Listening to the needs and preferences of adolescents living with HIV in Nigeria

May 2018

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Authors

Dibb, Zoe
Ohanyido, Chinedu

Reviewers

4Children Team

Adegoke, Motunrayo
Akpan, David
Beeler, Aften
Bunkers, Kelley
Elijah, Opeyemi
Hamadziripi, Alfred
Haruna, Ruth
Ibitoye, Oluwasegun
Itua, Obaitua
Langley, Meg
Lannap, Faith
Long, Sian
Murove, Tapfuma
Ukpoju, Benjamin

Implementing partners

Family Health International (FHI 360)

Sustainable Mechanism for Improving Livelihoods and Household Empowerment (SMILE)

Abbreviations and acronyms

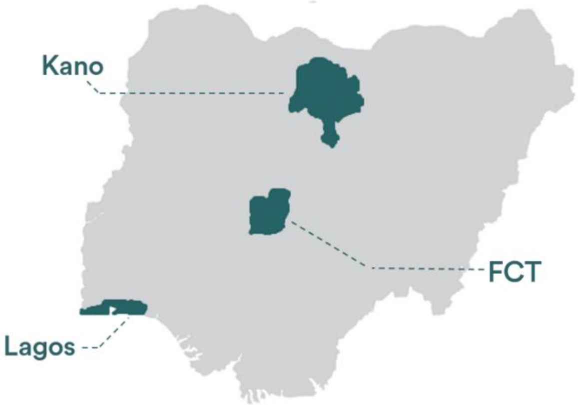
4Children	Coordinating Comprehensive Care for Children
AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescent Living with HIV
ART	Antiretroviral Therapy
CBO	Community Based Organisation
CDC	Centres for Disease Control
CRS	Catholic Relief Services
FCT	Federal Capital Territory
FMoH	Federal Ministry of Health
GEN	Girl Effect Nigeria
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
IP	Implementing Partner
LGA	Local Government Area
LP	Local Partner
OVC	Orphans and Vulnerable Children
PEPFAR	The U.S. President's Emergency Plan For AIDS Relief
PLHIV	People Living with HIV
SRH	Sexual and Reproductive Health
TA	Technical Assistance
TEGA	Technology Enabled Girl Ambassador
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund

Executive Summary

Nigeria has a very young population. Of the over 182 million people in Nigeria, more than 41 million are estimated to be aged 10-19 years. This is almost one quarter (23%) of the population[1]. The median age is 17.9 years old. Nigeria's Human Immunodeficiency Virus (HIV) epidemic affects all population groups and geographic areas of the country. By total number, it is the second largest epidemic globally, just after South Africa, and 2.6% of the population are living with HIV. Just 34% of those living with HIV know their status and 30% are enrolled on Antiretroviral therapy (ART), leaving a large proportion who are not accessing available testing and services[2].

Adolescents aged 10-19 form a significant part of the population living with HIV. However, there appears to be little evidence-based knowledge available to programmes providing adolescent-friendly interventions targeted at improving HIV related outcomes.

Coordinating Comprehensive Care for Children, (4Children), is a global five-year, United States Agency for International Development (USAID)-funded project improving the health and well-being of vulnerable children affected by HIV and Acquired Immune Deficiency Syndrome (AIDS) and other adversities. In Nigeria, 4Children is led by Catholic Relief Services (CRS) and provides technical assistance to implementing partners in order to improve the delivery of youth-friendly services for adolescents living with HIV.



This research report focuses on understanding the needs of adolescent boys and girls living with HIV in Kano, The Federal Capital Territory (FCT) and Lagos, with the intention of ensuring that services made available to them, and young people like them, are truly youth-friendly.

Girl Effect Nigeria (GEN) undertook this study using its Technology Enabled Girl Ambassadors (TEGA) methodology to explore the enablers and barriers to adolescent girls' and boys' HIV testing, disclosure, treatment, adherence and experiences of care and support. TEGAs are trained young female interviewers aged 18-24 who use a custom-made mobile phone app to conduct interviews containing both closed and semi-structured audio and video questions, as well as photographs. A team of 13 TEGAs, 4 each in Kano and FCT and 5 from Lagos respectively spoke to 118 respondents comprised of 94 adolescents (55 female and 39 male) aged 10-19, 9 parents/guardians, 9 child/youth club facilitators and 6 healthcare workers over two weekends. Interviews were designed to be highly engaging for adolescents, including an opportunity for the younger adolescents to use the mobile device to take photos of their favourite things.

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[1] UNICEF (2016). For Every Child, End AIDS: Seventh Stocktaking Report, 2016.

[2] UNAIDS (2016): Country - Nigeria (unaids.org/en/regionscountries/countries/Nigeria)

Key Findings

Adolescents involved in the study described experiences that broadly broke down into five areas: finding out their status; psychosocial care and support; accessing health services; adherence; and growing up.

Adolescents want to live ‘normal’ lives and keep their status a secret.

Adolescents living with HIV (ALHIV) have dreams and look positively towards a future cure for HIV. Many have hopes of being well educated and self-reliant, with professional careers and many want to become doctors and nurses to provide better care for sick young people. ALHIV shared hopes of having a better life in the future. Immediate interests for adolescents centred around their appearance, making friends, family ties, playing and schooling. Despite these hopes, adolescents also shared concerns about living with HIV, worrying about discrimination from friends, schoolmates, neighbours and future partners. Older adolescents, particularly girls, had more concerns about future relationships, getting married and having children of their own who would be HIV free.

Managing the secrecy regarding their HIV status and guarding against disclosure is a vital and active part of an ALHIV’s everyday life. Adolescents constantly worry that people around them will see their medications or ask about visible side effects. Concerns about societal discrimination and stigma associated with HIV affects attendance at clinic appointments and adherence, as adolescents worry they might be seen attending appointments or taking medicine. Older adolescents aged 15-19 feel embarrassment related to their HIV status, which can lead to them isolating themselves from their peers.

Parents avoid disclosing their child’s status for as long as possible to protect them from the stress of knowing. They are an essential source of support.

Parents/guardians of younger ALHIV (aged 10-14) were often reluctant to disclose their status to them and often rely on health workers to do so. Reluctance by parents to disclose is often due to the belief that they are protecting the child from stigma and discrimination and the burden of knowing they are living with HIV. Parents are the key to ALHIV living healthy lives. Adolescents acknowledged the importance of having family members remind them to take their medications at the prescribed times of the day. For most adolescents, their immediate families, and particularly their mothers, were their most trusted source of material and emotional support and adolescents rely heavily on them.

School is a major part of adolescents’ lives but can be a barrier to adherence and staying healthy.

School can make attendance at clinic appointments and adherence challenging, as adolescents fear their classmates working out that they are living with the disease. When friends do find out, they often start to avoid the adolescent, causing them to become isolated and potentially resulting in them avoiding school. School can also make it difficult to leave for appointments, which clash with lesson times. During exam periods older adolescents sometimes travel to take their exams, which leads to them forgetting to take their medication or being unable to find private spaces to do so.

Adolescents at boarding schools are likely to face specific challenges around privacy, clinic attendance and adherence but were not included in this study.

After being diagnosed, acceptance takes time and often follows a period of denial and depression.

Older adolescents interviewed by TEGAs talked about the difficulties of coming to terms with the reality of being HIV positive and the feelings of depression that resulted. This was more common with the adolescents who found out their infection was acquired as a child, rather than from birth, as they were angry that this could have been prevented. During the period after being diagnosed, these adolescents said they refused to take their medication, which was a constant symbolic reminder of their diagnosis with HIV. Even for adolescents infected from birth, many had experienced periods of resentment about being infected through no fault of their own, and rejected medication as a way to ignore the disease, putting their health at risk. Parents and health workers seem ill equipped to support adolescents dealing with feelings of resentment and depression during this period. Despite its importance in helping adolescents cope with their diagnosis, a third told TEGAs they had never received counselling (33 out of 94). Of those who did attend, the majority (89%) were tended to in a private room.

Friendly and supportive health workers are another key factor to adolescents staying healthy.

Overall, 91% of adolescent boys and girls living with HIV surveyed agreed that health workers treated young people in a friendly way. They describe health worker attitude as an important factor in adherence and retention in care. Despite the high rating for health worker friendliness, when probed many adolescents revealed stories of health workers who had treated them badly, shouted at them or explained things in a way that they did not understand. This was reported more frequently amongst older adolescents as they transitioned into adult care and felt that health workers treated them as adults, despite them still being teenagers and needing more support than those who were older who had been living with HIV longer.

Health workers could also be a key source for information as older adolescent's transition to adulthood, but lack of skills and confidence means they sometimes struggle to adequately support adolescents in this period. Confusion about whether abstinence-only messaging is mandated by the Federal Ministry of Health (FMoH) leads to adolescents receiving mixed messages about sexual and reproductive health.

Health services are not always set up to serve the specific needs of adolescents.

Some clinics have taken steps to ensure the environment is comfortable and welcoming for younger adolescents, with some holding specific adolescent clinic times and one even providing a TV showing cartoons. However, health centres do not always ensure privacy and confidentiality of ALHIV and this is a key concern for older adolescents and their parents. Administrative processes and procedures prolong waiting times, causing frustration and resentment, particularly when patients are not seen on a first-come-first-serve basis. Clinic times often clash with school and adolescents said they would prefer to attend appointments on the weekend. This would mean it was also less likely that others would know they were travelling to the health centre and guess they were living with HIV, as they would not have to leave school early.

The cost of transport and distance to health centres was a key barrier to keeping appointments and adolescents said having appointments less frequently would positively impact their lives, specifically requesting prescriptions that lasted longer than a month. Younger adolescents (aged 10-14) also said the taste, size and frequency of having to take pills stopped them sticking to their drug regimen.

Adolescents living with HIV face specific challenges as they transition to adulthood.

The transition from paediatric to adult health services can be a challenging time for ALHIV. Health workers struggle to communicate information in adolescent-friendly ways during this period and can sometimes treat 18-year-olds as if they had suddenly become adults overnight, when actually they still feel like children and require special care and, importantly, empathy.

As they grow up and think about entering romantic relationships, ALHIV need access to information about their sexual and reproductive health, such as menstruation and healthy relationships, just like any other adolescent. However, messages need to also address ALHIV's specific needs about disclosure to partners, HIV-related risks related to pregnancy and childbirth, and good nutrition. This is a particular concern for girls who worry about whether they will be able to become wives and mothers in the future. As it stands, adolescents receive very little and often inconsistent information related to their sexual and reproductive health; parents and guardians rarely talk to adolescents about this.

Older adolescents want to become independent and see economic empowerment programmes and microloans as a way to fulfil this wish and give them control over HIV, helping them visit health centres and supporting other needs like nutrition with their own money, rather than through relying on their parents.

Introduction

Adolescents represent a growing proportion of the share of people living with HIV globally and in 2015 the United Nations Children's Fund (UNICEF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recognised the vital need to involve them in ensuring that programmes and advocacy to tackle HIV responded to their unique needs. Between the ages of 10-19, adolescents experience cognitive, hormonal and emotional changes which result in them experiencing higher levels of stress and a risk appetite than children and adults. As they begin to explore romantic relationships, this combination of factors means HIV-positive adolescents face particular challenges in relation to their health and wellbeing.

Taking these factors into account, 4Children commissioned this research to inform its understanding of the opportunities for, and barriers to adolescent girls' and boys' HIV testing, disclosure, treatment, adherence, care and support needs, as experienced by adolescents living with HIV.

The findings of this qualitative study are intended to inform 4Children's mandate to provide technical assistance (TA) to USAID and Centres for Disease Control's (CDC) Implementing Partners (IPs) in the responsible graduation and transfer of Orphans and Vulnerable Children (OVC) and their households along with programming transition within IPs, communities, Local Government Areas (LGAs) and states as part of the U.S President's Emergency Plan For AIDS Relief (PEPFAR) pivot and reflective of PEPFAR 3.0 priorities. The study findings will be used to inform future programme design for adolescents by USAID/CDC PEPFAR partners, National Agency for the Control of AIDS and FMoH, who are currently exploring ways to enhance adolescent-friendly sexual and reproductive health and HIV services in Nigeria.

Objectives

The key objective of this qualitative study is to examine and understand the opportunities for, and barriers to, adolescent girls' and boys' HIV testing, disclosure, accessibility, treatment, adherence, care and support needs, as experienced by adolescents living with HIV who are accessing services supported by the 4Children project.

Research Questions

Specific research questions are as follows:

i. What works well, what does not work well and what can be improved for adolescent boys and girls who receive HIV care and treatment in facilities in the following areas of the HIV care continuum:

  - HIV testing
  - Enrolment on treatment
  - Treatment adherence
  - Post-treatment care (e.g. did you get the information wanted, how were the attitudes and treatment by care providers, did you feel accepted, were services consistent?)
  - Transition from paediatric to adult HIV support.

ii. What do adolescent girls and boys living with HIV in Nigeria identify as the main areas that can be improved to make their HIV treatment and support work well, in terms of:

  - HIV treatment and support at the facility
  - Non-HIV issues (e.g. SRH, communication with parents, etc.).

iii. Do adolescent girls and/or boys identify any gender-specific issues in uptake and retention of adolescent HIV treatment?

Methodology

This research project used an innovative qualitative data collection method developed by Girl Effect, known as 'TEGA'. The TEGA methodology utilises networks of 'Technology Enabled Girl Ambassadors' (TEGAs) aged 18-24 who use a mobile phone to collect data during interviews with respondents. Two TEGA networks were utilised for the 4Children study: 4 TEGAs in Kano, 4 who travelled from Kano to FCT and 5 based in Lagos.

In Nigeria the first TEGA network was launched in Kano in 2015 and to date, 43 TEGAs in Borno, Lagos, Abuja and Kano have conducted interviews with almost 2,500 respondents. All TEGAs have experience in talking to girls, boys, adults, community and religious leaders and teachers. Girl Effect continuously assesses TEGAs' ability to interview different respondent types and their qualification with the Market Research Society is contingent on them being able to demonstrate their ability to confidently conduct research with multi-demographic groups.

The four-step research process is outlined below:

Step 1	Step 2	Step 3	Step 4
TEGAs were trained in sensitivities of interviewing adolescents living with HIV	TEGAs conducted interviews using survey scripted on the TEGA app in their mobile phone	Data, in the form of audio, video, photo and survey data was automatically uploaded to a secure online Content Hub	The data was translated and exported to csv. files to allow offline thematic analysis

The unique benefits of TEGA over traditional qualitative research techniques, such as focus groups and in-depth interviews, relate to six proof points:

Authentic

TEGAs' shared identity with respondents is designed to inspire more authentic responses from multi-demographic audiences within the community, ranging from girls, boys and parents/guardians to community leaders, teachers and policy makers. TEGAs have a 'disarming' quality, which disrupts power dynamics and leads to open conversations, particularly with men and boys.

Holistic

TEGAs are able to confidently interview a wide range of community members, from children to community leaders. TEGA research uses triangulation to better answer research questions – for instance by talking to a girl, her siblings, parents and grandparents to understand barriers to accessing health services.

Agile

The TEGA community-based research infrastructure allows for more frequent, agile research as compared to the typical one-time fieldwork cycles of traditional approaches. The benefit of this agile approach is that it allows continued exploration into pre-determined and unexpected themes until robust conclusions are achieved.

Human

TEGA collects media content in the form of video, photo and audio, bringing the respondents to life beyond statements and statistics. The videos provide a real window into the lives and circumstances of respondents' communities, and provide an additional layer of colour and insight beyond what is included in a typical research report.

Real time

Within minutes of TEGAs completing their fieldwork, the programmatically analysed results can be viewed anywhere in the world via Girls Effect's highly secure Content Hub.

Positive Impact

Being a TEGA is shown to empower girls and increase their agency. TEGAs report being able to confidently share their opinions and raise their voices. They recognise their own value as girls and strengthen connections with peers as well as family and community members. Respondents who take part in TEGA research say they value sharing their opinions and being listened to by TEGAs.

Data Collection and Analysis

TEGAs are trained female researchers aged 18-24 who use a bespoke mobile phone app to interview respondents in a friendly and non-judgmental way. The methodology is particularly well-suited for conducting qualitative research on sensitive subjects, such as HIV. Qualitative and basic quantitative data was collected using the TEGA device, an Android enabled mobile phone which houses the TEGA app. Interviews were conducted by a team of 13 TEGAs; 4 each in Kano and FCT respectively and 5 in Lagos state.

The interviews, which were all conducted via the TEGA app, were primarily qualitative in nature, including audio, video and photo questions. In order to supplement this data, some closed quantitative questions were asked across audiences. However, this report is a qualitative study, and any quantitative data presented is indicative only.

Interview guides were designed in line with lean research principles[3] with a focus on keeping them short, engaging and focused. The guides, which were downloaded by the TEGAs onto their phones, were tailored for the different respondent groups. Adolescents' interviews were co-created with the TEGAs during training, ensuring they were participatory and non-threatening with an emphasis on making young people feel that the interview was an opportunity to share their expert opinion with a TEGA, rather than an extractive traditional interview process[4].

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[3] Lean Research (2015): Principles of Lean Research

[4] The survey tools are attached as Annex 1: Survey tools

TEGAs received additional training on adolescent-specific interviewing techniques, including modules on ethical issues and conducting interviews with adolescents living with HIV. The interviews conducted were held at general hospitals, health centres or community centres, in chosen places that offered privacy and convenience for the adolescents. All data collection took place between Mid-December 2017 and Mid-January 2018.

After conducting their interviews, TEGAs sent the findings back to an encrypted online Content Hub, where audio, video, photo and closed question responses (single/multi code and scale answers) were programmatically analysed. Video and audio interview data in the Content Hub was transcribed and translated into English and thematic content analysis was performed on the qualitative data. An analysis framework was designed to explore themes and findings emerging from each distinct demographic group and coding was used to identify and group different sub-themes.

Despite initial concerns about TEGAs interviewing men, due to social and gender norms and power dynamics, research has consistently shown that males appear to speak as candidly with TEGAs as females, including in conservative settings such in Kano and Borno States[5] in Northern Nigeria. Whilst Girl Effect have not yet embarked on a full study into the research effects of TEGAs on male respondents, male support staff working with partner organisations and the TEGAs have said that TEGAs 'catch men off-guard' and stoke curiosity, resulting in male respondents actually being more open than they would be with older female or male researchers. There appeared to be no bias.

The information gathered is not intended to be representative of the wider population of adolescents living with HIV in these states and is largely qualitative in nature. Where numbers are given, these reflect on findings from the sample of respondents and are in no way generalisable.

Data quality assurance

Before fieldwork commenced, training was conducted for TEGAs in Kano and Lagos to ensure they were fully prepared to conduct interviews with adolescents living with HIV, respond to safeguarding issues and show empathy and understanding if adolescents struggled with questions.

As part of the analysis, Girl Effect's project team in Nigeria and London reviewed every respondent interview, amounting to almost 1,000 individual audio and video files ranging from one to three minutes in length. These were translated and transcribed by an in-house team of translators, with a lead translator assigned to conduct quality assurance checks throughout the translation period.

Social desirability bias likely played a factor in some of the questions asked in interviews with both parents and adolescents. During analysis, processes were followed to attempt to prevent respondent bias by reviewing each respondent's interview as an entire 'story', allowing nuances and contradictions to be revealed and inform which parts

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[5] Based on interviews conducted by TEGAs in Borno State for Oxfam (2016) and DFID (2016)

were included in the thematic analysis. On the whole, both adolescent and adult respondents were open and forthcoming with answers and TEGAs managed to build a good rapport with them.

Ethical approval and considerations

The study was approved and conducted in accordance with the determined guidelines for the National Health Research Ethics Committees, Nigeria and provisions of the Declaration of Helsinki. Privacy and confidentiality were safeguarded consistently with standard guidelines for research involving young people.

Adequate information was provided to adolescents, their parents/ guardians, club facilitators and health workers in English and other local languages including Hausa, Yoruba and Pidgin. 4Children IPs confirmed in advance with parents/guardians, club facilitators and healthcare providers that all adolescents approached about the study already knew their HIV status.

Surveys were designed to keep identities of the respondents anonymous if they requested. In addition, participants were reminded by the TEGA at key intervals that they could opt out of the survey at any time and could skip any of the questions asked or have their data removed from the study entirely. However, not all respondents wished to remain anonymous during interviews and many chose to have their faces recorded in video responses. Despite this, all respondent data included in this report has been anonymised and only respondents who confirmed their consent to share their video data have been included in the accompanying film.

GEN conducted a 'consent collection' training for the focal persons in each state responsible for respondent recruitment. This training detailed the step-by-step process of how informed consent and assent needs to be collected for both adults and respondents under the age of 18 years. GEN local partners (LPs) were also given this training to ensure proper procedures were followed throughout recruitment. A contact person was provided for respondents and the consent and assent forms clearly indicated a named support staff member they could easily contact at any point to ask questions or withdraw consent after the interview.

A comprehensive consent form[6] was developed for this study which considered its sensitive nature and the safety of the respondents.

During field work, before TEGAs commenced an interview, the GEN LP checked the consent and assent forms, verified that the forms were duly signed and understood by the respondent. This was verified via short check back questions asked to the respondent. A picture of the signed consent page was also photographed using the TEGA device and automatically saved in the Content Hub to ensure that if paper forms were lost, record of consent would be maintained. After field work, all consent forms were collected by GEN LPs and transferred in-person to the GEN office in Abuja.

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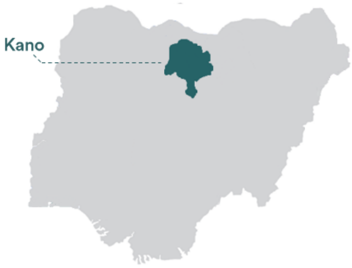
[6] See Annex 2: Consent form

Study Locations

The study locations were selected to represent the experiences of adolescents living with HIV in diverse social and cultural contexts with Kano state from the North, FCT from the Middle belt and Lagos state from the South. In all three states, adolescents recruited were living with HIV and accessing ART and other clinical services such as clinical consultations, HIV testing and counselling at government facilities. Some of the adolescents in the study were also accessing other non-clinical services such as psychosocial counselling in peer support groups provided by child and youth HIV clubs run by 4Children IPs and other non-governmental organisations.

All the adolescents interviewed in FCT are beneficiaries of the Sustainable Mechanism for Improving Livelihoods and Household Empowerment (SMILE) CRS OVC Program. They participate in the community youth clubs facilitated by Community Based Organisations (CBOs) contracted by SMILE CRS.

Kano State



Kano is the state capital of Kano State in North West, Nigeria. Kano is the commercial nerve centre of Northern Nigeria and Nigeria's second largest city. The state borders Katsina State to the north-west, Jigawa State to the north-east, Bauchi State to the south-east and Kaduna State to the south-west. The official language of Kano State is Hausa language, but Fulani is commonly spoken.

According to the 2006 National Population Commission (NPC) census figures for Nigeria, Kano State had a population totalling 9.4 million. Officially, Kano State is the most populous state in the country. Kano is majority Sunni Muslim, although there are small populations of Shia Muslims and Christians too. Kano State has a 48% youth literacy rate in English and a 77% youth literacy rate in any language[7].

Recruitment in FCT was conducted in urban and peri-urban communities at the Asiya Bayero Hospital, Murtala Muhammed Specialist Hospital, and the Yakasai Quarters and Sabon Titi communities in Kano state.

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[7] National Bureau of Statistics, Nigeria (June 2010): National Literacy Survey

FCT

The Federal Capital Territory, commonly known as FCT, or FCT-Abuja, is a federal territory in central Nigeria. Abuja, the capital city of Nigeria, is located in this territory. The territory is located just north of the confluence of the Niger River and Benue River. It is bordered by the states of Niger to the West and North, Kaduna to the northeast, Nasarawa to the east and south and Kogi to the southwest.

As of 2017, the city is one of the fastest-growing on the African continent and the world[8]. Abuja has witnessed a huge influx of people into the city; the growth has led to the emergence of satellite towns, such as Karu Urban Area, Gwagwalada, Lugbe, Kuje and smaller settlements towards which the planned city is sprawling. The unofficial metropolitan area of Abuja has a population of over 3 million, making it the fourth largest metropolitan area in Nigeria, surpassed only by Lagos, Kano and Ibadan. Abuja's rapidly growing population has implications for HIV programmes, as migrant and mobile populations have greater vulnerability to HIV contraction and transmission[9&10]. The FCT has a 76% youth literacy rate in English and 86% literacy rate in any language[5].

Recruitment in Abuja was conducted in Dutse Alhaji, Mpape, Kubwa and Jikwoyi: a combination of peri-urban and urban centres.

Lagos

Lagos, sometimes referred to as Lagos State to distinguish it from Lagos Metropolitan Area, is a state located in the southwestern geopolitical zone of Nigeria. The smallest in area of Nigeria's 36 states, Lagos State is arguably the most economically important state of the country, containing the nation's largest urban area. It is a major financial centre and in 2016 would be the fifth largest economy in Africa if it were a country.

While the State is essentially a Yoruba-speaking environment, it is a socio-cultural melting pot attracting both Nigerians and foreigners alike. The 2006 population census sets Lagos' population at around 9 million however the Lagos State government estimated this to be closer to 18 million[11].

Recruitment in Lagos was conducted in government-owned general hospitals in urban areas of the four LGAs of Lagos state; Agege, Ajeromi, Surulere and Apapa.

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[8] Euromonitor International (2017): Euromonitor Survey, 2017

[9] International Organisation for Migration (2003): Population Mobility and HIV

[10] UNAIDS (2014): The Gap Report

[11] Lagos State Government (2018): Lagos State Government (lagosstate.gov.ng)

Recruitment

As detailed above, respondents were purposefully sampled in three states where the 4Children programme is being implemented: Lagos, FCT and Kano State. Lead by 4Children, IPs helped identify adolescents aged 10-19 in communities supported by 4Children IPs currently accessing government hospitals, clinics and health centres supported by the programme. In addition, one facilitator from each community was interviewed, along with nine parents/guardians (one per community but not all parents/guardians of adolescents in the study). Finally, two healthcare providers from each of the three states were interviewed.

The original sample was designed by Girl Effect in collaboration with 4Children to reflect the number of communities supported in each of the states: Lagos has four, FCT has three and Kano has two. Originally, ten adolescents were to be recruited from each of the nine communities supported by a 4Children IP. However, in Lagos there were initial issues in recruiting adolescents resulting in oversampling during a second set of interviews, however all respondents attended, boosting the intended sample by four respondents. In FCT, there were challenges in recruiting boys and so the sample is skewed towards girls (22 girls to 8 boys).

A strategic set of inclusion questions were used to screen respondents during recruitment stages. Participants who did not fall within the required age range of 10–19 years, who were not currently living with HIV and those who couldn't speak any of the languages English, Hausa, Yoruba or Pidgin English were not recruited.

Adolescents were divided into two age groups: 10-14 and 15-19 years old. The rationale for these groupings was to allow for a clear distinction between younger adolescents, who may not fully understand the implications of their status yet, and older adolescents who could better comprehend the significance of living with HIV. Throughout the report, they are referred to as 'younger' and 'older' adolescents.

The study enrolled a greater number of adolescents (80%) in comparison with other groups because the primary purpose of the study was to explore adolescents' experience, perceptions and preferences. Data from the adult groups were primarily used to triangulate findings from the adolescent groups. It was particularly difficult to recruit and interview male parents and as a result the parent sample is skewed towards female caregivers.

All adolescents in the study were aware of their HIV status and were already accessing HIV treatment and support services provided by the 4Children IPs.

Characteristics of study participants

Table 1: Recruitment breakdown

Type of respondent	Lagos 4 communities		FCT 3 communities		Kano 2 communities		**TOTAL**
	Female	Male	Female	Male	Female	Male	

Facilitators of Kids/Youth Clubs	4	0	3	0	2	0	**9**
Adolescents	23	21	22	8	10	10	**94**
Parents/guardians of adolescents	4	0	2	1	2	0	**9**
Healthcare Workers	1	1	2	0	0	2	**6**
	Total number of Key informant interviews						**118**

Table 2: Respondent distribution by age and sex (10-20 year-olds)

Age	Male	Female	Total
10	6	1	**7**
11	3	6	**9**
12	2	6	**8**
13	4	8	**12**
14	4	7	**11**
15	5	6	**11**
16	4	7	**11**
17	3	4	**7**
18	3	3	**6**
19	4	7	**11**
20*	1	-	**1**
	39	**55**	**94**

* In Lagos a female ALHIV was recruited in Lagos who had only just turned 20 at the time fieldwork was conducted.

Table 3: Adolescent respondents accessing non-clinical services from child/youth HIV clubs

State	10 – 14 years old		15 – 19 years old	
	Attending	Not attending	Attending	Not attending
Kano	5	5	1	9
FCT	10	5	8	7
Lagos	15	7	13	9
	30	**17**	**22**	**25**

Educational profile of adolescent participants

74 out of 94 of the adolescent respondents (79%) in the survey were currently attending primary or secondary school. A small number (3) of 15-19 year-olds in FCT and Lagos had dropped out of primary school or completed primary and not enrolled in secondary school so it is difficult to infer the impact of school drop out on knowledge, attitudes and behaviours related to HIV in this study.

Table 4: Level of education of adolescents

Level of education	Count	%
Currently attend secondary school	49	52%
Completed secondary school	11	12%
Currently attend primary school	25	27%
Completed Primary did not enrol into secondary school	2	2%
Dropped out of secondary school	4	4%
Dropped out of primary school	3	3%
Total	94	100%

Respondent feedback on interview experience

At the end of each survey respondents were asked how comfortable they felt being interviewed by a TEGA and whether they would be happy to be interviewed again. Despite the sensitive nature of the research topic, there was a high level of respondent comfort and willingness to share information on these issues and to engage in further research. This is further evidence that valuing and consulting young people about the issues that affect them can be a positive and empowering experience, particularly for those who have never had an opportunity to share their opinions about the services and support they access.

Level of comfort with the interview

- 41/47 (87%) ALHIV aged 10-14, 46/47 (98%) ALHIV aged 15-19 felt comfortable or very comfortable being interviewed by the TEGAs.
- All 24 parents, facilitators and health workers felt comfortable or very comfortable being interviewed by the TEGAs.

Survey comprehension

- 42/47 (89%) of ALHIV aged 10-14, 46/47 (98%) of ALHIV aged 15-19 said survey questions were clear and easy to understand.
- All 24 parents, facilitators and health workers said survey questions were clear and easy to understand.

Use of information provided in the research

- All 118 respondents said they were still happy to have the information they shared used for the purpose of this research project.

Happy to be interviewed again

- 45/47 (96%) of ALHIV aged 10-14 and 46/47 (98%) of ALHIV 15-19 said they would be happy to be interviewed by a TEGA again.
- All 24 parents, facilitators and health workers noted that they would be happy to be interviewed by a TEGA again

TEGAs' observations of any safety risk to the respondent

- 45/47 (96%) of ALHIV aged 10-14 and 46/47 (98%) of ALHIV 15-19 said they would be happy to be interviewed by a TEGA again.
- All 24 parents, facilitators and health workers noted that they would be happy to be interviewed by a TEGA again

Findings

Section A: ‘Finding out’: Diagnosis of HIV

Section B: Family, friends, school and support groups

The impact of stigma and discrimination
School and adherence
The importance of friendly and supportive health workers
The potential for youth facilitators to support ALHIV
Religion and spirituality as a coping mechanism

Section C: Adolescent experiences of health services

Accessing health services
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  - Costs and transport

Confidentiality, privacy and disclosure
  - Health workers and confidentiality

Health centre environment
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Forgetfulness
Medication and side effects

Section E: The transition to adulthood

Communication and knowledge
Economic self-reliance
Sexual and reproductive health and living with HIV

Section A: 'Finding out': Diagnosis of HIV

> You might not know you are living with it, it might be when you have some health challenges and you get tested then you find out
>
> 15-year-old male, Lagos
>
> describing how young people first find out they are living with HIV

Adolescents are defined as individuals aged 10–19[12]. Adolescence is a phase characterised by acceleration of physical growth and psychological and behavioural changes, accompanied by sexual maturation which brings about the transformation from childhood to adulthood. During this phase of life, adolescents experience changes in social perceptions and expectations as their capacity for critical thinking, planning, risk taking and relationships develop. For adolescents living with HIV, the developmental challenges of this life phase, including puberty and the desire to be seen as 'normal' and fit in, are sometimes seriously challenged.

The Nigeria National Guidelines for Paediatric HIV and AIDS Treatment and Care[13] recommend that parents/guardians and health workers start the disclosure process with children living with HIV between the ages of 5 and 7, depending on their understanding and on the parent's consent. The process should be gradual and led by the child where possible. Whilst the recommendation makes sense, parents/guardians in the TEGA study raised many valid fears about their child knowing their status too early. These included concerns about robbing the child of their happiness with the knowledge of their diagnosis. They felt letting them know could also have the potential of making the child's status known to more people, putting them at risk of stigma and discrimination.

Parents and guardians in this study had made plans to tell their children their status from an early age but ended up delaying the conversation as long as possible. They said younger adolescents rarely knew their status but this was an effective way to control their drug regime without sharing details of why the drugs were being taken. One mother said she would tell her son when she judged it the right time:

> I am his mother, so it is me that will tell him, I have to educate him on how it is contracted, the drugs and every other thing involved. When the time is ripe and he is more grown to understand, I will tell him
>
> (Mother of 10-year-old male ALHIV)

This female guardian[14] said she had decided to tell her daughter of her status when she turned 15, when she would be old enough to take care of herself and would have finished secondary school:

> My daughter is not aware she is HIV positive, because she is still young she is just twelve. I and her mother plan on telling her when she gets to complete her secondary

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[12] World Health Organisation (2018): Adolescent Health (who.int/topics/adolescent health)

[13] Federal Ministry of Health, Abuja (2016): Nigeria National Guidelines for Paediatric HIV / AIDS Treatment & Care

[14] Of a girl not included in this study

> school education. By then she would be fifteen years of age, she would probably be preparing to start her tertiary education. She would be in a better position to care for herself, as she would not be under our care anymore. So, the plan is to tell her when she is fifteen. She also has an HIV positive sibling
>
> (Female guardian of 12-year-old female ALHIV)

Health workers report that parents often ask them not to disclose their children's status to them, but also say children work things out for themselves as they get older. For younger adolescents they will tell the child they have a 'germ in their blood system' and they sometimes recommend that parents/guardians keep their medication a secret from others to protect their status and avoid associated stigma.

> So, we told the mother to say [he has a germ], because if you tell the child he is taking HIV medication then the child might tell people outside the home that he is taking HIV medication
>
> (Female health worker, FCT)

The eventual decision to disclose the status to the adolescent is often carefully orchestrated by the parent or guardian, caregivers and health workers. Although it was not always clear who initiates the process between health workers and parents/guardians, it was clear steps were often agreed to use when the adolescent was perceived to be mature enough to handle the information. In some instances, parents/guardians, usually mothers, were more insistent on not disclosing the status but when young people are eventually told, it is often the mother, and rarely the father, who explains what the medication is for.

> I was told when I was 11 years old because I never knew the drugs I was taking at that time. My mum told me - "okay this is the drug you are taking and this was how you got infected, you got it from me from childbirth but now you have to take these drugs to stay healthy"
>
> (18-year-old female, FCT)

Like all adolescents, those living with HIV want to fit in and not be seen as different from their peers. Parents said younger children would take medication without asking questions but after understanding their status, some adolescents put up resistance and refused their medication out of anger. This was particularly the case with older adolescents, who said they refused medication when first diagnosed as a way to deny they were living with the disease.

ALHIV cohabiting with brothers and sisters who are not living with HIV are more likely to refuse ART and question why they are the only ones taking medication. Once adolescents become older and understand their condition, they become more likely to go back and adhere to their medications. However, for some the psychological toll of their disease and having to take medication can lead to extreme and dangerous behaviour, as described by this 16-year-old boy from Lagos:

> One time I threatened my mother with a knife that I do not like this life of taking medicines every day, I stopped the medications for long. I just resumed taking it that is why I look this unhealthy and lean. But I now know the benefit of taking my medicines

(16-year-old male, Lagos)

Even when adolescents have been diagnosed, many, and particularly those under the age of 15, did not appear to have a solid knowledge of their condition and a third (33/94) had never received counselling. Of those who did attend, the majority (89%) were tended to in a private room. Lack of knowledge was demonstrated by this 11-year-old girl in Lagos, ‘My mother told me that I contracted it from someone who beat me and she said all the people in the hospital have the same disease as me’.

Even when aware of their status and enrolled on ART, some adolescents clearly misunderstood the disease and saw the medication as curative, rather than a mechanism for managing the disease, as described by a 12-year-old girl in Lagos, ‘When your drugs finish and if you are still sick that means you still have HIV and need to buy more drugs’

Fear of getting ill, or even of death, is a common reason adolescents take their medication, although it is clear that consistency is a challenge and often it is only when adolescents feel ill that they end up taking their medication again.

> Sometimes I discontinue the medication but if I begin to fall ill I go back and continue my medication and when I feel better I discontinue again
>
> (17-year-old male, FCT)

> The hospital workers use to tell me if I don’t take the medication it will kill me then I will be getting afraid and start taking the medication
>
> (12-year-old female, FCT)

Section B: Family, friends, school and support groups

> My mum...was the one that encouraged me to know my HIV status. She was also the one that encouraged me to go for medication. I was scared of stigmatisation and imagining that my friends would know my status but my mum told me it is not the end of life. I live a normal life now
>
> (19-year-old male, Lagos)

Family attitudes toward the disease are a key factor to coping with diagnosis and subsequent wellbeing. For 83% of adolescents, their immediate families were their most trusted source of material and emotional support. The presence or lack of this support acted as an important facilitator or barrier to adherence to ART and adolescents acknowledged the importance of having family members remind them to take their medications at the prescribed times of the day.

Family beliefs about the seriousness of the illness and the belief in the efficacy of ART treatment also influence the adolescent's adherence. Adolescents who reported greater adherence were observed to be mostly those who reported that family members constantly reminded them to take their ART medication.

Whilst families can provide support and guidance to ALHIV, they are also able to prevent young people from accessing services, particularly girls, who are more likely to be kept at home to stay safe and help with household chores. A facilitator from Kano described how girls being kept at home and constantly accompanied by a parent or guardian lead to them being unable to discuss their diagnosis or other concerns with friends the way boys do. As a result, girls are less likely to receive information related to living with HIV.

> The difference is, the girl child is very shy and withdrawn and will most likely not open up when they have issues, but this is unlike the boy child who is open
>
> (Female facilitator, Kano)

The impact of stigma and discrimination

Privacy and confidentiality are major concerns for ALHIV, but particularly those aged 15-19. As they grapple with the challenges of growing up, puberty, sexuality and self-identity, adolescents are even more sensitive to the stigma associated with HIV compared to adults and children. These concerns lead to adolescents developing protective behaviours to deal with stigma. They keep silent about their HIV status and they are keen to maintain control over the disclosure of their status and may inform only those within their immediate family and support group. Adolescents rarely tell their friends about their status and when they do, they often suffer isolation as a result.

> Friends do not want to mix with me
>
> (19-year-old male, Lagos)

> At first, they act like they care but as time goes on they start isolating you one way or another. I do not think any classmate knows about it, it is something that should not be known to the public
>
> (16-year-old female, Kano)

For most adolescents and their families in this study, managing the secrecy regarding their HIV status has become a very important part of their lives. Gossip and rumours from neighbours and friends are one way that adolescents may first find out they are living with the disease, and the stigma continues to follow them even once their status has been confirmed by parents and doctors.

> They can find out through people that are gossiping or the doctor will just tell your mum that it is time for her to tell you. My mum fixed a date and told me, I felt it was not true until when she told me everything
>
> (15-year-old female, FCT)

Older adolescents interviewed by TEGAs talked about the difficulties of coming to terms with the reality of being HIV positive and the feelings of depression that followed. This was more common with the adolescents who found out their infection was acquired as a child, rather than from birth. During the period after being diagnosed, these adolescents said they refused to take their medication, which was a constant symbolic reminder of their diagnosis with HIV. Even for adolescents infected from birth, many had experienced periods of resentment about being infected through no fault of their own, and rejected medication as a way to ignore the disease. Isolation from friends also results as a result of diagnosis, deepening depression and loneliness, as described here:

> I found out in the hospital. I was not told out rightly that I was HIV positive, they kept telling me it was one disease to another before they finally told me the truth and it was revealed to me very carefully after counselling. They figured I was old enough to know about my status, and after I was told I became very withdrawn
>
> (19-year-old male, Kano)

> Most of these children when they are in school or at home they only keep their own company, they are usually loners, and they shun associating with others
>
> (Adolescent HIV club facilitator, FCT)

> He will mingle and do every activity with people, until he gets sick and taken to the hospital, he is then tested and knows he is positive, that is when he will be fearful and will be tired of the world
>
> (14-year-old female, Kano)

Adherence for adolescents living with HIV can be challenging as they often develop protective behaviours to enable them to negotiate and cope with societal stigma. The success with which ALHIV cope with the stress attached to HIV appeared to have direct impact on the quality of life they were living and their burden of depression. Older adolescents interviewed live with a constant struggle to cope with, manage or avoid stigma. Despite the stress of stigma, older adolescents find it easier to portray HIV as a smaller part of their life, therefore normalising it and seeing themselves less differently to those not living with HIV.

Some adolescents leverage on the misconception that healthy looking people do not have HIV infection. This facilitates their adherence to medication, as they do not want people to know they are living with HIV if they start 'looking unhealthy'. Older adolescent participants said that being perceived as looking normal was important to them as then they would not have to disclose their status or explain symptoms to people in the community. Looking healthy helps them hide their status from friends and generally improve social interaction, averting social isolation which they consider highly important in coping with the virus.

Older female adolescents sometimes skipped taking medication to avoid side effects that might change their appearance. However, HIV club facilitators said girls generally are more likely to adhere compared to boys, owing to them being mature and responsible in comparison. Further enquiry is needed to understand whether girls or boys skip medication more often as this study showed that generally both face similar challenges to adherence.

School and adherence

79% of ALHIV interviewed in this survey were in school, with 52% in secondary school and 27% in primary school. Poor adherence for school going adolescents living with HIV was linked to stigma, and this was influenced mostly by where and how the students took their medication. The study was conducted during the school season however adolescents living with HIV who attend boarding schools were not recruited to participate in the study. Participants were only drawn from students who attended day schools, or those who had completed either primary or secondary education and those who had dropped out of school, hence the study was unable to explore in depth specific nuances of ALHIV who attend boarding schools.

Privacy and confidentiality issues were a challenge for adolescents in school, particularly those who attend boarding schools as they live in close proximity with peers and often have little privacy to take medication. Fear of classmates finding out their status has a negative impact on adherence. This also prevents ALHIV keeping appointments at healthcare centres as they do not want peers asking where they are going if they have to leave school in the day. As often only immediate family knows of their status it can be a challenge for ALHIV to adhere to a drug regimen within school hours. Adolescents find it difficult to officially take permission to be absent from school to enable them to attend clinic appointments. This would involve making formal disclosure of their status or having to explain why they need to be absent from school to peers and teachers.

A female healthcare worker in FCT narrated her experience with a 19-year-old adolescent student who had serious adherence issues and was not taking medication because her peers were asking why she always taking some medication. In this case, a responsive and supportive school matron was the key to her staying well.

> The viral load was high and she was hiding from her peers in the dormitory but with the intervention of the matron, she started monitoring her

> (Healthcare worker, FCT)

Exams and changes to timetables can also affect adherence as routines are disrupted and privacy may be hard to come by, especially when students have to travel to write specific exams as described by this 19 year-old-girl, whose viral load increased when she stopped taking her medication:

> When I went to write WAEC in Kaduna, I somehow missed the drugs because the house I was staying is not my house so that is what affected me now, so they have changed my drugs from the first stage to the second stage
>
> (19-year-old female, FCT)

ALHIV were asked what their opinions were to the little cases provided for ALHIV to keep their pills safe. Some adolescents welcomed any means through which medication could be kept safe while in school. Some wanted a case to indicate how doses should be correctly taken. However, particularly among the in-school adolescents, there were concerns that the pill cases might be an indicator attached to being HIV positive by others.

> Because some teachers do seize students bag in school, if the drug is in the bag the teachers will want to know what the drug is used for. From there some teacher might hate you because of that, while some will not hate but it will not be secret again, they will be looking at you somehow unlike before
>
> (17-year-old male, Kano)

> No, because people will see it and start making all sorts of noise
>
> (15-year-old female, Kano)

The importance of friendly and supportive health workers

Supportive and non-judgmental healthcare workers are greatly valued by adolescents living with HIV and considered vital in helping them attend planned appointments and successfully adhere to ART. Data from this study supports the perception held by ALHIV that all clinic personnel - from doctors, nurses and facilities staff - play important roles in supporting adolescents with their health and adherence. Adolescents seek empathy from healthcare workers, as well as trust and confidentiality. Furthermore, adolescents value the availability and timely service of the healthcare workers on their appointment days, flexible appointment schedules and psychosocial support.

Overall, 91% of adolescent boys and girls living with HIV surveyed agreed that health workers treated young people in a friendly way and 95% agreed that health workers keep young people's information confidential. This was a very positive finding and demonstrated that despite facing barriers to accessing health services, when appointments were kept, health workers were generally friendly and confidential. There was a drop in the proportion of adolescents who said health workers listen to young people’s concerns and give them enough time to talk about their concerns. 77% said they did and the remaining 23% represent those who felt rushed or confused during appointments, which is detailed below.

> They are friendly, they always make us happy, they joke with us, they advise us to take our medications the right way and at the right time and the right dose and whenever you mix you drugs you come and meet them, and say that this is what I have done, I forgot to take my drug what should I do about it? They will then advise you more then you will go and continue from where you stopped
>
> (17-year-old male, FCT)

In Kano, FCT and Lagos most adolescents agreed that they felt comfortable asking any of their health-care providers questions about their general health. There was a very positive and trusting relationship between parents/guardians and healthcare providers. Parents/guardians greatly valued the counselling and support of healthcare providers and considered it a primary facilitator of adolescents' adherence to ART. Adolescents and their parents reported that quality interaction between adolescents and healthcare providers lead to better adherence.

> When I took my daughter to so see the doctor she attended to my child very well, she asked me if I have anyone around to help with running around and I said no, so she said she will take the girl to the lab herself to get her tested because she is worried that my girl takes her medication and still no improvement
>
> (Mother of ALHIV, FCT)

However, despite the overall positive perceptions of health workers by parents/guardians and adolescents, a significant number of adolescents and some parents reported the lack of communication between healthcare workers and ALHIV and time constraints during consultations as barriers to adherence. Some ALHIV and parents/guardians said that they were not always properly informed about how to take their medications by their healthcare providers when they started ART. ALHIV reported that healthcare providers sometimes rushed through their consultations and some felt that healthcare providers spent too much time on consultation with certain patients leading to them waiting for too long and in some instances having to return home without having been attended to. Some parents/guardians also felt that the information given under such time-constraints could potentially be misunderstood by their ward or child.

One 13-year-old girl in Kano described being made to feel 'dull' as a result of asking too many questions to a health worker, who walked away without answering her concerns. Another 14-year-old boy in Lagos said health workers could be 'harsh' and shout at young patients. Girls and boys living with HIV reported some differences in the way they are treated. A small number noted that girls and boys were given drugs differently and made to sit in different areas at the clinic, while a few others noted that male and female adolescents were treated differently by health workers.

> It is not fair that they attend to girls and women first, they keep us waiting, rather they should get more health workers, so they can attend to us at the same time
>
> (15-year-old male, Lagos)

The findings from child and youth club facilitators about challenges in the attitude of the health workers was varied and not as positive as the feedback from adolescents themselves. One said it is fine as there are places for treatment and services where counselling and medication are provided and they can see the doctor if required. Other responses indicated that the attitude of health workers can be harsh and cold to the child, not assisting them and supporting them as should be.

> At the facility [health workers] will be like "You do not want to take your drugs, stay there and die, was I the one that infected you with HIV?"
>
> (Female youth club facilitator, FCT)

> Health workers are the problem they should be very friendly and health workers' behaviour is usually a point that everybody is complaining about
>
> (Adolescent HIV club facilitator, FCT)

The negative attitudes of doctors were also described by this 18-year-old boy in Kano, who said 'The doctors sometimes are proud, just because God has placed them in that level, because he is putting on a white overall, he feels he is above everybody and abuses the patients, they do not come out early to attend to us.'

The potential for youth facilitators to support ALHIV

> I let them know that HIV is not an end to their life, career and whatever they want to achieve they can achieve it
>
> (Female youth club facilitator, FCT)

Child and youth HIV club facilitators play an important role in bridging the information gaps that sometimes arise from the communication between health workers and adolescents, especially during the transition from paediatric to adult care. Facilitators have received various training individually, some of which included SRH, gender based violence, and community trainings such as those from National Agency for the Control of AIDS, Women's Human Rights Lagos and the FMoH.

Training undertaken had focused on how to build good relationships with ALHIV, including communication skills. Self-esteem of the adolescents and convincing them to accept their status was another key training for facilitators. The facilitators understand the importance of building rapport and relationships with adolescents and parents over time and they are welcomed into their homes. They are seen as patient and listen and offer advice when ALHIV react to medicine. They also provide a resource to answer questions and give advice on medication, food, personal hygiene etc.

Facilitators appear sensitive to the needs of ALHIV and are in a unique place to support ALHIV with psychosocial care. It is not clear whether they had received specific training on this, but this could be a potential way to ensure adolescents had access to holistic care and support if referred to youth clubs after diagnosis. Despite this only 55% of adolescents in this study were attending youth clubs, leaving almost half without this support. It would be worth understanding what barriers ALHIV face in accessing youth clubs, to see if there are solutions that can be implemented to increase the proportion able to attend.

> Manner of approach, because people that come here do not like to be spoken to in a rude way because they are not happy. If you do not have a good manner of approach they will keep to themselves
>
> (Female facilitator, Lagos)

Religion and spirituality as a coping mechanism

Religion and spirituality appeared to be very important for adolescents in coping with illness and managing depression and anxiety, particularly amongst those aged 15-19. It was not clear whether the reliance on spiritual intervention was affecting adherence to drugs and this would be an area worth exploring in future. God finding an eventual cure for the disease was mentioned a number of times by older adolescents, sometimes in combination with other factors such as this 15-year-old girl in FCT who recognised the government's role in sourcing effective medication:

> I do not want to die young, I want to enjoy life. I will just keep taking these medications because one day God can help us and the government can go out of the country and bring the medications
>
> (15-year-old female, FCT)

Adolescents reported cultural beliefs, perceptions and practices affecting their adherence to ART. ALHIV adhere more to ART when the treatment outcome is positive, but some were reported to change to other options such as traditional or faith healing when their health status failed to improve when on ART. While some AHLIV believe that services rendered by traditional healers can complement those of orthodox medicine, others seemed to have conflicting notions about the efficacy of 'western' medicine when combined with the traditional.

> They rather go to Hausa traditional herbal practitioners who then combines some herbal concoction to take at home. They believe the hospital's only aim is to make people spend their money
>
> (13-year-old male, Kano)

> Some children when they go to religious places for prayer or traditional healers and they are given local medicines you find out they stop coming to the hospital to get treated
>
> (Female parent of an ALHIV, FCT)

> The challenges I am facing in the facility are numerous, some of them say their pastors will say if they are positive they should come out, so they can be prayed for the virus to leave. I believe in going to churches and mosques and meeting the pastors and imams and community leaders to announce to them, so they can be aware of it
>
> (Adolescent HIV club facilitator, Lagos)

Section C: Adolescent experiences of health services

Accessing health services

Access to care is defined in this study as the physical access to a healthcare facility that offers ART treatment for ALHIV. The main deterrents to accessing healthcare services were the potential to experience stigma and discrimination, long queues at the healthcare centres and the amount of time it takes to receive services. Additional barriers included negative attitudes of health workers, lack of flexible scheduling of appointments and the required frequency of visits to the healthcare centres, as well as availability of a parent or guardian to accompany the adolescent to the healthcare facility at the given appointment time.

Despite the barriers outlined above, there were diverse opinions from adolescents regarding the ease with which they could access a healthcare facility, which was mainly dependent on the distance they had to travel. Most adolescents interviewed in Kano found it easy to access a healthcare facility. In FCT and Lagos this varied from being a significant challenge to sometimes easy for adolescents.

The majority of the adolescents surveyed would travel for less than an hour to access the health facility. 63% of adolescents travelled for less than 30 minutes to get there. Only 15% travel for over an hour to access a healthcare facility. Apart from in Kano State, most of the adolescents who reported finding access either very difficult or sometimes difficult attended general hospitals or travelled for more than 30 minutes to get there. Across the groups there was no difference in ease of access between younger and older adolescents, or between girls and boys.

Adolescents were asked if they felt that attending appointments with healthcare providers interferes with their life. Around half (53%) of respondents felt that attending healthcare appointments did not interfere with their lives at all, a quarter (27%) felt that it sometimes interfered, while 20% felt that attending healthcare services interfered with their lives a great deal.

Chart 1: Kano ALHIV 10 – 19
"Do you feel that attending appointments with Health-Care Providers interferes with your Life?"

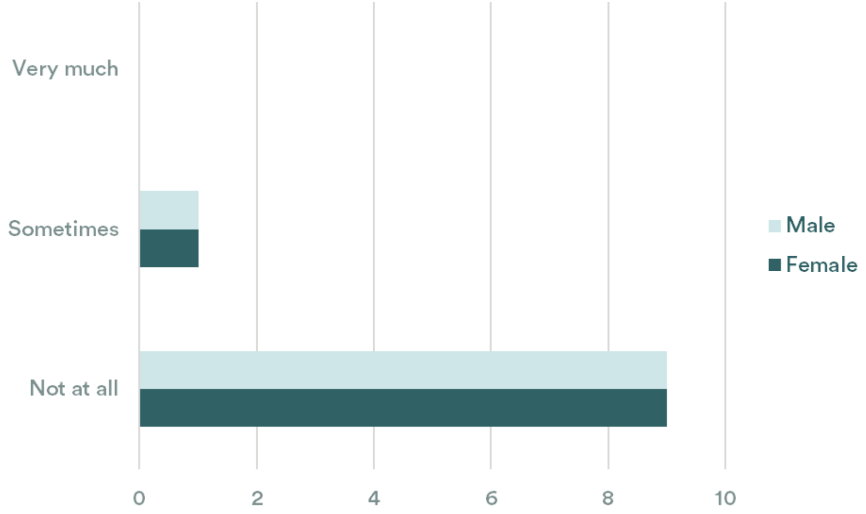


Chart 2: Lagos ALHIV 10 – 19

"Do you feel that attending appointments with Health-Care Providers interferes with your Life?"

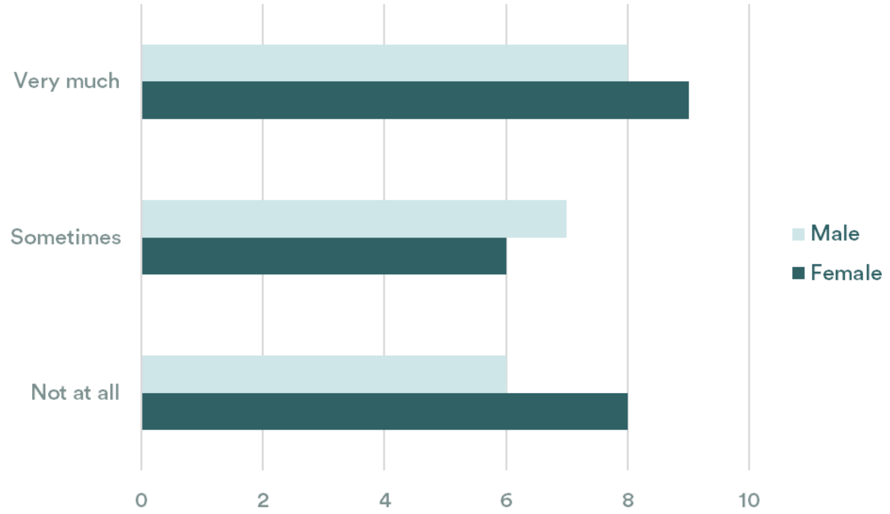
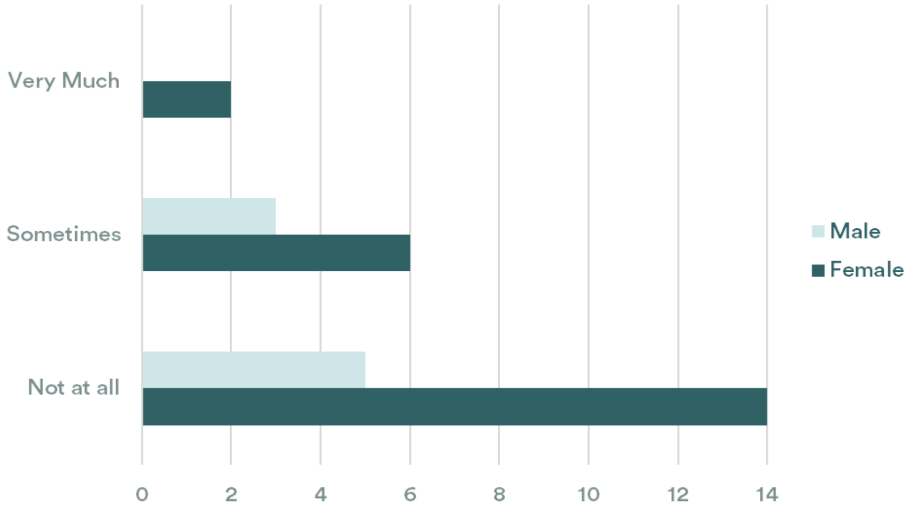


Chart 3: FCT ALHIV 10 – 19

Do you feel that attending appointments with Health-Care Providers interferes with your Life?"



The majority of the adolescents who agreed that attending appointments with healthcare providers interfered with their lives a great deal were from Lagos. More female ALHIV in Lagos and FCT agree that attending appointment with healthcare providers interfered with their life a great deal, suggesting that appointments were harder to access or held at times that were inconvenient for them.

However, it is noteworthy to highlight that aside from the Kano sample, Lagos and FCT had relatively higher number of Female ALHIV respondents recruited in the survey for both 10-14 years and 15-19 years old, for instance charts 1,2&3 are basic comparison of boys' and girls' responses. In Lagos there were 13 female and 9 male ALHIV 15-19 years old, while FCT had 10 female and 5 male ALHIV 15-19 years old respectively.

Those who found access somewhat or very difficult identified barriers to accessing services such as cost of transportation to the healthcare facility, frequency of obligatory visits to the healthcare centres, distance of the healthcare centres and a lack of sustainable means of transportation.

Qualitative data analysis identified a range of interrelated factors associated with the experiences of adolescents living with HIV regarding accessing healthcare services. These reasons were also ranked in a multi code question, with answers included in the table below.

Table 6:
When young people are living with HIV, what stops them from going to hospital regularly for their appointments? (%)

Reasons	**Age 10 – 14 Count /47**	**Age 10 – 14 Percentage**	**Age 15 – 19 Count /47**	**Age 15 – 19 Percentage**
Money	**28**	60%	**28**	60%
Fear of being labelled	**20**	42%	**19**	40%
Distance to clinic	**16**	34%	**16**	34%
I do not like going	**7**	14%	**11**	23%
Time of day	**9**	19%	**8**	17%
Afraid of going	**7**	14%	**6**	12%
Health worker attitude	**4**	8%	**3**	6%
School interferes	**4**	9%	**3**	6%
Permission from parent	**0**	0%	**2**	4%
Work	**0**	0%	**1**	2%

Quality and accessibility of health services

The quality of health services was shown to have a strong impact on adherence. Some of the factors cited by adolescents include access to adolescent friendly services, reliability in terms of availability of medications, clinic hours and clinic days for adolescents, access to the clinic in terms of the affordability of transportation cost, distance to the treatment centres, and the insistence by healthcare providers that an adolescent must be accompanied before they can access services. Additionally, the communication between the adolescent and the health service provider, the perceived level of trust in the adolescent relationship with the healthcare providers and the lack of adequate experienced adolescent healthcare providers also impacts adherence and attendance (detailed above).

Costs and transport

Money was one of the most commonly cited barriers to enrolment in care and adherence. Adolescent participants reported concerns related to the cost of transport, diagnosis, prescriptions and food. The cost of transport emerged as a major theme as ALHIV often did not have enough money to go to the health facility to get their monthly prescription, an interval which some said was too short. Most adolescents who attend public health clinics did not come from households that could afford private transport they relied on public transport, which in many cases is expensive and sometimes unreliable.

Adolescents who travelled more than an hour to a treatment centre agreed they were less adherent to ARTs as they were more likely to miss or not make appointments and suffer from a shortage of drugs on a more frequent basis. The cost of transport was an important factor with some failing to pick up prescriptions owing to lack of transport. This finding was consistent across all states but felt more in FCT and Lagos. Even when they could get there, sometimes on arrival adolescents were told their appointment is on the wrong day, forcing them to return home and wasting both time and money.

> Because sometimes when we come they will tell us we should go and come back again, this wastes our transport
>
> (11-year-old female, FCT)

Adolescents reported that they were unable to afford the food needed to satisfy their increased appetites, which is one of the side effects of the anti-retroviral treatment. The lack of adequate food may affect how regularly they take their ART doses, as they reported being counselled to take their medication only when they have eaten some food. When asked how adolescents could be supported to adhere better, many cited provision of food as a practical solution, as medication was hard to take on an empty stomach.

> Some will say they have not taken their drugs for some time because [they have] no food to eat and the drugs require that you feed well before using them
>
> (Mother of 10-year-old ALHIV, Lagos)

> They should be given some assistance. For instance, some people come to the hospital without eating and cannot afford to buy food so food should be given to them
>
> (19-year-old male, Kano)

In some cases, food support to adolescents was available but they did not always appear to know this. A healthcare worker in FCT, in response to the lack of support and concerns expressed by both male and female adolescents on the impact of lack of food to their adherence to ART, cited the existence of a nutrition department in the facility which provided food for ALHIV.

> The management here have made a provision that is why we have a nutrition office, we give them food, we give them provision, everything like rice, beans, groundnut oil, palm oil, tomato, geisha, sometimes egg sauce, a complete set of food, for that reason they will not tell us they do not have food to eat that is the reason why they are not taking the drugs
>
> (Female healthcare worker, FCT)

Along with problems accessing food, one of the adolescents said that there is a lack of funds to purchase drugs among parents and guardians. He said this leads to adolescents having to hawk and support their parents'/guardians' businesses when returning from school. In a couple of instances adolescents who said they are orphaned resort to begging to raise funds to meet up the demand for drugs and treatment.

> My mum and my dad are late, I do not have anyone, and I do not have any money, I will then go outside to go and look for money and looking for who I will beg, if I get little money, I will use it to buy drugs
>
> (10-year-old male, Lagos)

Despite the fears of their status being exposed during visits to health centres, parents said some of the motivation which ensures that adolescents attend their appointments in healthcare centres includes the support ALHIV get from the hospital and organisations like FHI 360 who provide free tests and ART.

Confidentiality, privacy and disclosure

Fear of stigma was identified as a major barrier, particularly for those aged 15-19 who would rather travel longer distances to access healthcare to mitigate stigma than attend closer options available. It is perceived that the farther away the healthcare facility was from the home of the adolescent, the less likely that he or she would be recognised by someone they knew. Some reported not going at all to avert the consequences of being recognised. Parents/guardians also sometimes avoided taking their children to local facilities for care for fear of stigma with one 17-year-old girl saying:

> When I wanted to come here my mum said I should go to Gwagwalada and it is far
>
> (17-year-old female, FCT)

Parents/guardians see their role as including keeping their children's status a secret from others, which also affects when they can access care:

> I think the best days for them to go to the hospital are on weekends not during school days, so they would not have to give excuse or explain themselves to their peers and teachers as to why they have to go to the hospital even when they look alright and are not ill
>
> (Mother of 12-year-old male ALHIV, FCT)

Health workers and confidentiality

Most adolescents surveyed believe that health workers keep their information confidential. However, adolescents were wary of unintended disclosure and have experienced the impact of stigma at the healthcare centres while enduring long queues. Some adolescents aged 15-19 pointed out that most times when their names are called that the health workers shout out these names. They were also concerned that certain locations in the healthcare facilities are known to be the treatment points for PLHIV and feel uncomfortable being there for long durations.

> Most times they shouted at all especially when they are calling our names and it stigmatises us
>
> (14-year-old male, FCT)

In some healthcare facilities with designated space assigned for PLHIV, adolescents are concerned that other people who visit the health facility know what those places in the hospital are designated for. Adolescents who go there have reported being afraid of being seen or recognised and the consequences of stigma. Most ALHIVs closely guard their status. Older adolescents tend to be more concerned about this and do not want close friends and sometimes even parents to know. It is inferred that this fear of being 'found out' leads to adolescents withdrawing from peers and becoming socially isolated.

> They should change firstly the waiting area, because it is an open place and when people who are not living with the virus walk in and ask for medicines they are told no that this is HIV medicines and is for HIV patients, that is the challenge that we have. Even the elderly who sit there and wait to collect their medicines, some of them will hide and only come out when their names are called to come take their medicines
>
> (19-year-old male, Lagos)

Another issue that emerged from the study that potentially impacts negatively to adolescent adherence was confidentiality in the treatment centres, especially during the dissemination of ART at the pharmacies. Some adolescents did not like the approach in some healthcare facilities where they are labelled as HIV positive or where the importance of their confidentiality is not taken into consideration.

> He is a worker in the hospital, he travelled home that is why he has not been around. He came home to talk to our parents about the disease, at first he was not allowed, it was later on when he spoke to our father that he was allowed to talk to us
>
> (19-year-old female, Kano)

> Some of the health workers mostly in government hospitals they want to stigmatise especially when they are full and lack rest so they shout and all that but there is nothing we can do. We do not have money to go to the private hospitals. At the pharmacy after seeing the doctor and when we want to collect our medications. We are made to sit down, others will still be looking at us and they say these are HIV patients they are attending to
>
> (19-year-old male, Lagos)

When asked whether they preferred seeing a health worker of the same gender:

- 24% (23/94) said they didn't mind either way;
- 61% (57/94) said they would prefer a health worker who was the same gender.

Health centre environment

Adolescents interviewed by TEGAs in Lagos, Kano and FCT mentioned the importance of the health facility environment and emphasised the importance of an environment that they could feel safe and comfortable in. They wanted to be welcomed into a ‘beautiful space’ with adequate seating and appreciated where efforts had been made to improve the clinic appearance, as described by this 11-year-old girl:

> Children said they would not come because of the sitting area that is bushy and may have snakes hiding around so they now cleaned up and repaired the place and cut all the grasses, the place is now clean
>
> (11-year-old female, FCT)

> We are all made to wait here both the young and the old, the female and male sections are close to each other, but there is no cover to hide our identities, our identities are supposed to be covered but it is not so here. They should just try and get a place in the hospital where we can be moved to so that we can be covered because sincerely it is not fine, some people are not used to wearing ''Niqab'' (a face mask like a veil for Muslim women) but they do wear it when they are coming here some are not used to wearing it when they do they will be breathing with difficulty, but they don't have a choice. If I come to the hospital most of the workers in our area work in this hospital, I couldn't wear Niqab, but it got to the extent that I got used to wearing the Niqab because once someone you know sees you that is all, sincerely if there is a way they can help us, we will be happy
>
> (19-year-old female, Kano)

Some health workers interviewed reported that facilities had set up adolescent friendly corners in hospitals and health centres to ensure that the health services are welcoming and that they have more space on adolescents’ clinic days to provide for improved adolescent-friendly health services and increased service engagement.

> We buy the things we know they will like and put on cartoon videos for the younger ones to watch
>
> (Health worker, FCT)

Timing of appointments and clinic days

Adolescents and parents generally preferred weekends for clinic days as it allows them to avoid the stress associated with getting permission from schools and the impact of absenteeism on their school performance.

> It is not a good experience, because each time I go there my child does not go to school because we need to pick up his drugs and if they do not see him they will not give me the drugs because they need to check his weight and how he is doing

> (Mother of 10-year-old ALHIV, Lagos)

> It clashes with my school work, sometimes I have appointments during school exams
>
> (16-year-old male, FCT)

Adolescents said it was common that their files and record cards were pushed to the bottom of the pile as they waited for their appointment, meaning they were not seen always see on a first-come first-served basis. Some adolescents cite cases where preferential treatment was given to some patients while they had to wait for long periods to be attended to, despite coming very early with expectations of leaving early for other activities such as school. One 17-year-old girl in FCT described being asked to put money on her record card in order to be seen quicker. This appears to be a form of 'dashing' (bribing) health workers in order to be moved up the waiting list.

> I have been here earlier, they said we should put the money in our cards, it does not matter if you have been here earlier or you are just coming, they only attend to those that have put money in their cards and it is not good. Many people that came after me have been attended to because of the money, I do not like it, it makes me angry
>
> (17-year-old female, FCT)

Section D: The struggles with adherence

Adherence is broadly defined as the extent to which a patient's health behaviours correspond with medical advice or recommendations[15]. For people living with HIV, adherence means sticking firmly to a drug regimen, which reduces the opportunity for HIV to multiply, protecting the immune system and allowing people living with HIV to live longer, healthier lives. For adolescents living with HIV, maintaining good physical health requires adherence to treatment and keeping engaged in a care plan.

A meta-analysis of patient-reported barriers to ART adherence from 125 studies across 38 countries[16] (16 in Africa) showed that forgetting, being away from home and a change to a daily routine were the most frequently reported barriers to adherence amongst all age groups (children, adolescents and adults). Depression was reported as a barrier for more than 15% of patients whilst alcohol and substance abuse was commonly reported by adults and adolescents. Secrecy and stigma were less commonly reported as a barrier, with 10% of patients across all regions reporting it. Health service-related barriers including distance to clinic and stock-outs were also frequently reported.

In this study, adolescents described multiple factors that helped and hindered their adherence and many concur with the findings from the studies mentioned previously. Most adolescent participants, particularly older adolescents have a good understanding and sometimes experience of the potentially serious health consequences that can result from adherence

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[15] World Health Organisation (2013): Consolidated Antiretroviral Guidelines

[16] Shubber et al (2016): Patient-Reported Barriers to Adherence to Antiretroviral Therapy: A Systematic Review and Meta-Analysis, PLOS Med

failures. Despite this, forgetfulness, busy schedules, medicine fatigue and travelling away from home all affected drug regimes. For older adolescents, depression was a serious factor, whilst younger adolescents felt drugs were harmful.

Table 7:
What are some of the reasons you think some young people don't take their medication as prescribed?

Reasons	**Age 10 – 14 Count /47**	**Age 10 – 14 Percentage**	**Age 15 – 19 Count /47**	**Age 15 – 19 Percentage**
Simply forgot	26	55%	24	51%
Had too many pills to take (medicine fatigue)	16	34%	7	14%
Busy with other things	11	24%	10	21%
Did not want others to notice them taking medication	5	17%	10	21%
Felt like the drug was harmful	17	36%	1	2%
Was away from home	7	15%	12	26%
Stopped after feeling unwell	8	17%	5	11%
Felt depressed	2	4%	11	23%
Had problems taking pills on time and on an empty stomach	4	8%	2	4%
Wanted to avoid side effects / felt ill	4	8%	4	8%
Change in time of taking medication	1	2%	2	4%

Forgetfulness

Simply forgetting, having something else to do, playing, busy schedules and attending school were some of the commonly cited reasons by adolescents why they did not take medications as prescribed. When it came to remembering to take drugs, adolescents did not have clear strategies for managing their regime. Some felt that a pill box to store drugs and have them handy was a good idea, however a few felt that peers would wonder what it was for and they might have to explain, so did not think it was a good idea. Like in the case of 13-year-old boy in FCT:

> If you use it in school some of your friends will get to know and you might be ashamed that you are using medicine in school and not at home, some might not want to come close to you because of that
>
> (13-year-old male, FCT)

Adolescents of all ages said that they considered it very important to involve family members or close friends who knew their status in reminding them to take their HIV medication.

Medication and side effects

> The tablets are really big and it is quite uncomfortable swallowing it
>
> (16-year-old male, FCT)

Dizziness, rashes, fever, nausea and changes in the colour of the skin were some of the side effects commonly associated with ART by adolescent participants. These are of concern adolescents who are increasingly conscious of their appearance as they grow up and want to look as healthy as possible. Adolescents reported the impact of the side effects and these worries increased non-adherence as some skipped taking medication with the intention of reducing the impact of the side effects on their physical appearance.

> They usually have a headache or feel dizzy, those are the signs I felt before I lay on the bed
>
> (12-year-old male, Lagos)

> When you went to urinate, your lower abdomen will be paining you or you might be feeling hurt or maybe you will feel like vomiting all the time
>
> (17-year-old female, Lagos)

Younger adolescents reported lower adherence as a result of the quantity of pills to be taken. 34% of adolescents aged 10-14 and 14% of adolescents aged 15-19 agreed that a large pill burden lowers their adherence. Additionally, 10-14-year-olds reported that the bitter taste of the medication impacted their adherence. Younger adolescents identified the large size of the pills made for difficult swallowing and was a barrier to adherence. Some wanted to have smaller pills prescribed.

Adolescents 10-14 surveyed in all three states were asked: 'What are some of the reasons you think some young people would not take their medications as prescribed?'. Male respondents missed medication as a result of forgetting or not feeling well or stopping after feeling well, while the female respondents commonly reported being busy doing other things, having too many pills to take or feeling the pills were harmful.

A similar trend emerged with the 15-19-year-old adolescent respondents who were asked the same question. Male respondents reported that they were more likely to miss their medication because they simply forgot or were busy with other things, while the female 15-19-year-old adolescents either simply forgot, wanted to avoid side effects or had reduced adherence when they were away from home. These results indicate that as adolescents grow older and become increasingly engaged with activities away from home such as school their adherence to ART reduces. Simply forgetting to take medication was an equally high response from both male and females aged 15-19 years old and more adolescents aged 15-19 skipped taking medication to avoid its side effects.

Adolescents found taking medications more than once a day a burden and wished they could take them at most once in a day. They wanted drugs that could be taken once a week or an injection that could last for a year. Healthcare workers and HIV club facilitators also agree that having to take medication less frequently would enhance medication compliance with adolescents and reduce cases where adolescent discard their pills. Girls were seen as more likely to adhere to their medication due to their levels of maturity compared to similar aged boys. This youth club facilitator in Kano describes the difference as such:

> You know the girls are a little bit scared unlike the boys, even among the matured ones the girls are more responsible than the boys, some of the boys have this ''I do not care

attitude'' they don't care that is the first thing that causes the default if among the girls you find 10% defaulters I bet you will find 50% among the boys

(Youth club facilitator, Kano)

Section E: The transition to adulthood

> Some other concern I hear from adolescents living with HIV is that some of them erroneously believe they can't have their own children
>
> (Female facilitator, FCT)

In this survey, the key questions that directly addressed the transition from paediatric to adult care were only asked of the ALHIV in the 15-19 years group. Transitioning HIV positive adolescents into adult care was seen as a stressful process for healthcare providers, especially with regards to the engagement of the adolescent. HIV management is a complex concept for adolescents to grasp and making the transition from paediatric to adult health services was a daunting prospect for some adolescents and their parents.

> We do not have a paediatric centre. We attend to all patients - adult, paediatric and others – here
>
> (Female health worker, Lagos)

Adolescent HIV club facilitators acknowledged the lack of adequately trained health workers to manage the transition from paediatric to adult care as a separate process, especially in relation to the treatment, care and support and understanding of the peculiarities related to the reproductive health, social and psychological needs of adolescents and young adults. Healthcare workers reported that some adolescents and young adults may not be psychologically prepared for their transition into adult care.

Parents and guardians on the other hand were mostly concerned about the quality of care in the adult clinics and were hesitant at the prospect of their child or ward transitioning. Parents/guardians feared their child falling into depression as a result of the transition and them not being supported in the same way as they were during childhood. Some parents worry that the transition from paediatric care to adult care can pose challenges for the adolescent due to changes in medication. Whilst it was not clear what exactly they were worried about, this parent described their concern that taking adult medications would bring more problems, which is taken to mean ‘side effects’:

> I worry because now they have changed the medication from the children's own to adult medications and you can see even before they used to have problem, what of now when they change to the adult medication? So, you can see that the change will bring little problem
>
> (Mother of ALHIV, Kano)

Child and youth HIV club facilitators interviewed by TEGAs say one of the main challenges during the transition from paediatric to adult care tends to be fear of stigma. Adolescents build trust with healthcare workers in the paediatric care. When they are moved and new untrained health workers come in it often presents a challenge for adolescents to build a new cycle of trust, especially with the workers in the adult care or a new healthcare worker.

Communication and knowledge

Communication between adolescents and physicians around transition to adult care varied significantly across the three locations. TEGAs asked adolescents 15-19 if they had in the past had any conversation with their healthcare provider on transition to adult care. 4 out of 10 in Lagos, 5 out of 10 in FCT and 9 out of 10 in Kano had never had a conversation regarding transition to adult care before.

There appears to be a disconnect between the perception of healthcare workers and the support needs and expectations of adolescents with regards to appropriate care. A healthcare worker in Lagos was asked what the concerns of adolescents were regarding the transition from paediatric to adult care:

> Actually, for that, I do not think the teenagers have any issues about it but the only thing I will just say is that it is not easy for them
>
> (Male healthcare worker, Lagos)

Some adolescents felt that they are given information in a way that made it hard for them to understand and shared that communication was not always done in a friendly or age appropriate way. One 18-year-old girl said that just because she was now considered an adult this did not mean that she necessarily understood things communicated to her by health workers:

> If you asked them they will say they are trying to advise us, it is a lie, that is not advising. They are even making it worse. Because a girl is 18-year-old you conclude she is an adult, there are ways you should talk to them without shouting at them. It is wrong, they should stop doing it. They should give them support and make them comfortable
>
> (18-year-old female, FCT)

Inconsistency and lack of tailored messaging was also reported by healthcare workers and facilitators to be a common challenge faced by adolescents who are making the transition from paediatric to adult care. A healthcare worker in FCT said often confusing messages are passed to the adolescent. An example was in the case of HIV prevention information where two different messages were given to adolescents depending on who was giving it.

Economic self-reliance

23% of adolescent participants in this study had either completed secondary education or dropped out of school. All six of the participants aged 15-19 who dropped out of school are female. The disproportionate number of female ALHIV highlights the economic challenges they are likely to face in terms of caring for themselves while living with the virus, and the barrier it would have on their successful transition to adult care and to adherence and retention in care. Adolescents identified a number of empowerment programmes with the potential of reducing discrimination and stigma and gender inequalities that can be associated with illiteracy or low educational status.

> I need money so I can get take my medications, I need money when I need to go to the hospital, they feel I am too dependent on my parents, I need to do something on my

> own. They have to provide us with skills to do things in order to have our own money so that they will not look for money when I want to like go to the hospital
>
> (18-year-old female, FCT)

> We try to help them acquire a skill, let them learn something. When they grow up they can use that to establish themselves, anything they want to buy they can buy and take care of themselves, they will not be moving from one place to another spreading the virus
>
> (Healthcare worker, Kano)

Sexual and reproductive health and living with HIV

In Nigeria, communities often believe that the contraction and transmission of HIV is associated with prostitution and other forms of sexual promiscuity. This can lead to people believing that HIV is the result of some moral failure on the part of a person living with HIV. Because HIV infection is associated with behaviour that is considered deviant, some older adolescents interviewed by TEGAs reported that fear of stigmatisation and discrimination prevents young people living with HIV from accessing testing and seeking treatment, which makes them vulnerable to infection and complications. The fear of stigma from others inhibits them from disclosing their HIV status, increasing the risk of transmission, co-infection and reinfection. This perception was more common with the older adolescents.

> When I knew I was infected, I felt like falling because some do say people get infected through adultery or prostitution
>
> (19-year-old female, FCT)

Whilst many older adolescents living with HIV may already be sexually active, or entering romantic relationships, social norms around sex and sexuality make it difficult for them to access reliable information, which could help protect them from future sexual and reproductive health risks. Particularly in rural households, parents, if they talk of it at all, consign sex to 'the domain of the dangerous, unpleasant, and unsavoury'[17]. For parents of adolescents living with HIV, these taboos around discussing sex can make it difficult to discuss the disease with the children for fear of being asked questions about transmission.

> It should be discouraged, this is because when you let them know that there are easy methods of pregnancy prevention it will be a gateway for them to go ahead and have indiscriminate sex. My suggestion is to discourage them totally from engaging in sexual practices
>
> (42-year-old mother of an ALHIV, Kano)

Despite sexual health and HIV being intrinsically linked, health workers interviewed by TEGAs reported that owing to deeply entrenched social norms around sex, reflected in the quote above, adolescents face difficulty talking to healthcare providers about sexual health, even when they are already sexually active.

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[17] Izugbara, C (2008): Home-Based Sexuality Education: Nigerian Parents Discussing Sex with their Children

Whilst some health workers are open in talking about sex with adolescents, others do not have the skills and confidence to tackle the subject, as they have received inadequate training or fear 'encouraging' sex by talking about it with young people. Some have organised talks with older adolescents but even then, a healthcare worker in FCT pointed out that adolescents do not readily ask questions about their sexual health for fear of being judged by health workers.

The transition to adulthood presents particular problems for adolescent girls living with HIV as they have concerns about marriage, relationships and having children in the future. They reported being particularly worried about how they will disclose their disease to potential partners and are concerned about missing out on the chance to fully embrace their 'womanhood' due to limitations placed on them compared to girls who are not living with HIV.

> Some of the females have concerns and think that since they are HIV positive they cannot get married, they ask; "Is it possible for me to have a partner in future?", "Is it possible for me to play with other children?", "Is it possible for me to see my period?" - You know all those kind of things
>
> (Female facilitator, FCT)

Gender considerations and norms also affect the way that youth club facilitators interact with boys and girls. Boys are seen as having a more careless attitude to how they deal with living with HIV, whereas girls are seen as more responsible. Worryingly, one facilitator said boys may react to their diagnosis by trying to spread it:

> While young boys are told that they cannot marry the girl of their choice only one that is the same status as him, thus they are restricted and it affects them, he may be upset with this and go out to spread the virus
>
> (Female facilitator, FCT)

Conclusion

Adolescents represent a growing proportion of the share of people living with HIV globally and in 2015 UNICEF and UNAIDS recognised the vital need to involve them in ensuring that programmes and advocacy to tackle HIV responded to their unique needs. This study effectively engaged adolescents living with HIV aged 10-19 and allowed them to share their experiences in an open and supportive conversation with a trained TEGA researcher. This unique approach placed adolescent voices at the heart of the study and all those who took part said they would be happy to speak to a TEGA again in the future.

The key objective of this qualitative study was to examine and understand the opportunities for, and barriers to, adolescent girls' and boys' HIV testing, disclosure, accessibility, treatment, adherence and care and support needs, as experienced by those accessing services supported by the 4Children project. Adolescents in the study talked openly about their concerns about growing up living with HIV, fears around stigma and discrimination, experiences of health services and challenges when it comes to adherence.

The study also revealed the importance of supportive family and care networks for adolescents, including the need for support to parents to help with communication to children when diagnosed with HIV, whilst they are coming to terms with their diagnosis and when transitioning to adulthood. Most of all, adolescents want to get on with their lives and be treated in the same way as their peers not living with HIV. In order to support this, families, schools, health workers and others that come into contact with ALHIV need to treat them with respect and care, involve them in decision making in a way they can understand and provide them with space, advice and guidance to help them as they transition to adulthood.

Specific recommendations revealed by the study are detailed below.

Recommendations

The recommendations made below are made in relation to the group or service that could be supported or strengthened to positively impact ALHIV. Many are pragmatic solutions offered by the adolescents and adults involved in this study. Others are innovative ideas that may require new programmes and additional funding to be sought by 4Children and partners working with ALHIV in order to be implemented. It is the hope that regardless of available resources, this report marks a positive step towards integrating youth voice into programme monitoring and will encourage implementers to integrate human centred design principles[18] into the improvement of existing ALHIV programmes and the creation of new ones in the future.

Families

- Parents delay telling children and adolescents that they are living with HIV for as long as possible. Whilst this is a decision made to protect children, it can lead to resentment, denial and depression when left too late, as well as health problems. Parents should be supported by health workers in the best ways to disclose their child’s status to them and be given access to support groups where they can meet parents who have been through the same process with their own children.
- Denial and anger is a common reaction by older adolescents finding out their status. Adolescents and children recently diagnosed with HIV should receive one to one counselling to help them accept their diagnosis, understand that they can still live long and healthy lives and stress the importance of adherence to ensuring their wellbeing.
- Child and youth groups could be expanded to include tailored sessions for parents to seek information and guidance on supporting their children, including how to find ways to talk about growing up, marriage and childbearing, which is a concern for girls.

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[18] IDEO (2009): Human Centred Design Toolkit (ideo.com/post/design-kit)

- The support of parents is key to regular attendance at health appointments, adherence and mental and physical wellbeing. Health workers should encourage parents to keep on top of their child's drug regimen and equip them with information to help answer questions their child may have about their status as they get older.
- The success with which ALHIV cope with the stress attached to HIV appeared to have direct impact on quality of life they choose to live. Most older adolescents interviewed live with a constant struggle to cope with and manage or to avoid stigma. Tailored psychosocial counselling should be made available from an early age to avoid fear and anger developing into more serious long-term depression, which also affects adherence and therefore physical health.
- Religion and spirituality were common themes identified among adolescents in this study and appeared to be very important for them in coping with illness, managing depression and anxiety, particularly those aged between 15-19. It was not clear whether the reliance on spiritual intervention was affecting adherence to drugs and this would be an area worth exploring with young people in the future.

Schools and youth clubs

School

- Stigma and discrimination needs to be addressed head on and at multiple levels – in the community, at schools, and within families. Social media and other mass media platforms like radio could be an effective way to reach communities and increase understanding of living positively whilst decreasing stigma related to HIV. Engaging teachers, celebrities and other public role models to become advocates for HIV Testing and Counselling (HTC) could also increase adherence among ALHIV.
- Adolescents have high educational aspirations but their schooling is being disrupted by attendance at clinic appointments, drug regimens and fear of other students discovering their status. School administrators and teachers should receive specific training on supporting ALHIV – providing them with privacy to take medication and time off to attend appointments discretely.
- ALHIV live in fear of schoolmates finding out their status. Programmes that sensitise students, teachers and school administration about living positively with HIV, rather than just on the prevention of HIV, could help reduce stigma and discrimination.

- Adolescents in boarding schools may be experiencing unique barriers to treatment and support, particularly if they are not allowed to leave to attend clinic appointments. Future programmes focusing on ALHIV should consider the needs of those in boarding school, and out of school.

Youth clubs

- Facilitators of youth clubs for children and adolescents living with HIV are in an ideal position to become role models for them when it comes to living positively with HIV. They are already important in the lives of ALHIV and help bridge the information gaps between ALHIV and health workers/parents/guardians. They should be supported to deliver regular group sessions with ALHIV that complement the information and support given to ALHIV by parents and guardians and health workers.

- Despite youth clubs being a safe space for ALHIV to learn and grow, only 55% of adolescents surveyed in this study were currently attending them, highlighting the potential for more ALHIV to be linked with clubs through better promotion via health workers and by making them more appealing to ALHIV by providing fun activities and useful, relevant information.
- A club facilitator in Kano stated that girls are less likely to come to ALHIV clubs and receive support as they are often confined to their homes. This also limits them speaking with peers in the way that boys do. As a result, girls are less likely to receive information related to living with HIV and sex and reproductive health (SRH) more generally. This is more likely to be a factor affecting girls in the North but gender specific considerations should be applied across the 4Children programme to ensure girls have the same opportunities as boys when it comes to accessing information, services and support.
- Targeting parents to ensure girls living with HIV are given permission to attend clubs and clinics is key.
- Content delivered at youth clubs for adolescents living with HIV should also be tailored for girls - who face increased risk of reinfection and co-infection - as they enter puberty and therefore potential sexual relationships, earlier than boys. Content should draw on recent research to understand adolescence, sexuality, SRH and risk taking[19].
- Girls are also in need of counselling around relationships, marriage and getting pregnant as many have fears that they will not be able to achieve these milestones whilst living with HIV.

Health services

Access

- Poverty is a key factor affecting attendance at clinics, adherence to drug regimens and good nutrition. ALHIV want to be economically independent and support themselves as much as possible. Skills building and microfinance programmes would reduce the burden on families to find money to support older adolescents living with HIV, and help their transition into adult clinical services by increasing their self-reliance.
- The cost of transport to clinics is a challenge for many families. Whilst it would not be sustainable to provide transport or reimbursements for costs, providing longer prescriptions to ALHIV would reduce the need to travel so frequently.
- Miscommunication about appointment times also leads to wasted trips, and their associated cost. Systems to provide discrete automated (or manual) phone calls or SMS reminders would reduce confusion and minimise the number of missed appointments.

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[19] Saewyc, E (ed.) (2017): A Global Early Adolescence Study: An Exploration of the Factors that Shape Adolescence, Journal of Adolescent Health 61(4) S1-S54 (geastudy.org/publications)

- Communication about stock-outs would also reduce wasted trips as sometimes ALHIV arrive to pick up prescriptions only to find out drugs are not available.
- ALHIV clinics held outside of school hours and on weekends would also make attendance easier for adolescents and their families, as parents who accompany adolescents are often working on weekdays.
- Providing more HTC services within communities would also help more ALHIV and others to attend regularly.

Health workers

- Health workers should follow best practice guidelines to support disclosure to children up to the age of 12. Whilst parents are often keen to delay this, evidence shows that early disclosure leads to health benefits and there is 'little evidence of psychological or emotional harm from disclosure of HIV status to HIV-positive children'[20]. Health workers should spend time explaining the benefits of disclosure to parents and support them on the journey from partial disclosure to children to full disclosure for adolescents.
- Overall data from this study supports the perception held by ALHIV that clinic personnel, from doctors, nurses and administrative staff, play important roles in supporting adherence to ART. Adolescents seek empathy from health care workers, as well as trust and confidentiality. Whilst the majority of health workers treat ALHIV in a friendly way, they should receive regular refresher training on respecting privacy and confidentiality and best practice in supporting and communicating with ALHIV, who have different needs from children and adults.
- Adolescents worry about unintended disclosure and have experienced the impact of stigma at healthcare centres while enduring long queues and being seen by people they know. Providing specific times for ALHIV to attend clinics would eliminate risk of their status being revealed to others.
- Whilst most health workers respect confidentiality, some older adolescents pointed out that when their names are called that the health workers shout out these names, revealing their identity to other patients. They were also concerned that certain locations in the health care facilities are known to be the treatment points for people living with HIV (PLHIV) and feel uncomfortable being there for long durations. Making health facility processes more efficient and reducing waiting time for ALHIVs whilst offering safe, confidential and private waiting and drug dispensing spaces within health facilities will contribute to improved retention in care.
- ALHIV should also receive information from health workers on how best to manage their drug regime and side effects and be linked to psychosocial support services to manage mental wellbeing and depression.

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[20] World Health Organisation (2011): Guideline on HIV disclosure counselling for children up to 12 years of age

Environment

- A number of health workers reported that facilities had set up more adolescent friendly ‘corners’ in the hospitals and health centres to ensure more privacy and that they have more space on adolescents’ clinic days. Learning from setting up these corners should be documented and shared with health facilities to enable their replication at all centres where ALHIV access services.
- In some instances, references were made to files and cards being mixed up and lost, with manual administration systems in the health facilities potentially contributing to slower services. Digitising patient records and finding ways to register them and locate records using tablets or computers would create more efficient and patient-friendly services and reduce waiting times.

Drug Regimens

- Caregivers should be allowed to pick up prescriptions on behalf of ALHIV and take more proactive measures in getting ARTs to them, especially when school activities are hindering them from meeting appointments.
- Programmes to help adolescents develop life skills such as managing time/appointments, drug regimen and dealing with stigma and discrimination could be integrated into curricula for youth clubs.
- Health workers should inform young people of potential side effects from their medication, particularly those that can change the adolescent’s appearance or make them feel unwell. They should proactively communicate strategies for coping with side effects so ALHIV do not stop taking them as soon as they face a problem, but instead understand how to manage and overcome side effects.
- Caregivers of younger adolescents should be given information on ways to mask bad tasting medication and create effective strategies for helping ALHIV cope with medicine fatigue.
- Lack of food stops some ALHIV taking their medication regularly. Some health centres already provide food support but not all eligible families are accessing this. Health workers should pass on information about all available support services to families with ALHIV. This could be as simple as talking through a printed list of service providers that can then be taken home by the caregiver for future reference.

Transition to adult services

- The transition of adolescents to adult HIV treatment and support services is sometimes difficult. Holding dedicated clinics that focus on the transition to adult care for ALHIV could help ensure continuity of care and adherence as adolescents graduate out of paediatric care.

- Health workers, youth clubs and parents should provide more targeted information and counselling to girls about body awareness, including menstruation and pregnancy, and marriage to help correct misconceptions and empower them with information.
- Train and re-orient adolescent HIV service providers and counsellors at government clinics to provide adolescent friendly services, including specific training for staff on adolescent needs and related challenges. This should also be tailored to the specific needs of girls and boys in early, mid and late adolescence as described in the Age and Stage research report[21].
- Skills building, economic empowerment and microfinance programs can help adolescents become more independent and facilitate their own care. Integrating economic empowerment and skills building into ALHIV youth clubs could increase their effectiveness and impact on adolescents.

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[21] Girl Effect & Johns Hopkins Bloomberg School of Public Health (2017): Adolescence: Age & Stage

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Annexes

Annex 1: Survey tools

- ALHIV 10-14 survey tool
- ALHIV 15-19 survey tool
- Parents survey tool
- Club facilitator survey tool
- Health worker survey tool

Annex 2: Consent form

Annex 3: TEGA 4Children research proposal

Annex 4: Ethical review

- TEGA 4Children Ethical review application
- TEGA 4Children Ethical review approval