita income. The World Bank estimates current gross domestic income (GNI) per capita at \$581.40 in Uganda [22]. Converting this to local currency means a GNI per capita of UGX 1,275,000. Thus for adults, out-of-pocket expenses amount to 20% of GNI per capita and for children 13% of GNI per capita.

There were only minor differences in the rankings of the most-often received services by adult and pediatric patients in the study sample. Septrin/cotrimoxazole as a prophylaxis, the most frequent service, was received among 90% of adults and 90% of children. ART was received by 83% of adults and 73% of children among patients sampled. Adherence counseling was the top ranking service among children (91%) and was third in line for adults (78%.) Pain control using non-opioids and pain assessment were in the top ten services received by adults (45% and 44% respectively), but did not rank in the top ten services for children. We found it interesting that among our adult respondents, 42% had received family planning counseling.

Our estimate of the overall current annual burden of HIV on national health care costs is low at 4.2%. However, this is likely to increase in the future. First, universal access targets for ART, if met, will increase the proportion of patients on ART and therefore the costs. Also, recent upward trends in prevalence, together with an increased population and longer survival of those on ART, points to increased numbers of HIV+ patients and costs in the future. Since ARV and laboratory costs are the main cost drivers for both children and adult patients, costs are tied directly to the number of patients. Given that drug and lab costs are determined largely by the international market there is not much that Uganda's service providers can do to reduce costs without changing regimens or reducing service levels. It is therefore important that the Ministry of Health, Uganda's effort to purchase ARVs at the most favorable prices remains a priority. This will be increasingly the case in the likely event that donor funding for HIV care and support, including ARVs, decreases in the future.

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Appendix 1: Sample Size Calculation for Patient Interviews

Site name	Adult patients	Sample size	Pediatric patients	Sample size	Total number of patients on program
Gulu Regional Referral Hospital	2,503	46	408	22	2,911
Mbarara Regional Referral Hospital	8,500	156	650	35	9,150
Mbuya Reach Out	4,034	74	384	20	4,418
Mujuku H/CIV	1,809	33	120	6	1,929
Busiu H/CIV	694	13	42	2	736
Virika Hospital	2,998	55	362	19	3,360
Arua Regional Referral Hospital	4,732	87	676	36	5,408
Kayunga Hospital	1,054	19	201	11	1,255
St Joseph's Hospital Kitgum	3,066	56	309	16	4,716
Kawempe H/CIV	1,384	25	237	13	1,621
Holy Cross Kikyusa	920	17	49	3	969
Kiswa H/C III	902	17	319	17	1,221
Totals	32,596	600	3,757	200	



Appendix 2: Information Sheet

June 2011

COSTING OF HIV TREATMENT CARE AND SUPPORT SERVICES AT 12 SITES IN UGANDA

You are being invited to take part in a study. Before you decide, it is important for you to understand why the research is being done, and what it will involve.

Please take time to read / listen to this information carefully and discuss it with friends, relatives and your doctor if you wish. Please ask us if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are trying to establish the cost of providing HIV treatment care and support services at 12 sites in Uganda. To address this objective we are using two approaches: one involves reviewing facility financial records, and the second involves interviewing patients / carers on components of care received in the previous thirty days.

Why have I been chosen?

By talking to different patients / carers who are cared for and supported by this organization, we hope to obtain information on time spent in care, what components of care people receive and costs incurred in care, and this will help us to estimate the cost of the services. In this way, you have been asked to take part because we would like to hear your story about the treatment, care and support you / your child receives.

Do I have to take part?

No, you don't have to take part in the study if you don't wish to. If you decide to participate, you are free to withdraw from the discussion at any time, and you don't have to give a reason. Taking part, withdrawing at any time, or a decision not to take part at all will not affect the standard of care you receive from this organization in any way.

What will it involve?

If you do agree to participate, you will be given this information to keep and asked to sign a consent form to show that you have agreed to take part. A researcher who is working with the African Palliative Care Association (APCA) will arrange a convenient time with you and the other people asked to participate to hold a short interview.

The discussion will last no more than 15 minutes, unless you wish to talk for longer. After these discussions there will be no more things for you to do with this study.

Will my taking part in this study be kept confidential?

All the information which we collect will be kept strictly confidential. We will be making notes on the discussion. None of the people who provide your care will be involved in the discussion or have access to the notes.

You will not be identified in any way, and your personal details (for example, your name) will be kept separately from the information you give. We will NOT let anyone have any information that could identify you. Any information you give us during the discussion will NOT be kept with anything that could identify you (like your name or address). You may withdraw your data from the project at any time up until it is used in the final report.

What happens to the results of the research study?

We will use the interviews in which you participate to write up reports on the costs of HIV treatment, care and support. Nothing you say will be identified as coming from you.

Who is organizing the research?

This study is being organized by the African Palliative Care Association (APCA) in conjunction with Constella Features. The Uganda National Council for Science and Technology has reviewed this study and approved it for your protection.

Who can I contact?

If you would like to talk to someone about the study, or get more information, please contact Eve Namisango, the Research Coordinator, on 0414 266 251 or the Secretary of the Uganda National Council for science and Technology on 0414 234 579.



Appendix 3: Consent Form June 2011

COSTING OF HIV TREATMENT CARE AND SUPPORT SERVICES AT 12 SITES IN UGANDA

Participant's Statement for Interviews:

- I confirm that I have read and understand the information sheet dated June 2011 for the above study and have had the opportunity to ask questions.
- I understand that if I decide at any other time during the research that I no longer wish myself to participate in this project, I can notify the researchers involved and be withdrawn from it immediately without my legal rights being affected.
- I consent to the processing of personal information about me for the purpose of this research study. I understand that such information will be treated as strictly confidential.
- I agree to take part in the above study.

Print name: _____

Signature or fingerprint: _____

Date: _____

Researcher's statement

I _____ (name) confirm that I have carefully explained the nature and demands of the proposed interviews to the health care professional involved in the pilot study.

Signature: _____

Date: _____

Appendix 4: Demography Questionnaire

D1	Facility ID	<input type="text"/>	<input type="text"/>	<input type="text"/>	D3	carer's gender	1=male, 2= female	<input type="text"/>
D2	Type of respondent 1= adult patient 2=carer	<input type="text"/>	<input type="text"/>		D4	carer's age	<input type="text"/>	<input type="text"/>
P1	Please indicate the patient's gender		male=1, female=2	<input type="text"/>	<input type="text"/>			
<i>I would like to ask you a few questions about your or this child's background:</i>								
P2	How old are you (in years)? Write age of the child if it is a carer reporting on behalf of a child			<input type="text"/>	<input type="text"/>			
P3	What is the highest level of education you attended?		none=1 attended primary=2 attended secondary=3 diploma=4 degree or higher=5	<input type="text"/>				
P4	On average how much do you earn in a month?		shillings	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
P5	What is the main material used to make the floors of your house?		natural finished	earth, mud, sand=1 cement=2 linoleum=3 parquet/polished wood=4 tile=5 carpet=6 stone=7	<input type="text"/>			
P6	What is the main material used to make the walls of your house?		natural rudimentary finished	thatched/straw=1 mud and poles=2 un-burnt bricks=3 burnt bricks with mud=4 cement blocks=5 stone=6 Wood timber=7 burnt bricks with cement=8	<input type="text"/>			
P7	What is the main material used to make the roof of your house?		natural finished	thatched=1 wood/planks=2 corrugated iron sheets=3 asbestos=4 tiles=5 tin=6 cement/concrete=7	<input type="text"/>			
P8	What type of toilet do you use at home?		private flush=1 private VIP latrine =2 private traditional pit (covered)=3 private traditional pit (uncovered)=4 public/shared=5 bush/field/other=6	<input type="text"/>				
P9	How far from the facility do you live? (kilometres) If not known,		don't know=888	<input type="text"/>	<input type="text"/>	<input type="text"/>	km	
P10	Using your regular means of transport, how long does it take you to reach this facility			<input type="text"/>	<input type="text"/>	<input type="text"/>	mins	
P11	How many dependants do you have? for adults and carers only (family members who are dependent on you including children)			<input type="text"/>	<input type="text"/>			

P12	What is the main source of drinking water for your house?	safe bottled=0 piped inside house=1 piped outside house (yard, public tap)=2 protected well=3 borehole=4 spring/rain water=5 unsafe unprotected well=6 river/stream/pond=7 tanker truck=8	<input type="checkbox"/>
P13	What type of fuel does your household mainly use for cooking?	electricity=01, lpg/natural gas=02 biogas=03, paraffin/kerosene=04 coal=05, charcoal from wood=06 firewood=07, straw/shrubs/grass=08 dung=10, no food cooked in household=11	<input type="checkbox"/> <input type="checkbox"/>
P14.1	Does anyone in the household own a ...?	car bicycle refrigerator television mobile phone radio	yes = 1, no = 2
P14.2			<input type="checkbox"/>
P14.3			<input type="checkbox"/>
P14.4			<input type="checkbox"/>
P14.5			<input type="checkbox"/>
P14.6			<input type="checkbox"/>
P15	How many working/school days have you or your child lost due to HIV-related illness in the previous 30 days?		<input type="checkbox"/> <input type="checkbox"/>
P16	Do you /your child have an informal carer at home? 1 yes 2 No		<input type="checkbox"/> <input type="checkbox"/>
P17	In the last 30 days how many days did your carer spend attending to you or this child ?		<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
P18	Estimate the money worth of this lost time (how much would you pay someone to do the work your carer lost or could not do then? Shs		<input type="checkbox"/>
P19	What date did you /this child enrol into this facility?	dd/mm/yy unknown day= 15, unknown month= 06, unknown year =08/08/888	<input type="checkbox"/>
P20	ECOG rated by the Interviewer Physical Function of the patient 0= fully active, able to carry on all pre-disease performance without restriction 1=Restricted in physically strenuous activity but ambulatory and able to carry out light work, e.g., light house work, office work 2=Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours 3=Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours 4=Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair		<input type="checkbox"/>
P21	date diagnosed HIV+	dd/mm/yy unknown day= 15, unknown month= 06, unknown year =08/08/888	<input type="checkbox"/>
P22	date started on ARV treatment	dd/mm/yy unknown day= 15, unknown month= 06, unknown year =08/08/888 777777=not on ARV	<input type="checkbox"/>
P23	Current WHO clinical stage (1-4)	8=don't know	<input type="checkbox"/>

Appendix 5: Client Service Receipt Inventory

CSRI date

Facility ID

Please indicate type of clientele

1= Pediatric 2=Adult

Ask the patient /carer if they have received the following care in the last 30 days. If yes, where? Time spent with provider in minutes

Category of care	Component of care	Have you/this child received care from any facility in the last month? 1=yes, 2=no A	This facility=1 elsewhere=2 If A=2 or 8, B=7 B	if A=2 or 8, C=7 C
------------------	-------------------	---	---	--------------------

Question number	Question section:			
C1	Spiritual visit by pastor etc	<input type="checkbox"/>		
C2	prayer with staff	<input type="checkbox"/>		
C3	contact with traditional healer	<input type="checkbox"/>		
C4	Psychological pre and post test counselling	<input type="checkbox"/>		
C5	adherence counselling	<input type="checkbox"/>		
C6	family planning counselling	<input type="checkbox"/>		
C7	patient HIV support groups	<input type="checkbox"/>		
C8	family counselling	<input type="checkbox"/>		
C9	psychiatric therapy	<input type="checkbox"/>		
	Clinical			
	Prevention	<input type="checkbox"/>		
C10	prevention with positives	<input type="checkbox"/>		
	General	<input type="checkbox"/>		
C11	wound care	<input type="checkbox"/>		
C12	other nursing care	<input type="checkbox"/>		
C13	ART/ARV	<input type="checkbox"/>		
C14	assess ART treatment	<input type="checkbox"/>		
	Pain	<input type="checkbox"/>		
C15	assessment of pain	<input type="checkbox"/>		
C16	strong opioids eg morphine	<input type="checkbox"/>		
C17	weak opioids eg codeine	<input type="checkbox"/>		
C18	non-opioids eg paracetamol	<input type="checkbox"/>		
C19	treatment for neuropathic pain	<input type="checkbox"/>		
	Symptom management	<input type="checkbox"/>		
C20	anxiety/depression treatment	<input type="checkbox"/>		
C21	treatment for nausea/vomiting	<input type="checkbox"/>		
C22	treatment for skin rash/itching	<input type="checkbox"/>		
C23	treatment for diarrhoea, including ORS or drip	<input type="checkbox"/>		
C24	treatment for constipation/laxatives	<input type="checkbox"/>		
C25	treatment for genital thrush	<input type="checkbox"/>		
C26	treatment for oral thrush/candidiasis	<input type="checkbox"/>		
C27	treatment for cryptococcal meningitis	<input type="checkbox"/>		

Category of care	Component of care	have you/this child received th care from any facility in the last month? 1=yes, 2=no, 8=don't know	If yes, where? this facility=1 elsewhere=2 If A=2 or 8, B=7	Time spent with provider in minutes If A=2 or 8, C=7
Question number	Question section:	A	B	C
C28	treatment for other fungal infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C29	treatment for herpes (e.g. acyclovir)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C30	treatment for malaria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C31	TB testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C32	TB treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C33	therapeutic feeding for severe malnutrition, i.e. drip or RUTF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C34	treatment for other opportunistic infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C35	management of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C36	physiotherapy i.e. excercises to help improve movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Prophylaxis			
C37	food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C38	multivitamins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C39	nutritional advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C40	malnutrition assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C41	nutrition counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C42	provided access to safe drinking water at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C43	septrin/cotrimoxazole to take every day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C44	isoniazid (INH) to prevent TB	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C45	condoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C46	mosquito bednets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C47	Social provide household items	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C48	home help e.g. help with bathing, housework, cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C49	employment training/IGA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C50	transport/money for bus to care centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C51	legal services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C52	memory book work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C53	loans/microfinance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C54	infection control training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C55	Did you/this child sleep under a bednet last night?	1=yes, 2=no	<input type="checkbox"/>	<input type="checkbox"/>
C56	Did you/this child take cotrimoxazole yesterday?	1=yes, 2=no	<input type="checkbox"/>	<input type="checkbox"/>
How much have you spent on your care in past month (inclu transport to facility and drugs)				
C57	At this facility?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C58	Anywhere else?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C59	On transport to the facility today ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C60	What means of transport do you commonly use to come to the health facility	1 Walking <input type="checkbox"/> 2 Taxi/Bus 3 Bicycle 4 Motor cycle		

Appendix 6: Costing Tool

Facility number Date

Completed by : Type of clinic clientele 1=Adult clinic 2=Pediatric clinic

(1) Patient numbers

1	total number of individuals cared for in past year (2010):	<input type="text"/>							
2	# individuals provided with any HIV care in past year (2010), including ART and non-ART:	<input type="text"/>							
3	of those, total number of individuals provided with ART in past year (2010):	<input type="text"/>							

NB: All following questions refer to **HIV care only and in the context of patients being HIV positive**

(2) staff

ask a range of staff (doctor, nurse, counsellor, CHW)

staff type	Total number of HIV patients you see in a typical day	Total number of hours spent with HIV patients per week	Total hours worked per week
4.1.1 doctor 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.1.2 doctor 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.2.1 nurse 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.2.2 nurse 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.3.1 counsellor 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.3.2 counsellor 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.4.1 community health worker 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.4.2 community health worker 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.5.1 <i>clinical officer</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.5.2 Pharmacist	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.5.3 Dispenser	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.6.0 <i>lab staff</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.7.0 psychiatric nurse	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.7.1 Palliative care nurse	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.7.2 <i>Psychologist</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.8.0 Nutritionist	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.9.0 volunteer	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.10.1 play therapist	<input type="text"/>	<input type="text"/>	<input type="text"/>

Facility number

Date

(3) medicines		ask pharmacist Option A	OR ask clinician/pharmacist option B	
medicine	Actual quantity dispensed in last 3 mths of 2011 (tabs)	Estimated quantity used by typical pt in 3 mths (tabs)		
		on ART	pre-ART	
5	Abacavir (ABC)			
6	Didanosine (ddI)			
7	Efavirenz (EFV)			
8	Indinavir (IDV)			
9	Lamivudine (3TC)			
10	Lopinavir (LPV) + Ritonavir (RTV)			
11	Nelfinavir (NFV)			
12	Nevirapine (NVP)			
13	Stavudine (d4T)			
14	Stavudine + Lamivudine			
15	Stavudine + Lamivudine + Nevirapine			
16	Tenofovir (TDF)			
17	Tenofovir + Emtricitabine (FTC)			
18	Zidovudine (ZDV)			
19	Zidovudine + Lamivudine			
20	Zidovudine + Lamivudine + Nevirapine			
21	strong opioids e.g. morphine			
22	Septrin/cotrimoxazole			
23	weak opioids e.g. codeine			
non-opioid painkillers (name 3 most common)				
24.1	1. _____			
24.2	2. _____			
24.3	3. _____			
25	* TB treatment			

Facility number

Date

(3) medicines continued		ask pharmacist Option A	OR ask clinician/pharmacist option B	
medicine	Actual quantity dispensed in last 3 mths of 2011 (tabs)	Estimated quantity used by typical pt in 3 mths (tabs)		
		on ART	pre-ART	
other antibiotics for opportunistic infections (name 3 most common)				
26.1				
26.2				
26.3				
Name 2 most common first line ART regimens:		Actual number of patients on this regimen	Estimated number of patients on this regimen	
27.1	1. _____			
27.2	2. _____			
Name 2 most common second line ART regimens:				
28.1	1. _____			
28.2	2. _____			

(4) lab tests

test	ask lab staff and doctor	Option A	or Option B	
		Actual number of tests this facility conducted in last 3 mths	Estimated number of tests a typical patient receives in 3 months	
			on ART	pre-ART
29	liver function test (LFT)			
30	AFB smear (TB)			
31	CD4 count			
32	haematology test (FHG)			
33	viral load			

Facility number

Date

(5) building infrastructure and utilities (all, not only HIV)

ask accountant/manager

34	Utility costs per month (shillings) Include water, electricity, generator fuel, communications, waste disposal etc	
35	Transport costs, fuel, drivers, maintenance (shillings)	
36	Clinical consumable costs per month (shillings) Include gloves, syringes, cotton wool swabs, plasters, soap, sterilising solution etc	
37	amount spent on volunteer staff (inclu training, travel reimbursements, payment in kind) in past 3 months (shillings)	

(6) capital costs

ask accountant

(operations and maintenance officer)

38	approximate total facility space (sq m)	
39	approximate facility space for HIV care (sq m)	
40	rent per month, or estimated rental value	
41	number of four-wheeled vehicles	
42	number of two-wheeled vehicles	

Reliability of the data: -----

Sources : -----

Designations and names of personnel interviewed

Appendix 7: HIV Cost Study Summaries

Source	\$ Year (data year)	Country	Number of facilities	Setting	Patient population	Annual per-patient cost
Simms, et.al.	2009 (2009)	Uganda	6	Public PEPFAR-supported facilities	Adult HIV+	\$41–719
Simms, et.al.	2009 (2009)	Kenya	6	Public PEPFAR-supported facilities	Adult HIV+	\$77–1,160
McCoy, et al.	2010 (2011)	Uganda	6	Public and private; various geographic locations	Adult ART patients	\$199–473
Menzies, et al.	2009 (2006–2007)	Uganda	7	Unclear; geography unclear	Adult and pediatric HIV+ patients	Pre-ART: \$142 ART: \$843 Adult ART: \$947–967 Paediatric ART: \$347–454
Rosen, et al.	2006 (2005)	South Africa	4	Public, private, and NGO	Adult ART patients	\$756–,126
Bikilla, et al.	2005 (2003–2006)	Ethiopia	1	Public	HIV+ patients over age 15	ART: \$235 Non-ART: \$38
Martinson, et al.	2004 (2004–2005)	South Africa	1	NGO	Adult HIV+ Patients	Stable ART: \$1,428 Non-Art: \$754
Koenig, et al.	2004 (2003–2005)	Haiti	1	Urban HIV clinic (funding source unclear)	Adult ART patients	\$960
Harling, et al.	2004 (2004–2006)	South Africa	1	Public/NGO partnership; periurban	All HIV+ patients	First year ART: \$2,502 Second year ART: \$1,372

Appendix 8: List of Facilities by Clinic Number and Name

Clinic Number	Clinic Name
1	Busiu
2	Gulu
3	Kawempe
4	Kayunga
5	Kitgum
6	Kiswa
7	Mbarara
8	Mbuya
9	Mukuju
10	Virika
11	Kikyusa
12	Arua

MEASURE Evaluation

Carolina Population Center
University of North Carolina at Chapel Hill
206 W. Franklin Street
Chapel Hill, NC 27516

www.measureevaluation.org