

## Adolescent HIV Care and Treatment in Uganda: Care Models, Best Practices and Innovations to Improve Services

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### Abstract

**Background:** The number of adolescents living with HIV (ALHIV) in Uganda is growing. Improving access to HIV services among this population requires a lot of innovation. This study describes service delivery models and innovations to improve access to HIV care and treatment services by adolescents in Uganda.

**Methods:** It was a mixed methods study in which the qualitative aspects included in-depth interviews, Focus Group Discussions and Key Informant Interviews with adolescents and various stakeholders. Quantitative data was obtained by a cross-sectional design using a questionnaire for 30 health facilities from 10 representative districts of Uganda.

**Results:** The integrated HIV clinic model was used by 63% (19/30) of the facilities. The most preferred "Stand alone Adolescent HIV clinics" were present in only 17% (5/30). Separate adult and children's HIV clinic models were 20% (6/30). Only 1/30 (3%) had a transition clinic. Health workers were ignorant about transition clinics but ALHIV expressed a great need for them. Only 30% (9/30) of the health facilities had Youth corners.

"Peer support groups" were the commonest innovation present in 36% (9/25) of government facilities and 80% (4/5) of the private facilities. Other innovations included HIV testing at night, in schools, making community outreaches, avoiding clinic appointments during school time, use of social media, reducing waiting time, providing privacy, food, skills and transport among others.

**Conclusion:** Stand-alone adolescent clinics are the preferred model of care for ALHIV. Youth corners in health facilities and peer support clubs were valued innovations but funding was a significant hindrance.

**Keywords:** Adolescents; HIV; Care models; Best practices; Uganda

**Abbreviations** AIDS: Acquired Immunodeficiency Syndrome; ALHIV: Adolescents Living with HIV; ART: Antiretroviral Therapy; FGD: Focus Group Discussions; HC: Health Center; HIV: Human Immunodeficiency Virus; HCT: HIV Counseling and Testing; IDI: In depth interviews; KII: Key Informant Interviews; MOH: Ministry of Health; OVC: Orphans and Vulnerable Children; SUSTAIN: Strengthening Uganda's Systems for Treating AIDS Nationally; TASO: The AIDS Support Organization; USAID: United States Agency for International Development; WHO: World Health Organization; YPLHIV: Young Person Living with HIV.

### Background

About 2.1 million adolescents aged 10-19 years are living with HIV worldwide [1]. This growing number is due in part to the growing number of new HIV infections in this age group [2]. With many children living with HIV [3] accessing antiretroviral therapy (ART), the population of adolescents living with HIV (ALHIV) will increase. About 127,000 adolescents aged 10 to 19 are living with HIV in Uganda [4] and there was increased prevalence among the 15-24 age

group [5]. This trend of increasing HIV prevalence is a call for action by the Uganda Ministry of Health (MOH). The MOH therefore conducted a baseline survey on ALHIV which found that despite an HIV Counseling and Testing (HCT) acceptance rate of 97%, only 29% of the 43,333 eligible ALHIV were actually receiving ARVs [6]. This was far below the adults and children who are at 75% and 41% respectively according to the Annual Health Sector Performance Report 2012/2013 [7]. This finding of low access to HIV services as well as previous research which indicated that adolescents were the only group where HIV related mortality was going up [8] led to increased focus on this age group.

Adolescents living with HIV (ALHIV) include long-term survivors of mother-to-child transmission and those who contracted the disease through sexual relationships. Studies show that adolescents generally shun health services if they are not adolescent friendly [9,10]. This calls for innovations in attracting and keeping them in care. The various implementation partners supporting HIV care in Uganda have a range of innovations to support ALHIV with diverse outcomes and challenges which need to be documented. This study therefore set out to assess the current adolescent HIV care and treatment service models and innovations in Uganda and gather data on best practices which can be emulated.

## Methodology

The study was conducted between December 2013 and March 2014. It employed both quantitative and qualitative methods and involved all 10 sub regions of Uganda. One district was purposively selected from each region and these included; Arua, Gulu, Serere, Mbale, Iganga, Kampala, Kiboga, Masaka, Kiruhura and Kabarole districts. Of the 10 districts, 30% were randomly selected from districts which recorded good services (Cotrimoxazole prophylaxis above 80%, 6 months CD4 access above 80% and 70% linkage to care for ALHIV), 30% from those without and the rest were districts with unique situations according to the baseline quantitative adolescent survey by MOH [6]. Due to logistics, it was predetermined that only 30 health facilities were included. In each district, 3 health facilities offering ART services for adolescents were selected; one of which had to be a hospital, a Health Center (HC) IV and a HC III. By stratified sampling, selection of facilities was made in a way to capture those that had good services for ALHIV according to the baseline quantitative survey as earlier described, and those who do not. The selection was also made in such a way that different health facility levels, providers and various implementation partners were involved.

For the qualitative component, we conducted 33 FGDs involving 227 ALHIV and 5 FGDs with 46 caregivers of ALHIV, 10 districts involved in the study, ALHIV were selected from 5 purposively selected districts according to the gaps, presence of best practices, to represent urban and rural adolescents, implementing partners and providers whether MOH or private. The 5 selected districts included; Kampala, Kiboga, Gulu, Mbale and Kiruhura districts. Adolescent FGDs were held in homogeneously constituted categories according to sex and age. Two age group categories were used; young adolescents aged 10 to 14 years and older ones aged 15 to 19 years. Only ALHIV who knew their HIV status were selected. There was 1 FGD for caregivers per district. We observed the FGD norms including use of a FGD guide, a moderator, observer taking notes, ensuring anonymity and confidentiality and use of appropriate local languages.

We conducted 69 KIIs with major stakeholders at the different levels. For sensitive and private data, 40 IDIs involving four ALHIV per district in the following categories; lost-to-follow-up from HIV care, those in long term relationships/married/cohabiting, in-school and out-of-school adolescents. All interviews and discussions were audio taped.

For the quantitative part, all 30 health facilities were assessed using a facility based checklist to describe the services for ALHIV.

## Data management and analysis

For the qualitative part, transcription and translation of all the recordings was done. Analysis was done using computer based analysis; Atlas-ti software. Quantitative data was entered into an Epi-data (version 3.1) database which was designed with appropriate controls and validation checks and analyzed using STATA 10.0 (College Station, TX, USA).

Quality assurance was ensured by using a multi-disciplinary research team of experienced medical, public health and social scientists. All research assistants were trained before data collection, field supervision took place and all interviews were audio recorded. To increase reliability, two independent raters analyzed the data.

Informed consent was obtained from ALHIV aged 18 years and older, their caregivers, all respondents of KII, IDI and FGD

participants. Assent was obtained from adolescents below 18 years and their caregivers consented before the adolescents participated in the study. Ethical approval was obtained from Makerere University College of Health Sciences; School of Public Health Institutional Review Board and Uganda National Council for Science and Technology before data collection.

## Results

A total of 227 ALHIV were involved in the FGDs. Table 1 describes their baseline characteristics while Table 2 provides a summary of the key informant respondents.

Variables		Frequency (N=227)	Percent
Sex	Female	136	59.90%
	Male	86	37.90%
Location	Rural	98	43.20%
	Urban	129	56.80%
Health Facility Level	HC IV	66	29.10%
	General Hospital	42	18.50%
	RRH	26	11.50%
	Special clinic	93	41.00%
HIV Transmission	Mother to child	146	64.30%
	Horizontal	32	14.10%
	Unknown	40	17.60%
Orphan	Yes	142	62.60%
Sexual experience	Yes	83	36.60%
Ever used condom	Yes	64	28.20%
On ARVs	Yes	186	81.90%
In school	Yes	162	71.40%

**Table 1:** Baseline characteristics of adolescents involved in FGDs.

Category of Key Informants	Numbers
National Key Informants in 3 relevant ministries	8
Education Sector (school staff)	4
UN agencies and donors	5
District administrators and technical staff	9
Political Leaders	4
Implementing Partners	11
Health Workers, Social Workers and Counsellors	14
Civil Society Organizations and NGOs	7
Religious leaders	3
Community Resource persons	4
Total Key informants	69

**Table 2:** Categories of key informant respondents.

### Care and treatment models for adolescents living with HIV

There were 4 different models of care for ALHIV as shown in Table 3. “Specific Adolescent HIV clinic” refers to HIV clinics for only adolescent age group. In this study, specific adolescent HIV clinics were present in only 17% (5/30) of health facilities as shown in Table 3. They were more in the private sector 60% (3/5) compared to government facilities (2/25) as shown in Table 4. Regarding health facility level, adolescent clinics were mainly in the special clinics (3/3) and RRH (2/4). During FGDs, most adolescents expressed a need for their own adolescent clinics where they interact with peers, encourage each other and share ideas freely in their own language (slang).

Model	Target	Frequency
Integrated Clinic	HIV +adolescents	19/30 (63%)
Children and Adults clinics	HIV +adolescents	6/30 (20%)
Adolescent clinic	HIV +adolescents	5/30 (17%)
Transition Clinics	HIV +adolescents	1/30 (3%)
General Adolescent centers	All adolescents	Not Applicable
Youth Corners	All adolescents	9/30 (30%)

Table 3: Care models for HIV among adolescents.

	Government		Private		HC III		HC IV		Hospital		RRH		Special clinic		Total	
	25		5		7		12		4		4		3		30	
Adolescent peer support group	9	36%	4	8%	2	2%	3	2%	2	5%	3	7%	3	10%	13	43%
OVC program	10	4%	3	6%	2	29%	5	42%	1	25%	2	50%	3	100%	13	43%
Transport refund	4	1%	3	6%	0	0%	1	8%	2	5%	2	5%	2	6%	7	23%
Telephone follow up	14	5%	5	100%	2	29%	8	67%	2	50%	4	100%	3	100%	19	63%
Home/Community Health workers	21	8%	5	100%	5	71%	11	92%	3	75%	4	100%	3	100%	26	87%
Skills training for ALHIV	3	12%	4	80%	0	0%	2	17%	1	25%	1	25%	3	100%	7	23%
Income Generating Activities for adolescents	24	96%	2	40%	7	100%	12	100%	4	100%	3	75%	0	0%	26	87%
Provide Food supplements	6	24%	2	40%	2	29%	1	8%	1	25%	2	50%	2	67%	8	27%
Food given while in the waiting area	21	84%	3	60%	5	71%	11	92%	4	100%	3	75%	1	33%	24	80%

Table 4: Innovations and best practices for ALHIV by provider and facility level.

One ALHIV said, “it is good for adults to be alone, adolescents alone and children alone” IDI male ALHIV. Some felt that targeted interventions can be arranged through adolescent clinics. One female ALHIV noted, “For example, a teen mother should not be given similar counseling with an adolescent. The adolescent should not be counseled like a five year old child”. IDI female ALHIV Kampala. The caregivers also emphasized the need for adolescent clinics and mentioned that adult clinics daunt to them. Many service providers also expressed this need but reported constraints of space and staff to run adolescent HIV clinics.

“Transition Clinic” refers to a clinic day or space for older adolescents who are ready to join adult clinics. Transition clinics are meant to prepare older adolescents and youth to smoothly change to adult HIV clinics. There was only one transition clinic 3% (1/30) which was a special clinic as indicated in Table 3 above. Although they are supposed to be temporary placements for the older adolescents, this program keeps the adolescents and young people together but they do not move on to adult clinics. ALHIV suggested that transition to adult

clinics should be a gradual process as stated below. “They can start by reminding you that you will be going to the adult clinic, not just coming one day and sending you there” FGD ALHIV Gulu. Much as the ALHIV expressed a need for transition, service providers did not appreciate the concept of transitioning and reported no plans for transitioning ALHIV.

Integrated HIV Clinics were the major HIV clinic model practiced by 63% (19/30) of the facilities in the study. In the integrated clinics, adults, adolescents and children were seen together on the same HIV clinic days. The advantage of this method is that families can be seen together on the same clinic day. However, the adolescents’ special needs do not get catered for and this makes them more likely to get lost to follow up. We established that generally ALHIV did not like integrated clinics because the adults treated them like “young children”. Some adults are rude to them and make them uncomfortable by commenting negatively about their dress code. They also reported that the adult clinics were overcrowded. They reported experiencing judgmental sentiments from adults as stated below. “They may say

things like “what was she looking for?” not knowing that sometimes you can be born with it” FGD female ALHIV Kampala.

In the adult and Paediatric HIV Clinics Model, the adolescents attended one of the two depending on their age. The clinics usually run on separate days. Only 20% (6/30) of facilities had separate children’s HIV clinics. The disadvantage of this model is that younger adolescents are handled like children and the older ones like adults, therefore, their specific needs are not met.

## Models of Care for Adolescents in General

From the qualitative aspect of the study, we came across two models of care for adolescents; general adolescent centers and youth corners in health facilities. The former are adolescent-friendly health centers open to all adolescents and they mainly provide Sexual and Reproductive Health (SRH) services. Since they are not specific to HIV, they attract large numbers of adolescents. However, this model is very expensive to maintain and it tends to depend on donors. In addition, since they provide HCT but do not provide on-site HIV care, adolescents may be lost in the process of referral to the HIV care centers.

The Youth Corners are designated spaces in health facilities which provide adolescent-friendly services which mainly include SRH. Youth corners were present in 30% (9/30) of the health facilities in the study. However, even where they existed, some were not functional because of funding gaps. Like the model above, youth corners very attractive to young people and would improve access to SRH including HCT. However, the disadvantage of this method is that it is expensive, needs space and does not cater for HIV positive adolescents since it is not integrated with ART clinics. Uganda being a youthful country with 55% under 18 years, one key informant had this comment. “The strategy for youth corners may not stand over time. Instead of small youth corners we may change to small old people’s corners and the rest of the facilities designed for young populations. Youth corners are small yet the beneficiaries are many leading to discouragement of their use” KII MOH.

## Best Practices and Innovations for Adolescent HIV Testing and Care

### HIV testing

Night time HIV testing has been practiced by some programs mainly for out-of-school male adolescents. Others bring HIV testing closer to adolescents in places where they watch football matches, music shows and other youth gatherings. Testing for HIV at school either by offering a voluntary free HIV test at school or making it part of the routine pre- school medical checkup has been tried. Others use adolescent peers to sensitize others for HIV testing at school and communities.

### Innovations with linkage to care after HIV testing

One of the innovations is physical linkage to care after testing HIV positive using volunteers in large hospitals. Some linkages are at community level where all who test HIV positive from community outreaches are followed up.

## Innovations to support adherence, retention in care and psychosocial support

Various innovations as summarized in Table 4 below are taking place in the health facilities to support adherence, retention in care and for on-going psycho social support. Adolescent peer support groups were present in 36% (9/25) of the government facilities and 80% (4/5) of the private facilities as shown in Table 3 above. The peer support related activities reported ranged from use of trained peer educators, sports, life skills training, music, dance and drama. They vary in frequency of meetings, costs involved, activities and presence of and design of curriculum. Much as the need for peer support is acknowledged by all, many key informants expressed that it was very expensive to sustain them. Many programs have 3 meetings a year during school holidays mainly because of lack of funding. These few meetings take the format of a big party or celebration and the life skills training is minimal “Three times a year for a young brain is too long. At worst maybe every 6 weeks. By nature, the longer we take the more we forget because of finances, we should make it every 6 to 8 weeks” KII Implementing partner, Kampala.

Other innovations include use of trained peer educators, peer treatment supporters, caregiver support groups, peer support for pregnant adolescents and individual and group counseling. Some key informants suggested that psychosocial services should either involve ALHIV or be adolescent-led. Adolescents prefer youthful counselors who can easily relate with them as stated below “there are some things I am supposed to share with my fellow youth. For example you cannot tell an old counselor that you had sex and she does not look at you weirdly (laughter). I have ever experienced it myself and it was not only me” KII Young Person living with HIV (YPLHIV) Kampala.

In one health facility, providing a special clinic day for the pregnant ALHIV was received with mixed feelings. While many were impressed, one stated, “... and we have many experiences from Baylor, when a young person gets pregnant they send you away so that you do not spoil others. Actually this was hurting so many young people”.

## YPLHV Kampala

### Attractions at facilities

Several attractions at health facilities were reported including good and caring health workers, quick services, entertainment, food, transport refund, free services and Orphans and Vulnerable Children (OVC) support among others as shown in Table 4. Entertainment is provided by watching educative movies, playing games, doing handcrafts or through music, dance and drama while waiting to be served. The younger ones are given toys and balls to play while the older ones read newspapers and magazines. Others include board games, a library for adolescents to borrow books and computer rooms. Some others offer quick service and flexibility for ALHIV especially if they were wearing school uniforms and clinic appointments are given only during school holidays.

Study respondents reported that school fees, scholastic materials, transport, drinking water, food support and involvement in IGAs like making crafts, sandals and ear rings motivate them to stay on treatment.

Use of social media was an interesting innovation for urban school-going ALHIV in one facility. This facility (Alive Medical Services) opened a face book page for youths which is used to communicate

with each other, their youth leaders and doctors. They also post messages to fight stigma and comfort each other. Using Google hangouts, these ALHIV make regular interactions with their counterparts in other countries. This facility also provides regular supportive phone messages to their adolescents. A youth activist KI also suggested that social media is very appealing to the youth.

Other innovations included regular camps for adolescents, involving local politicians to mobilize for funds, use of Radio programs to promote HIV testing, fighting stigma and encourage enrolment into HIV care by youth.

Key informants from the Ministry of Education and Sports revealed that they have an office dedicated to HIV in schools at the national level. There is also an HIV program in schools called Presidential Initiative on AIDS Strategy for Communicating to the Youth (PIASCY) which was rolled out in primary and secondary schools in 56 districts.

## Discussion

The most preferred care model by ALHIV and other stakeholders was the special adolescent HIV clinics. Although the 2013 WHO guidance document for adolescents and HIV recommend dedicated spaces and activities for ALHIV where they can be with peers, they do not specifically comment on setting up adolescent HIV clinics [11]. Adolescent HIV clinics were present in special clinics and referral hospitals which have support but rare in public and lower facilities. HWs reported heavy workload and lack of space as a hindrance for adolescent clinics.

The concept of transition clinics was foreign to most HWs in the study but was expressed as a need by ALHIV similar to findings in 2009 [12]. Like other studies, our study re-echoed fears by adolescents to move on to adult clinics [13-15]. Despite the fears, it is rarely discussed with health care providers. For instance, of 282 ALHIV receiving pediatrics or adolescent services, only 38% had discussed a transition to adult care with their provider on at least one occasion [11]. A study in USA involving 14 HIV sites also demonstrates the need for consensus on definitions and key elements of transition [16]. The WHO guiding document on HIV and adolescents recommends that transition from childhood to adulthood should be a focus for policymakers and program managers [11].

Adolescent centers are a good strategy to improve HIV testing since they attract many adolescents. However, since they are expensive to run, youth corners in health facilities can be scaled up at minimal costs [17,18].

Peer support and meaningful involvement of ALHIV in the design, delivery and evaluation of treatment and support programs is highly recommended by WHO [11,19]. Many studies have shown that peer support groups have very positive effects on ALHIV [20-22]. However, they were considered very expensive by many providers. Socioeconomic support has been documented to improve retention in care in a program in Uganda [23].

Communication and media interventions have been recommended by WHO to improve testing and retention in care [11]. Our study found that there are interventions to help testing and support ALHIV in the ministry of Education and Sports. However, there is lack of coordination and need for training teachers. The involvement of the education sector is vital and is recommended for countries [11].

The strength of this study is that it had both qualitative and quantitative aspects which yielded rich data. It involved the ALHIV, their caregivers, schools and others in the education sector, various health workers and resource persons. It also had good representation of rural, urban, providers and regions of the country.

Our study limitation was that information was gathered from only 10 out of 112 districts in the country. However, efforts were made to ensure regional representation by involving one district per region.

In conclusion, the preferred model of care for ALHIV is the Stand-Alone Adolescent HIV clinic and transition clinics should be set up wherever possible. Youth corners in health facilities should be promoted and used as an entry point to HIV care for adolescents. Of the many innovations to support ALHIV, peer support groups are widely acknowledged but there is need for guidance and consensus on activities and sustainability.

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## Competing Interests

The authors declare that they have no competing interests whether financial or any other.

## Author Contributions

NNB participated in proposal development, designing study tools, data collection and manuscript writing. PE contributed to the conception of the study, acquisition of funds, proposal development and manuscript writing. BA participated in proposal development, revising the manuscript for important intellectual content and gave final approval of version to be published. CK participated in proposal development and manuscript writing. IL did the Quantitative data analysis and participated in designing study tools. ENM participated in proposal development and revision of the manuscript for intellectual content. JM participated in the proposal development and conception of the study. LA participated in proposal development, designing study tools, qualitative data analysis and manuscript writing. NT was involved in proposal development, acquisition of funds and manuscript writing.

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