

Using The 'Positive Health, Dignity, and Prevention Framework to Explore the Lived Experiences Of YPLHIV in Uganda

Findings from a Baseline Survey



Conducted By
UGANDA YOUNG POSITIVES (UYP)
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About GNP+

GNP+ is the global network for and by people living with HIV. GNP+ builds capacity of people living with HIV Globally to meaningfully advocate for improved quality of lives. GNP+ works towards having equitable access to health and social services for people living with HIV worldwide with human rights and gender sensitive approaches. More details can be found on: www.gnpplus.net and infognp@gnpplus.net

About Stop AIDS now

STOP AIDS NOW! is an independent and partnership-driven organization. STOP AIDS NOW! Aims to expand and enhance the quality of the Dutch contribution to the AIDS response in developing countries. It works towards halting the AIDS pandemic and its consequences which it does through expanding and enhancing the AIDS response in developing countries. STOP AIDS NOW! Works together towards a world without AIDS. More details can be found on: <http://stopaidsnow.org/>

About Population Council

Population Council (PC) is an International agency that conducts research to address critical health and development issues. PC conducts research and programs in more than 50 countries. PC work, among other things, empowers girls to protect themselves and have a say in their own lives. PC works in developed countries, where they use state-of-the-art biomedical science to develop new contraceptives and products to prevent the transmission of HIV. More details can be found on: <http://www.popcouncil.org/>

About UNYPA

Uganda Network of young people living with HIV mandate is to create an enabling environment for young people living with HIV and AIDS in Uganda. The organisation empowers young people living with HIV and those at risk of the HIV infection. UNYPA took leadership of the advocacy agenda (in chapter 4) which was guided by the findings of this baseline study; a position paper (in appendix one) is one of the products to this effect. More details can be found on: <http://www.unypa.org>

Table of contents

LIST OF TABLES.....	III
LIST OF FIGURES	IV
LIST OF ACRONYMS	V
OPERATIONAL DEFINITIONS	VI
1.0 INTRODUCTION.....	1
1.1 HIV AND YOUNG PEOPLE IN UGANDA	1
1.2 ABOUT UGANDA YOUNG POSITIVES (UYP).....	1
1.3 UGANDA YOUNG POSITIVES (UYP) MODEL	1
1.4 BACKGROUND.....	2
1.4.1 About PHDP	2
1.4.2 PHDP related studies.....	2
2.0 STUDY OVERVIEW	2
2.1 RATIONALE	3
2.2 STUDY OBJECTIVES.....	3
2.3 DATA COLLECTION	4
2.4 DATA ANALYSIS.....	5
2.5 STUDY LIMITATIONS	5
3.0 FINDINGS.....	6
3.1 SECTION ONE: CHARACTERISTICS OF THE STUDY POPULATION	6
3.2 SECTION TWO: AN OVERVIEW OF PHDP AMONG YPLHIV IN UGANDA	9
3.2.1 Health Promotion and Access	10
3.2.2 Sexual and Reproductive Health and Rights	13
3.2.3 Prevention of Transmission	18
3.2.4 Human Rights, including Stigma and Discrimination Reduction.....	20
3.2.5 Empowerment	23
3.2.6 Gender Equality	25
3.3 SECTION THREE: BASELINE SCORES FOR PHDP COMPONENTS.....	25
4.0 KEY RECOMMENDATIONS FOR ADVOCACY.....	28
5.0 REFERENCES	29
APPENDIX 1:.....	30

List of tables

TABLE 1: CHARACTERISTICS OF THE STUDY POPULATION..... 7

TABLE 2: HEALTH PROMOTION AND ACCESS 10

TABLE 3: KNOWLEDGE, ACCESS AND USE OF ARVS/ART 12

TABLE 4: MESSAGES FROM HEALTH CARE PROFESSIONALS ON MANAGING SEXUAL HEALTH AND RIGHTS SINCE DIAGNOSIS 14

TABLE 5: DISCUSSION WITH A HEALTH CARE PROFESSIONAL(S)/COUNSELOR(S) ON ANY OF THE FOLLOWING SUBJECTS IN THE LAST 12 MONTHS..... 16

TABLE 6: PREVENTION OF NEW HIV INFECTIONS..... 19

TABLE 7: WHAT DO YOU THINK WOULD HAPPEN IF YOU DISCLOSED YOUR HIV STATUS? 21

TABLE 8: ADDRESSING DISCRIMINATION AMONG YPLHIV IN UGANDA..... 22

TABLE 9: ORGANIZATIONS/GROUPS THAT PROVIDE SUPPORT SERVICES TO YPLHIV 23

TABLE 10: EXPERIENCES OF INTIMATE PARTNER VIOLENCE SINCE BEING DIAGNOSED..... 24

TABLE 11: EXPERIENCES OF INTIMATE PARTNER VIOLENCE SINCE BEING DIAGNOSED (DISAGGREGATED BY SEX) 25

TABLE 12: QUESTIONS SELECTED FOR COMPOSITE SCORE ANALYSIS..... 26

List of figures

FIGURE 1: PERCENTAGE DISTRIBUTION OF RESPONDENTS BY PERSONAL GROUP IDENTIFICATION IN UGANDA	9
FIGURE 2: DISCLOSURE OF HIV POSITIVE STATUS AMONG YPLHIV IN UGANDA.....	20
FIGURE 3: BASELINE PERFORMANCE INDICATORS FOR UGANDA	26
FIGURE 4: COMPOSITE SCORES BY AGE COHORTS AMONG YPLHIV AGED 15-30 IN UGANDA.....	27

List of acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti retroviral therapy
ASK	Access Services and Knowledge
GNP+	Global Network of people living with HIV
HIV	Human Immunodeficiency Virus
IRB	Internal Review Board
MSM	Men who have sex with men
NCST	National Council of Science and Technology
NAPWA	National association of people living with HIV association
PC	Population Council
PHDP	Positive Health Dignity and Prevention
PLHIV	People living with HIV
SGBV	Sexual and Gender Based Violence
SRHR	Sexual Reproductive Health and Rights
SW	Sex Workers
TASO	The AIDS support organisation
UAC	Uganda AIDS Commission
UNAIDS	United Nations joint effort against HIV and AIDS
UNYPA	Uganda Network of Young People living with HIV and AIDS association
UYP	Uganda Young Positives
VCT	Voluntary Counselling and Testing
WHO	World Health organisation
YPLHIV	Young People Living with HIV
YP	Young People
ZNP+	Zambia Network of people living with HIV

Operational definitions

Town: A place with buildings close to each other with shops and some level of business transactions going on, with vehicles passing-by and with some level of noise and commotion with people occasionally fighting, grappling, competing and shouting

Village: A place with scattered buildings often located in the countryside, with some old fashioned people, houses, dress-code, with some level of satisfaction over limited resources available, and often with home steeds surrounded by plantations and gardens and with people primarily digging to get something to eat.

Vertical transmission: Infection of HIV from infected parent(s) to a child

Stakeholder: A person or group of people in a given arrangement, organisation, project or intervention with similar/related interests in a given mission, have similar goals and are committed to a common change in a given society where the involvement could be as a result of investing some money, identifying a common need and making an effort to addressing it, together with challenges and aspirations of given people or situation.

Young people: A time in life when a person is growing into a young adult, defined in this study to mean a person ranging from age 15 to 24

Adolescents: A time in life when a person is growing into a youth normally used interchangeably with "teenager" to this study we mean someone between age 10 and 19

Youth: A time of life when a person is young, just before becoming an adult, normally, the Ugandan youth ranges from age 15 to 30.

Networks of young people living with HIV: A group, an organisation, a network or a civil society entity recognised legally to bring together young people living HIV and AIDS for action.

Advocacy: A set of targeted action directed to policy makers and programmers intended to create change in the existing programmes and or policies or to lead to creation of new policies and or programmes.

Non random purposive sampling: A sampling technique normally used for qualitative studies and sometimes for quantitative, especially when there are resource constraints for conducting a rigorous sample size determination, when it isn't easy to determine the sampling frame and other scientific processes including randomization.

IRB: An ethical review committee made of people with technical mix and often huge experience where proposals (academic and programme) are reviewed for ethical and technical soundness.

1.0 Introduction

1.1 HIV and young people in Uganda

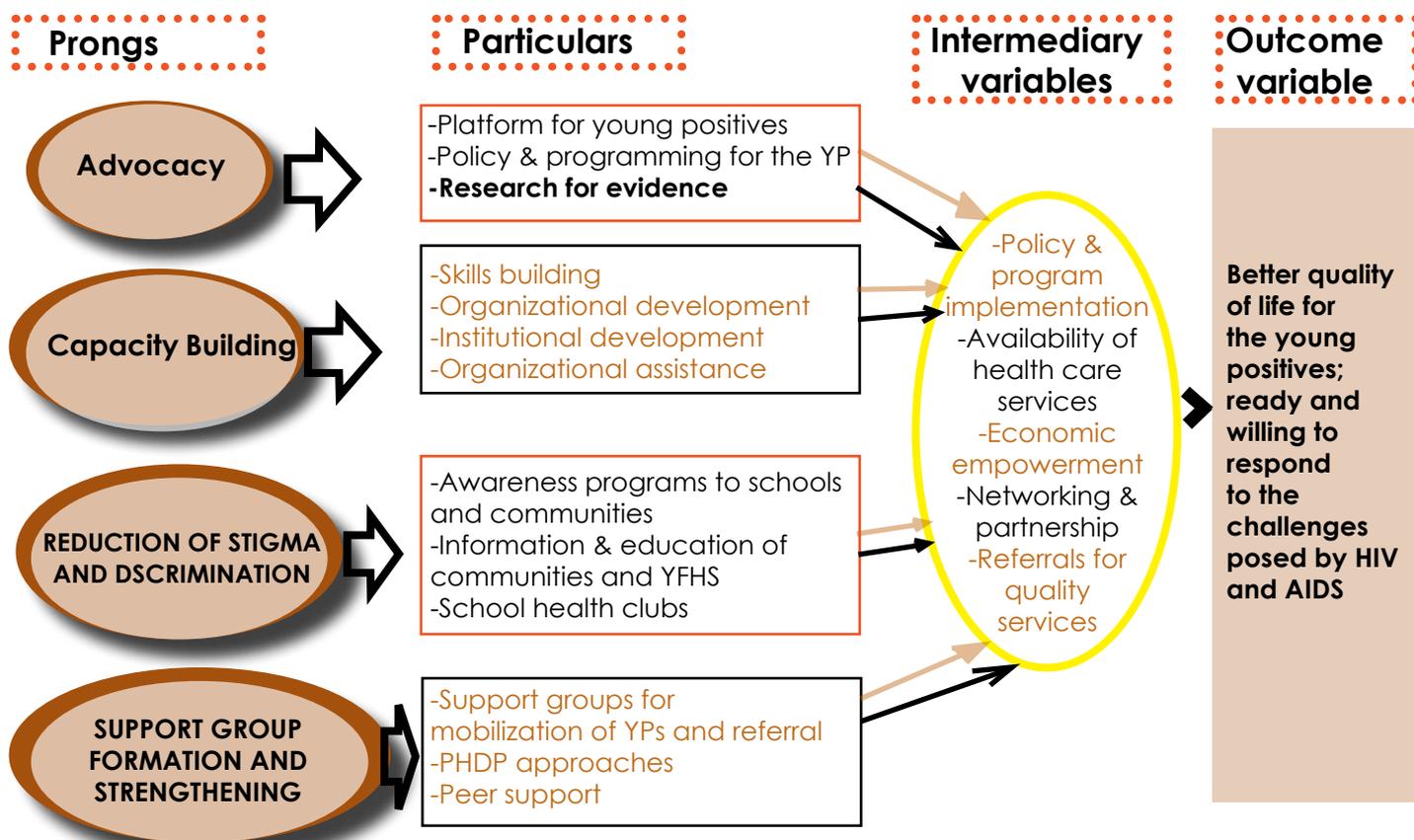
Uganda has experienced a generalized HIV epidemic for more than two decades. The 2011 AIDS Indicator Survey in Uganda reported HIV prevalence at a national average of 7.3% with 7.1% among female young people 20-24 years (UAC, 2014). Uganda's population is predominantly young and HIV and AIDS has hit this population most, especially the girl child. Several interventions have been initiated to address the epidemic among young people and to work towards healthy wellbeing of young people in the country.

1.2 About Uganda Young Positives (UYP)

Uganda Young Positives (UYP) is a National Non Governmental organization whose mission is to bring together all young people living with HIV in Uganda for action in scaling up prevention, care and support services. UYP was born to promote better quality of life of Young people living with HIV/AIDS and to address issues of vulnerability among the youth population. It took this up after acknowledging and recognizing that issues of young people were unique and therefore needed tailored approaches.

Born in October 2003, UYP has greatly impacted on the lives of the young positives countrywide. Today, UYP actively operates nationally with membership of over 60,000 individual young positives. UYP's core business, like many civil society organizations, is to create demand for services among communities. Details about UYP can be found on <http://www.ugyoungpositives.org>. UYP administers a community approaches package and a community-based model

1.3 Uganda Young Positives (UYP) Model



1.4 Background

1.4.1 About PHDP

Positive Health Dignity and Prevention (PHDP) is a new global policy framework that highlights the importance of placing people living with HIV (PLHIV) at the center of managing their health and wellbeing. This framework, among other things, takes us beyond the concept of Positive Prevention (PP) which was more limited since it focused only on PLHIV preventing transmission of HIV and nothing else. In contrast to PP (which could be construed as treating PLHIV as vectors of transmission), PHDP emphasizes the improvement and maintenance of the health and well-being of PLHIV, their partners, families, and communities (WHO, 2009) by focusing on the trajectory as they move from testing to support, care, and treatment, PHDP situates the health and social needs and experiences of PLHIV with a human rights approach.

PHDP recognizes the complex and competing needs and desires of PLHIV. It is a broader, more holistic, human rights-based approach which emphasizes that policies and programs that are designed and implemented with the meaningful involvement of PLHIV treat PLHIV humanely and with dignity, provides with knowledge, skills, social and legal support and focus on the holistic health. By so doing, related needs of PLHIV have a higher chance of being accepted and implemented and this approach is likely to be more effective than narrowly focusing on preventing new infections (GNP and UNAIDS, 2011). Ultimately, by this approach, shall foster a reduction in HIV-related stigma and discrimination, thus, reaping benefits for PLHIV, their partners, families, and communities. PHDP also emphasizes the leadership roles of PLHIV in responding to policy and legal barriers within the socio-cultural and legal contexts in which they live, and in driving the agenda forward towards better health and dignity.

1.4.2 PHDP related studies

Being a relatively new framework, the PHDP has had just a few studies conducted around it and these have been led by networks of PLHIV. A Kenya-based study found out that integrating components of PHDP into HIV prevention work in Kenya could strengthen the effectiveness of such efforts while also helping the national PLHIV network promote its aims of respect for PLHIV's human rights and improving their quality of life (NEPHAK and GNP, 2012). A similar study conducted in Nigeria found that the programmatic components for supporting a PHDP approach were either neglected or underdeveloped in this country context. Where they did exist, this was primarily due to civil society and non-governmental organization efforts, and dependent on international donor support (NEPHAK and GNP, 2012). In Ethiopia, particularly low levels of vertical transmission service utilization were observed in a PHDP study, with 28percent of PLHIV respondents reporting having a child(ren) known to be HIV-positive. Only 18percent of female respondents that were HIV-positive during pregnancy reported ever being given anti-retroviral treatment to prevent vertical transmission of HIV (NEP+ and GNP+ 2013). Despite the country's progressive policy for the equality of all citizens (irrespective of sexual orientation, gender, race, and HIV status), a PHDP study in South Africa highlighted a trend of institutionalized homophobia toward homosexual PLHIV in settings such as schools, police and justice departments, clinics, churches, work places, and youth clubs (NAPWA, GNP+ 2013). A similar study in Zambia revealed the lack of national policies that specifically mention and address the sexual and reproductive health (SRH) needs of adolescents living with HIV in this context (NZP+, GNP+, 2013).

Evidence from each of these studies has since been used by individual networks of PLHIV to engage policy-makers, program specialists, the media, community leaders, and other stakeholders in tailored advocacy for supportive health, social, political and legal environments for PLHIV.

2.0 Study overview

2.1 Rationale

The essence of conducting this baseline study was to explore implications of the PHDP concept within the settings of YPLHIV and to explore the lived lives of these young people using PHDP principals.

A commonality shared by these studies above, however, is that they were all exploratory in design, with a focus on the availability of core programmatic elements to support a PHDP approach in various countries. Notwithstanding, none of the studies were designed to assess the potential effects of advocacy efforts, neither were any of them specifically focused on young people living with HIV (YPLHIV), including young adolescents below the age of 15. Uganda Young Positives, a national network whose mandate is to bring together all young people living with HIV in Uganda for action in scaling up prevention, care and support services, proposed and implemented this study focusing on the perspectives and experiences of YPLHIV in regard to Positive Health, Dignity and Prevention.

The PHDP framework comprises 8 distinct components. Six of these components (the first six) were selected by the YPLHIV themselves according to their priorities for their communities.

- Health promotion and access
- Sexual and reproductive health and rights
- Prevention of transmission
- Human rights, including stigma and discrimination reduction
- Gender equality
- Empowerment
- Social and Economic support
- Measuring impact

2.2 Study Objectives

The study sought to address three specific objectives:

1. Assess the extent to which the lives of YPLHIV in Uganda reflect the ethos of PHDP
2. Provide a baseline against which the effect of advocacy interventions to promote a PHDP approach in Uganda may be measured; and
3. Determine salient areas which would guide the YPLHIV advocacy agenda



Source: YPLHIV Participants and facilitators of the PHDP workshop at a Kampala Hotel

2.3 Data Collection

The baseline survey was carried out from May to September, 2014, using structured questionnaires administered by trained research assistants. A total of 275 YPLHIV (aged 15-30 years) took part in the baseline survey.

Individual, written informed consent was obtained from all participants before conducting the interviews. The survey tool was translated into the relevant local languages of Acholi and Lusoga, pre-tested, and adjusted as needed. The research assistants, all of whom YPLHIV, participated in a four-day training session which covered the project goals, the survey contents, participant recruitment procedures, data collection, and research ethics. The Ethical Review Committee of The AIDS Support Organization (TASO) and the National Council of Science and Technology (NCST) provided ethical and research clearance for the study.

The study used non-random, purposive sampling techniques to identify respondents. Research assistants introduced the study to YPLHIV seeking services at health centers, and to members of YPLHIV networks. Informed consent/assent was administered to those that

expressed interest in participating, provided they met the study's eligibility criteria. Those that satisfied the following criteria were eligible for individual interviews:

- Young person living with HIV, aware of their HIV sero-status, and aged 15-30
- Diagnosed with HIV at least 6 months prior to the interview
- Resident in one of the study regions (Gulu and Iganga Districts)
- Willing and able participate in an interview (along with parental consent to do so, in the case of respondents under the age of 18)



Source: A Population-Council-staff demonstrating the use of a tablet for data collection at the data collectors training at a Kampala Hotel

2.4 Data analysis

Data was collected using tablets (specifically, the Samsung Galaxy Tab 3) which was then downloaded into ACCESS database. Analysis at this baseline phase entailed the generation of simple frequencies and percentages using STATA and SPSS.

Selected results were also analyzed as a composite score for specific components of the Positive Health, Dignity and Prevention Framework, of the first six, above.

2.5 Study Limitations

The study was devoid of a sampling frame as a result of limited financial resources and time. Young people living with HIV and AIDS were not fully mobilised and there was no database to enable systematic and other vigorous processes like sample size determination, randomisation and others.

The study was conducted when the anti-homosexuality bill had just been enacted into law which made the environment quite unfriendly for some respondents who might have not been straight, to freely open up, speak and associate with their sexual orientation.

3.0 Findings

Results of the baseline survey are presented in three sections. The first section describes the characteristics of the study population. The second section examines the extent to which the lives of YPLHIV in Uganda reflect the ethos of PHDP, drawing on six of the major components or programmatic elements of the PHDP framework. The third section present baseline scores and key recommendations for advocacy are highlighted in Section Four.

3.1 Section One: Characteristics of the Study Population

This section summarizes the characteristics of the study population in Table 1, which shows that the baseline survey covered a total sample of 275 male and female YPLHIV from rural and urban areas. 46percent of the total population was drawn from Gulu, while the complement was selected from Iganga District. The respondents (92 percent) were selected from two major locations: PLHIV Groups/Networks and Health Centers. The interviews were mostly conducted in Luo and Lusoga, and 10% were carried out in English.

Table 1: Characteristics of the Study Population

District of Residence	Frequency (percent)	Total (n)
Gulu	45.5	125
Iganga	54.5	150
Location of Residence		
Urban	56.7	156
Rural	43.3	119
Place of Recruitment		
Care and treatment center	1.8	5
PLHIV group/network	43.6	120
Health center	48	132
Other specify	6.5	18
Language Of Interview		
Luo	43.6	120
Lusoga	46.5	128
English	9.8	27
Sex of Respondent		
Male	35.6	98
Female	64.4	177
Sexual Orientation		
Heterosexual /Straight	44.7	123
Homosexual/Gay/'Lesbian	1.1	3
Bisexual	0.7	2
No response	53.5	147
Age of Respondent		
15-19	40.7	112
20-24	26.2	72
25-29	24	66
30	9.1	25
Religious Practice		
Catholic	37.1	102
Protestant	34.2	94
Muslim	8	22
Hindu	1.1	3
Others	19.6	54
Current marital status		
Single (Never Married)	54.2	149
Come-we-stay/Co-habiting	9.1	25
Married	29.5	81
Divorced/Separated/Widowed	7.3	20
Highest educational attainment		
No schooling	10.9	30
Primary	35.3	97
Secondary	41.5	114
Post secondary	9.5	26

Other	2.9	8
Current Employment Status		
Unemployed	26.3	72
Student	34.7	95
Informal	31	85
Formal	8	22
Present financial status		
A Dependant	43.4	119
Barely enough to get by	17.9	49
Go without	25.2	69
Enough to pay for the basics	9.5	26
Very comfortable	4	11
+Total may not add up to 275 in all categories because of missing cases		

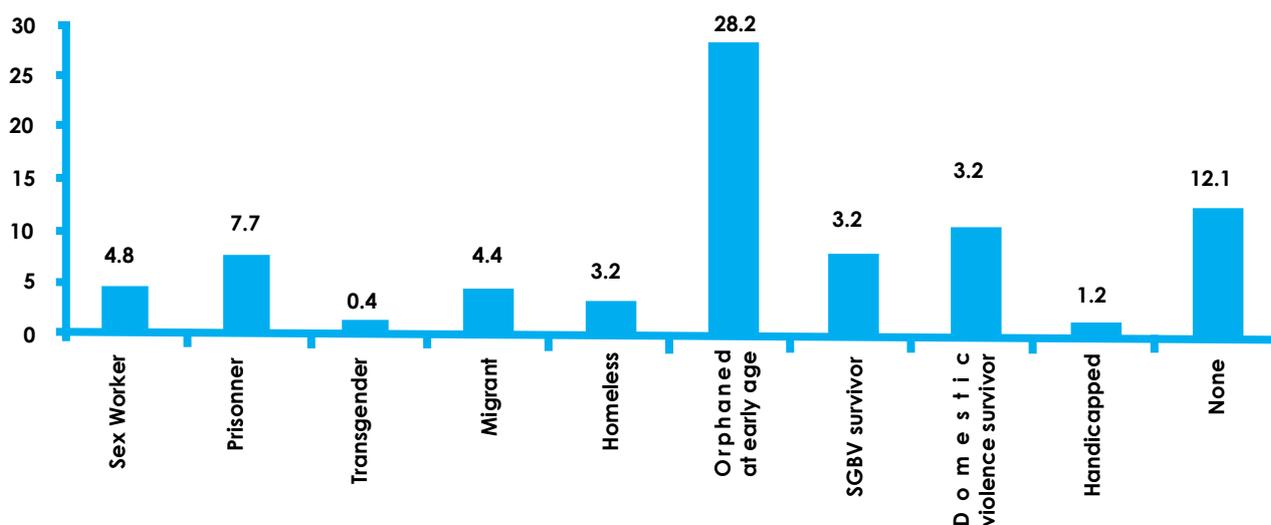
Majority of the respondents were Christians (Catholics: 37 percent; Protestants; 34 percent), while 8 percent were Muslims. Over half of the sample (54 percent) offered no response to the question of how they would describe their sexual orientation, while 2 percent identified as homosexual, gay, lesbian, or bisexual. This may have to do with stringent laws around same-sex relationships in Uganda which were receiving heightened publicity around the time of the survey.

Forty-five percent respondents self-identified as heterosexuals. In terms of marital status, 54 percent of the respondents had never been married, while 30 percent were married. While 9 percent of respondents were not married but living with a partner, 7 percent were divorced/separated /widowed. Education levels were high among the respondents, with 51 percent having attained secondary education or higher and 11 percent having no formal education.

Twenty-six percent of respondents were unemployed. Of those in employment (39 percent), more respondents were informally employed (31 percent). Thirty-five percent of those interviewed were students. The overall financial status of respondents may be a reflection of the general employment profile: over 60% of YPLHIV in this survey were either dependents or barely had enough to get by. A quarter of respondents (25 percent) reported going without basic needs. Only 10 percent of respondents indicated that they have enough to pay for the basics of living, and another 4 percent suggested that they were very comfortable.

Figure 1 shows that respondents self-identified in a variety of ways which were widely distributed across several groups that are susceptible to HIV infection, including sex workers, gay/lesbian, MSM, homeless, early age orphans, sexual and gender-based violence (SGBV) survivors, and domestic violence survivors. The vast majority of YPLHIV self-identified as being orphaned at an early age (28 percent), however. It is noteworthy that none of the YLHIV in Uganda identified as gay, lesbian or MSM. This is plausibly related to the legal implications of these identities in the country, and of the politics surrounding them at the time of the survey. It is also important to note that violence seems to be an issue in the lives of a considerable proportion of YPHLIV (18 percent), who self-identified as either survivors of sexual and gender-based violence in general, or as survivors of domestic violence in particular.

Figure 1: Percentage distribution of respondents by personal group identification in Uganda



3.2 Section Two: An Overview of PHDP among YPLHIV in Uganda

This section presents the extent to which the lives of YPLHIV in Uganda reflect the ethos of PHDP. To this end, several questions were addressed to respondents regarding core components or programmatic elements of the PHDP framework, and respondents' lived experiences with regard to each of them. Findings are categorized under each PHDP component examined in this study.

3.2.1 Health Promotion and Access

Several questions were asked in order to assess the 'Health Promotion and Access' component of PHDP. Responses from respondents summarized in Table 2, suggest substantial levels of health promotion and access to health services among YPLHIV in Uganda. Nonetheless, there is still some ground to be covered if we have to achieve the universal access to HIV prevention, treatment, care, and support, as well the Uganda National Strategic Plan for HIV and AIDS (2011/2012 to 2014/2015)¹ targets.

The majority of respondents were diagnosed in the last five years (65 percent), while about 31 percent received their diagnosis more than five years from the date of survey. A total of 87 percent had had their CD4 count taken, out of which 87 percent knew their CD4 count. This leaves about 12 percent who did not get their CD4 count results or who indicated outright that they did not know their CD4 count. For those who had never had their CD4 count taken (a total of 13 percent), their main specified reason for not having done so were that they did not know about these tests (47 percent). Seventeen percent of those who had not had their CD4 count done did not think it was necessary to do so, while 14 percent mentioned the lack of services as their reason for not taking this test.

When asked about their health status since their diagnosis, majority of the respondents indicated that their health had improved (85 percent) or remained the same (8 percent). Only 7 percent of respondents indicated that their health condition had worsened since

¹ The overarching goal of this revised national strategic plan is to achieve universal access targets for HIV and AIDS prevention, care, treatment and social support and protection by 2015

they were diagnosed. Similarly, only 3 percent of respondents indicated that the status of health services had worsened since their diagnosis, while the complementary 61 percent observed an improvement in health services. Thirty-five percent indicated no change in the status of health services received since their diagnosis.

Responses to question of where respondents' first HIV test was carried out were consistent with high access to services, with about 94 percent of respondents being tested in Government Health facilities (75 percent), Private Health Facilities (12 percent), or VCT Centers (7 percent).

The same was evident in the proportion of youth who received both pre- and post-test HIV counseling (60 percent), only pre-test HIV counseling (10 percent) and only post-test HIV counseling (12 percent) at the time of their first HIV test. Only 3 percent of the youth interviewed did not receive any form of counseling, and 14% indicated that they did not know whether they received any counseling as part of their first HIV test.

Table 2: Health Promotion and Access

	Frequency (percent)	Total*(n)
How many years since diagnosed?		
Less than one year	19.3	53
1-5 years	46	126
Over 5 years	31.4	86
Don't Remember	3.3	9
Had CD4 count ever taken?		
Yes	85.7	215
No	10.8	27
Don't Know	3.6	9
Knowledge of CD4 Count		
Less than 200	11.2	24
200-350	33.5	72
More than 350	42.8	92
Did not get result	8.4	18
Don't Know	4.2	9
Health Status Since Diagnosis		
Improved	84.5	212
Worsened	7.2	18
Remains the same	8	20
Not applicable	0.4	1
Status of Health Services		
Improved	60.8	152
Worsened	2.8	7
Remains the same	34.8	87
Not applicable	1.6	4

Place of first HIV Test		
Don't Know [Was Young]	5.6	14
VCT	7.2	18
Government Health Facility	75.2	188
Private Health Facility	11.6	29
Others	0.4	1
Received pre/post-test counseling?		
Don't know	14.8	37
Received both pre/ post-test counseling	60.4	151
Received only pre-test HIV counseling	9.6	24
Received only post-test HIV counseling	12.4	31
Did not receive any counseling	2.8	7

Totals vary depending on the questions asked.

Beyond HIV testing, respondents were asked about their knowledge of, access to, and use of anti-retroviral treatment (ARVs/ART). Their responses, summarized in Table 3, indicate not only high levels of knowledge, but also high levels of access to treatment. About 96 percent of respondents had heard of ARVs/ART, and 84 percent were currently attending an HIV Care and Treatment Center. Eighty-four percent were currently attending an HIV care/treatment center, and 93 percent of respondents were currently taking ARVs. Nonetheless, critical hindrances with potentially important implications for addressing HIV prevention and treatment were identified. For example, only 64 percent of respondents indicated the availability of ARVs/ART in their residential neighborhoods. Furthermore, beyond the small proportions of respondents who had not heard of ARVs/ART (4 percent), and those who were not currently attending an HIV care and treatment center (16 percent), are the 7 percent of respondents who had shared their ARVs with someone else – a practice that is detrimental to compliance with prescriptions and effective treatment. The sharing of ARVs has been noted to occur in Uganda due to reasons such as medication stock-outs.² Elsewhere in the East African region, the sharing of ARVs has been attributed to stigma against individuals who are identified as being HIV-positive when they present at certain health facilities for services. To keep their status private, some PLHIV opt to relying on sharing the ARVs obtained by their HIV-positive partners.³

A substantial proportion of respondents (30 percent) indicated non-availability of ARVs/ART in their residential neighborhoods. Despite this challenge, the YPHIV in this study were cognizant of where to obtain ARVs/ART. The vast majority named government health facilities (85 percent), followed by private health facilities (12 percent).

Table 3 demonstrates that there is some concordance between health providers and YPLHIV with regard to the regularity of attendance of care and treatment centers: 94percent of YPLHIV indicate that their doctors expect them to regularly attend care and treatment centers at one- to three-month intervals, and 85 percent of YPLHIV agree that such an attendance schedule is necessary.

² See, for example: <http://www.irinnews.org/report/95490/uganda-rising-arv-resistance-threatens-hiv-fight>.

³ See, for example: <http://www.irinnews.org/report/82423/kenya-sharing-arvs-puts-patients-at-risk-of-resistance>.

Barriers to attending care and treatment centers include not feeling such attendance is necessary (20 percent), not wanting to be identified as HIV-positive (10 percent), long distances to care and treatment centers (20 percent), and lack of money (15 percent). Another notable result of concern is that while 9 percent of YPLHIV do not want an HIV care and treatment center located where they live, distance to care center emerged as a barrier to care-seeking. This perhaps speaks to the anonymity which YPLHIV crave, given persistent associated stigma.

The length of time that regular visits to care and treatment centers take is equally important for health promotion and access to HIV care and treatment. While 28 percent of regular visits last between one to two hours, a notable 44 percent of such visits last for more than four hours. These lengthy visits can have a negative impact on health promotion and access for YPLHIV.

Table 3: Knowledge, Access and Use of ARVs/ART

	Frequency (percent)	Total*
Ever heard of ARVs/ART?		
Yes	96	240
No	4	10
Availability of ARVs/ART treatment where you live?		
Yes	64.2	154
No	30	72
Don't Know	5.8	14
Currently attend HIV Care/ Treatment Center?		
Yes	84	210
No	16	40
Main barriers to attending a Care and Treatment Center?		
Not Necessary	20	8
I don't feel sick	12.5	5
I don't want people to know I'm HIV+	10	4
Too far from where I live	20	8
No money	15	6
Others	22.5	9
Currently taking ARVs?		
Yes	93.4	114
No	6.6	8
Have you ever shared ARVs with someone else for any reason?		
Yes	7	8
No	93	106
In regard to the supply of ARVs, would you say		
There is constant supply of ARVs	71.6	83
Rare supply interruptions of ARVs	16.4	19
Regular supply interruptions of ARVs	1.7	2

Don't Know	10.3	12
Doctor's CARE AND Treatment Center attendance requirement		
Every month	49.6	124
Every 2 months	40	100
Every 3 months	4.8	12
Every 6 months	2.8	7
Other	2.8	7
Respondents view of care and treatment center attendance		
Every month	42.8	107
Every 2 months	29.6	74
Every 3 months	12.4	31
Every 6 months	3.2	8
Other	3.6	9
Would you want a Care/Treatment center where you live?		
Yes	86.8	217
No	8.8	22
Not applicable	4.4	11
How much time does regular visits to a Care/Treatment center take?		
One hour or less	14.4	36
1-2 hours	28.4	71
2-4 hours	13.2	33
More than four hours	44	110

Totals vary depending on the questions asked.

3.2.2 Sexual and Reproductive Health and Rights

To explore lived experiences of YPLHIV in Uganda in regard to sexual and reproductive health and rights (SRHR), respondents were asked about the kind of messages they have received from health care professionals since their diagnosis in regard to the management of their intimate partnerships. Their responses, summarized in Table 4, are consistent with very high levels of awareness of different SRHR dimensions for people living with HIV. Since their diagnosis, messages received by respondents from health care professionals indicate that YPLHIV have the right to have sex (85 percent), and can continue to have sex (70 percent). However, providers were reportedly much less likely to indicate that YPHLIV could engage in sexual relations with any partner of their choice. Only 38 percent of YPHLIV had received this message from a provider, including HIV-positive partners (63 percent) or HIV-negative partners (36 percent).

Nonetheless, YPHIV had been well-informed by providers about the fact that they can get married to any partner of their choice (85 percent) and can have children (92 percent). When asked whether they received messages that YPLHIV could not have sexual intercourse, 76 percent of respondents answered to the contrary. Consistent with high levels of SRHR awareness informed by health care professionals, respondents received information on the need: for condom use (92 percent), to reduce sexual

partners or have only one sexual partner (88 percent), to be faithful (95 percent), to avoid sex while intoxicated (65 percent). A large proportion of respondents had received messages on the possibility of delivering vaginally if pregnant (73 percent) and of accessing other contraceptives beyond the condom (72 percent).

The problematic dimension of the responses that needs closer attention includes the 25 percent of respondents who reported being informed by health professionals a C-section delivery was their only option if pregnant, and the 14.2 percent of respondents who were not informed that they can deliver vaginally, if pregnant.

Table 4: Messages from health care professionals on Managing Sexual Health and Rights since diagnosis

	Frequency (percent)	Total (n)*
PLWHIV have the right to have sex?		
Yes	84.5	131
No	11	17
Don't Know	4.5	7
Respondent can continue sexual intercourse		
Yes	70.3	109
No	27.7	43
No Response	1.9	3
Respondent can have sex with others HIV+		
Yes	63.2	98
No	36.1	56
No response	0.6	1
Respondent can have sex with others HIV-		
Yes	36.1	56
No	54.8	85
No response	9	14
Respondent can have sex with partner of choice		
Yes	38.1	59
No	60.6	94
No response	1.3	2
Respondent can get married		
Yes	84.5	131
No	13.5	21
No response	1.9	3
Respondent can marry a HIV+ partner		
Yes	73.5	114
No	25.8	40
No response	0.6	1
Respondent can marry a HIV- partner		
Yes	41.5	65
No	47.7	74
No response	10.3	16

Respondent can have children		
Yes	92.3	143
No	7.1	11
No response	0.6	1
Respondent have to use condoms for sexual intercourse		
Yes	91.6	142
No	7.1	11
No response	1.3	2
Have only one sexual partner		
Yes	88.4	137
No	10.3	16
No response	1.3	2
Respondent being Faithful		
Yes	94.8	147
No	4.5	7
No response	0.6	1
If Pregnant, Terminate		
Yes	6.5	10
No	80.6	125
No response	12.9	20
If pregnant, can deliver Vaginally		
Yes	72.9	113
No	14.2	22
No response	12.9	20
If Pregnant can only deliver through C-Section (Yes)	25.2	39
Can access other forms of contraceptives beyond condom		
Yes	72.3	112
No	16.1	25
No response	11.6	18

Totals vary depending on the questions asked.

Other issues of concern that require further attention include the YPLHIV who were unaware that they can continue to have sex (11 percent), with any partner of their choice (61 percent), including HIV-positive (36 percent) and HIV-negative (55 percent) partners.

Respondents were asked whether they had had a discussion with a health care professional/counselor on any of the several specific SRHR-related issues in the last 12 months. Their responses, summarized in Table 5, show the proportions of YPLHIV who had discussions with a health care professionals/counselors in the last 12 months in relation to dating and relationships (40 percent), having pleasurable sex (41 percent), sexual problems (36 percent), emotional stability (56 percent), pregnancy prevention methods (67 percent), safe pregnancy (65 percent), and pregnancy termination (15 percent). Discussions on other behavioral dimensions of SRHR in the last 12 months

between respondents and health professionals/counselors include use of alcohol and sexual relations (17 percent), use of illegal drugs & sexual relations (15 percent), use of ARVs & sexual relations (34 percent), and safer sex (76 percent).

The lower tempo of discussions between respondents and health care professionals in the last 12 months prior to the survey on issues around pregnancy prevention methods, safe pregnancy and pregnancy termination is notable. The danger of communication gaps around sexual relations and pregnancy outcomes is exacerbated by evidence that young people’s sexual activities in many countries in sub-Saharan Africa (SSA) are linked to high levels of early and unwanted pregnancies, clandestine abortions, maternal morbidity, and mortality (Bankole et al, 2006). In Uganda, unintended pregnancy is common and is linked to high levels of unplanned births, unsafe abortions, and maternal injury and death. In 2008, an estimated 1.2 million unintended pregnancies occurred in Uganda, representing more than half of the country’s 2.2 million pregnancies, and resulting in two main outcomes—unplanned births and abortion (Vlassoff et al., 2009). Adolescents and young adults are particularly at risk for unintended pregnancy (Guttmacher, 2013). Available estimates put abortion rates in Uganda at 54 abortions per 1,000 women of reproductive age – or one abortion for every 19 such women. This rate is nearly twice the average rate for Eastern Africa, put at 36 abortions per 1,000 women (WHO, 2011). In 2008, the Ugandan Ministry of Health estimated that abortion-related causes accounted for 26% of maternal mortality, figures that are considerably higher than the World Health Organization’s estimates for the Eastern Africa sub-region (18%) and for the world as a whole (13%).

Table 5: Discussion with a health care professional(s)/counselor(s) on any of the following subjects in the last 12 months

	Percentages	F r e q u e n c y (N=154)
Dating & relationships		
Yes	39.6	61
No	48.7	75
Not applicable	8.4	13
No response	3.2	5
Having pleasurable sex		
Yes	40.9	63
No	51.9	80
Not applicable	0.6	1
No response	6.5	10
Sexual problems		
Yes	36.4	56
No	58.4	90
Not applicable	0.6	1
No response	4.5	7
Emotional Stability		
Yes	55.8	86
No	41.6	64

Not applicable	0.6	1
No response	1.9	3
Pregnancy prevention methods		
Yes	66.9	103
No	27.3	42
Not applicable	3.2	5
No response	2.6	4
Safe pregnancy		
Yes	64.9	100
No	25.3	39
Not applicable	3.9	6
No response	5.8	9
Pregnancy termination		
Yes	14.9	23
No	74	114
Not applicable	5.8	9
No response	5.2	8
Use of alcohol and sexual relations		
Yes	16.9	26
No	81.2	125
Not applicable	1.9	3
No response	0	0
Use of illegal drugs & sexual relations		
Yes	14.9	23
No	78.6	121
Not applicable	5.2	8
No response	1.3	2
Use of ARV's & sexual relations		
Yes	33.8	52
No	59.7	92
Not applicable	2.6	4
No response	3.9	6
Safer sex		
Yes	76	117
No	22.1	34
Not applicable	1.9	3
No response	0	0

3.2.3 Prevention of Transmission

According to the 2011 National HIV Indicator Survey, the prevalence rate of HIV among Ugandans aged 15-49 is going up and currently stands at 7.3% (an increase from 6.4%). The Uganda AIDS Commission has highlighted that if new infections continue to rise, there will be more than 700,000 cases of new HIV infections over the next five years, with about 25,000 babies to perinatally infected each year (UNAIDS, 2012). Universal prevention activities try to address the three main routes of transmission: sexual transmission, transmission through blood, and mother-to child transmission. Prevention methods such as HIV testing and counseling, HIV awareness education, promotion of condom use, male circumcision, safer sex education and treatment – especially to prevent mother-to-child transmission of HIV – are central to prevention activities.

To evaluate the lived experiences of the study population in regard to these key prevention strategies, respondents were asked sets of questions relevant for the prevention of new HIV infections. Their responses, summarized in Table 6, reveal some encouraging outcomes as well as discouraging dimensions.

On the important question of who is responsible for preventing the transmission of HIV, the opinions of respondents spread dangerously wide. While majority of the respondents were sexually active (with 73 percent having had sexual intercourse in the six months prior to the survey), 19 percent of respondents opined that they are more responsible for preventing HIV transmission because they were HIV-positive, and 10 percent were of the view that they are 100 percent responsible because of their positive HIV status. On the other hand, 46 percent of respondents believed that each person is responsible for him/herself, while only 25 percent of respondents opined that they and their sexual partner are equally responsible for preventing HIV transmission. Further, over a third of respondents (34 percent) either did not use a condom the last time they had penetrative sex, or could not remember if they had done so. This may be reflective of the 25 percent of respondents who had acquired a sexually-transmitted infection since they were diagnosed with HIV.

When asked whether they disclosed their HIV status to their last sexual partner, 70 percent of respondents answered in the affirmative, while 30 percent either did not disclose, or could not remember whether they did or not. About half of the respondents (51 percent) either thought that their partner would leave them if they disclosed their status, or were simply not sure if this would happen. This concern may account for the large proportion of YPLHIV who did not disclose their HIV status to their last sexual partner.

Nineteen percent of respondents had used substances such as kuba, marijuana, petrol, and other drug-related substances during the last 12 months. Of these, 95 percent had used any of these substances once, 3 percent had used 2-10 times and 2 percent had used any of these substances more than 10 times in the last 12 months. Eighty-one percent of respondents reported never getting drunk at all in the course of a week, versus 13 percent who reported getting drunk once a week. Those that reported getting

drunk at all in the course of any given week admitted to using sometimes (8 percent), most times (4 percent), always (2 percent), or never (3 percent), prior to engaging in sexual intercourse.

Only 3 percent of respondents (n=7) had injected illegal drugs since their HIV-positive diagnosis. No single respondent who reported having injected illegal drugs since their diagnosis, reported having access to a drug rehabilitation program.

Table 6: Prevention of New HIV Infections

	Percentage (percent)	*Frequency (n)
Have you engaged in sexual intercourse in the past 6 months?		
Yes	72.5	111
No	27.5	42
In a sexual encounter, who is responsible for preventing transmission of HIV?		
Each person is responsible for him/herself	46.4	71
I am more responsible because I am HIV-positive	19	29
Me and my sexual partner are equally responsible	24.8	38
I am 100percent responsible because I am HIV-positive	9.8	15
Since diagnosed, have you acquired any sexually-transmitted infection?		
Yes	25.2	28
No	73	81
No response	1.8	2
The last time you had penetrative sex, did you use a condom?		
Yes	64.9	72
No	31.5	35
Don't remember	2.7	3
Did you disclose your HIV status to your last sexual partner?		
Yes	69.9	107
No	26.1	40
Don't remember	3.9	6
During the last 12 months, how often have you used these substances (kuba, marijuana/bhang/weed, petrol, other)?		
Once	95.2	236
2-10 times	3.2	8
More than 10 times	1.6	4
Have you injected illegal drugs since you were diagnosed?		
Yes	2.8	7
No	89.5	222
No response	7.7	19
How often do you use illegal drugs prior to engaging in sexual intercourse?		

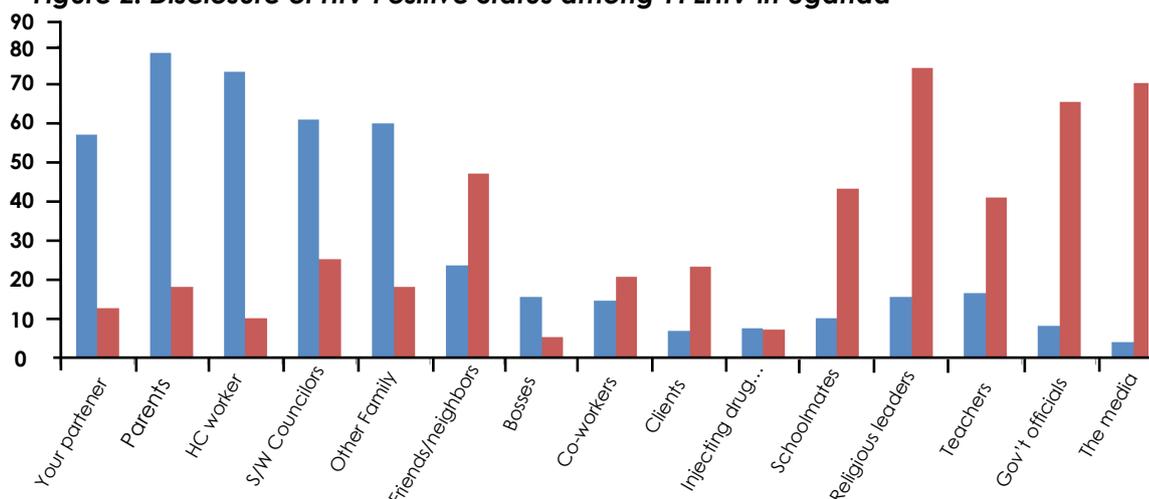
Always	14.3	1
Most times	0	0
Sometimes	14.3	1
Never	71.4	5
Do you have access to a drug rehabilitation program?		
Yes	0	0
No	100	7
How often do you get drunk in a week?		
Never	81	201
Once	12.9	32
Two days per week or more	6	15

- Totals vary depending on the questions and the number of responses provided

3.2.4 Human Rights, including Stigma and Discrimination Reduction

In terms of disclosure of their HIV status to relevant networks, Figure 2 (which compares those who had disclosed to those who had not), shows high levels of non-disclosure of HIV status by respondents. Apart from partners, parents, other family members, health care workers, and counselors, every other group in the social network of respondents is less likely to know respondents' HIV status than otherwise. This is highly pronounced among school mates, friends/neighbors, co-workers, bosses, clients, religious leaders, teachers, government officials and the media. While social desirability bias, as well as fear of discrimination and stigma, may have informed non-disclosure, the situation as it is portends great danger for HIV prevention and care as well as for addressing bias, discrimination and stigma. In actual fact, disclosure of status could be the starting point for determining the actual extent of discrimination and stigma, and for understanding how they can be effectively addressed.

Figure 2: Disclosure of HIV Positive Status among YPLHIV in Uganda



To further understand the level of HIV status disclosure presented above, respondents were asked what they thought would happen if they disclosed their status. Their responses, summarized in Table 8, highlight a fairly supportive

environment with friends and family as well as with authorities at work and at school. While there are fears among some respondents around being expelled from school (9 percent); rejection by friends (37 percent) and neighbours (42 percent); abandonment by family (17 percent); getting fired (27 percent); being denied leadership opportunities (40 percent); being left by a partner (40percent); and losing inheritance rights (40 percent), a considerable proportion of respondents were convinced that they would not suffer any harm if they disclosed their status. In fact, 40 percent of respondents were certain that they would receive support if they disclosed their status. Findings show that a third of respondents (33 percent) reported experiencing any form of discrimination in the last 12 months because of their HIV status, which may explain some of the reticence toward disclosure.

Table 7: what do you think would happen if you disclosed your HIV status?

	Percentage (%)	Frequency (n)
Nothing would happen		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29
Expelled from School		
Yes	9.3	23
No	70.4	174
Don't Know	20.2	50
Rejected by my friends		
Yes	37.2	92
No	58.3	144
Don't Know	4.5	11
Family would abandon me		
Yes	17	42
No	75.7	187
Don't Know	7.3	18
Rejected by neighbors		
Yes	41.7	103
No	53	131
Don't Know	5.3	13
Get Fired		
Yes	26.7	66
No	49.4	122
Don't Know	23.9	59
Partner would leave me		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29

Denied Leadership		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29
Lose right to inherit		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29
Children separated from me		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29
Get support		
Yes	39.7	98
No	48.6	120
Don't Know	11.7	29

In regard to discrimination, relevant questions relating to respondents' experiences in the last 12 months and the actions they have taken in response were asked. Their responses, summarized in Table 9, show that 33 percent of YPLHIV reported facing discrimination in the last year.

Despite as many as 28 percent of respondents indicating that they have access to free legal services, no legal response was taken in all the discrimination cases. Further, while 68 percent of respondents indicated that they know their rights as PLHIV, an overwhelming 90 percent of these did not know any laws in Uganda that protect them from discrimination as persons living with HIV.

Table 8: Addressing Discrimination among YPLHIV in Uganda.

	Percentages (percent)	Frequency (n)
In the last twelve months, have you experienced any form of discrimination?		
Yes	32.8	81
No	66.5	165
Don't know	0.4	1
What kind of action did you take to respond to this discrimination?		
Confronted the person involved	50	2
Didn't do anything	50	2
Do you have access to free legal services?		
Yes	27.9	69
No	72.1	178
Don't know		
Do you know your rights as a person living with HIV?		

Yes	67.6	167
No	32.4	80

Do you know of any laws in this country that protect you from discrimination as a person living with HIV?

Yes	10.5	26
No	89.5	221

3.2.5 Empowerment

Protective roles of civil society (or community groups/associations) for minorities and vulnerable groups have been identified and severally documented. Social scientists have used membership of such groups as a proxy measure of current social embeddedness and as a form of insurance against social isolation/exclusion and consequent vulnerability to social and economic hardships – especially in urban areas, which often lack traditional support networks (Mberu et al. 2012). For YPLHIV in Uganda, Table 10 shows that the importance of organizations or groups that provide support to YPLHIV is not lost on the study population, with 88 percent of respondents seeing these groups as either important or very important. However, knowledge of the kinds of organizations or groups that provide support services to people living with HIV was relatively lower (54 percent). Even fewer (32 percent) actually belonged to a civil society/community group/association. Of these, 63 percent had supported other people living with HIV. The forms of support that participants reported provided were varied and included emotional/psychological, health care, social, physical, spiritual/moral, legal, and capacity-building support, as well as support in terms of providing referrals and information.

It's important to note the fact that only a small proportion of YPLHIV (8 percent) reported knowing about departmental or national HIV and AIDS committees or councils. This highlights the low level of access that this population has to this level of decision-making and reinforces the need for youth engagement at this level.

Table 9: Organizations/Groups that provide support services to YPLHIV

	Percentages (percent)	Frequencies (n)
How important would you say it is to belong to a network of YPLHIV?		
Very important	54.1	133
Important	34.1	84
Not Important	1.2	3
I don't Know	10.6	26
Do you know of any organizations or groups that provide support services to people living with HIV?		
Yes	53.8	91
No	46.2	78
Do you belong to any civil society/community group/association as a person living with HIV?		
Yes	31.6	79
No	66.8	167
In the last 12 months, have you supported other people living with HIV?		
Yes	63	155
No	37	91

3.2.6 Gender Equality

MDG Goal 6, Target 6B was to achieve universal access to treatment for HIV and AIDS for all those who need it by 2010. That target is yet to be met and while the rate of new infections has decreased, the total number of people living with HIV in Africa continues to rise (UNAIDS 2010b). Additionally, in sub-Saharan Africa (SSA), it is estimated that the percentage of women living with HIV is at 59 percent. A young woman in SSA is up to eight times more likely to acquire HIV than a young man, and AIDS remains a leading cause of death among women of reproductive age globally (UNAIDS 2010b). Experts identify poor gender analysis or gender imbalance in programming as hindrances to efforts by Governments and health agencies towards universal access in many cases and optimistic of more effective programming if there are better gender indicators in program design, analysis, implementation and evaluation (VSO, 2014). According to the UNFPA, reversing the spread of HIV must address the critical role that gender relations play in sexual and reproductive life, and how it affects HIV prevention.

YPLHIV were asked about their perceptions and experiences in relation to the issue of gender equality. Table 11 shows that 59 percent of respondents reported a wide range of abuses, with psychological forms of intimate partner violence being the most widespread violence form experienced by YPLHIV (being threatened by a partner: 11 percent; being abandoned by a partner: 11 percent; being denied sex by a partner: 8 percent; being psychologically abused: 5 percent; being ignored: 3 percent). Across the board, YPLHIV aged 20-30 were much more likely to be experiencing each of these forms of abuse than their younger peers aged 15-19.

Table 10: Experiences of intimate partner violence since being diagnosed

	Percentages (percent)	Frequency (n)
Physically abused by a sexual partner	12	30
Abandoned by a sexual partner	12	30
Denied financial support by a sexual partner	4.8	12
Deliberately ignored (not talked to) by a sexual partner	3.6	9
Denied sex by a sexual partner	8.8	22
Denied the right to negotiate non-penetrative sex	4.4	11
Denied the right to negotiate a contraceptive method	1.6	4
Psychologically abused (shouted at, insulted, despised, blamed)	5.2	13
Denied the right to negotiate the use of condoms	2.4	6
Forced to have sex against your will	4.8	12
Forced to terminate pregnancy	0.4	1
Forced to be separated from your family (No contact)	0.8	2
Being threatened by a partner	11.6	29
None	44.8	112

As Table 12 indicates below, experiences and levels of abuse were quite comparable for female and male YPHLIV respondents alike.

Table 11: Experiences of intimate partner violence since being diagnosed (disaggregated by sex)

Since you were diagnosed, have you experienced any of these situations? Being ...	Male		Female		n	(%)
	98	(%)	177	(%)	275	
PHYSICALLY ABUSED BY A SEXUAL PARTNER	10	(10.2)	20	(11.3)	30	(10.9)
ABANDONED BY A SEXUAL PARTNER	12	(12.2)	18	(10.2)	30	(10.9)
DENIED FINANCIAL SUPPORT BY A SEXUAL PARTNER	4	(4.1)	8	(4.5)	12	(4.4)
DELIBERATELY IGNORED (NOT TALKED TO) BY A SEXUAL PARTNER	4	(4.1)	5	(2.8)	9	(3.3)
DENIED SEX BY A SEXUAL PARTNER	7	(7.1)	15	(8.5)	22	(8)
DENIED THE RIGHT TO NEGOTIATE NON-PENETRATIVE SEX	4	(4.1)	7	(4)	11	(4)
DENIED THE RIGHT TO NEGOTIATE A CONTRACEPTIVE METHOD	1	(1)	3	(1.7)	4	(1.5)
PSYCHOLOGICALLY ABUSED BY A SEXUAL PARTNER (SHOUTED AT, INSULTED, DESPISED, BLAMED)?	4	(4.1)	9	(5.1)	13	(4.7)
DENIED THE RIGHT TO NEGOTIATE THE USE OF CONDOMS	0	(0)	6	(3.4)	6	(2.2)
FORCED TO HAVE SEX AGAINST YOUR WILL	0	(0)	12	(6.8)	12	(4.4)
FORCED TO TERMINATE YOUR PREGNANCY	0	(0)	2	(1.1)	2	(0.7)
FORCED TO BE SEPARATED FROM YOUR FAMILY (I.E., YOU CANNOT CALL OR VISIT THEM)	1	(1)	1	(0.6)	2	(0.7)
BEING THREATENED BY A PARTNER?	8	(8.2)	21	(11.9)	29	(10.5)
NONE	44	(44.9)	68	(38.4)	112	(40.7)

To address the abuse observed, 52 percent of respondents took some form of action. While 16 percent of respondents confronted the situation or tried to sensitize those involved, 7 percent made complaints of a legal nature, or complaints to a civil society organization, or sought for some form of social protection. Majority of those who took any action simply spoke to someone about it (21 percent). However, nearly half (48percent) of respondents took no identifiable action, underscoring both the great challenge exists and the greater opportunity to address intimate partner violence issues among YPLHIV.

3.3 Section Three: Baseline Scores for PHDP Components

To generate a composite score for each of the PHDP components examined in this study, key baseline survey questions related to each component were carefully selected and aggregated. This process helped to determine each component's performance prior to the introduction of any advocacy interventions. While each baseline survey question and the related responses (presented in previous sections of this report) provide unique insight into the PHDP framework as it plays out among YPLHIV in Uganda, the composite scores take into account a group of questions and the collective and simultaneous implications of all responses.

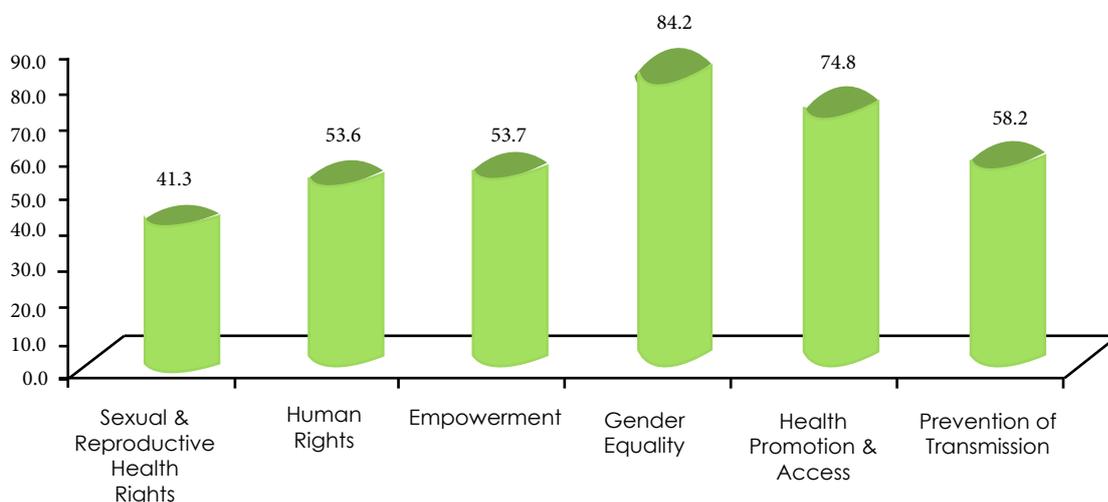
The questions selected⁴ and analyzed for each component are summarized in Table 13.

Table 12: Questions selected for composite score analysis

Components of PHDP Framework	Questions selected	Total
Health Promotion and Access	Q12, 18, 19, 21, 23, 40, 41	7
Sexual & Reproductive Health and Rights	Q44, 50, 54, 55, 60	5
Prevention of Transmission	Q61, 63, 65, 67	4
Human Rights	Q82, 87, 88, 90	4
Empowerment	Q98, 100, 102, 106	4
Gender Equality	Q92, 93	2

All parameters that were believed to encapsulate the essence of each PHDP component were summarized into percentage distributions. Inverting negative measures by including the proportion of respondents who responded to the contrary allowed for inclusion of these measures in these composite indicators. For example, in a baseline survey question such as: ‘What do you think would happen if you disclosed your HIV status?’ (Q87),⁵ those responding ‘YES’ to ‘NOTHING WOULD HAPPEN’ were included together with those who responded ‘NO’ to ‘I WOULD BE EXPELLED FROM SCHOOL,’ since they both measure a ‘better off’ dimension of human rights awareness for YPLHIV. A weighted proportion of the selected responses was further computed by taking an average of all the affirmative responses in each component, divided by all expected responses and multiplied by 100. Figure 3 below shows the actual performance of the population in terms of each of these indicators, simultaneously taking into account all the selected questions and all responses.

Figure 3: Baseline performance indicators for Uganda



Accounting for all selected questions and their responses, the results show that the two highest performing PHDP indicators/components among YPLHIV in Uganda at baseline are ‘Gender Equality’ at 84 percent and ‘Health Promotion and Access’ at 75 percent.

The ‘Prevention of Transmission’ component scored 58% among respondents. The ‘Human Rights’ and ‘Empowerment’ components of PHDP scored 54 percent each,

⁴All baseline survey questions may be found in the Appendix.

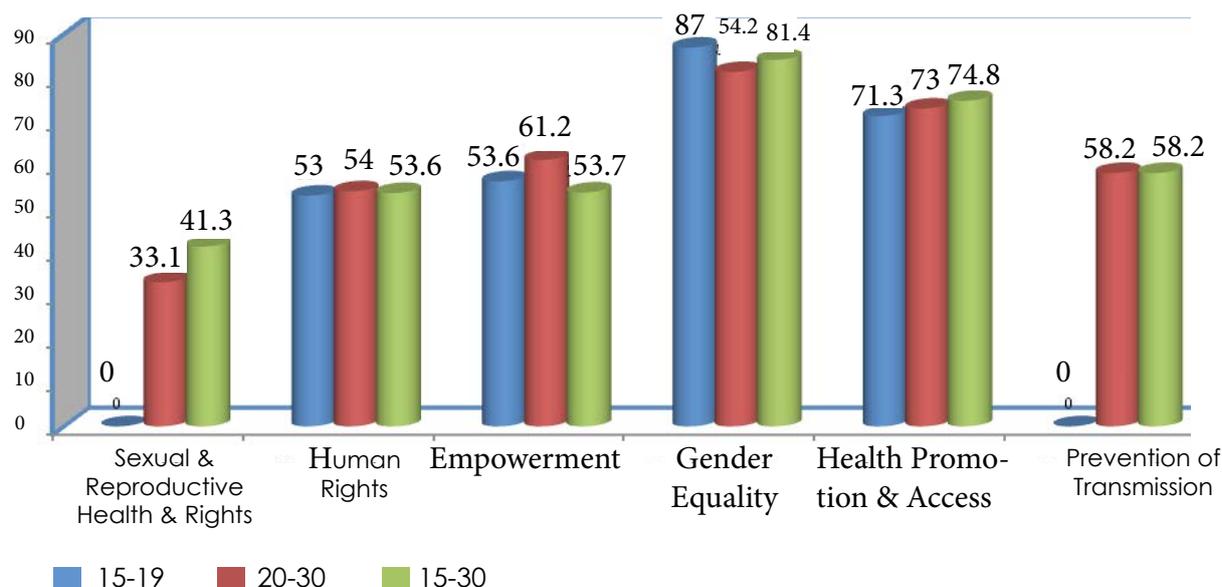
⁵See Appendix for a complete list of the baseline survey questions.

while 'Sexual and Reproductive Health and Rights' scored a distant 43 percent.

As alluded to already, results of this baseline study indicate progress in Uganda across six of the PHDP components as they relate to YPLHIV, while also clarifying the challenges that remain to be addressed and the opportunities that can help facilitate this process.

To examine the age effect in the achievement of PHDP among YPLHIV in Uganda, the composite scores were also examined by age, repeating the same process described above for younger adolescents aged 15-19 and older youth aged 20-30 separately.

Figure 4: Composite Scores by Age Cohorts among YPLHIV aged 15-30 in Uganda



The results, summarized in Figure 6, compare outcomes for the two age cohorts to scores for all youth collated together, and show an overall advantage for young people aged 20 and above, compared to those aged 19 and below when it comes to Sexual and Reproductive Health and Rights, Empowerment, Health Promotion and Access, and Prevention of HIV transmission. The gap between the two age cohorts is marginal when it comes to Human Rights, but younger youth scored higher on issues related to Gender Equality. A plausible explanation for this is the gradual progression of younger youth from the age of innocence to the point where social norms and values begin to moderate gender attitudes and behavior later in life.

Important to note are the marked differences between younger and older YPLHIV in relation to 'Sexual and Reproductive Health and Rights' and 'Prevention of Transmission,' with adolescents ages 15-19 having no scores at all. The age-related differences identified, underscore the need for targeted, age-specific intervention programs.

4.0 Key Recommendations for Advocacy

Basing on the above findings, the young people participants at a PHDP workshop held in Kampala arrived at the following key advocacy recommendations which they carried forward in their advocacy agenda.

Increase awareness, knowledge and capacity of YPLHIV on the existing HIV and SRH policies and in ASK program districts

Promote meaningful engagement of YPLHIV in policy and program development including programming processes at national level and in the ASK programme districts

Empower YPLHIV with knowledge, information on policies and laws on human rights to enable them demand for protection and observance of their rights and access to legal services in the ASK program districts

Address stigma and discrimination against YPLHIV in the health sector and communities in the ASK programme districts

Promote access to a comprehensive package of HIV and SRH information and services by YPLHIV in the ASK program districts

Improve utilization of HIV care, treatment and support services by YPLHIV in the ASK program districts

5.0 References

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Appendix 1:

Position paper by Young people living with HIV to help address the issues based on the PHDP research done in 2014.

Statement of main recommendation:

By linking the social, health, and prevention needs of the Young People living with HIV within a human rights framework, Positive Health, Dignity and Prevention results in a more efficient use of resources, with outcomes that are more responsive to the needs of young people living with HIV and more beneficial for their partners, families, and communities. This has to include; Health promotion and Access to SRHR-HIV services Gender Equality and Human Rights, Empowerment issues, SRHR issues.

Background:

Uganda is acclaimed as a champion against the HIV epidemic for close to 30 years with tremendous Strides in curbing the spread of the epidemic. However, current statistics depict a drastic increase of HIV incidence where young people constitute the group most seriously affected. According to the 2011 National HIV Indicator Survey, the prevalence rate among Ugandans between the ages of 15-19 is going up-at 7.3 per cent and even higher in women at 8.3 per cent which is up from 6.4 per Cent in the 2004-2005 survey. In addition, the number of new infections has risen from 124,000 in 2009 to 128,000 in 2010 and approximately 145,000 in 2011. Statistics show that, if new infections continue to rise, the HIV burden is projected to increase by more than 700,000 over the next five Years. Also Data from Uganda show we will not end HIV, if we do not pay special attention to key populations. A study in Kampala by the Most At-Risk Population (MARPs) Network in 2012 Highlighted the following HIV prevalence rates among different key populations: 35.7 percent among sex workers; 16.7 percent among injecting drug users; 9.3 percent among fisher folk; 9.1 percent among in men who have sex with men (MSM); and 6.6 percent among truckers. Furthermore, according to the recent UNAIDS GAP Report seven to eleven percent of newly acquired HIV in Uganda is thought to be among sex workers, their clients and clients' regular partners. Additionally, two recent studies on women in Uganda (15–49 years) and South Africa (15–26 years), also highlighted in the UNAIDS GAP Report, found that women who had experienced intimate partner violence were 50% more likely to have acquired HIV than women who had not experienced violence. With this background we as young people living with HIV believe that HIV can only be combated if the recommendation in this position paper is put in consideration.

There are many Laws, international treaties, decrees, policies, etc., which support our recommendation and these include:

The universal declaration of Human Rights that recognizes the rights of young people to access health services and information.

The National Policy Guidelines and Service Standards for Sexual Reproductive Health and Rights of 2011 recognize the relevance of providing adolescent-friendly health Services as a way of increasing service coverage for Reproductive Health (RH) amongst adolescents.

The Health Sector Strategic Plan II (2010/11-2014/15) highlights the need for increased RH service provision for young people through environments that are supportive and conducive.

Article 16 section c) of the African Youth Charter (2006) supports the provision of Youth

Friendly reproductive health services including contraceptives, antenatal and post natal services.

National policies such as the Adolescent Health Policy and service standards May 2011 by the Ministry Of Health. States that "Adolescents will be given information and where necessary counseled on the approved prevention methods and technologies"

The Continental Policy Framework for Sexual and Reproductive Health & Rights and Maputo Plan of Action 2007-2010 are all some of the regional policy frameworks that recognize the need to provide Youth friendly services in order to improve reproductive health for young people.

The universal declaration of Human Rights, which recognizes the rights of young people to access health services and information.

The ESA commitment that recognizes the role of the MOE & MOH in promoting comprehensive sexuality education (CSE), and integrated sexual reproductive health services.

Evidence supporting the recommendation: From the PHDP Research study that was carried out in Iganga and Gulu among 275 young people living with HIV in Uganda, Reports provided results that:

Providers play a critical role in shaping YPLHIV sexual behaviours and fertility desires however the information provided is not comprehensive enough and stigmatize more the YPLHIV;

About ¼ told YPLHIV can't have intercourse

38% told sex with any partner of choice is permissible (whether HIV Positive or HIV negative)

25% told C-section is the only delivery option

27% not told about pregnancy prevention

Alcohol/drug use and sex a low discussion priority for providers

Stigma, discrimination and human rights violations against PLHIV represent some of the most significant barriers to achieving universal access to prevention, treatment, care and support for PLHIV;

A third reported experiencing discrimination in last year due to their HIV status

Fear of discrimination permeates many areas of life (schooling, employment, leadership, inheritance, friendships, etc.)

90% know of no laws to protect PLHIV from discrimination in Uganda

28% had access to free legal services, but none took any legal action against discrimination

Ministry of Health and Gender; why are young girls more infected by HIV in Uganda? (UAC-457 infections per week).

Our position:

YPLHIV travel long distances to access information, services, and poorly structured health centers prohibit YPLHIV to access SRH services, thus increasing the scourge of HIV among the young people.

Marriage should be based on love and choice but not on one's HIV status. We ask that all religions to stop asking for HIV test results, because this violates the right of choice for Young People Living HIV.

YPLHIV accesses inadequate information on the existing HIV and SRHR policies and program development at national level. This has been proved by the PHDP analysis that showed that young people know no laws to protect them from discrimination

and stigma. This there for has resulted into a barrier for meaningful participation of the YPLHIV in the existing policies.

90 percent of YPLHIV are dependents, plus being in school thus can't afford the cost Involved in affording and accessing SRHR services. Therefore these services should be integrated, youth friendly and comprehensive to cater for all the sexual reproductive health of the Young People

With the majority of HIV infections globally occurring through sexual transmission, ensuring the sexual and reproductive health and rights of YPLHIV is not only important in terms of the ability of YPLHIV to access their human rights, but it also has a major impact on preventing new infections. For their sexual health and wellbeing, YPLHIV require access to services related to the diagnosis and treatment of STIs and other sexual health illnesses, comprehensive sexuality education and counseling, and other services integrated into sexual and reproductive health (SRH) and HIV-related services where and when appropriate.

Recommendations: Specific, realistic actions that the decision-maker can take, i.e. Stop compulsory testing, increase education and access to health care; YPLHIV should be empowered with information on these existing policies and programs ensuring that they're meaningful involved at all levels by policy legislators, program makers and development partners.

We ask that SRHR services should be integrated and provided to all YPLHIV in ART sites. Cervical cancer is now a recognized killer of women especially Young Women Living with HIV, services for prevention and treatment screening to be available at all ART clinics.

Government and development partners: Invest in community based and peer led interventions

Uganda Aids Commission: Design youth friendly information sharing mechanism, toll free calls and expert clients to disseminate information With YPLHIV

Health center in-charge should bring more YPLHIV on board so as to ease access to services through mobile out reaches to distant clients.

Organizations supporting this position paper

Uganda Young Positives (UYP)

People In Need Agency (PINA)

Uganda Network Of Young People Living With HIV (UNYPA)

