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**PREVALENCE, BARRIERS AND FACILITATORS OF AGE APPROPRIATE  
TRANSITION FROM PAEDIATRIC TO ADULT CARE AMONG HIV INFECTED  
ADOLESCENTS/YOUTH AT KENYATTA NATIONAL HOSPITAL**

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**A dissertation submitted in fulfillment of the requirements for the award of  
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**DECLARATION**

This dissertation is my unique work and has not been displayed for the honor of the degree in any other university

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## **DEDICATION**

I dedicate this study to all the adolescents/youth affected or infected by HIV or any other chronic illness in Kenya and around the world.

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## **ABBREVIATIONS**

AAP	American Academy of Pediatrics
AIDS	Acquired immunodeficiency syndrome
ALHIV	Adolescents living with HIV
ART	Antiretroviral therapy
CCC	Comprehensive HIV Care Centre
CD 4	Cluster of differentiation 4
COPA	Committee on Pediatric AIDS
FGD	Focused Group Discussion
HIV	Human immunodeficiency virus
HCW	Health care worker
KAIS	Kenya Aids Indicator Survey
KII	Key informant interviews
KNH	Kenyatta National Hospital
NASCOP	National AIDS and STD Control Programme
NIH	National Institutes of Health
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitors
OI	Opportunistic Infections
PEPFAR	Presidents Emergency Plan for AIDS Relief
PI	Protease Inhibitors
SSA	Sub-Saharan Africa
UNAIDS	United Nations Joint Program on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization



## DEFINITION OF TERMS

- **Adolescents** - is defined as an individual in the 10 – 19years age group
- **Youth** - is defined as an individual in the 15 – 24years age group
- **Transition** - is a process of supporting adolescents living with HIV to graduate into adult services when he/she ages out of the Pediatric clinic.
- **Full Disclosure** – is defined as when the child has been told they have “HIV infection” and the child has the cognitive and emotional maturity to process knowledge of his /her HIV status.
- **Health Provider** - Anybody that is in charge for the medical and/or psychosocial care of an individual. This can include primary care and other physicians, nurses, social workers, mental health professionals, pharmacists, nurse counsellors, nutritionists.
- **Pediatric provider** - A doctor, nurse or registered clinical officer who deals with babies, children and teenagers.
- **Adult care or Internist** - A specialist who is prepared to take care of adults.
- **Age appropriate transition from Pediatric to Adult HIV services:** Adolescent package of care for Kenya desirable age bracket for transition (>19 years)
- **HIV infected** - An individual who has been infected with the Human immunodeficiency but does not have AIDS
- **Current WHO HIV staging** – this is described as staging done in the last 6 months
- **Perinatal HIV infection** – is a vertically transmitted HIV infection from a mother to her child amid pregnancy or delivery.
- **Behaviorally HIV infected** – HIV infection horizontally transmitted by sexual contact, injecting with contaminated needles, blood products, drug use.
- **Barriers** - Is defined as an obstacle or factors that prevents an individual from gaining access to services
- **Facilitators** - is this study will be defined as the factors that the adolescents and health care providers consider significant enabler for effective transition

## ABSTRACT

**Background:** Rates of Human Immuno-Deficiency Virus infection among adolescents and youth in Kenya continues to rise and due to wide access to life saving anti-retroviral therapy there has been an improvement in survival rates, resulting in more adolescents and youth who must eventually transition from pediatric to adult HIV health care services. HIV-infected adolescents and youth must learn to figure out on how to explore a complex health regime, the society stigma and discrimination associated with HIV. It is important that this process go smoothly to guarantee congruity of care and maximize patient outcomes.

**Objectives:** The study aim was to determine the proportion, and identify barriers and facilitators to age appropriate transition of HIV infected adolescents/youth from pediatric to adult HIV services during follow-up at the Comprehensive HIV care services at Kenyatta National Hospital.

**Study Design:** This was a cross sectional study employing both quantitative and qualitative methods.

**Methods:** HIV infected adolescents/youth between the ages of 15 -24 years in long term care at KNH CCC were enrolled after consent was obtained using consecutive sampling over a period of four months on clinic days. Adolescents/youth were interviewed using standardized questionnaire and relevant clinical data was abstracted from their medical records. Different variables were analyzed using a SPSS version 23 and quantitative data was summarized into frequencies, proportions and measures of central tendency and a p-value of < 0.05 was considered significant. Focused group discussions were conducted among HIV infected adolescents/youth to gain insight into their perceived facilitators and barriers to transition. In depth, key informant interviews were conducted among health care workers using an open-ended interview guide. Qualitative data were transcribed verbatim and analyzed which were then reported in form of themes and quotes.

**Results:** We enrolled 96 HIV infected adolescents/youth who were of median age of 18yrs, IQR (15-24yrs), had been in follow up for median period of 7yrs IQR [0.6 – 17yrs]. Fifty-six (58.3%) were females, 23 (24%) were full orphans, 57 (59%) had vertically transmitted the infection and the median age of disclosure was 13yrs, IQR (9 – 23yrs). Their most recent median CD4 count was 460 IQR [ 1.1 – 1307], 83 (86%) were currently of WHO clinical stage I/II and current ARV regimen NNRTI based were 41 (43%) and PI based were 56 (58%).

Overall 48 (50%) of the 96 adolescents/youth age between 15 -24 years had transitioned to adult care services. Three (6%) transitioned before 18yrs of age (early transition), 11 (23%) at appropriate age of 18 -20yrs and 34 (71%) had delayed or late transition between 21 – 24yrs.

Most adolescents/youth described feeling not prepared for transition and felt anxious and worried amid the transition process. The youth demonstrated that the change was overpowering, and used expressions like: “being scared,” “a shock,” and “don’t know what to expect” to describe first hearing about transition. Every key informants (health care workers) concurred that transition to adult care was an vital issue that was expanding in urgency as HIV infected adolescents/youth advanced towards the age of 19yrs.

Key barriers to transition to adult care were: fear of letting go of the bond and relationship that the adolescents/youth and health care providers have formed over the years, stigma and discrimination by the adults attending the adult clinic, difference in care between pediatric and adult clinics and poor preparedness on transitioning. Facilitators that were identified were: being independent and having sense of responsibility, early preparation to transition, transitioning as a group and having a supportive system from caregivers and HCW’s.

**Conclusion and Recommendations:** Nearly a quarter of adolescents/youth successfully transition to adult HIV services at an appropriate age and majority transition late. Early transition is rare in our setting. Significant barriers remain including stigma, difficulty letting go, and abrupt transfer. The major facilitators to transition include: support by peers, HCW’s and caregivers as well as empowering the adolescent/youth to take ownership over their care and early preparation to transition.

Transitioning successfully, adolescents and youth with HIV to adult clinic settings depends on having continuous and sufficient dialogue amongst pediatric and adult HIV care teams, readiness of patients and their families through particular transition plans, have an incorporated and stepwise approach and robust support structures that address stigma and numerous other difficulties to growing-up with HIV.

## CHAPTER 1: INTRODUCTION

The world is currently awakening to the fact that there is an urgency to make a difference in adolescent/youth health. Their needs are specific but least served by health services(2). Transitioning to HIV care and other health services is just one of many transitions that adolescents/youth with human immunodeficiency virus (HIV) confront. Adolescence is a period of turbulent change even when there are no complex health concerns to address, yet when the adolescents/youth journey to adulthood is exacerbated by a complex chronic illness such as HIV the adolescent, their caregivers and health care providers are periodically faced by the multifaceted array of issues that must be addressed (3).

Adolescence is a transitional phase of growth and advancement between the ages of 10 to 19 years. It is characterized by physical, psychological, economic and social changes. 'Youth' is globally defined as people between 15 and 24 years of age. In spite of the fact that 18 years is the legal age of adulthood in numerous countries in Sub-Saharan Africa, adult behaviors are not completely embraced at that point. Therefore, many nations continue to give "youth" health and social support programs for people well into their 20's (3).

Transition from pediatric to adult clinic settings for chronic illness, corresponds with adolescence, a phase that is typified by self-exploration and risk-taking behaviors for example sexual debut, short-term consecutive partners, and experimentation with alcohol and drugs and desire to fit in; psychological adjustment, identity development (4-6). However, HIV-infected adolescent and youths must figure out how to explore through unpredictable health system and the social stigma that is related with HIV. It is also during this time that the adolescent experiences separation and individualization from their family/caregiver, further developing a sense of self and building new relationships with peers. This stage of development can lead to challenges at the individual, family, and community level (3).

Adolescents and youth are particularly vulnerable to HIV infection, they account for approximately 40% of new HIV infections globally. An estimated 2.2 million youths are living with HIV, around two thirds of who are girls. Additionally, this age group also has the highest rates of sexually transmitted infections. According to the Kenya Aids Indicator Survey (KAIS) final Report 2012, HIV prevalence among 15 to 24 years old was 2.1%.

Transitioning adolescents with chronic illnesses to adult healthcare systems has become progressively vital as more new up to date medications prolong survival into adulthood. The introduction of highly active anti-retroviral therapy has dramatically improved survival among HIV infected adolescents (7). Thus, an expanding number of adolescents/youth living with

HIV are faced with making the transition from pediatric care to adult care. The change can be unpleasant for individuals who need to start up new relationships with health care providers while building up the knowledge and aptitudes important to deal with their health.

Unlike HIV-negative adolescents/youth, adolescents/youth living with HIV confront particular difficulties during the transition process, which includes:

- disclosure of their HIV status to friends, family and health care providers and stigma (8)
- Neurocognitive impedances and psychological well-being issues associated with HIV (9)
- Identify and acknowledge that they confront the risk of transmitting HIV to future sexual accomplices and possibly children (10)

One of the definition of transition often utilized in the literature is that recommended by the Society for Adolescent Medicine, (11) which sees transitioning as a deliberate, planned process that addresses the medical, psychosocial, vocational, and educational needs of adolescents and young adults with chronic conditions when moving from a pediatric service to adult-health care services. This change ought to be identified as merely one part of the broader set of educational, personal, family-related, and social transitions that adolescents encounter.

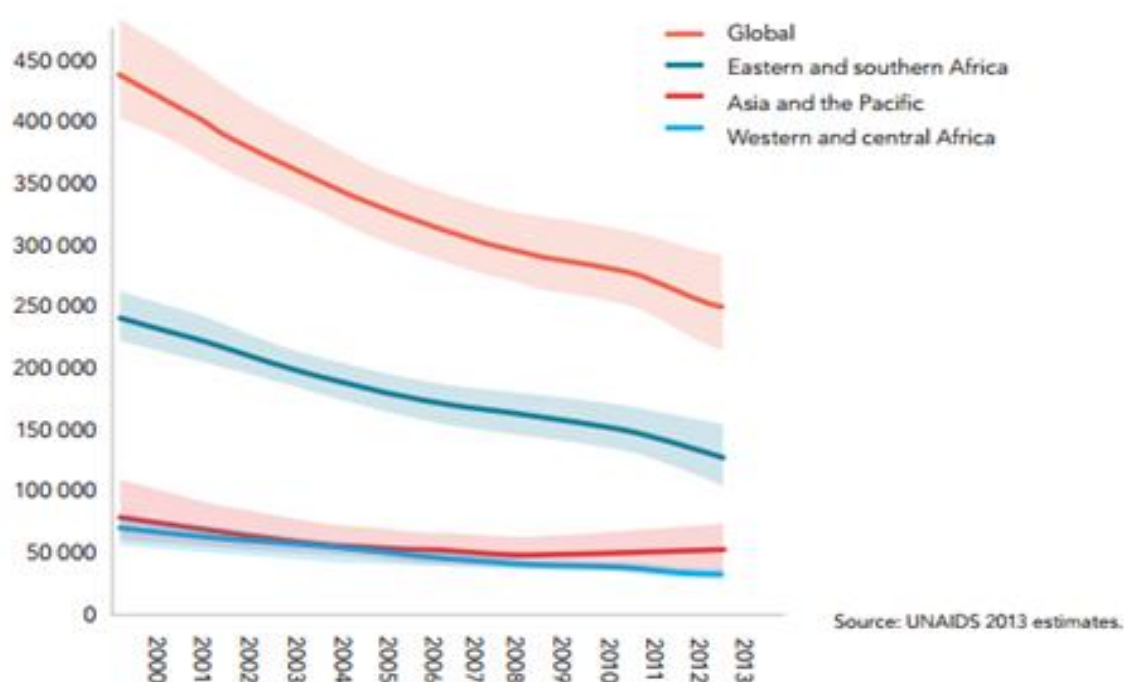
The need to develop more protocols for enhancing transition process to adult health care services in this age group becomes very important, as there exists no studies in our region on transition process.

## CHAPTER 2: LITERATURE REVIEW

### 2.1 Epidemiology

Currently, 1 billion adolescents are living in the world. Among adolescents new HIV infections are not declining as fast as they should. In every two minutes an adolescent/youth are newly infected between the ages of 15 to 19years (12).

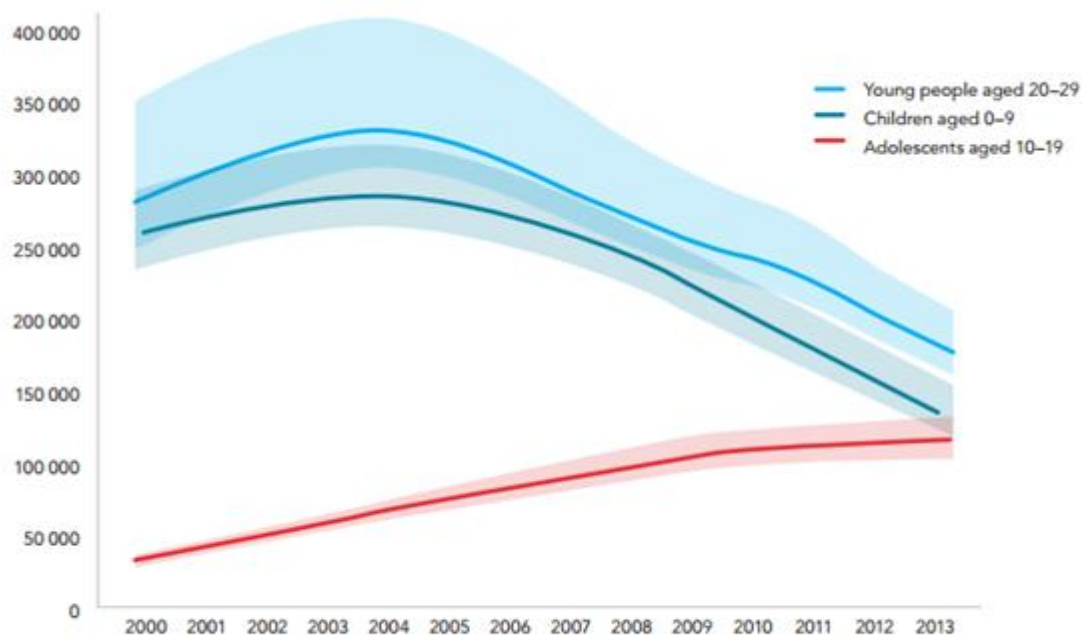
Globally, roughly 2.1 million adolescents/youth are living with HIV, with the dominance part located in sub-Saharan Africa (2). Of the total number of adolescents living with HIV globally in 2013, 83% dwelled in sub-Saharan Africa. Progress is also uneven across various districts as shown in figure 2.1, the number of new HIV infections has remained moderately stable in Asia and the Pacific since 2005, while they have declined in eastern and southern Africa (12).



**Figure 2.1 Approximate number of new HIV infections among adolescents (aged 15-19) over the time period of 2000-2013: global and three countries with the largest number of new adolescent's infections (Global report UNAIDS, 2013) (12)**

Globally, HIV/AIDS is now the second most common cause of death among adolescents and youth and number one cause in Africa among adolescents. In 2013, 120 000 [100 000–130 000] adolescents died of HIV/AIDS-related complications. As indicated by UNAIDS adolescents are the only age group in which deaths due to AIDS are not declining—while all

other age groups combined experienced a decline by one third in AIDS-related deaths between 2005 and 2013, as shown in figure 2.2 below (12).



Source: UNAIDS 2013 estimates.

**FIGURE 2.2 Approximate number of AIDS- related deaths among children (aged 0-9), adolescents (aged 10-19) and youth (aged 20-29) over the time period of 2001 – 2013 (Global report UNAIDS, 2013) (12)**

These adolescents are both infected from mother to child and behaviorally infected who are developing into adulthood. In spite of the universal call to support HIV self-care among adolescents (13), including adherence to medications, HIV infected adolescents and their caregivers in SSA frequently cannot access adolescent-specific services and the aptitudes expected to deal with a highly stigmatized chronic illness (14). Globally, the gap in HIV services has risen by half in HIV-related deaths among adolescents from 2005 to 2012, while the overall global number of deaths across different age categories declined by one third (13). The World Health Organization attributes this growth in mortality in part to “a lack of support for adolescents to remain in care and to adhere to antiretroviral therapy” (13).

Approximately over 40 million people live in Kenya, and it is growing at about one million each year, with half of them aged less than 15 years, and 19% aged between 15 and 24 (15). In Kenya, approximately 29% of all new HIV infections are among adolescents and youth. (Kenya HIV Estimates; UNAIDS/NASCOP)

## **2.2 Transition of Adolescents/Youth from Pediatric to Adult Health Care Services**

In 1990s, the Society for Adolescent Medicine published its first position statement on transition, and recognized some features of the pediatric-to-adult care services transition process. They found that the process includes not only health care, as well as the mental, social, and educational needs of the adolescent and youth. Besides, each adolescent/youth transition at unique time, and this relies on components such as preparedness or readiness on the part of the adolescent and their family dynamics, and may also depend on patient's overall health condition (16).

It is important to distinguish between the terms "transfer" and "transition"(17). Transfer is characterized as an activity of moving somebody or something from one place then on to the next, and is viewed as a solitary or onetime occasion. Transferring a patient from one clinic to another is likewise perceived as no more than an event, unlike transition, which is regarded as a life-change process that individuals, family members, and health workers experience together, and for which protocols or written action plans should be put in place to expand the likelihood of success. Hence, the word "transition" in health care context carries more meaning as a process of mental adjustment to a change (18).

The transition into adulthood is a crucial stage of human development, during which adolescence and youths take on new roles and ownership of their health, which increases various emotional and psychosocial challenges and bring about major choices and decisions (19).

Betz et al (20) noted that in preparation for successful transition, special emphasis needs to be assessed on the capacity of adolescents understanding to take responsibility of their own treatment, involvement of patient in illness management prior to transition, displays ownership, freedom, and build their relationship with his or her team of clinicians.

Due to the significance of this theme, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine a suggestion was published looking at building a transitional policy of adolescents/youth to adult health services. This record provided with proof of the need for an expert in every service who is in charge with conducting and coordinating the transition process, as well as preparing and meeting the different of adolescents and youths. Patient documents or files must be readily accessible to the receiving adult care team, and transition criteria ought to be formulated with suggestions from the adolescents/youth, their health care providers, and their guardians (20).



Transition to self-care ought to be individualized and patient-centered based on the physical development, emotional maturity, and health status of the patient. The objective of transition is to make sure that health care providers facilitate the transition process through provision of continuous, well coordinated, age and developmental appropriate and integrated care throughout the process of transition.

Transition is a process, not an outcome and it begins early in adolescence. It should be an age and developmental centered approach and is not a onetime event. HIV infected adolescents may come across difficulties in their transition to adult clinic and may need to function autonomously and learn to take care of themselves. The transition process ought to therefore improve the adolescents' self-determination, develop a sense of personal responsibility, encourage independence and self-efficiency and boost the adolescents and youth ability for self-care and self-support (3).

A Massachusetts study on transition framed the issues and the common factors for young people in simple terms. The youth, their caregivers, and their health providers are fearful of change because the process is complicated. There is no standardized process for transition, and no clear model; therefore, every institution has its own protocol. Additionally, youth lack the skills and confidence to adapt to confusing adult service foundations, and be adherent to medications and health care plans is many a times difficult. Parenting HIV-infected adolescents and youth is also not an easy task. Most guardians do not have the help they require and there is regularly a quandary of an excess of child rearing or too minimal parental contribution. Youth require bolster as they take control of their care (21).

A well-coordinated transition enables adolescents to advance in well-being, to autonomously deal with their illness and to develop into adapting adult roles and taking charge of their health (11). Also, lack of transition planning may lead to withdrawal from care, regards to HIV can prompt to emergence of multidrug-resistant to various virus strains, decline the immune status, raise disability and death rates and increase probability of HIV transmission to others. Making sure that the transition process is done effectively from pediatric to adult care which is a national priority for improving the well-being of HIV infected adolescents and youth, and crucial for reducing the rates of HIV transmission to extensive communities (22).

### **2.3 Two unique cultures – Pediatric- versus Adult-health care services**

Planning for transition is fundamental as pediatric services which are for the most part family focused and developmentally centered, contrast essentially from adult health care services which endeavor to recognize patient self-determination.

Adult health care providers have recognized many worries about adolescents who have transitioned to adult clinics, particularly the poor adherence to proposed treatment regimen, lack in learning about the disease and restricted self-care abilities (23,24). The distinctions might be somewhat clarified by enormous differences amongst the directive and functioning of pediatric and adult health care. Services provided by the Pediatricians is family centered, depends on formatively appropriate care with consideration of parental contribution in decision-making and endorsing care within a multidisciplinary team.

Adult health care is patient centered and usually requires self-direction, free consumer aptitudes without numerous multi-disciplinary resources (25). Adult health care services are distinct from pediatric services in the sort and level of help given, support provided during making of any crucial decisions, assent processes and parents inclusion. The elements assume a part in the reduction in follow-up clinics by adolescents after transitioning to the adult care services. Few investigators trust that this decrease is, to some extent, credited to absence of planned transitional process and inadequate communication with adult health care services (26).

AnneLoes van Staa et al did a study in the Netherlands between 2004 to 2007, a qualitative survey which was looking at the encounters of adolescents and youth with chronic illnesses, guardians and providers during transitioning into adult care. And how they could improve the transition experience among this group. There were 65 participants of which, 24 were adolescents and youth (mean age 19 years; range 15-22), twenty-four guardians, and seventeen clinicians. A quarter of adolescents were about to transition, eighteen had transitioned to adult clinic. The health care professionals portrayed contrasts between the Pediatric and adult care services as shown on Table 2.1 (27)

**Table 2.1 Cultures of care: Usual contrasts amongst pediatric and adult health care professionals (AnneLoes van Staa et al:2011) (27)**

<b>Pediatrics</b>	<b>Adult care</b>
Typical patient is healthy, only a minority is chronically or terminally ill	Typical patient has complex, chronic and often progressive condition
Patient seen as fragile, vulnerable, dependent	Patient seen as coresponsible, self-reliant
Family-centered care: parents always involved	Individual-based care
Shared decision making and education focuses on parents rather than on patients	Empowerment of patient by means of with information and expectations of self-reliance
Informal, relaxed communication style; empathic but also more paternalistic	Formal and direct communication style; more distant and 'business-like'
Holistic care: attention to developmental and learning issues, social functioning	Disease-oriented care: strong focus on treatment complications and adherence
Interdisciplinary team approach	Specialist orientation, less team work and care coordination

## **2.4 Approaches to transitioning Adolescents**

The period of transition may be a vulnerable time for the adolescent because he or she may not have a ton of experience or practice in dealing with his or her own health care. It is vital to work with adolescent and youth to urge them to routinely attend their appointments, adhere to their medications, recognize what's more utilize extra sources of help such as other community-based services, and abstain from drugs and alcohol that may adversely affect their wellbeing.

According to the Adolescent Package of Care in Kenya by the Ministry of Health the following was proposed be considered during the transition process: (3)

- HIV status disclosure is crucial for transition; Supportive parameters in place to provide the family/ caregiver to disclose if the adolescent and youth is not aware of his or her HIV status

- Develop a transition plan; Multidisciplinary team ought to build up a facility transition protocol with inputs from the adolescent and their guardians; plan ought to be looked into all the time
- Review the client's medical history, encourage them to raise their fears and concerns on their care and medicines and discuss any future changes
- Ensure adolescents understands medication use and importance of adherence
- Promote linkages to peer support groups
- Organize health seminars for adolescent and youth who are transitioning; conduct health talks driven by peers who have successfully transitioned to adult services
- Encourage young adults to take ownership for their care and clinic appointments (for example having a clinic appointment and medication diary)
- Consider transitioning adolescents to adult care in groups, if possible, so that the adolescents can bolster one another.
- Always assess patient readiness before transitioning.
- Involve parents and caregivers during the transition process

Markers of successful transition in care have also primarily been viewed from the medical model perspective with few studies that reflect the patients' social, mental, or familial perspectives (1). Behavioral pointers included scheduling their own appointments, being adherent to their medications, and exhibiting responsibility towards their health care. Clinicians also recognized biological pointers towards successful transition, particularly viral load and CD4 count (30,31). Several studies did assess "readiness" as a valuable perspective of adolescent and youth transition. Weiner et al. a study done in the USA, used the "Transition Readiness Questionnaire" which assesses barriers to an effective transitional pathway including recognition of an adult clinician, having a health insurance, and information of illness status and drug regimens (32). These discoveries also were reflective of the medical providers' perspectives.

## **2.5 Barriers to Successful Transition**

Numerous barriers to transitioning successfully have been recognized, (33) some are institutional, some health related, and some behavior and social related. Some examples include:

- unexpectedly transition with practically no prior preparation;
- Lack of or truant planning;
- Resistance by adolescents/youth, guardians, and even pediatric clinicians;
- Delay in booking visits at the adult clinic after transitioning from the pediatric service;
- Lack of readiness with respect to adult- health care services to receive and treat adolescents with chronic illnesses;

- Distinction in providing care among pediatric (which usually utilize a more supportive, family-focused approach) and adult-health care (in which more individual autonomy is expected);
- Truant communication between pediatric and adult clinicians;
- Lack of institutional support.

As opposed to other work *Fair et al* conducted discussions with 40 HIV infected adolescents who acquired the disease via vertical transmission, (31) that concentrated particularly on barriers, they tried to extensively describe the desires of HIV infected adolescents and youth and their caregivers. A number of HIV infected adolescents displayed an overall poor understanding about transition. Parents/caregivers were more familiar with the topic, however had a latent view and wanted their children or the clinicians to introduce the agenda of transition to them. Some caregivers figured that moving to adult clinic would be useful to enable their children to achieve more responsibility and maturity in their lives in general. Most HIV infected adolescents and their parents were worried about losing bonds with pediatric staff members. Adolescents were worried that adult clinicians were more serious and less personal in relating with them.

In a comparative report, *Sharma et al.* likewise centered on vertically HIV infected adolescents and led discussions with fifteen adolescent and youth and eight guardians to evaluate perception towards transition, was an assessment in a solitary pediatric clinic in Miami. A quarter adolescents/youth and parents saw themselves not being fully ready for transition. They dreaded about having to leave behind their medical home and the associations they had formed in the pediatric clinic. During the same period, adolescents perceived the urge to create life skills as they matured. HIV infected adolescents/youth and guardians had thoughts on how the center could assist to make them ready for transition, starting this process much early on (i.e., 13 years old) but postponing the real transition for whatever length of time, getting a different transition clinic, and preparing them on how to function independently without any fear (34).

*Vijayan et al.* also led focused group discussions with eighteen vertically HIV infected adolescents, fifteen parent/guardians and nine pediatric clinicians with the aim of investigating difficulties in providing services as well as barriers to transitioning to adult clinics (35). The research was based in a solitary pediatric clinic in the USA. Adolescents and guardians reported, stigma related with HIV made them be on the edge and mindful about meeting new clinicians. Pediatricians dreaded that internists might expect adolescents to have more autonomy than their adolescent patients actually had, and all these cohorts expressed uneasiness about ending their present associations with each other.

As indicated by Viner, (28) lack of planned transitions might be related to raising the risk of not able to adhere to their treatment and could be vulnerable to lost to follow-up. This eventually may have lamentable outcomes, for example rise in complications related to HIV, illness progression and consequent increments in mortality, and social and instructive repercussions.

From the healthcare perspective, the primary barrier to successful transition was the lack of, or poorly coordinated transitional planning. Issues included no written plan, poor communication mechanisms among pediatric and adult clinicians, and no formal health-care team responsible for the transition (36). These factors were consistently reported across the studies for transitioning of children with chronic diseases such as cystic fibrosis, diabetes mellitus, sickle cell disease, and other chronic illnesses. Currently, only a handful of articles exist on HIV transitional process, but congruency was evident in the available studies.

Another systems issue identified was the need to consider developmental age rather than simply basing transitional plans on the chronological age of the adolescent. Absence of preparing in adolescent development has been identified as a significant barrier to the implementation of effective transitional programs

Other barriers noted were issues such as deficiency in knowledge for disease management among the receiving provider and the transitioning young adult and their caregiver/parent. Healthcare providers may also need training and preparation to receive the complex care responsibilities. One study of general internists, for example, found that only 32% felt comfortable being the primary provider for HIV-infected individuals (26).

Unsuccessful transition can bring about:

- Increased rates of adolescents/youth who are lost on follow up
- Adolescents having low immune systems
- Rise in disabilities/complications and deaths, and
- Plausibility of adolescents having developed resistance to medications (32,40).

From various studies conducted on transition, we infer that numerous barriers are usually expected by guardians and clinicians prior to transition happens. The most obviously mentioned barriers among transitional studies incorporated a sentiment of giving up relationship with their pediatric staff clinic members, uneasiness about expanded independence within the healthcare system and logistical difficulties related to social services.

## **2.6 Facilitators to Successful Transition**

Facilitators to continued attendance centered around enabling factors including information on what to expect, being shown round the adult facility, being involved in the decision

making on when to move and shorter appointment times. Being treated as an adult and open communication with staff were the main reinforcing factors.

Gilliam et al led a qualitative study in South Florida, USA looking at attributes and current practices of HIV infected adolescents transitioning to adult services. The attributes distinguished as facilitators to a successful transition were recorded by the respondents, these attributes were distinctly grouped as intrinsic or extrinsic to the adolescent. The inherent qualities included emotional development alongside with the capacity and enthusiasm to function freely. Outer elements included for example having a strong support system, receiving benefits provided by the health insurance, easily accessible clinic via available transport system and stable lodging were perceived to facilitate a successful transition (41).

Respondents saw facilitators as characteristics of the patients, guardians, or providers that assisted in conquering barriers to successful transition. These included particularly mature patients, guardians ideally engaged in the patient's care, and sufficiently supportive health care providers.

#### *Exceptionally Mature adolescents with sense of responsibility towards their wellbeing*

Adolescents/youth who were mature compared to their chronological age and took responsibility towards looking after themselves were frequently identified to have successfully transitioned by all participants. HIV infected adolescents and youth were identified as using sophisticated reasoning and/or having developed resilience in the face of adversity. This drove adolescents to enhanced adaptive coping mechanism towards their good health, an eagerness and capacity to consider fruitful results of the choices they make along the way. The adolescents usually asked thoughtful inquiries regarding their health and treatment which were at times exemplified by their comprehension of their illness and by their maturity (41).

#### *Guardians Involved in the Adolescents/youth Care*

The guardians have been associated in the care of their adolescents/youth and this approach was found to have facilitated towards transition. Parents who supported their children developed more sense of responsibility of their health and they trusted their choices and provided with support and the knowledge regarding their illness when needed (41).

#### *Adequate Health Care Provider Skills in Proactively Recognizing and Addressing the Needs of the Patients and Guardians and Effective Care Coordination with Other Providers*

Adolescents reported how their pediatric health care providers helped them get through the process of transition by proactively preparing them and providing with constant support. While there was great debate on the recommended age at which transition should start, all concurred that the transition process ought to start way before in early adolescence period. Helicopter Child rearing by discussing about moving out of the pediatric clinic from early age with parents and the adolescents was found to be a facilitator to successful transition for example seeing the adolescent without the parent, speaking directly to the adolescent during clinic visits and asking the parent to “let go” by empowering their adolescent step by step and increase more sense of (41).

## **2.7 Study Justification**

Kenya is estimated to have high overall prevalence of HIV among adolescents and youth. AIDS related mortality among this age group has expanded by half over the last few years, however declined for other age categories, according to UNAIDS estimates. This prevalence is estimated to be rising in different areas placing a significant burden on health care resources countrywide.

In late adolescence HIV, infected teenagers must make the transition from pediatric to adult clinic services. The transition process can be very stressful for those who need to build up new relationships all over again with clinicians while developing the knowledge and abilities important to deal with their well-being and can be easily lost during transition. There has been a rise in the rates of HIV- infected adolescents who are faced with multiple challenges during this process, because of this they are at increased risk of dropping out of health services due to discomfort with adult oriented services.

As the rates of HIV-infected adolescent population continues to rise, there is distinct requirement to facilitate a clear process and an intergrated pathway to prepare them, their parents, healthcare providers, policymakers, and others involved in their care and well-being. Attention must be focused on developing a comprehensive care approach for their unique health and social support needs and the potential barriers that preclude their healthy transition into adult HIV care.

Currently, there is paucity of literature on experiences of adolescents during transition process and poor understanding of what barriers and facilitators exist among HIV infected adolescents and health care providers during transition process from pediatric to adult care in our region.



## **2.8 Study Utility**

Being the first survey that considered transition process among HIV infected adolescents in the East African region, this research hopes to provide valuable information on age appropriate transition of HIV infected adolescents and youth presenting at the comprehensive care centre and describe barriers and facilitators that affect transition process in our setting. This will provide baseline data for further studies in the future in our region.

This study will provide information and help guide health care workers dealing with HIV infected adolescents in planning early for transition, to achieve successful transition and minimize on losing adolescents during this process.

Additionally, we trust that our findings will be valuable to inform health care planners and policy makers to focus on priority areas that need improvement in existing transition checklist and guidelines among HIV infected adolescents.

We therefore hope that the study can be used to inform HIV care programmes and health care workers looking after HIV infected adolescents for better planning and establish successful transition to adult care.

## **CHAPTER 3: RESEARCH QUESTION AND STUDY OBJECTIVES**

### **3.1 Research Questions**

- 1) What proportion of HIV infected adolescents and youth living with HIV transition at appropriate age of 19years from pediatric to adult HIV services at Kenyatta National Hospital?
- 2) What are the Barriers and Facilitators of Successful Transition among HIV infected Adolescents and Youth from Pediatric to Adult HIV services at Kenyatta National Hospital?

### **3.2 Study Objectives**

- 1) To determine the proportion of HIV infected adolescents and youth that have transitioned at the appropriate age of 19years from pediatric to adult HIV care services at Kenyatta National Hospital
- 2) To identify barriers and facilitators to transition from pediatric to adult HIV services among HIV infected adolescents and youth in care at Kenyatta National Hospital as informed by HIV infected adolescents and youth and the Health Care Providers.

## CHAPTER 4: RESEARCH METHODOLOGY

### 4.1 Study Design

This was a descriptive cross-sectional survey employing both qualitative (focused group discussions and key informant interviews) and quantitative (questionnaire and abstraction of medical records from electronic data base) methods.

### 4.2 Study Site

Patients were successfully enrolled from the adolescent clinic at Comprehensive HIV Care centre (CCC) of Kenyatta National Hospital.

Kenyatta National Hospital is largest referral, teaching and research hospital in Kenya, located in Upper Hill about 4 kilometres from the central business district of the capital city of Kenya, Nairobi. The city has an approximate population of 3.36 million inhabitants living within 696 km square area. The hospital covers an area of 45.7 hectares and has a capacity of 1800 beds and serves 47 counties of Kenya.

The CCC offers HIV services to adults, children and adolescents. This is a PEPFAR supported program in collaboration with MoH under NASCOP, which was established in 2002. The facility currently offers treatment to approximately 500 adolescents. The CCC provides free antiretroviral therapy (ART), treatment of opportunistic infections, nutritional counseling and supplementation, psychosocial care and laboratory and radiologic tests.

The centre also provides linkage of patients with other HIV service providers close to where the patients live. Additionally, the centre also runs regular support groups for adults, children and adolescents who are on treatment.

### 4.3 Study Population

#### 4.3.1 Adolescents and Youth

Adolescents and Youth were eligible for inclusion if they met the following criteria:

- Confirmed HIV infection

All HIV infected adolescents and youth enrolled at Kenyatta National Hospital, CCC

Aged between 15 – 24 years.

- Age 15 – 24 years

Informed consent for those  $\geq$  18 years for study participation.

Parental/Guardian consent and child assent for those < 18 years

- Have received full disclosure of HIV diagnosis.

Adolescents and Youth were excluded if:

- HIV infected adolescents and youth who were severely ill requiring admission and were unable to give consent or assent on the day of recruitment.
- HIV infected adolescents who did not receive full disclosure of their HIV status.
- Adolescents/Youth who did not intend to enroll in long term care at CCC, KNH and are referred out.

#### 4.3.2 Health care providers

Health care providers were eligible for inclusion if:

- Health care workers (Doctors, Nurses, counselors, pharmacists, social workers, nutritionist) were caring for HIV infected adolescents and youth at the Kenyatta National Hospital Comprehensive Care Clinic
- The Health Care worker who have worked at CCC, KNH with adolescents and youth for a minimum of 6 months.

#### 4.4 Case Definitions

- **Adolescents** - is defined as an individual between 10 – 19 years age group
- **Youth** - is defined as an individual between 15 – 24 years age group
- **HIV infected** - An individual who has been infected with the Human immunodeficiency virus. Verified the HIV infected status from the case files of adolescents enrolled at CCC.
- **Transition** – defined as successful graduation from pediatric to adult HIV services.
- **Age appropriate transition** – in this study will be defined as adolescents and youth who successfully transition from pediatric to adult care services of the age of 19yrs +/- 1yr (18 – 20 years)
  - ✓ Early transition age: Adolescents and youth who transition between the ages 15 to < 18yrs
  - ✓ Delayed/ late transition age: Adolescents and youth who transition after the age of 20 years.

#### OUTCOME DEFINITIONS

- Potential barriers or facilitators to age appropriate transition were explored in various categories:
  - i) **Adolescent and Youth related factors:** Age, gender, clinical (viral load/CD4 count, WHO staging), drug regimen, mode of transmission (vertically/horizontally), come alone to clinics or accompanied, involvement in decision making, self- stigmatization, knowledge and management on HIV
  - ii) **Health care system related factors:** communication among health care providers and adolescents, preparedness to move from pediatric care and to

receive and treat at adult care services, clinic settings, appointment keeping, waiting time, support groups

- iii) **Socio-economic related factors:** schooling, orphan, employment, substance abuse, involvement of parents during transitioning

#### 4.5 Sample Size Determination

The Sample Size was determined by Fischer's Formula for sample size determination in prevalence studies:

$$\begin{aligned} N &= [ z^2 \times p (1 - p) ] / d^2 \\ &= [ 1.96^2 \times 0.5 \times (1 - 0.5) ] / 0.10^2 \\ &= 96 \end{aligned}$$

N = estimated minimum sample size

z = normal standard deviation taken with a 95% confidence interval; set at 1.96.

p = proportion of eligible adolescents / youth who successfully transition to adult services by the age of 19 years (50%) (p was estimated at 50% since it was unknown)

d = level of precision (set at 10%)

#### 4.6 Study Procedures

##### 4.6.1 Procedure for Adolescent and Youth Recruitment

Potential study participants were identified from the comprehensive care centre database and client's files on adolescent/youth clinic days before the commencement of the clinic on every Thursday and Friday. The principal investigator identified HIV infected adolescents and youth living with HIV and verified the diagnosis before recruiting between the ages of 15 to 24 years who meet the eligibility criteria.

A consecutive sampling approach was used, whereby every adolescent/youth who met the eligibility criteria attending the clinic was recruited until the sample size of 96 was achieved. Of these, 48 adolescents/youth were recruited from Pediatric clinic and 48 adolescents/youth were recruited from adult clinic. The Investigator approached the specific adolescents and youth and their caregivers and explained the purpose and methods of the study allowing the study participant and their caregiver to provide voluntary informed consent and assent.

The Consent and assent was given in written form. The consent and assent form provided described the purpose of the study, the study procedure to be followed and also the potential advantages and risks of partaking in the study.

Following selection of study subjects, data was collected from the eligible participants by administration of a structured pre-tested questionnaire administered by the interviewer. The questionnaires assessed the following aspects regarding the HIV infected adolescents and youth:

- ✓ The HIV infected adolescents and youth socio-demographic details.
- ✓ Enrolment date into HIV care services abstracted from medical records.
- ✓ Age at which the adolescents and youth living with HIV were fully disclosed
- ✓ The medication regimens they are currently taking for their HIV infection.
- ✓ The most recent CD4 count, viral load and current WHO staging will be abstracted from their medical records.
- ✓ Among adolescents/youth of age 15 - < 18 years if they had any information or discussion on transition, at what age, if not at what age would they like to have the discussion.
- ✓ The age when the adolescents and youth living with HIV were first communicated about transition by the health care provider.
- ✓ Where applicable, the age at which the adolescent or youth transitioned from pediatric to adult services

#### **4.6.2 Procedure for Focused Group Discussions**

Five focused group discussions were conducted among HIV infected adolescents and youth attending the CCC at Kenyatta National Hospital. They provided in depth insights into what their understanding was on the process of transition.

They were recruited on the days of the clinics, Thursday and Friday after meeting the inclusion criteria. The sampling procedure that we used was purposeful sampling until a sample size of 8 was achieved. Two criteria were considered when recruiting the adolescents for FGD's:

- i) Adolescent/youth who had shown leadership skills in the peer support groups based on the rich knowledge they were able to provide.
- ii) Beyond that purposeful sampling

The principal investigator and research assistants underwent a formal training to conduct these focused group discussions by trainers provided by the KNH research department. We aimed at conducting 6 focused group discussions and these were divided based on who have transitioned to adult clinic and adolescents/youth who have not yet transitioned and receiving pediatric services, further divided them into age groups of 15- 17yrs, 18-20yrs and 21-24yrs.

The discussions were held in a closed room in the patient support centre at KNH to ensure privacy. The sitting arrangement was circular to ensure that participants could face one another during the discussions. All participants were referred by numbers allocated to them before the start of the discussion to protect their identity and maintain confidentiality. The responses were recorded by subject numbers without name identifiers.

The investigator introduced the purpose of the study to the participants and assured them of confidentiality. A tool guide of 5 to 6 open ended questions was used. (Appendix VII) Discussions were continued until a point of information saturation had been attained i.e. when no more new information was derived. However; the average time of discussions was between 30 - 45 minutes.

During the FGD we explored, generally regarding transition; what did the adolescents/youth understand by transitioning, whether they had been communicated by their health care provider on transitioning, what would make it difficult or easy to transition and why and their recommendations regarding transition in their clinic setting.

#### **4.6.3 Procedure for Key Informant Interview of Health Care Providers**

We conducted Key informant interviews, with the health care providers who take care of the HIV infected adolescents and youth and have worked with this group for a minimum of 6 months. In depth interviews of 11 health care providers were conducted and selected based on their first-hand knowledge about the topic of transition among HIV adolescents and youth living with HIV and their availability. These included: Clinicians (Pediatricians), nurses, counsellors, social workers and pharmacists. The technique to obtain information from each key informant was done face to face at their working area.

The key informant interviewer (principal investigator) had scheduled a convenient time and place for conducting the interview was sort after the consent was obtained. The interviewer used an interview tool to guide the discussion. This tool guide contained 5 to 6 open ended questions which were aimed at answering the studies second objective on barriers and facilitators to transition among HIV infected adolescents and youth from pediatric to adult care. (Appendix VIII) The interviewer took notes and recorded the interview on a tape recorder. The interview on average lasted for 20 to 30 minutes.

We ensured to let the key informants know that we will not use their names or any other conceivably recognizing data and assured them that their responses will be kept classified. The outcomes focused on the substance of the discussion rather than identifying who said what.

## **4.7 Data Management and Analysis**

### **4.7.1 Quantitative Data**

The data was entered windows 2010 version 10 access databases. It was cleaned for any errors and inconsistencies in responses. The statistical package for social sciences (SPSS) version 21 and EpiInfo software were used for statistical analysis of the data. Data was secured using passwords, which was only available to the investigator and statistician.

Descriptive statistics for socio-demographic characteristics was obtained to characterize the study participants. Depending on the type of a variable, appropriate summary statistics for measurement scale was used to describe the distributions of variables. Continuous data was presented using medians and interquartile ranges (IQR) and Categorical data using frequencies and percentages.

### **4.7.2 Qualitative Data**

The focused group discussions and key informant interviews were recorded utilizing a tape recorder and taking notes and the data was analyzed by reading the transcripts numerous times to recognize major themes. Interview responses was partitioned by question and autonomously coded by the principal investigator and a research assistant for cross verification.

There were multiple readings and reviews of focused group discussion and the key informant interview responses, which were transcribed verbatim and analyzed which were then reported in form of themes and quotes.

## **4.8 Control of Biases and Errors**

The following measures were taken to reduce different forms of bias and errors:

1. Selection Bias: All HIV infected adolescents and youth attending the CCC at KNH were given an equal chance of being recruited into this study.
2. Measurement Bias: the questionnaire was pre-tested to reduce insensitive measure bias, ensuring the questions are sensitive enough to detect what might be important difference in the variable of interest.
3. Information bias: each assistant was familiarized with the study and the questionnaire. They received a copy of the definitions of terminologies to ensure uniform interpretation of terms. The principle investigator assessed the responses given on daily basis to ensure validity of collected data.



4. Recall bias: data collected was entered within 24hrs for each participant. Also, the age at which the adolescent first informed about transition.

#### **4.9 Ethical Considerations**

1. Permissions were sought from the University of Nairobi/ Kenyatta Hospital Ethics and Research Committee to collect and analyze data collected in the study as part of the Thesis Dissertation.
2. Permission was also sought from the KNH Department of Research and from the CCC Manager to conduct the study and access to medical records of HIV adolescents and youth as well as approach Health care workers.
3. The reason of the Study was carefully disclosed to the adolescent's, Parents or Guardians and adolescent's above 18years old with a view to obtaining informed written assent and consent as relevant, prior to enrolling any adolescent in the study.
4. No Experimental Investigations or Products were employed in this study.
5. Confidentiality of all participants in this study was strictly kept and their names did not appear in any of the questionnaires or in the final report of this study.

## CHAPTER 5: RESULTS

The study was carried out over a period of four months from July to October 2016 at the Kenyatta National Hospital, Comprehensive HIV Care Centre. A total of 105 HIV infected adolescents and youth were screened of which 96 were enrolled after meeting the eligibility criteria for inclusion. Nine HIV infected adolescents/youth were excluded of which 5 denied providing with consent and 4 were partially disclosed of their HIV status.

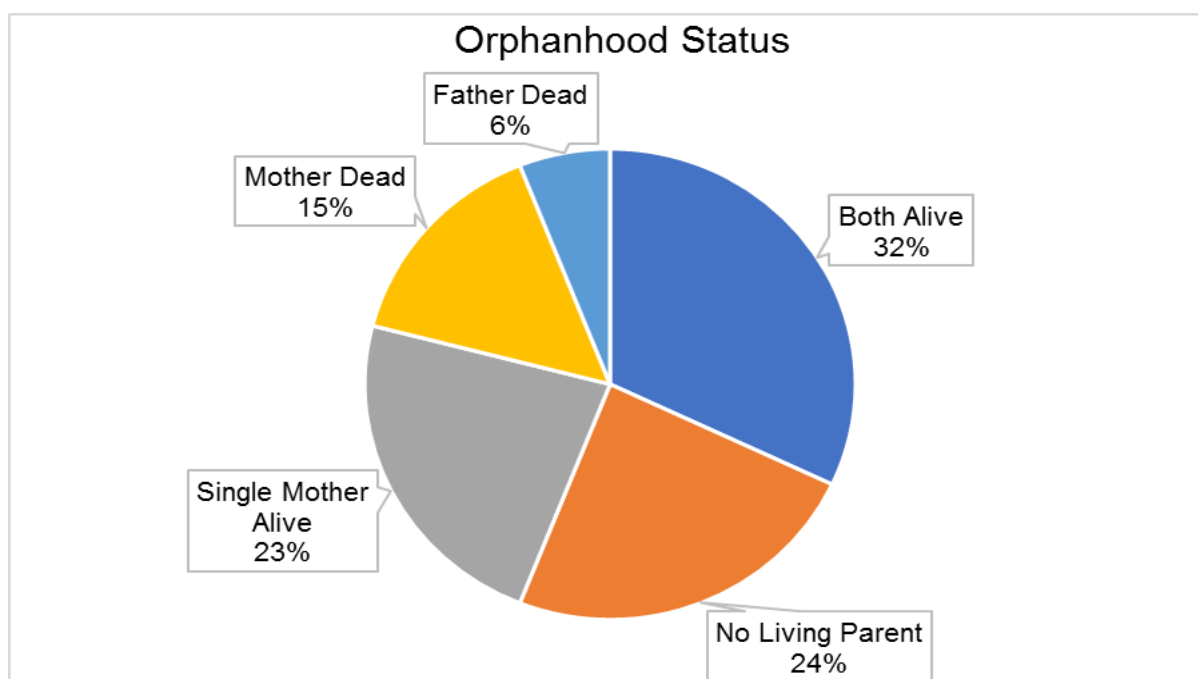
### 5.1 Characteristics of Study Population

#### 5.1.1 Socio Demographic Characteristics

Of the 96 adolescents and youth studied 40 (42%) were males and 56 (58%) females with a female to male ratio of 1.5:1. Regarding age, adolescents/youth studied were mainly in their late adolescence with median age of 18 years IQR [15-24yrs]. Of the total adolescents/youth interviewed, 48 (51%) were single and not in a relationship and 42 (44%) were single in a relationship. Of the 96 adolescents and youth, 57 (59%) reported to be attending school or college at time of the interview and the 39 (41%) who were not in school out of these, 37 (95%) were being employed and 2 (5%) were unemployed. Twenty-nine (30%), 35 (36%) and 32 (33%) had attained at least primary, secondary and college education respectively. Of the adolescents and youth interviewed, 31 (32%) both the parents were alive, 23 (24%) were total orphans while the rest were either paternal or maternal orphans. Of those orphaned, 26 (27%) were under the care of relatives while the rest were in children's home or were taking care of themselves or by their spouse. (Figure 5.1)

**Table 5.1: Socio-demographic characteristics of study population (N=96)**

Characteristic	Detail	N (%)
Age (years)	15 – 18yrs	27 (28.7)
	19 – 21yrs	17 (18.1)
	22 – 24yrs	50 (53.2)
Sex	Male	40 (41.7)
	Female	56 (58.3)
Orphan status	Orphaned	23 (24)
	Not orphaned	73 (76)
Marital status	Single, no relationship	48 (51.1)
	Single, in relationship	42 (43.6)
	Married	6 (5.3)
Currently Attending school/college	Yes	57 (59.4)
	No	39 (40.6)
Education Level	Primary	29 (30.2)
	Secondary	35 (36.4)
	College	32 (33.4)



**Figure 5.1 Orphan hood status of HIV infected adolescents and youth (N=96)**

### 5.1.2 Clinical Characteristics at enrolment to CCC

The median age at enrolment to CCC was 10 years with a mean age of 11years [ IQR: 3 – 16yrs]. Of the 96 adolescents/youth, 25 (26%) of the adolescents/youth were referred from other facilities such as 5 (20%) KNH VCT and 4 (16%) KNH PMTCT, and 16 (64%) were referred from other health care facilities.

Most of the HIV infected adolescents and youth were diagnosed to be at WHO HIV stage I with 57 (59%) at WHO HIV stage I, 20 (21%) at WHO HIV stage II, 15 (18%) at Stage III and 4 (4%) at WHO HIV stage IV. Thirty adolescents and youth (34%) were found to have CD4 counts >500 cells/ml at enrolment and 21 (24%) had CD4 counts <200 cells/ml (Table 5.2)

**Table 5.2 Clinical characteristics at enrolment into CCC (N = 96)**

Clinical Characteristics	Detail	N (%)
Age at Enrolment	< 10yrs	28 (29)
	> 10yrs	68 (71)
Duration of care in years	Median 6.8 years	IQR [0.6 – 17yrs]
Referred from another facility		25 (26)
HIV WHO stage at start of ART	I	57 (59)
	II	20 (21)
	III	15 (16)
	IV	4 (4)
CD4 Count at enrolment (cells/ml)	<200	22 (23)
	200 – 350	18 (19)
	351 – 500	27 (28)
	>500	29 (30)

### 5.1.3 Current Clinical Status

#### ***HIV Disclosure Status***

Of the 96 participants recruited, all 96 participants were fully disclosed of their HIV status of these majority, 77 (80%) had their status of HIV disclosed between the age of 11 – 15yrs and 12 (13%) were disclosed between the ages of 7 – 10 years. Forty-five of the adolescents/youth (47%) were disclosed of their status by the parent, 36 (37%) was done by the health care workers and 15 (16%) by others i.e. by relatives or guardian.

#### ***Recent CD4 Count***

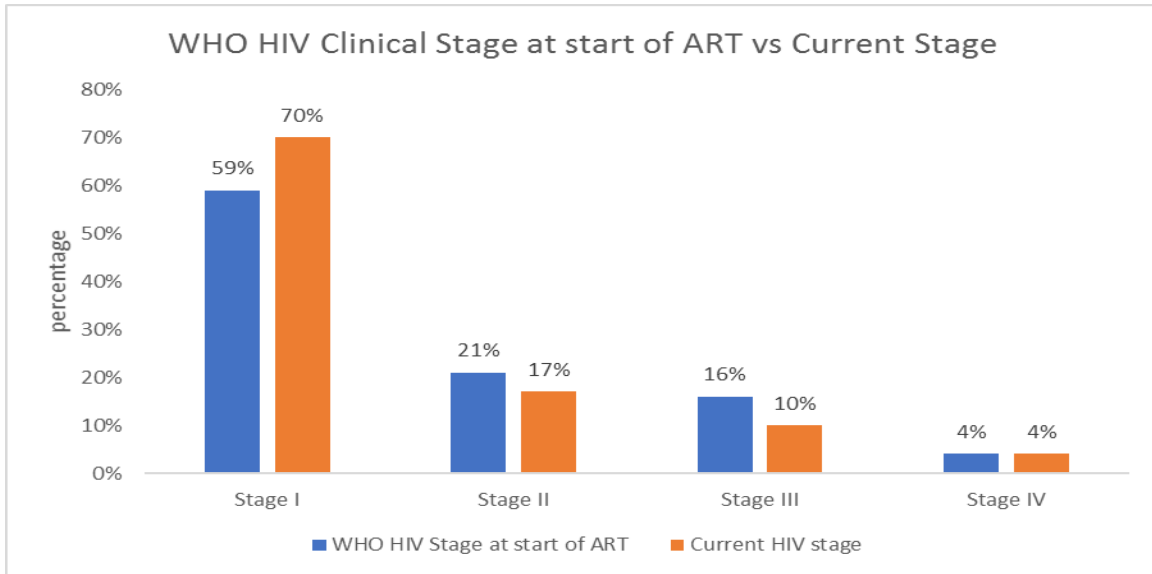
We abstracted the most recent available CD4 count (done within the previous 12 months) and found a median of recent CD4 count to be 460 cells/ml IQR [1.1 – 1307] with 36 (38%) of CD4 count > 500 cells/ml, 29 (30%) with CD4 count 350 - <500 cells/ml and 31 (32%) with CD4 count of < 350 cells/ml.

#### ***Current WHO HIV Stage***

We determined the recent WHO HIV stage by examining each HIV infected adolescents/youth morbidity over the past 12 months as indicated in their medical records and from our clinical evaluation of each adolescent/youth at enrolment into the study. Currently, 67 (70%) of the HIV infected adolescents/youth were at WHO HIV stage I, 16 (17%) were at HIV stage II, 9 (10%) were at HIV stage III and 4 (4%) were at WHO HIV stage IV. (Table 5.3)

**Table 5.3: Current Clinical Characteristics of HIV infected adolescents and youth at CCC. (N= 96)**

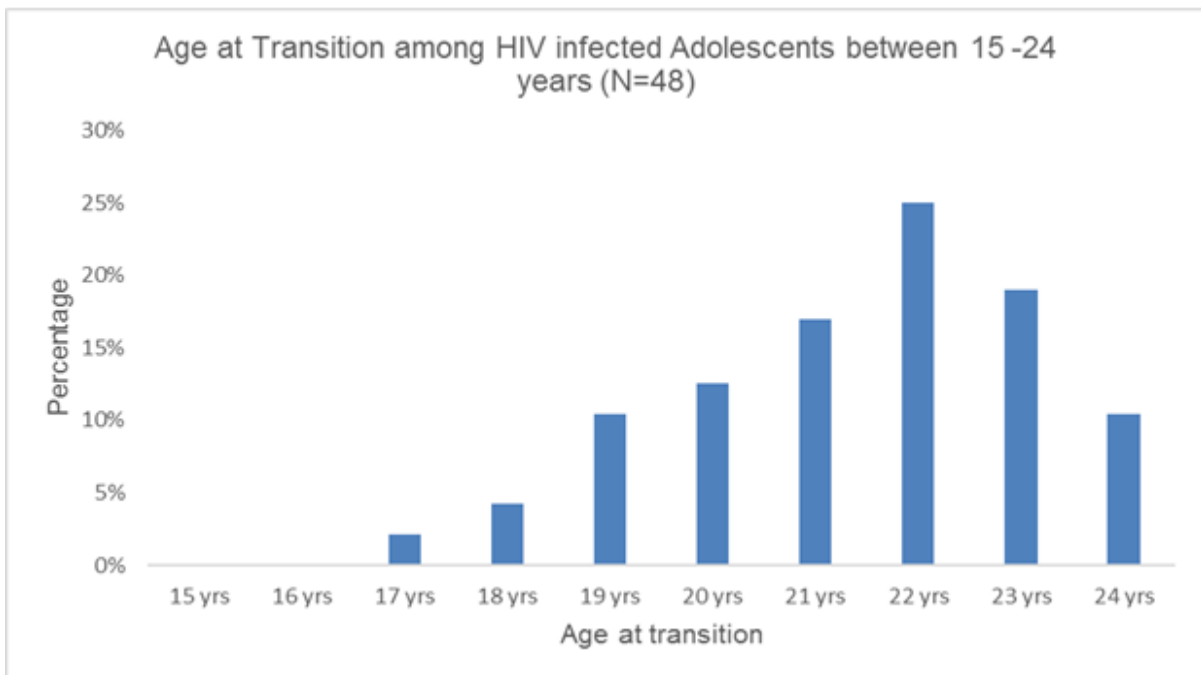
Characteristics	Detail	Frequency (%)
Age at Disclosure	7-10yrs	12 (13)
	11-15yrs	77 (80)
	>15yrs	7 (7)
Current HIV Stage	I	67 (70)
	II	16 (17)
	III	9 (10)
	IV	4 (4)
Current CD4 count	<200	12 (12)
	200-350	19 (20)
	351-500	29 (30)
	>500	36 (38)
Current ARV regimen	2NRTI + NNRTI	41 (43)
	2NRTI + PI	56 (58)



**Figure 5.2 WHO HIV Clinical stage of HIV infected adolescents and youth (N= 96)**

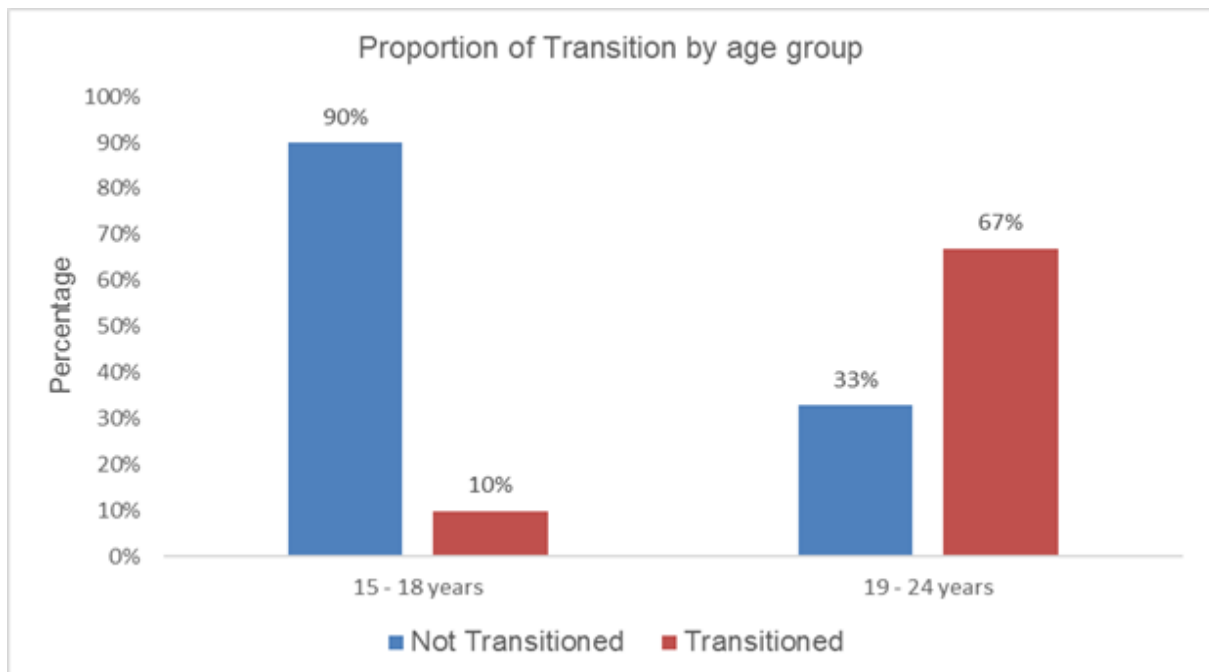
### 5.2 Objective 1: Transition of HIV infected adolescents and youth from Pediatric to Adult Care services

Of the 96 adolescents and youth that we enrolled between the ages of 15 – 24yrs, 48 (50%) (95% C.I 40 – 59) had transitioned to the adult care when this study was being conducted. The median age to transition was 22 years with IQR [17 – 24yrs].



**Figure 5.3 Age at transition to adult care services among HIV infected adolescents and youth between 15 – 24 years (N= 48)**

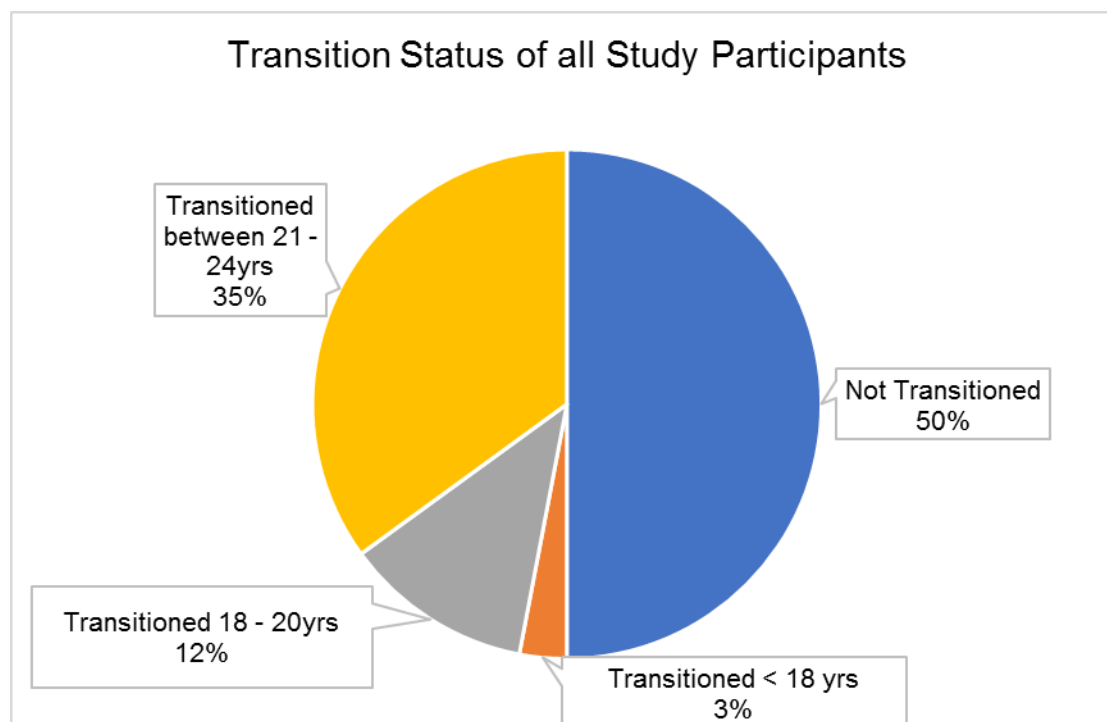
Of the 48 adolescents/youth who had transitioned to the adult care services, 1 (2%) (95% C.I 0.3 – 11) and 2 (4%) (95% C.I 1.1 – 15) had transitioned early at the ages of 17yrs and 18yrs respectively. The three adolescents/youth were all females who transitioned early due to teenage pregnancy and they had to be transferred to adult care services without any form of support or transition process. Five adolescents/youth (10%) (95% C.I 4.5 – 22) and 6 (13%) (95% C.I 6 – 25) adolescents/youth had transitioned at appropriate age of 19yrs and 20yrs respectively, 8 (17%) (95% C.I 9 – 30) transitioned at age of 21yrs, majority 12 (25%) (95% C.I 15 – 39) transitioned at the age of 22yrs, 9 (19%) (95% C.I 10 – 32) transitioned at 23yrs and 5 (10%) (95% C.I 5 – 22) transitioned at the age of 24yrs. These were known to have delayed or late transition. The most common reason for the delayed transition which was described during the focused group discussion was stigma and difficulty in letting go of the relationships and bond they had formed with their caregivers at the CCC.



**Figure 5.4 Proportion of HIV infected adolescents and youth who had transitioned in two age groups: 15 – 18 yrs. group and 19 – 24 yrs. group (N=96)**

Of the 96 adolescents/youth, 29 (30%) adolescents/youth were between the age category of 15 – 18 years and 67 (70%) were in the age category of 19 – 24 years. Of the 29 adolescents/youth between the ages of 15 – 18 years, 3 (10%) (95% C.I 4 – 26) had transitioned early to adult HIV care services and 26 (90%) (95% C.I 74 – 96) were still receiving care at the Pediatric HIV clinic. Of the 67 adolescents/youth in age group of 19 – 24 years, 45 (67%) (95% C.I 55 – 77) had transitioned to adult HIV clinic and 22 (33%) (95% C.I 23 – 45) had failed or were not ready to transition. Of all the study participants, 48 (50%) had not transitioned. Of the 48 (50%) who had transitioned, 3 (3%) had transitioned before

18yrs of age, 11 (12%) had transitioned at appropriate age between 18 – 20yrs and 34 (35%) had delayed transition between 21 – 24yrs of age.



**Figure 5.5 Transition status of all study participant enrolled between 15-24yrs (N=96)**

**5.2.1 Timing of Transition: Early, Age Appropriate or Late/delayed Transition between age 15 – 24 years**

Among the 48 adolescents/youth who had transitioned, we categorized them into those who transitioned early (before the age of 18 years), at appropriate age (> 18 – 20 years) and late/delayed (at age 21 – 24yrs). We found that 3 (6%) (95% C.I 2 – 17) transitioned before the age of 18 years (early transition), 11 (23%) (95% C.I 13 – 37) transitioned at the appropriate age of between 18 – 20 years and 34 (71%) (95% C.I 57 – 82) had delayed or late transition between 21 – 24 years.

**5.2.2 Sub-set Analysis, Adolescent/Youth age 18 years and above**

We then restricted our analysis to the sub set of adolescents/youth who i.e. had achieved the age of 18 years and above and should have therefore transitioned to adult HIV care services.

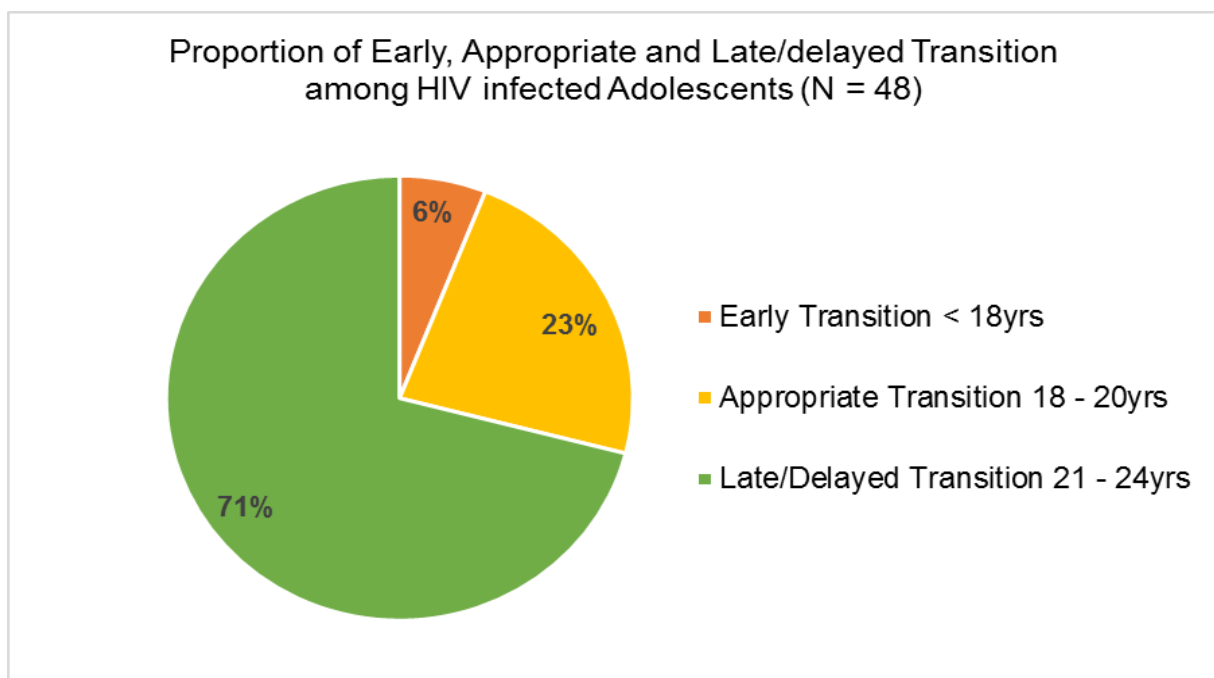
Sixty-seven of our enrolled study subjects had attained the age of 18 years and above. Forty-five (67%) (95% C.I 55 – 77) of the 67 adolescents/youth had successfully moved to the adult HIV services and 22 (33%) (95% C.I 23 – 45) had not transitioned. Twenty-nine of

the study subjects were below the age of 18 years and of these only 3 subjects (10%) (95% C.I 4 – 26) had transitioned < 18 years.

The age at which they transitioned varied as follows: (denominator 48 transitioned adolescents/youth)

- Appropriate age (18 – 20 years) – 11 adolescents/ youth (23%) (95% C.I 13.3 – 36.5)
- Early age at transition (< 18 years) – 3 adolescents/ youth (6%) (95% C.I 2.1 – 16.8)
- Late/delayed age at transition (21 – 24 years) – 34 adolescents/youth (71%) (95% C.I 56.8 – 81.7) (Figure 5.5)

We therefore found that among the adolescents/youth who had attained the adult age, the prevalence of age appropriate transition was 23% (95% C.I 13.3 – 36.5)



**Figure 5.6 Proportion of Early, Appropriate and Late Transition among HIV infected Adolescents/Youth (N=48)**



### **5.3 Objective 2: Barriers and Facilitators to Transition to adult care services among HIV infected adolescents/Youth**

#### **5.3.1 Adolescents/Youth Questionnaire findings regarding experiences around transition to adult care services.**

In the following section of result's, we report quantitative findings obtained during individual adolescent/youth interviews using a structured questionnaire (FGD's shall be presented in a later section of results).

We interviewed 48 adolescents/youth who had successfully transitioned to adult HIV care services. Most participants portrayed feeling of being caught off guard for transition and depicted uneasiness and specific worries amid the process of transition. The respondents reported that the moving out was overpowering, and to express their feelings they used words like: "being scared," "a shock," and "don't know what to expect" to describe first hearing about transition.

Of the 48 HIV infected adolescents/youth who had transitioned, 26 (54%) (95% C.I 40.2 – 67.4) adolescents/youth reported it was easy to transition to adult care services and 33 (69%) (95% C.I 54.6 – 80) reported moving to adult care was as expected because the pediatric and adult clinics were in the same center. When asked how they felt during transition, 3 (6%) (95% C.I 2.1 – 16.8) reported the felt scared, 8 (17%) (95% C.I 8.7 – 29.5) were excited to move, 25 (52%) (95% C.I 38.3 – 65.5) expressed that they were not sure what to expect when transitioning, 6 (12.5%) (95% C.I 5.8 – 24.7) were looking forward to moving and 6 (12.5%) (95% C.I 5.8 – 24.7) did not want to move to adult clinic.

Majority 47 (98%) (95% C.I 89 – 99.6), reported they were never oriented to the adult care services nor introduced to the adult physician during transitioning. Though 46 (96%) (95% C.I 86 – 99) said they did not have difficult time being adherent to the ARV treatment during and after transitioning. Twenty-seven (56%) (95% C.I 42.2 – 69.3) were linked to the support group services but 34 (71%) (95% C.I 56.8 – 82) adolescents reported that these services were not beneficial to them and had difficult time finding a stable support system in the health facility.

The barriers that were found were lack of orientation to the adult care services and introduction to an adult clinician during the process of transition. Secondly, though the adolescents/youth were linked to a support group but they did not find it to be beneficial. Thirdly, the adolescents/youth expressed their feelings regarding transition, majority expressed feelings of uncertainty of not sure what to expect when they were being transitioned this could be explained due to poor preparedness on transition.

On the other hand, the facilitators were that the pediatric and adult clinics were in the same center so it was easy to transition as the site was familiar to the adolescents/youth. The adolescents/youth that function independently and were peers in their support groups or in the society successfully transitioned to adult care services. The health care workers and adolescents/youth also stated that early preparation to transition was a major facilitator to successful transition.

**Table 5.4 Experiences of HIV infected adolescents/youth who transitioned to Adult care services (N=48)**

Characteristic	Detail	N (%)
Transition to adult care	Difficult	26 (54)
	Easy	22 (46)
Was the moving to adult care As expected	More difficult than expected	33 (69)
	As expected	15 (31)
Adolescents/Youth feelings during transition	Scared	3 (6)
	Excited	8 (17)
	Not sure what to expect	25 (52)
	Looking forward to it	6 (12.5)
	Didn't want to leave	6 (12.5)
Orientation to adult clinic	Yes	1 (2)
	No	47 (98)
Difficult time taking medications as instructed and being adherent	Yes	2 (4)
	No	46 (96)
Having more health needs or complications	Yes	3 (6)
	No	45 (94)
Linked to support group services	Yes	21 (44)
	No	27 (56)
Benefit from support services	Yes	14 (29)
	No	34 (71)

### **5.3.2 Support Services Given by Health Care Team Relevant to Transition**

Of the total 96 adolescents/youth interviewed, 45 (47%) (95% C.I 37 – 57) confirmed during the study time that their health care provider had never communicated to them about moving from pediatric clinic to adult care services. This was significant with a p-value <0.0001 from a chi square test (Table 5.5). Eighty - one (84%) (95% C.I 76 – 90) were linked to the adolescent/youth support groups. Of the 48 HIV infected adolescents/youth who had transitioned to adult care services, 9 (19%) (95% C.I 10 – 32) had not been linked to or did not know about the adolescent/youth support group services at CCC.

Of the 96 adolescents/youth, 38 (40%) (95% C.I 30 – 50) reported that the discussion on transition was just done once by health care worker mostly by the psychologists. Thirty-one (32%) (95% C.I 24 – 42) reported that they had never been told about transition of which 21 (68%) were still in pediatric care and 10 (32%) had transitioned to adult care services without ever being told about transition. This was a significant barrier that came out clearly; lack of communication by HCW's on transition, majority of adolescents reporting having just been told once on transition.

**Table 5.5 Transition of HIV infected adolescents/youth from pediatric to adult clinic (n=96)**

	Transition status			p-value
	Not transitioned	Transitioned	Total	
	n (%)	n (%)	N (%)	
<b>Communication by HCW to adolescents/youth on transitioning</b>	20 (42)	31 (65)	51 (53)	<b>&lt;0.0001</b>
Yes				
No	28 (58)	17 (35)	45 (47)	
<b>Linked to an adolescent/youth support group</b>				
Yes	42 (88)	39 (81)	81 (86)	0.588
No	6 (12)	9 (19)	15 (14)	
<b>Frequency of Discussion on transitioning by HCW</b>				
Every clinical checkup	2 (4)	0	2 (2)	-
Individual counselling sessions	2 (4)	8 (17)	10 (10)	-
Adolescent group session	4 (8)	11 (23)	15 (16)	0.96
Just talked once	19 (40)	19 (40)	38 (40)	0.06
Never	21 (44)	10 (21)	31(32)	-

### 5.3.3 Adolescent/Youth Focused Group Discussion

#### *a. Characteristics of Adolescents/youth in FGD's*

We identified adolescents and youth for inclusion into six FGD's, A to F. The groups constituted to separate

- i) Those who had successfully transitioned from those who had not transitioned
- ii) Place those of similar age group together due to maturity level at different ages

A total of 48 participants were invited for the six groups, 38 (79%) came on the proposed group discussion date enabling us to proceed with the FGD's for groups A – E. (Table 5.6). Adolescents/youth for FGD F did not turn up on the proposed date and therefore were unable to do their FGD.

Of the 5 FGD's that were conducted with a total of 38 adolescents/youth, 58% (22) comprised of female adolescents/youth. Out of all FGD's, Group C that consisted of adolescents/youth who had not transitioned between the ages of 21-24yrs had turned up in large numbers (11 adolescents/youth) for the discussion compared to any other group and gave their insights on transitioning which was very valuable.

**Table 5.6 Characteristics of Participants of Focused Group Discussion (N=38)**

Group	Transition Status	Age group	Sex	No.	Total No (N=38)
Group A	Not transitioned	15 – 17yrs	Female	5	8
			Male	3	
Group B	Not transitioned	18 – 20yrs	Female	4	7
			Male	3	
Group C	Not transitioned	21 – 24yrs	Female	6	11
			Male	5	
Group D	Transitioned	19 – 21yrs	Female	4	6
			Male	2	
Group E	Transitioned	22 – 24yrs	Female	3	6
			Male	3	

**b. Findings from Focused Group Discussions**

The focused group discussions were recorded using a tape recorder and taking notes and the data was analyzed by reading the transcripts numerous times to identify major themes. Interview responses were partitioned by question and independently coded by the principal investigator and a research assistant for cross verification. There were multiple readings and reviews of focused group discussion responses, which were transcribed verbatim and analyzed which were then reported in form of themes and quotes.

**Table 5.7 Adolescent/Youth FGD's Findings with Emerging Themes**

<b>Barriers: Emerging Themes</b>	<b>Factors</b>
<ol style="list-style-type: none"> <li>1. Difficulty in letting go</li> <li>2. Stigma</li> <li>3. Lack of support from families/ peers and HCW's</li> <li>4. Difference in care between pediatric and adult clinic</li> <li>5. Poor preparedness on transition</li> </ol>	Patient Clinician bond Patient psychological factor Interpersonal relationship / socio economic Health system/ Health Care Worker factor Health system/ Health Care Worker
<b>Facilitators: Emerging Themes</b>	<b>Factor</b>
<ol style="list-style-type: none"> <li>1. Function independently</li> <li>2. Transition as a group</li> <li>3. Early preparedness to transition</li> </ol>	Patient Patient / Social Health care worker/ Health system
<b>Cross cutting issues/ Common Themes</b>	<b>Factors</b>
<ol style="list-style-type: none"> <li>1. Difficulty in letting go</li> <li>2. Poor preparedness to transition</li> </ol>	Patient Clinician bond Health system/Health Care Worker

## **BARRIERS TO TRANSITION**

Findings of this study found many barriers from the perspective of HIV infected adolescents/youth. The most common themes that emerged during the FGD's to being barriers to successful transition to adult care included fear of the adults in the clinic leading to stigma and trouble in relinquishing long standing relationships with their friends and providers. These common themes that emerged during FGD's are emphasized below with quotes:

### **1. Difficulty in letting go**

All adolescents/youth described having a challenge in ending their relationships with the pediatric health care worker in view of having developed a sense of a strong bonds like having an extended family within the Pediatric clinic. Relationships had been built on working together over many years in circumstances that were challenging, emotional, and even isolating because of the associated stigma.

*Responses from Adolescents/youth during FGD's:*

"...well it is because of fear of decision making, someone do not know how difficult it is to let go of your friends at the pediatric and you go and you are alone now in the adult clinic so it is kind of hard to make new friends."- FGD E, Female 24yrs: Transitioned

Adolescents/youth depicted positive traits of their current clinicians which could not be normally expected in a new clinical setting. They expressed that their pediatric clinicians offered a non-pressurized surroundings and expected that the adult physicians would not provide the same. As one adolescent described, "*..It is hard considering the bond that we have now because like for me now I have been here for years, I have been coming here since I was young so now telling me to move to the other side, seeing other faces, other doctors, pharmacists are different, everyone is just different it is kind of hard because I am already used to this side, some friendship has been formed and you know when you have a problem you know you can talk to this person and in adult I cannot trust that person so telling me to move to the adult side is like forcing me..*"- FGD C, Male 24yrs: Not transitioned

### **2. Stigma**

A few participants associated the adult clinic with stigma. This was due to being judged by the adult patients attending the adult clinic because they thought the adults would wonder why are they here and how did they get HIV at such a young age and hence look at them as though judging them.

*Responses from Adolescents/Youth during FGD's:*

*"It is uncomfortable, we have been peers so that is why I have been opposing this whole thing of transitioning because when you go there they are not your peers first so there is this mentality of she is coming here and she is young so they look at you sideways and it is very uncomfortable. That is what I think I will be very uncomfortable so I will try and sit with my peers those I know and not those I don't know"- FGD C, Male 24yrs: Not transitioned*

Another adolescent/youth stated; *"there is a fear of being judged on the other side because when we are together we are a bit much better in accommodating each other"- FGD B, Male 20yrs: Not transitioned*

An adolescent/youth who had transitioned to the adult clinic reported an experience she had while attending the adult clinic she said; *"To me I personally hide myself because I don't want to be seen by someone I know... there is a day I came put my card there I bumped into one of my neighbors and I don't want to be seen because you know people can go and bully you so if I have been put to adult people I don't know the way I will survive because I really don't want to be bullied."- FGD E, Female 24yrs: Transitioned*

Most adolescents/youth stated that, due to this they had difficulty communicating and bonding with the adults. *As one adolescent/youth said; "for me I think it is not good because when we are here it is free, we are free to talk to anyone how you think you feel but when you are there it is rare to talk to a woman of forty-five and above."- FGD B, Female 21yrs: Not transitioned*

### **3. Difference in care between pediatric and adult clinicians**

Adolescents described pediatric health center as more youth friendly, with vibrant support groups and the health care providers as an extended family. Thus, adolescents/youth perceived adult clinics as boring which had more sicker patients, more overt HIV related stigma and unfriendly staff.

*Responses from Adolescents/youth during FGD's:*

*"Adult clinicians have a bad attitude ...because you see our doctors in pediatric clinic we interact with them very well, they don't have attitudes, they are very happy and all that, they don't judge you but the rest once you just get in to that room they are like aah, even when you just... they ask you a question like okay do you have a boyfriend, and then you are like no, wacha kundanganya niambie ukweli hukutumia protection, you see such things and then when you are there you are being tried and all that and maybe it is a male who is in charge*

*that day and then you are asked uliona damu yako ya mwisho lini, there is an attitude in which you can ask a person a question and I get to answer you, there is no way you will ask me do you have a boyfriend and I can tell you yes". – FGD E, Female 24yrs: Transitioned*

Another adolescent/youth said; *"Adult clinicians don't understand the adolescents, ...it is just they don't know how to relate with us, the same way they talk to grownups the same way they talk to me". – FGD D, Female 21yrs: Transitioned*

*"Lack of encouragement and support in adult clinic, I would not be comfortable because there isn't a lot of encouragement and support group on the adult side." – FGD C, Male 23yrs: Not transitioned*

#### **4. Poor preparedness on transitioning**

Most adolescents/youth during the FGD's reported that their provider had not discussed or communicated to them on the topic of transitioning and hence were not prepared on what to expect when they transition to adult clinic. On the other hand, some of key informants especially the doctors and nurses said they were not aware of any transition criteria checklist at their clinic site and only the counsellors used the transition checklist to see whether the adolescent was ready to transition or not. Therefore, there is a gap in terms of communication and preparing adolescents/youth for transition among health care providers.

*Response from Adolescent/Youth during FGD's:*

*"No, I have never been told by a doctor, no one has ever mentioned that to me, none not even the doctor or the counsellor, no one yaani and I don't know why?"- FGD B, Male 21yrs: Not transitioned.*

#### ***FACILITATORS TO TRANSITION***

Different factors were identified during discussions as facilitators to successful transition of HIV infected adolescents/youth to adult clinic. HIV infected adolescents/youth described facilitators which included emotional development alongside the capacity and motivation to function freely. Also, transitioning as a group rather than individually was described as a facilitator for transition by the adolescents/youth.

The common themes that emerged as facilitators were as follows:

## **1. Transition as a group**

Most of the adolescents/youth described transitioning as a group as a facilitator to successful transition because when they transition as a group their friendship bonds are maintained and are not alone in the adult clinic.

*Response from an Adolescent/youth during FGD's:*

*"Transitioning as a group, will make it easy, if we move as a group and a day we have like Friday is for twenty to twenty something, I think that will be a bit easier because we will not have the fear of being judged because when we are together we are a bit much better in accommodating each other". – FGD C, Male 24yrs: Not transitioned*

## **2. Early preparation to transition**

Early preparation to transition was stated as a facilitator by the adolescents/youth. Most of the adolescents/youth described that if the process of transitioning started as early as after full disclosure is done, it would make transitioning much easier when they reach the age of 19yrs.

*Responses from Adolescents/youth during FGD's:*

*"I think we need to be told about transitioning at an earlier age maybe fourteen or even after disclosure of HIV status, so that I am well prepared once it's time to move to the adult side". - FGD A: Male 17yrs: Not transitioned*

## **4. Function Independently and take ownership of care**

Adolescents/youth during discussions described those who were self-reliant and independent and peers in their support groups who had shown leadership qualities were found to most likely to transition successfully. The adolescents/youth had sense of responsibility, life care skills and provided support to their age mates who were struggling with issues like stigma and missed appointments.

*Responses from the Adolescents/youth During FGD's:*

One of the adolescent/youth from the FGD group C stated; "... *the adolescents transitioned at the age of twenty-eight or thirty when they are much older it would be easier because by then they are independent, stable and are now responsible adults and able to make their own decisions*"- FGD C, Male 24yrs: Not transitioned



### 5.3.4 Health Care Worker Key Informant Interview

#### a. Characteristics of Key Informant Interviews.

We approached 15 HCW's in CCC and invited them to participate as key informants. Out of those approached 11 (73%) were successfully interviewed. The HCW's were of varying disciplines with at least six months experience of working with HIV infected adolescents and youth; The key informants consisted of clinicians 2 (18%), nurses 2 (18%), counsellors 2 (18%), psychologists 2 (18%), social workers 2 (18%), and pharmacist 1 (10%) working at the CCC. Of the 11 KII conducted, 82% (9) were female health care workers and majority of these HCW's were working in the pediatric CCC. The median years of having worked with the adolescents/youth was 3.2 years [IQR 1 – 6 years]

**Table 5.8 Characteristics of Key Informant Interviews of Health Care Workers (N= 11)**

Designation	Work Station	Age	Sex	Duration worked with adolescents	Total
Medical Doctor	Pediatrics	43yrs	Female	3 years	2
	Pediatrics	38yrs	Male	3 years	
Pediatric Clinical officer	Pediatrics	43yrs	Female	6 years	4
	Pediatrics/ Adult	32yrs	Female	1 year	
Nurses	Pediatrics	48yrs	Female	5 years	
	Pediatrics/ Adult	40yrs	Female	3 years	
Counsellors	Pediatrics	43yrs	Female	6 years	4
	Pediatrics/ Adult	32yrs	Female	1 year	
Psychologists	Pediatrics	46yrs	Female	2 years	
	Pediatrics / Adult	35yrs	Female	3 years	
Social Workers	Pediatrics	41yrs	Female	4 years	2
	Pediatrics/ Adult	49yrs	Female	2 years	
Pharmacist	Pediatrics	44yrs	Male	5 years	1

#### b. Health Care Worker Key Informant Findings

Every respondent concurred that transition to adult clinic services was an essential issue that was expanding in urgency as HIV infected adolescents/youth moved towards the age of 18 years. They additionally underlined the significance of consistent transition to maintain care continuity and well-being (e.g. viral load suppression) for HIV infected adolescents/youth. We found many barriers and facilitators to transition among HIV infected adolescents/youth from the perspective of health care worker. The common themes that emerged during the KII's were as follows with quotes:

## **BARRIERS TO TRANSITION**

### **1. Difficulty in letting go**

The health care workers, each one conveyed a sense of challenging in ending their association with the adolescents and having formed a bond that had been built on working together over many years in circumstances that were challenging, emotional and even isolating because of the associated stigma. All HCW's reported that they have walked with the adolescents/youth through each step of their life and are treated as their own children hence finding it difficult in letting go of them to adult care services.

#### *Responses from Health care worker during KII's*

The health care providers also mentioned difficulty of letting go as a barrier to transition as indicated in the following statement: *" there is a Fear among Health care providers in pediatrics side that the adolescents/youth will not make it when alone, then of course the other one is from the health care provider point of view you fear that once now the guardian is not there, the parent is not there and you are also not there since you have been with them for many years, you feel as if they cannot continue on their own so you also fear sometimes."* - KII, Pediatric Counsellor

Another health care worker stated; *Strong ties among themselves have formed over the years so you see they are used to staying together here so if you separate like one or two of them they feel like aah why are we been separated from our friends so they find it hard and they feel like they want to stay with their friends just in the same youth clinic.* - KII, Paediatric Clinician.

### **2. Stigma**

Some health care workers reported stigma especially from the adults receiving care at the adult HIV clinic contributing to one of the barriers to transition among HIV infected adolescents/youth. Adolescents/youth at the age of transition brought this issue during the adolescent/youth support groups, and fear to move due to the hostile environment in the adult clinic.

#### *Response from Health Care Worker during KII's:*

This issue of stigma also came out very clearly in the interviews with the health care providers and one key informant stated: *". they are also facing stigma from the adults; where did you get this HIV and you are still young, when they want to ask questions in support groups about sexuality they are being asked why do you want to get a baby? Do you want to*

*have a boyfriend and you are HIV positive? So, such, I am not quite sure how to put this but they fear the adults do not understand them, they look down upon them and it is like they don't want the youth to live as normal people, you know things to do with sexuality, getting babies and those kinds of things so they don't want to mix with the adults". – KII, Pediatric Pharmacist*

### **3. Difference in care between Pediatric and Adult clinics**

All health care workers described how the clinical environment influenced efforts to link, retain and transition adolescents. They described pediatric clinic's more vibrant with the level of support provided and more youth friendly. Pediatricians are more engaged with families, and provide with appropriate care with significant parental inclusion in decision making with a multi-disciplinary approach. On the other hand, the adult clinic provides individual based care with strong focus on treatment and adherence and one is expected to be more self-reliant.

*Responses from Health Care Workers during KII's:*

*One of the key informants stated that; "The services don't meet the needs of the adolescents, there is too much seriousness in the adult clinic, it is boring, I mean the services don't deliver what they expect, the services are not meeting their needs and that is why earlier I had said it is important even as we transition if we are able to train the health care providers to understand the adolescent transition to adulthood so that they can be able to manage them appropriately in meeting their needs." – KII, Pediatric Nurse*

*The other key informant said, there was lack of vibrant support groups in adult clinic; "...so there are those who transition who actually did not want to join the adult support group so some of them are still coming to pediatric side just because of the support services they receive here, the support group for example is not as vibrant as the adolescent group so that is one of the challenges even when transitioning these adolescents"- KII, Counsellor*

*One of the HCW said, "the way the systems work the other side; in the adult side, there is a lot of queuing, you know here in the Pediatric clinic; this side there is no queuing they just stay in a room where they are entertained with music, they dance but the other side they just sit there, they also find it is like they are in a prison sort of, they don't feel free"*

### **4. Poor preparedness with abrupt transfer**

Majority of the HCW's reported there was lack of or poorly coordinated process to transition adolescents/youth. Some of the issues included were no written plan, poor communication mechanisms between pediatric and adult clinicians and no formal health care team

responsible for the transition. After adolescents/youth are transferred there was no proper documentation on the number of adolescents/youth transitioned and if any have dropped out after transitioning to adult clinic. Some adolescents/youth were abruptly transferred to adult clinic with no form of preparedness after they fell pregnant.

*Response from Health Care Worker during KII:*

The key informant reported; *“There is no such guideline or criteria, not that I know but I participated in an online training on the same on evaluation on transition so I only know on that area but not a plan on this place or maybe it is there with the psychologists who use it.”*

– KII, Pediatric Doctor

One HCW responded, *“there exists no specific guidelines, and we don’t specifically use any sort checklist because we do not have one that helps us to transition our adolescents to adult side”* – KII, Psychologist

## **FACILITATORS TO TRANSITION**

### **1. Functioning independently**

The health care providers during discussion described being independent and responsible as main facilitator to transitioning. These included, able to come to the clinic alone, making appointments, coming for re-fills of medications, seek medical attention when needed.

*Response from Health Care Worker during KII:*

During the key informant interview, one of the providers reported that, *“I think for a smooth transition you find that most of those adolescents are independent already, independent in managing their own affairs and they don’t rely much on the parents or peers, those ones transition comfortably, in fact we have some in the adult care and they are doing well. You see after twenty-four years some of them feel that they are mature enough and they don’t need to stay with the young ones here so they want to feel that they are responsible for their own health so they feel it is good if they are seen on the other side with the adults”*. – KII, Counsellor

### **2. Support from caregivers and health care providers.**

The support from parents or caregivers and health care providers was mentioned mostly by the key informants as a facilitator to transition. Some of the statements made were as follows by the key informants during the interviews:

*“I think also the socialization, the social environment where they are coming from that is their families that is where there is enough support unlike those who are not well supported transition is hard from where they are staying, the social environment in the family, it plays a part because when we are trying to explain about the transition and also the parents and the relatives they are not stigmatizing them they are also supporting us you find such children they transit smoothly unlike those who are having barriers of where they are coming from and also there are issues in the clinic.” – KII, Social Worker*

The other key informant stated; *“Attitude of the health care provider towards the adolescents is important, if the health care provider has a positive attitude towards this so the way we receive and give information to these adolescents would make them feel they want to perceive this care even to transition to the other side of the adult clinic more positively”.* – KII, Pediatric Doctor

### **3. Qualities of leadership**

The key informants mentioned that those adolescents who showed some qualities of leadership or were peers in adolescent’s support groups transitioned smoothly due to having abundance knowledge and sense of maturity. Below are a few statements made by health care workers during the key informant interviews:

*“...apart from independence probably people with leadership qualities transition smoothly because you find that during adolescent support groups there are normally health talks when they come on the clinic day and during those health talks opportunities are given to the adolescents to share so there are those who are bold enough to be able to want to share their experiences with others.” – KII, Counsellor*

### **4. Early preparation to Transition**

All health care workers agreed that when the process of transition starts early after fully being disclosed of their status, adolescents/youth transition smoothly to adult care with the understanding of their disease and how to seek for medical attention when sick. This was described as the main facilitator to transition, as adolescents/youth are more likely to be retained in the adult clinic without being lost to follow up.

*Responses from Health Care Workers during KII’s:*

*One key informant stated “Their [adolescents] psychological status needs to be established before transitioning them because these are people who need to have been talked early may be immediately after disclosure on transition at a level that they understand and are ready to*

move and are not been forced in any way. Moving to adult care is healthy for the continuity of care of this adolescent – KII, Pediatric Nurse

Another HCW said “...for example to combat the challenge of change first there is information, before you transition someone you take them through a process; transit. You equip them with knowledge so that they know if I go to the adult clinician what do I expect, you know what to expect so at the end of the day it becomes easy. If you know it, then it is easy to do it. It will be easy to transition if the process is started much earlier like when they are 14 or 15 years old” – KII, Counsellor

**Table 5.9 Summary of KII findings: Factors impacting HIV infected Adolescent/Youth Transition**

<b>Health system Factors</b>
<p><b>Barriers: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Difference in care between pediatric and adult care services</li> <li>2. No clear guidelines/protocol for transitioning</li> <li>3. Poor or absent institutional support</li> </ol> <p><b>Facilitators: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Early preparedness to transition</li> </ol>
<b>Health Care Worker Factors</b>
<p><b>Barriers: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Difficulty in letting go</li> <li>2. Poor communication on transition</li> <li>3. Abrupt transfer with practically no earlier preparation</li> </ol> <p><b>Facilitators: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Providing support to HIV infected adolescents during transition process</li> <li>2. Transitioning adolescents as a group</li> </ol>
<b>Patient Related Factors</b>
<p><b>Barriers: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Stigma</li> <li>2. Difficulty in letting go</li> </ol> <p><b>Facilitators: Common Themes</b></p> <ol style="list-style-type: none"> <li>1. Function Independently</li> <li>2. Leadership qualities</li> </ol>

## **5.4 Suggestions on Improving Transition Process with Possible Solutions.**

### **5.4.1 Suggestions from the Adolescents/youth:**

Participants were then requested to provide with recommendations on the best ways of improving the transition process. The following themes emerged which included: to have adult clinic to be youth friendly, early preparation to transition, involve the adolescents/youth in decision making. Specific comments made by the adolescents/youth on recommendations during focused group discussions were as follows:

*“if it is a clinic for youths let it be a clinic for youths, no kids and no adults because I remember there is this time they introduced us to be coming on Friday, they said it was a youth day and everyone was here so if it is a Friday for us it is for us only” – FGD C, Female 24yrs: Not transitioned.*

*“first of all I would say we are growing up and eventually one day one time we will be adults and people will be complaining not wanting to sit with us over there but if the clinic is going to be made in a more friendly way in that the people who are going to come the day of the clinic are not sixty year old or fifty year old, forty year at most maybe a thirty year old should be here in that I don’t have to have that torture seeing a sixty year old who has come he is bedridden or he is in a wheelchair he cannot control the way he is passing his urine maybe or maybe he has a certain problem and then I sit there and say to myself so one day one time I am going to be like that so it is going to torment me so if they are going to make the clinic in a much more friendly way at least thirty year old no forties, fifties, sixties”- FGD E: Female 24yrs: Transitioned*

*“We are the ones who are transitioning therefore should be involved in the decision-making process of whether to transition or not and if I am ready to move I shouldn’t be forced to transition”- FGD C: Male 22yrs: Not transitioned*

*“I said that maybe from the age of seventeen eighteen there we should be told that at this age you will have to move from here to there and they tell you why it has to happen. They prepare you psychologically so that once the right time comes you are totally ready”- FGD B: Male 19yrs: Not transitioned*

### **5.4.2 Suggestions from health care workers**

The health care workers suggested to have a structured process or criteria for transition and continued training of HCW’s on transition and adolescent care. The following recommendations were made by the HCW’s during the key informant interviews:

*“maybe a structured way of transitioning them is also very important because they will not be transitioned by everyone in the clinic at least now it needs to be a duty of specific people if it is the counsellors, the psychologists or social workers”- KII, Paediatrician.*

*“maybe sensitizing the staff more about being more youth friendly even in how they ask their questions. You know for an adult you can ask a question like are you sexually active or your last menstrual period for some adolescents they may feel shy about how direct the question is so it has to be a bit friendly and sensitive so that they open up more so the attitude and the youth clinic, I think it would help”- KII, Counsellor*

*“...we have a protocol that was done within, everyone should be taken through that, everyone should have the checklist or the protocol on transitioning so that we can read from the same page and it becomes very easy so that you don't just guess on what to do but you know what to do”- KII, Counsellor*

*“I think it is very important that you train a few of them on transition because basically this is a group that has enjoyed adolescent services and so it is important as we transition we are not saying they have come to the end of adolescent but it is transition, it is important that even the health care providers receive information that can enable them to walk with these adolescents in this transition appropriately enough for them to be retained in the adult care”- KII, Psychologist*



**Table 5.10 Potential Solutions – Suggestions Given by Adolescents/Youth and Health Care Workers on Transition**

Area/ Issue	Solution	Source
<b>Health system / HCW Issues</b>		
Poor Preparedness and communication on Transition	Early preparedness to transition and involve the adolescents/youth in the process of transition.	HCW and Adolescents/Youth
Hostile Adult care services	Need for more youth friendly clinics	Adolescents/Youth
No clear protocols/ guidelines on transition at the clinic site	Develop clear local guidelines and train HCW's on transition process	HCW's
<b>Patient Issues</b>		
Difficult of letting go of friends and pediatric HCW's	Transition as a group to adult clinic to give support to each other.	Adolescents/Youth and HCW's
Stigma and intimidation when with adults in the adult clinic	Address this issue, during support groups and create more tolerance and awareness towards each other and build strong relationships among adolescents/youth and adults attending the adult clinic.	HCW's

## CHAPTER 6: DISCUSSION

This study determined the proportion of HIV infected adolescents/youth transitioning to adult clinic and explored the barriers and facilitators to transitioning. As far as prevalence of appropriate age of HIV infected adolescents/youth to transition is concerned, this is the first study in Kenya. Our results specifically highlight's the barrier and facilitators on transitioning. Despite that transition distinctly relies on individual patient attributes, concurrent transitions for example evolving independence (e.g. coming to the clinic alone, making their own appointments, employed), schooling (e.g. secondary schooling to university) and difference in peer connections influence transition (Philbin et al, 2014, Fegran, Hall, Uhrenfeldt, Aagaard and Ludvigsen, 2014). In this manner, the key strategy of transition to adult care should be regarded as a process as opposed to a onetime event.

### 6.1 Age appropriate transition among HIV infected adolescents/youth

The proportion of age appropriate transition at 19 +/- 1 year among HIV infected adolescents/youth from pediatric to adult clinic in this study was found to be 23%. Of the 48 adolescents/youth who had transitioned, 11 (23%) had transitioned at an appropriate age of 18-20yrs, 34 (71%) had delayed transition between the age of 21 – 24yrs and 3 (6%) had an early transition less than 18yrs to adult care services. The adolescents/youth who did not transition by the age of 19 years, 22 (33%) were found that they were mentally unprepared to move, did not know what to expect, were afraid of losing their friends and of losing the relationship and bond which had been developed with their clinicians over years. Some said that they were not communicated on transition by their health care provider. And of those who had transitioned, most of the adolescents/youth reported that they were struggling in finding support services in the adult care services. This was because in the adult center everyone seems to be more responsible and mature and adults were not very accommodating to the adolescents and this lead to communication gap and stigmatization. The adolescents/youth who were found to have transitioned early, became pregnant and had to transition to adult care services without any preparation or receiving any form of psycho-social support.

After an extensive literature review, no studies were found to compare the prevalence results from this study. This is the first study that looked at the prevalence of age appropriate transition among HIV infected adolescents/youth. Though there were nine articles that identified the appropriate timing of transitioning to adult care services. Of these, eight articles stated that appropriate timing to transition related to their chronological age which took place around mid-teens and in early twenties (8,41,46,47,48,49,50,51). Others are of the view that the timing of transit ought to not depend on chronological age, but rather on the level of

responsibilities that each patient takes on and maturity (41,51, 52). Four studies demonstrated that transition happens around the age of 18 years, or in the wake of graduating from secondary school, to 19 years (41,48,53,54). The rest of the studies reported more noteworthy delays with adolescents transitioning into their early twenties (55). This was consistent with what our study found, most (71%) adolescents/youth transitioned in their early twenties to adult HIV clinic which was considered delayed/late transition.

## **6.2 Adolescent/Youth experiences on Transition: Barriers and Facilitators**

Our study confirmed that the adolescents/youth often regularly encounter the moving out a challenging period, because transferring to adult care suggests going into a new and totally different clinical setting and acclimatizing to the new surroundings while departing from familiar environment and trusted health care providers. Particularly sudden and ill-equipped transition will influence the adolescents/youth as well as the health clinicians.

As for understanding transition, a general theme that came up was the contrast in adult and pediatric ways of providing services, and subsequent difficulty adolescents had in adjusting. Pediatric care setting was easily adaptable in regards to consultations, being provided with constant reminders for missed visits, and receiving their drugs on time. The loss of these services was troublesome for adolescents to adjust as they lacked the tools and adequate preparation prior to moving out. The outcomes of this study were similar to past qualitative investigations recognizing barriers in the transition process (35,42-44), as well as absence of exchanging of information among the providers (45), absence of preparedness (37) and dreading going to clinics with adults (43).

Most talked about barrier to transitioning by the HIV infected adolescents/youth was that stigma plays a significant part in both difficulty in accessing health care and barriers to transition if the adolescents/youth are transitioned to adult care. This finding was consistent with other studies where they found stigma to be a major barrier to transition adolescents/youth to adult clinics. (56,57).

In keeping with the studies in other context, second most reported barrier to the transition was the adolescents/youth had trouble in giving up relationship with the health care provider. The health care providers in the pediatric facility were pleased with the care they rendered in the center, also identified the adolescents were equally attached to the health care providers.

On the other hand, the adolescents/youth stressed the importance of early preparation as early as after disclosure and functioning independently and being mature as a major facilitator to transition. Few studies investigated on appropriate timing to start the training of

pediatric patients with diseases/disabilities regarding the transition process. A couple of studies recommended that between the age of 11 – 12 years which was the early teens was the appropriate period to initiate transition process or at the time of the diagnosis between 10 – 14 years (51,58); on the other hand Sebastian *et al*; in 2012 (48) contended fourteen years and after. This was found to be consistent with other studies done by Fair CD *et al*; 2012 and Miles K; 2004 (30,43)

In this investigation, The adolescents/youth participants gave an understanding into methods of enhancing the procedure to transition, with recommendations that contained expanding readiness for transitioning with expanded obligation before moving out, a time of shared responsibility amongst adult and pediatric providers until point of successful transition has taken place. Postponing transition was also suggested by a few, with an inclination between the ages of 24-30yrs or until judged by both the adolescent and the clinician to be “ready”.

### **6.3 Health Care Workers Insights on Barriers and Facilitators to Transition**

From the healthcare perspective, the primary barrier to successful transition was the lack of, or poorly coordinated transitional planning. Issues included no written plan, absence of correspondence mechanisms among the clinicians, and no formal healthcare team responsible for the transition. These factors were consistently reported across the studies for transitioning of children with chronic diseases such as inflammatory bowel disease, type 1 diabetes mellitus, sickle cell disease, and other chronic illnesses (36). Only a handful of articles currently exist, but congruency was evident in the available studies (44).

In order for transition programs to succeed focus requires to be put on clinicians who provide with these services and build conveyance systems at both the pediatric and adult centers. We found that adult clinicians provided with less emotional and psychosocial support and need to expand patient responsibility, which raises inquiries concerning the quality of a transition friendly adult clinical space and approach provided. The current process of transition needed structure and successful correspondence among clinicians from both sides, pediatric HCW's dreaded they were transitioning the adolescents/youth ill-equipped into judgmental, depersonalized and overburdened space.

The health care workers also mentioned as a main facilitator that when the transition process is started early, they have seen adolescents being more responsible for their own health, start coming to the clinics without their parents, make their own appointments and pick their own drugs. This helps the adolescents to be more confident and can navigate through the complex system easily with good clinical outcomes. Similar findings were also documented by Gilliam *et al.*, 2010 and Miles *et al.*,2004 (41,43)

There is impressive proof in the literature that the procedure of transition is absent in most settings (26). Respondents in this investigation suggest that procedure to transition have a community oriented planning among adolescents/youth and health care providers, be given more time to be ready for transition and help coordinating and linkage to adult HIV services.

The adolescent package of care for Kenya that was published in 2014 for use by the health care providers taking care of these adolescents gave an outline on what should to be considered amid the transition process. The first part is revelation of HIV status is a pre-essential for transition. Our study found that all 48 (50%) of the adolescents who transitioned had been fully disclosed of their status. The second part was to have a transition plan in place, and our study found that there was no transition plan that existed in the CCC making it difficult to transition adolescents smoothly. The third part is to review the client's medical history, encourage them to raise their fears and concerns on their care and medicines and future changes. Our study found gaps in terms of missing data from client's files and electronic data base though most adolescents reported that they received psycho social support from health care providers which addressed their concerns and fears regarding their status and ARV therapy in terms of side effects. The fourth part in the process of transition is to ensure that the adolescents/youth understands medication use and importance of adherence. Our study found during the FGD's that all 38 adolescents/youth new the importance of taking medications and they were aware that this is a life-long treatment and the importance of taking medications and keeping appointments. The fifth part looks at promoting linkages to peer support groups, and our study found that all 96 adolescents/youth were linked to the support groups where they got health talks and they talked freely without any fear with their peers and their experiences. The sixth part was moving out adolescents/youth to adult care in groups of 5 -6 adolescents. Our study found that this was a facilitator to transitioning successfully to adult clinic so that adolescents/youth can support one another. All adolescents/youth recommended this to be implemented when transitioning to adult clinics. The seventh part in the process to transition in the adolescent package of care was to assess the patient readiness before transitioning and our study found during the KII that no tool to assess readiness exists yet in CCC, which is considered to be a barrier as this will tend to not smoothly transition adolescents/youth. The other point in the adolescent package of care for Kenya for transition process is to involve parents and caregivers during the transition process. And our study found there are gaps that exists as not all parents and caregivers are involved during the transitioning process of adolescents. This can be partly explained by that most of the adolescents when they reach the age of 15 years, they start coming alone to the clinic, pick their ARV treatment and make their own appointment. They become more independent when they achieve the age of transitioning

which causes the parents and caregivers not to be a part of the transition process and this can be a barrier to transition as much as the adolescent is independent. It is very important to involve parents and caregivers during the transition process so that they can support this adolescent/youth. Lastly, the need for follow up plan for transitioned adolescents. We found that there is on plan for of follow up that exists in the CCC and so there is no data no whether the adolescents who have transitioned are still being retained in the adult clinic or have been lost to follow-up. This can be considered as a barrier and can have an affect on HIV infected adolescent's health and outcome of their well-being. There is a need to develop a plan to follow up these adolescents after they have transitioned.

#### **6.4 Study Strengths and Limitations**

While this was not a big study and the outcomes may not be generalizable, it is among the first research studies in East African region to document on transition experiences from pediatric to adult care services from point of view of HIV infected adolescents/youth and the health care workers. It's also the only study so far, to document on the prevalence of age appropriate transition among HIV infected adolescents/youth.

Our findings develop on past studies done on barriers and facilitators by featuring particular segments of transition process and preparedness that thwart and encourage successful results, thus identifying imperative areas to focus on various intervention.

The design of this study was a mixed method, so we could triangulate the data obtained in the qualitative with the quantitative data for analysis. The interviews with health care providers at CCC gave further insight on the transition process who have worked closely with the HIV infected adolescents and youth.

The study was limited with missing records from electronic database and adolescents and youth case files. (e.g. WHO HIV staging, CD4 counts). The sample in this study only included adolescents from the age of 15 to 24yrs. Adolescents less than 15yrs were excluded and therefore this study was not a representative of the entire group of adolescents.

This study was conducted in one centre which is situated in an urban area. Therefore, the HIV infected adolescents/youth from other areas especially the rural areas may be under represented as most participants were from within and around Nairobi. Though this limitation however is not expected to significantly affect the outcome given that KNH is a national referral centre and clients come from all parts of the country.

## **6.5 Concluding Comments and Study Implications**

Our study exhibits how challenging the transition process really is, particularly among adolescents/youth infected with HIV. Only one quarter of the HIV infected adolescents/youth could transition at the appropriate age of 18-20yrs. Barriers such as stigma, difficulty in letting go, poor preparedness and lack of communication were clearly brought up by both the adolescents/youth and health care workers during FGD's and KII respectively. Main facilitators for successful transition that were highlighted during the discussions were early transition, functioning independently and transitioning as a group.

This study has some important implications for practice, policy and research. Firstly, the finding that stigma and discrimination against adolescents/youth is an important barrier to transition has an important implication. The impact on practice can be through targeted stigma reduction interventions at the clinic setting provided by the HCW's and during adolescent/youth support groups done by the peers. Moreover, stigma reduction intervention need commitment from government in form of policy statements and there is definite need for more research to find effective ways to fight stigma among the adolescents/youth.

Secondly, the HCW's need to implement the transition readiness questionnaire from the adolescent package of care of Kenya to start early preparation of transition. This will help the HCW's to assess which adolescents are ready to transition and who need more time.

Lastly, Transition is new concept in Kenya and in the field of health, and this has implications on adolescents/youth health outcome if this process is not done well. There is a need to make clear policy on transition and develop a "transition road map" that will be a guide not only for HIV infected adolescents/youth but any adolescent with long standing illnesses transitioning to adult health care services.

## **CHAPTER 7: CONCLUSION AND RECOMMENDATIONS**

### **7.1 Conclusions**

1. In this study, only one quarter (23%) of the HIV infected adolescents/youth transitioned at the appropriate age of 19 +/- 1 year from pediatric to adult clinic and majority transition late. Early transition is rare in our setting.
2. The common barriers to age appropriate transition are stigma and discrimination, poor preparedness and lack of communication among HCW's, difficulty in letting go by both adolescents and HCW's and difference in care among pediatric and adult clinicians
3. The common facilitators to age appropriate transition included: early preparation to transition, transitioning as a group, adolescents/youth who were extraordinarily mature for their age and took responsibility over their care and support from caregivers and HCW's.

### **7.2 Recommendations**

Effectively moving adolescents/youth HIV infected to adult health care settings relies on adequate and effective communication amongst pediatric and adult HIV care teams, readiness of youth and their guardians via particular transition criteria, have a coordinated approach and have good support systems that address stigma, life skills, and other difficulties to growing-up with HIV.

We recommend that the adolescents/youth be engaged in the decision making and be a part of the transition process. This can be a positive thing, as adolescents/youth can suggest on ideas on how they would like to be transitioned and this can help adolescents/youth to support each other during the process. Communication between the HCP and the adolescents/youth be more open on transition.

Evaluation of the transition program at CCC is important so that improvements can be made to better prepare the adolescents/youth for independent management of their HIV infection and thereby success in the long run as they become adults.

The CCC needs to establish a system to identify and track the HIV infected adolescents/youth as they advance through the transition process to assure key bench marks are met and they are not lost to follow up in the wake of transitioning to adult care.

Train regularly the health care providers including adult clinicians dealing with HIV infected adolescents/youth on Adolescent Package of Care in Kenya, which will enable them to handle any issues that pertain to adolescence/youth and be able to use the transition template form to assess and start the process of transition.



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**9: APPENDICES**

**9.1 APPENDIX I: STUDY TIMELINES**

ACTIVITY	MM YEAR	11 2015	01 2016	02 2016	03 2016	04 2016	05 2016	06 2016	07 2016	08 2016	09 2016	10 2016	11 2016	12 2016	01 2017	02 2017
RESEARCH CONCEPT		■														
PROPOSAL DEVELOPMENT			■	■	■											
ETHICAL REVIEW					■	■	■	■								
PRETESTQUESTIONNAIRRE								■								
DATA COLLECTION									■	■	■	■				
DATA ANALYSIS												■	■			
DISSERTATION WRITE UP														■	■	
SUBMISSION OF DISSERTATION																■

## 9.2 Appendix II STUDY BUDGET

Components	Unit of Measure	Duration/ Number	Cost (kshs)	Total (Kshs)
<b>Personnel</b>				
Research Assistant	1	30	1,500.00	45,000.00
Statistician	1			30,000.00
Transport	48	1	200.00	9,600.00
<b>Printing</b>				
Consent Form	1	4	10.00	40.00
Assent Form	1	2	10.00	20.00
Questionnaires	1	6	10.00	60.00
Interview guide	1	3	10.00	30.00
Final Report- Coloured	6	25	10.00	1,500.00
Final Report- Black and White	1	75	10.00	750.00
<b>Photocopying</b>				
Consent Form	142	4	3.00	1,704.00
Assent Form	48	2	3.00	288.00
Questionnaires	96	6	3.00	1,728.00
Interview Guide	5	3	3.00	45.00
Final Report-Black and White	5	75	3.00	1,125.00
Final Report Binding	6	1	500.00	3,000.00
<b>Other costs</b>				
ERC Fees				2,000.00
Training	3	1	500.00	1,500.00
Airtime	48	10	4.00	1,920.00
Batteries for tape recorders	2	1	200.00	400.00
<b>Total</b>				100,710.00

### **9.3 a Appendix III: CONSENT FORM FOR PARENTS / GUARDIANS OF PARTICIPANTS (<18 YEARS) AND ADOLESCENTS/YOUTH ABOVE 18 YEARS**

**STUDY TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

**SCOPE:** The informed consent is for enrolled participants in the study, and will be read to them by the principal investigator or a qualified research assistant before answering the questionnaire.

**Investigator:** Dr. Grewal Gurpreet Kaur (MD) Pediatric Resident, University of Nairobi

TEL: 0733-636614 Email: [preetybains85@gmail.com](mailto:preetybains85@gmail.com)

**Supervisors:** Prof. Elizabeth Maleche Obimbo (MBChB, MMed, FPulm, MPH)

Prof. Dalton Wamalwa (MBChB, MMed, MPH)

Dr. Irene Inwani (MBChB, MMed, MPH)

#### **Part 1: Information Sheet**

**Introduction:** We would like to invite you to take part in this study to determine the prevalence and describe the barriers and facilitators of age appropriate transition among HIV infected adolescents and youth from pediatric to adult care at the CCC, KNH. Many adolescents who were either infected perinatally or behaviorally are now surviving into adulthood due to advent of HAART. It has become very important that the HIV infected adolescents and youth who are surviving are given support. Transition from pediatric to adult care is very important process in this age group for them to continue receiving health care services, maintain good health and be adherent to their medications.

You do not need to decide today whether you will participate in this study or not. Before you decide, you can converse with anyone you feel comfortable with about this study. This consent form may contain words you don't get it. Please stop the principal investigator or research assistant as you go through the information and they will take time to clarify any concerns you might have. If you have questions later, you can call the investigator any time and we shall try and address them.

**Scope of the study:** This study primarily aims to describe what makes transition among HIV infected adolescents easy or difficult when moving to adult care services. This information will help us in making certain recommendations regarding service provision to improve health care services among this age group.

**Procedures:** You will be provided with a questionnaire. You may write your answers on the questionnaire yourself, or it can be read to you and you can say out aloud the answer for the investigator or assistant to write it down. If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. This interview is expected to last about 20 minutes. The information is classified, your name is not going to appear on the forms, only a number will identify you or your child, and no one else except the research investigators will have access to your details.

**Risks:** We are asking you to share with us some very personal and classified information, and you may feel awkward answering some of the questions. You do not have to answer any question if you don't wish to do as such. You do not have to give us any explanation for not responding to any question.

**Benefits:** You shall gain from improved quality of services provided at the CCC because of this study.

**Voluntariness:** The study will be fully voluntary. There will be no financial rewards to you for taking part in the study. One is allowed to participate or pullback from the study at any time. Refusal to take part will not compromise your care in any way.

**Confidentiality:** We won't share data about you to anybody outside of the research group. The data that we gather from this study undertaking will be kept private. Any data about you will have a number on it rather than your name. Just the research team will comprehend what your number is and we will bolt that data up safely secured. It won't be imparted to or given to anybody with the exception of the exploration group who will approach the data.

**Sharing Results:** Nothing that you reveal to us today will be imparted to anyone outside the research group, and nothing will be credited to you by name. The information that we get from this study will be imparted to you and different young people going to the CCC before it is made generally accessible to the general population. Every member will get a rundown of the outcomes.

**Inquiries:** If you have any inquiries, you can ask them now or later. On the off chance that you wish to make inquiries later, you may contact the foremost research team member on the contacts given in this consent form.

This proposition has been reviewed by the Kenyatta National Hospital/University of Nairobi Ethics and Review Committee (KNH/UON ERC) whose task it is to ensure that research participants are protected from any harm. If you wish to find out more about the IRB, contact

The Chairman,

Kenyatta National Hospital/University of Nairobi Ethics and Review Committee

P.O.BOX 20723 Nairobi, Kenya.

*If illiterate:* I have witnessed the precise reading of the consent form to the potential participant, and the individual has had the chance to make inquiries. I confirm the individual has given the consent openly.

*If literate* witness must sign (if possible, this person ought to be selected by the participant and should have no association to the research team). Participants who are illiterate should incorporate their thumb print as well.

**Part II: Consent.**

I have read the foregoing information, or it has been read to me. I have had the chance to make any inquiries and any questions I have asked to have been answered to my satisfaction. I consent willfully to take part in this study

Print Participant Name \_\_\_\_\_ Thumb Print \_\_\_\_\_

Participant Signature \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)



Print witness name \_\_\_\_\_

Witness Signature \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

*(Adolescents under the age of 18 years of age will be required to return a completed and signed informed consent form obtained from parents/guardians in addition to the assent form)*

**Statement by the researcher/person taking consent**

I have precisely perused out the information to the potential participant, and to the best of my capacity ensured that the participant comprehends that a survey will be regulated to the participant. I affirm that the participant was given a chance to make inquiries about the investigation, and every one of the inquiries have been addressed accurately and to the best of my capacity. I affirm that the individual has not been forced into giving consent, and the consent has been given openly and intentionally.

Name of Researcher/person taking the consent \_\_\_\_\_

Signature of Researcher /person taking the consent \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

### 9.3 b APPENDIX III b: Kiswahili Consent Form: Fomu ya Idhini kwa wazazi / walezi wa washiriki (< 18 years) na Vijana juu 18years.

**Kifunguo:** Hii fomu ya kupata idhini ni kwa ajili ya vijana walioambukizwa virusi vya ukimwi katika CCC, Hospitali ya Taifa ya Kenyatta, ambao tunuwakaribisha kushiriki katika utafiti. Jina la mradi wa utafiti wetu ni “vikwazo vya maambukizi na wawezeshaji wa umri sahihi mpito kutoka huduma kwa watoto kwa huduma ya watu wazima miongoni mwa vijana walioambukizwa virusi vya ukimwi katika hospitali ya taifa ya Kenyatta.”

Mimi ni Dk. Grewal Gurpreet Kaur, mwanafunzi katika Chuo Kikuu cha Nairobi kutafuta masomo ya utaalumu katika afya ya watoto. Mimi ninafanya utafiti juu ya, vikwazo vya maambukizi na wawezeshaji wa umri sahihi mpito kutoka huduma kwa watoto kwa huduma ya watu wazima miongoni mwa vijana walioambukizwa virusi vya ukimwi katika hospitali ya taifa ya Kenyatta. Nitakupa taarifa na kukukaribisha kwa utafiti huu. Kunaweza kuwa na baadhi ya maneno ambayo huelewi. Tafadhali uliza na mimi nitachukua muda kueleza. Kama una maswali baadaye, unaweza bado kuniuliza

**Sababu ya utafiti:** Vijana wengi ambao walikuwa ama perinatally kuambukizwa au behaviorally sasa wanaishi ndani ya watu wazima kutokana na tangazo la HAART. Imekuwa muhimu sana kuwa vijana walio na HIV wanaishi wanapewa support. Mpito kutoka huduma kwa watoto kwa huduma ya watu wazima ni muhimu sana mchakato katika umri huu ili kwa wao kuendelea kupata huduma za afya, kudumisha afya njema na kuwa kuendelea na kumeza dawa zao.

**Maandalizi ya utafiti:** Utakuwa zinazotolewa na dodoso. Unaweza kujibu dodoso mwenyewe, au inaweza kusomwa kwa wewe na unaweza kusema kwa sauti kubwa jibu kwa uchunguzi au msaidizi wa kuandika. Kushiriki katika utafiti huu ni wa hiari kabisa. Ni uchaguzi wako kama kushiriki au la. Usipochagua kushiriki bado utapokea huduma zote katika hospitali hii. Unaweza kubadilisha mawazo yako baadaye na kuacha kushiriki hata kama walikubaliana awali. Unaweza kujiondoa katika utafiti huu wakati wowote. Mahojiano haya inatarajiwa kudumu dakika 20. habari ni ya siri, jina lako ni kutokuwa pamoja na kwenye fomu, tu idadi itakuwa kutambua wewe au kijana wako na Hakuna mtu mwingine isipokuwa wachunguzi utafiti na upatikanaji wa maelezo yako.

**Maadhara:** Utafiti wetu haitamthuru mtoto wako.

**Habari** kukuhusu ambayo tutakusanya kutoka mradi wa utafiti huu utakuwa siri.

Mawasiliano: Kama una maswali yoyote unaweza kuuliza hivi sasa au baadaye, hata pia baada ya utafiti imeanza. Kama unataka kuuliza maswali baadaye, unaweza kuwasiliana nami kupitia nambari hizi: 0733-636614.

Nimesoma/ Nimesomewa maelezo haya na nimepewa nafasi ya kuuliza maswali kuhusu hayo maelezo. Nimeidhini kwa hiari kushiriki katika utafiti huu.

Jina la Mshiriki \_\_\_\_\_

Sahihi la Mshiriki \_\_\_\_\_ Tarehe \_\_\_\_\_ (siku/mwezi/mwaka)

Nina uhakika kuwa nimemsomea mwakilishi fomu hii, na kwa kadri ya uwezo wangu nilihakikisha kwamba mshiriki ameelewa.

Nilithibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti nakuyajibu vema kwa kadri ya uwezo wangu. Mimi nathibitisha kwamba mwakilishi hakulazimishwa kutoa kibali

Jina la Mtafiti / Mtu kuchukua kibali \_\_\_\_\_

Sahihi la Mtafiti / Mtu kuchukua kibali \_\_\_\_\_

Tarehe \_\_\_\_\_ (siku/mwezi/mwaka)

#### **9.4 a Appendix IV: ASSENT FORM FOR ADOLESCENTS LESS THAN 18 YEARS HIV INFECTED ADOLESCENTS/YOUTH TRANSITION STUDY ASSENT FORM**

**STUDY TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

**Investigator:** Dr. Grewal Gurpreet Kaur (MD) Pediatric Resident, University of Nairobi  
Tel Number: - 0733-636614

**Supervisors:** Prof. Elizabeth Maleche Obimbo (MBChB, MMed, FPulm, MPH)  
Prof. Dalton Wamalwa (MBChB, MMed, MPH)  
Dr. Irene Inwani (MBChB, MMed, MPH)

#### **Introduction:**

We want to give you information regarding something we are doing called a research study. A research study is when people collect a lot of data to learn more about a topic. I Grewal Gurpreet am doing a study to learn more about HIV infected adolescents who are moving out from pediatric to adult care. After we provide you with sufficient information, we will inquire if you'd like to take part in this study or not.

#### **Reason of doing this study:**

We need to discover what challenges you look amid the way towards moving out from pediatric to adult clinics. So we are getting data from loads of young men and young ladies like you.

#### **If you decide to take part in the study:**

If you say yes to take part in the study, two things will happen:

We shall provide a questionnaire which will consist questions related to your condition and will be required to fill. We will ask you questions only regarding about what you think. You are not being examined so feel free to answer the way you want to, there is no wrong or right answer.

A few adolescents of your age between 15 to less than 18years will be asked to come for a focused group discussion where you will talk about your experiences, fears and expectations regarding transition.

#### **If you have any questions:**

You can ask now. You can ask later or at any time. You can also speak to me or you can speak to someone else.

#### **Is it necessary to be in this study?**

No, you don't. Nobody will be distraught at you in the event that you would prefer not to. On the off chance that you would prefer not to be in this investigation, simply let us know. Or, on

the other hand in the event that you would like to be in the investigation, reveal to us that. What's more, you can state yes now and alter your opinion later. It's dependent upon you.

In the event that you would prefer not to be in this study, simply let us know.

In the event that you need to be in this study, simply let us know.

The investigator will give you a duplicate of this assent to keep.

I have disclosed the investigation to \_\_\_\_\_ (print name here) in dialect he/she can comprehend, and the juvenile has given assent to be in the study.

Participant Name \_\_\_\_\_

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_ (Day/month/year)

Witness Name \_\_\_\_\_ witness signature \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

Print Researcher/person Name taking the assent \_\_\_\_\_

Researcher /person Signature taking the assent \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

#### **9.4 b APPENDIX IV b: Kiswahili Assent Form: Fomu ya Idhini kwa Vijana chini ya 18years.**

Kifunguo: Hii fomu ya kupata idhini ni kwa ajili ya vijana walioambukizwa virusi vya ukimwi katika CCC, Hospitali ya Taifa ya Kenyatta, ambao tunuwakaribisha kushiriki katika utafiti. Jina la mradi wa utafiti wetu ni “vikwazo vya maambukizi na wawezeshaji wa umri sahihi mpito kutoka huduma kwa watoto kwa huduma ya watu wazima miongoni mwa vijana walioambukizwa virusi vya ukimwi katika hospitali ya taifa ya Kenyatta.”

Mimi ni Dk. Grewal Gurpreet Kaur, mwanafunzi katika Chuo Kikuu cha Nairobi kutafuta masomo ya utaalumu katika afya ya watoto. Mimi ninafanya utafiti juu ya, vikwazo vya maambukizi na wawezeshaji wa umri sahihi mpito kutoka huduma kwa watoto kwa huduma ya watu wazima miongoni mwa vijana walioambukizwa virusi vya ukimwi katika hospitali ya taifa ya Kenyatta. Nitakupa taarifa na kukuaribisha kwa utafiti huu.

Kunaweza kuwa na baadhi ya maneno ambayo huelewi. Tafadhali uliza na mimi nitachukua muda kueleza. Kama una maswali baadaye, unaweza bado kuniuliza

**Kwa nini tunakutana na wewe?** Sisi nataka kukuambia kuhusu kitu tunafanya inaitwa utafiti. Utafiti ni wakati madaktari wana kukusanya mengi ya habari kijifunza Zaidi kuhusu jambo Fulani. Tutachofanya ni utafiti tujifunza Zaidi kuhusu Vijana walioambukizwa virusi vya ukimwi ambao ni kipindi cha mpito kutoka huduma kwa watoto kwa huduma ya watu wazima. Baada ya sisi kukuambia Zaidi kuhusu utafiti huu, sisi tutakuuliza kama ungependa kuwa katika utafiti huu au hapana.

**Kwa nini unafanya utafiti huu?** Tunataka kujua ni nini mambo ambayo kufanya kuhama kutoka huduma kwa watoto kwa huduma ya watu wazima rahisi au vigumu kwa ajili yenu. Hivyo sisi kupata habari hii kutoka kwa kura ya wavulana na wasichana kama wewe.

#### **Nini kitatokea kwa wewe kama wewe utachagua kua katika utafiti huu?**

Kama wewe unakubali, mambo mawili yatatokea:

Utapewa dodoso ambayo itakuwa na wajumbe wa maswali kuhusiana na hali yako na watatakiwa kujaza. Maswali sisi, kuuliza nit u kuhusu nini unafikiri. Hakuna majibu sahihi au haki kwa sababu hii si mtihani.

Vijana chache wa umri wako kati ya umri 15 hadi chiini ya umri 18 watatakiwa kuja kwa ajili ya kundi ya majadiliano umakini baada ya Idhini. Hii majadiliano zitakua kuhusu hofu yako, uzoefu na matarajio kuhusu kipindi cha mpito.

#### **Je, una maswali yoyote?**

Unaweza kuuliza maswali wakati wowote, unaweza kuuliza sasa, unaweza kuuliza baadaye. Unaweza kuzungumza na mimi au unaweza kuzungumza na mtu mwingine.

#### **Je, unatakiwa kuwa katika utafiti huu?**

Hapana, si lazima kuwa katika utafiti huu. Hakuna mtu atakulazimisha kama hutaki kufanya hivyo.

Kama unataka kuwa katika utafiti huu, tuambie na kumbuka unaweza kusema ndiyo sasa, na kubadilisha baadaye hutaki kuendelea na utafiti huu. Ni juu yako.

Nimesoma/ Nimesomewa maelezo haya na nimepewa nafasi ya kuuliza maswali kuhusu hayo maelezo. Nimeidhini kwa hiari kushiriki katika utafiti huu.

Jina la Mshiriki \_\_\_\_\_

Sahihi la Mshiriki \_\_\_\_\_ Tarehe \_\_\_\_\_ (siku/mwezi/mwaka)

Nina uhakika kuwa nimemsomea mwakilishi fomu hii, na kwa kadri ya uwezo wangu nilihakikisha kwamba mshiriki ameelewa.

Nilithibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti nakuyajibu vema kwa kadri ya uwezo wangu. Mimi nathibitisha kwamba mwakilishi hakulazimishwa kutoa kibali

Jina la Mtafiti / Mtu kuchukua kibali \_\_\_\_\_

Sahihi la Mtafiti / Mtu kuchukua kibali \_\_\_\_\_

Tarehe \_\_\_\_\_ (siku/mwezi/mwaka)

## 9.5 Appendix V: PARTICIPANT CONSENT FORM – FOCUSED GROUP DISCUSSION

**TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

**SCOPE:** This informed consent is for enrolled participants in the study, and will be read to them by the principal investigator or a qualified research assistant before enrolling into focused group discussion.

**Investigator:** Dr. Grewal Gurpreet Kaur (MD) Pediatric Resident, University of Nairobi  
TEL: 0733-636614 Email: [preetybains85@gmail.com](mailto:preetybains85@gmail.com)

**Supervisors:** Prof. Elizabeth Maleche Obimbo (MBChB, MMed, FPulm, MPH)  
Prof. Dalton Wamalwa (MBChB, MMed, MPH)  
Dr. Irene Inwani (MBChB, MMed, MPH)

**Introduction:** You are being asked to take part in a discussion as part of a research study. You have been selected as a possible participant in this group. Your participation is voluntary and you may make inquiries whenever. The study aims at describing the barriers and facilitators of age appropriate transition among HIV adolescents and youth from pediatric to adult care at the CCC, KNH. Many adolescents either infected perinatally or behaviorally are now surviving into adulthood due to advent of HAART. It has become very important that the HIV infected adolescents and youth who are surviving are given support. Transition from pediatric to adult care is very important process in this age group for them to continue receiving health care services, maintain good health and be adherent to their medications. You don't need to choose today whether you will take an interest in the discussion. Before you choose, you can converse with anybody you feel great with about the study. This consent form may contain words you don't get it. If you don't mind stop the primary investigator or researchers right hand and they will set aside opportunity to clarify. On the off chance that you have inquiries later, you can call the examiner whenever.

**Scope of the study:** The purpose of the focus group discussions is to determine and describe what makes transition process easy or difficult for you, what have been your experience during and after the transition process and how can we best improve this process. This research will gather HIV infected adolescents and youth perspectives on both what it is that they experience during and after the transition process but also what you feel could be changed or improved to minimize challenges you face during transitioning. Research of this type is important because too often the perspectives of adolescents and youth get overlooked. It is also important because the ideas of adolescents and youth will help to inform efforts address the gaps in services and in support that currently exist, enhancing the resilience of HIV infected adolescents and youth in the future.

The focus group will last approximately 1 – 2 hours and will be held in a venue that will be communicated to you. There will be a group of 8 – 10 adolescents of the same age category and sex. Participants will be asked variety of questions around the topic of transition process. On the off chance that member don't feel good noting particular inquiry for any reason, he/she doesn't have to reply. The discussion will be recorded utilizing a recording device and notes will be composed to keep record of your responses for further analysis.



**Potential Risks:** It is possible that you may experience embarrassment during the discussions. To minimize this risk, I will direct the conversation to avoid potential problems. Refusal to participate will in no way jeopardize your treatment.

**Benefits:** The outcomes of the study will be shared with you and your health care provider.

You will likewise get instruction on the most proficient method to best enable you amid the process from pediatric to grown-up mind effectively. The results of the research will also be utilized by the health care providers in this clinic and other clinics to take better care of other HIV infected adolescents and youth who are transitioning or have transitioned from pediatric to adult care.

**Compensation:** To compensate you for any inconvenience related to your participation, after the focus group discussion you will be served with snacks and beverages.

**Voluntary:** Taking part in the discussion is voluntary and you may stop at any time or skip any inquiry you do not want to answer. Participants will be chosen in the order in which they return signed/completed informed consent/assent forms i.e. we will take the first 10 that return their completed forms.

**Confidentiality and privacy of Data:** The focus group discussions will be recorded using a tape recorder and notes from the discussion will be written and records will be kept confidential. Nonetheless, the mediator and research collaborators have no power over the data shared by members outside of the discussion. On the off chance that you don't feel great noting particular inquiries for any reason, you don't have to reply.

Records will only be accessed by the researchers; information obtained during the focus group discussion will be anonymous and in the publication using such information, no identifiable data will be used. Records will be stored on the researchers' password-protected computer and tape recorder tapes and notes will be held in a locked filing cabinet.

**Inquiries:** If you have any inquiries concerning anything you have perused here or in regards to your cooperation in the discussion, please ask now or you can ask later. On the off chance that you wish to make inquiries later, you may contact the investigator on the contacts given below.

This proposition has been evaluated by the Kenyatta National Hospital/University of Nairobi Ethics and Review Committee (KNH/UON ERC) which is a board of trustees whose undertaking it is to ensure that participants are shielded from any harm. In the event, that you wish to find out more, contact

The Chairman,

Kenyatta National Hospital/University of Nairobi Ethics and Review Committee

P.O.BOX 20723 Nairobi, Kenya. Tel: +254 (20) 2726300 Ext. 44355.

Please record your response to the following:

I consent to the discussion to be recorded YES/NO

I consent to some of my remarks or proclamations being cited verbatim in the report, gave that my name isn't put to the remark YES/NO

I might want to check any verbatim remarks that might be cited in the provide details regarding the understanding I can pull back the remark on the off chance that I so wish YES/NO

I wish to get a synopsis of the key findings from this investigation YES/NO

**Consent**

I have perused the substance of this consent and have been urged to make inquiries. I have gotten answers to every one of my inquiries. I consent to partake in this discussion.

Participant Name \_\_\_\_\_

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_ (day/month/year)

Witness name \_\_\_\_\_

Witness signature \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

*(Adolescents under the age of 18 years of age will be required to return a completed and signed informed consent form obtained from parents/guardians in addition to the assent form)*

**Consent Statement by Researcher**

I have precisely perused out the information to the potential participant, and to the best of my capacity ensured that the respondent comprehends that a survey will be directed to the participant. I affirm that they were given a chance to make inquiries about the investigation, and every one of the inquiries asked by the participant have been addressed effectively and to the best of my capacity. I affirm that the individual has not been constrained into giving consent, and the consent has been given openly and willfully.

Researcher/person name taking the consent \_\_\_\_\_

Researcher /person signature taking the consent \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

## **9.6 Appendix VI: HEALTH CARE PROVIDER CONSENT FORM FOR KEY INFORMANT INTERVIEW**

**TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents at Kenyatta National Hospital.

**SCOPE:** This informed consent is for health care providers who will be enrolled into the study, and will be given before enrolling for key informant interviews.

**Investigator:** Dr. Grewal Gurpreet Kaur (MD) Pediatric Resident, University of Nairobi

TEL: 0733-636614      Email: [preetybains85@gmail.com](mailto:preetybains85@gmail.com)

**Supervisors:** Prof. Elizabeth Maleche Obimbo (MBChB, MMed, FPulm, MPH)

Prof. Dalton Wamalwa (MBChB, MMed, MPH)

Dr. Irene Inwani (MBChB, MMed, MPH)

**Introduction:** We request you to take part in a key informant interview as major aspect of our research study. You have been selected as a conceivable participant in this meeting. Your participation is voluntary and you may ask questions at any time. The study aims at describing the barriers and facilitators of age appropriate transition among HIV adolescents and youth from pediatric to adult care at the CCC, KNH. Many adolescents either infected perinatally or behaviorally are now surviving into adulthood due to advent of HAART. It has become very important that the HIV infected adolescents and youth who are surviving are given support. Transition from pediatric to adult care is very important process in this age group for them to continue receiving health care services, maintain good health and be adherent to their medications. You don't need to choose today whether you will take an interest in this exploration. If it's not too much trouble stop the investigator or research associate as you get more information and they will set aside opportunity to clarify. In the event, that you have any inquiries later, you can call the investigator whenever.

**Scope of the study:** The scope of the key informant interviews is to determine and describe the process of transition at the HIV CCC. What have been your experience on transitioning HIV infected adolescents and youth living with HIV from pediatric to adult care. and how can we best improve this process. This research will gather health care providers perspectives on both what their they experience has been during transition process but also what you feel could be changed or improved to minimize challenges you face during transitioning. Research of this type is important because for transition to be successful for this age group. It is also important because your ideas will help to inform efforts to address the gaps in services that currently exist.

The Key informant interview will last about 45 minutes and can be held in a venue convenient to you. This will be a one on one interview. Participants will be asked variety of questions around the topic of transition process. In the event that you don't feel great noting particular inquiry for any reason, you doesn't have to reply.

Key informant interview will be recorded by utilizing a recording device and notes will be composed to provide records of your responses for further analysis.

**Potential Risks:** It is possible that you may experience embarrassment during the discussions. Refusal to participate will in no way jeopardize your work or practice at the CCC.

**Benefits:** The results of the study will be shared with you and other stakeholders at the CCC. You will also receive a final report on findings of this investigation.

The outcomes of the investigation will also be utilized by the health care providers in this clinic and other clinics to take better care of other adolescents and youth who are moving to or have moved from pediatric to adult care.

**Voluntary:** Participation in the KII's is voluntary and you may stop whenever or skirt any inquiry you would prefer not to reply. You may choose to decline to participate at any time and this will not affect your work and practice in any case.

**Confidentiality and privacy of Data:** The KII's will be recorded utilizing a recording device and notes from the talk will be composed and records will be kept classified. In the event, that you don't feel great noting particular inquiries for any reason, you don't have to reply. Access to the records will be limited to the researchers; information obtained during the KII's will be anonymous and in the publication using such information, no identifiable data will be used. Records will be put away on the scientists' secret key secured PC and recording device tapes and notes will be held in a bolted file organizer.

**Inquiries:** If you have any inquiries concerning anything you have perused here or with respect to your interest in the KII's, please ask now or you can ask later. In the event, that you wish to make inquiries later, you may contact the investigator on the contacts given below.

This proposition has been audited by the Kenyatta National Hospital/University of Nairobi Ethics and Review Committee (KNH/UON ERC) which is a council whose assignment it is to ensure that participants are shielded from any harm. On the off chance that you wish to find out more, contact

The Chairman,

Kenyatta National Hospital/University of Nairobi Ethics and Review Committee

P.O.BOX 20723 Nairobi, Kenya. Tel: +254 (20) 2726300 Ext. 44355.

Please record your response to the following:

I consent to the Key Informant Interview being to be recorded YES/NO

I consent to some of my remarks or articulations being cited verbatim in the report, gave that my name isn't put to the remark YES/NO

I might want to check any verbatim remarks that might be cited in the write about the understanding I can pull back the remark in the event that I so wish YES/NO

I wish to get a synopsis of the key discoveries from this investigation YES/NO

**Consent**

I have perused the substance of this consent and have been urged to make inquiries. I have gotten answers to every one of my inquiries. I consent to take part in this key informant interview.

Informant name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_ (day/month/year)

Witness name \_\_\_\_\_

Witness signature \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)

**Researcher/person taking consent statement:**

I have precisely perused out the information to the participant, and to the best of my capacity ensured that the informant comprehends the investigation and meeting process. I affirm that the informant was given a chance to make inquiries about the study, and every one of the inquiries asked by the informant have been addressed accurately and to the best of my capacity. I affirm that the individual has not been forced into giving consent, and the consent has been given unreservedly and willfully

Researcher/person name taking the consent \_\_\_\_\_

Researcher /person signature taking the consent \_\_\_\_\_

Date \_\_\_\_\_ (Day/month/year)





19. Do you use any of the following substances?
- |  |               |              |
|--|---------------|--------------|
| i) Cigarettes                          | a. YES (....) | b. NO (....) |
| ii) Bhang                              | a. YES (....) | b. NO (....) |
| iii) Miraa                             | a. YES (....) | b. NO (....) |
| iv) Cocaine (powder, crack, injection) | a. YES (....) | b. NO (....) |
| v) Sniffing glue                       | a. YES (....) | b. NO (....) |
- If yes, at what age did you start using it? .....

**PART 2 DISCLOSURE**

20. Please tell me what is the nature of your illness?  
 a. HIV (....)                      b. Don't know (....)                      (go to question 22)  
 If HIV, continue below

21. Age at which HIV status known? (Age).....  
 Who told you? .....  
 Do you know how you got infected?  
 a. Sexual contact (....)                      b. Perinatal (....)                      c. don't know (....)  
 Others (specify) .....

22. Who else knows about your status apart from your health care provider?  
 a. No one (....)  
 b. Parent (....)  
 c. Spouse/ sexual partner (....)  
 d. Close relative (....)  
 e. Close (non-sexual) friend (....)  
 f. Other (specify) .....

**PART 3 APPOINTMENT KEEPING**

23. Have you been transferred from another facility?    a. Yes (....)    b. NO (....)
24. What facility have you been transferred from?  
 a. VCT    b. PMTCT    c. MCH    d. Home based inpatient    e. other facility.....
25. Do you use money for transport to come to the CCC?    a. YES (....)    b. NO (....)
26. Who provides you with this money?  
 a. Self (....)  
 b. Parent (....)  
 c. Relatives (....)  
 d. Friends (....)  
 e. NGO/research project (....)  
 f. Other (specify) .....
27. Have you missed an appointment or drug refill in the (not filled within one week of appointment date)  
 a. Last month (....)  
 b. Last three months (....)                      how many times .....  
 c. Last six months (....)                      how many times .....  
 When was the missed appointment due: Date (.....)  
 When did you come for the missed appointment: Date (.....)
28. If missed any appointment, why?  
 a. Forgot (....)  
 b. Was in school (....)  
 c. No transport money (....)  
 d. Was sick (....)  
 e. Others (specify) .....



29. i) where are you receiving medical care for currently?  
**a.** Pediatric clinic (....)  
**b.** Adult care (....)
30. Are you taking medications?  
**a.** YES (....) **b.** NO (....)  
 If NO, please explain why?
31. medication regimen you are currently taking for your condition?  
**a.** Pediatric Regimen (....)  
**b.** Adult Regimen (....)
32. Are you currently taking?  
**a.** First Line regimen (....) **b.** second line regimen (....)
33. Your last CD4 count?.....  
 When was it taken? .....
34. Your latest viral load?.....  
 When was it taken?.....
35. have you been ADMITTED recently?  
**a.** YES (....) **b.** NO (....)  
 IF YES, how many times?.....
36. What were you admitted for?  
**a.** Health issue (....)  
**b.** Change of regimen (....)  
**c.** Others, specify.....

**PART 4 TRANSITION**

37. Has your health care provider ever communicated to you about moving out of pediatric clinic at your site of care?  
**a.** YES (....) **b.** NO (....)
38. What are your contemplations about moving to adult clinic?  
**a.** Scared (....)  
**b.** Excited (....)  
**c.** Not sure what to expect (....)  
**d.** Looking forward to it (....)  
**e.** Don't want to leave (....)  
**f.** Others (specify).....

Proceed to question no. 40 if you are still receiving care in pediatric clinic and if currently in adult care proceed to question 34.

39. i). Has your health care provider before moving you to adult care communicate to you about transition?  
**a.** YES (....) **b.** NO (....)
- ii) If yes, please describe what is that they talked about moving out of pediatric clinic to adult clinic?  
 -----  
 -----  
 -----

iii) How old were you when you were communicated about moving out of pediatric clinic to adult clinic?

-----

40. i). How simple or difficult was it to move to adult health care?

- a. Very simple (....)
- b. simple (....)
- c. Hard (....)
- d. Very Hard (....)

ii) Please explain? Why simple or hard?

.....  
.....

41. moving to adult clinic was it?

- a. As anticipated (....)
- b. Better than anticipated (....)
- c. More hard than anticipated (....)

42. How could the process of moving out made easier for you?

.....  
.....  
.....

43. Where you oriented to adult health care services before moving out of pediatric clinic?

- a.YES (....)
- b. NO (....)

44. Have you had the following since moving to adult clinic:

- i) Hard time taking medications as prescribed a.YES (....) b. NO (....)
- ii) Having more health needs or issues a.YES (....) b. NO (....)
- iii) Lack of supportive care a.YES (....) b. NO (....)

If yes, please tick of one them:

- psychosocial support services (....)
- Financial support (....)
- Group support services (....)
- Other type of support, specify .....

45. Have you been linked to an adolescent support group? a.Yes (....) b.NO (....)

46. How often does your health care provider discuss to you about moving out of paediatric clinic to adult clinic?

- a. Every clinical checkup (....)
- b. Individual counselling sessions (....)
- c. Adolescent group session (....)
- d. Just talked once (....)
- e. Never (....)
- f. Others (specify) .....

**QUANTITATIVE: MEDICAL RECORDS ABSTRACTION FORM**

Study number: \_\_\_\_\_

Date: \_\_\_\_\_

<b>Date of Enrollment to CCC</b>	
<b>Weight:</b> Baseline	
Weight: 6months, 12 months, 18months, 24 months	
<b>HIV WHO staging</b> on enrollment	
Current HIV WHO Staging	
<b>CD4 Count:</b> Baseline	
6 months, 12months,18 months, 24 months	
<b>Viral Load:</b> Baseline	
6months, 12months,18 months, 24 months	
<b>Medication:</b> regimen started on	
Changes made (1 <sup>st</sup> /2 <sup>nd</sup> regimen)	

## 9.8 APPENDIX VIII FOCUSED GROUP DISCUSSION TOOL: NOT TRANSITIONED

**STUDY TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

Study Group Number:..... Focus Group Category:.....

Site: ..... Moderator:.....

Number of Participants:..... Note-taker:.....

Date:..... Start time:..... End time:.....

**Instructions to the facilitator:** Introduce ourselves and make the participants feel comfortable. Have the participants introduce themselves. Thank them for agreeing to participate and reassure them of confidentiality. Request permission to tape record the session and re-confirm consent for participation.

### STANDTARD PROCEDURE FOR DISCUSSION:

1. YOU SHALL TO DO THE TALKING.  
We might want everybody to take an interest. I may approach you on the off chance if I haven't heard from you yet.
2. WE Will CALL YOU NOT BY NAMES But rather BY PRE-Appointed NUMBERS With a specific end goal to Keep up YOUR identity classified.
3. THERE ARE NO Setin stone ANSWERS.
4. Every person's experiences and opinions are important.  
Talk up whether you concur or oppose this idea. We want to hear a wide range of opinions.
5. WHAT IS SAID IN THIS ROOM Remains HERE.  
We need everybody here to feel good sharing when touchy issues come up.
6. WE WILL BE recording the discussion with a recording device AND TAKING NOTES

### **SECTION A: GUIDE QUESTIONS FOR FGDs FOR HIV INFECTED ADOLESCENTS AND YOUTH ATTENDING PAEDIATRIC CARE**

**(Exclude adolescents who have not been disclosed to their HIV status)**

1. What does transition mean to you?
2. Has your health care provider communicated to you about transition?
3. What are your views about moving to adult care?
4. What do you think will make your transitioning into adult care difficult?
5. What do you think will make your transitioning into adult care easier??
6. What do you recommend that will make the process of transitioning more easy and successful for you?

**Closing session:** The moderator will ask if there are any additions or questions to be asked and close the session by thanking everyone for their time and participation in the discussion. Refreshments will be served thereafter.

## 9.9 APPENDIX IX: FOCUSED GROUP DISCUSSION TOOL: WHO HAVE TRANSITIONED TO ADULT CARE

**STUDY TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

Study Group Number:..... Focus Group Category:.....  
Site: ..... Moderator:.....  
Number of Participants:..... Note-taker:.....  
Date:..... Start time:..... End time:.....

**Instructions to the facilitator:** Introduce ourselves and make the participants feel comfortable. Have the participants introduce themselves. Thank them for agreeing to participate and reassure them of confidentiality. Request permission to tape record the session and re-confirm consent for participation.

### **STANDTARD PROCEDURE FOR DISCUSSION:**

1. YOU SHALL TO DO THE TALKING. We might want everybody to take an interest. I may approach you on the off chance if I haven't heard from you yet.
2. WE Will CALL YOU NOT BY NAMES But rather BY PRE-Appointed NUMBERS With a specific end goal to Keep up YOUR identity classified.
3. THERE ARE NO set in stone ANSWERS. Every person's experiences and opinions are important. Talk up whether you concur or oppose this idea. We want to hear a wide range of opinions.
4. WHAT IS SAID IN THIS ROOM Remains HERE.  
We need everybody here to feel good sharing when touchy issues come up.
5. WE WILL BE recording the discussion with a recording device AND TAKING NOTES

### SECTION A: GUIDE QUESTIONS FOR FGDs FOR HIV INFECTED ADOLESCENTS AND YOUTH ATTENDING ADULT CARE AFTER BEING TRANSITIONED

1. What do you understand by transition?
2. When did your health care provider communicate to you about transition?
3. Where you prepared by your health care provider when transitioning? What sort of preparation was done?
4. What was so difficult about transitioning into adult care?
5. What made it easy for you to move to adult clinic?
6. How was the experience of transitioning into adult care?
7. What do you recommend that needs to change to improve transition process?

**Closing session:** The moderator will ask if there are any additions or questions to be asked and close the session by thanking everyone for their time and participation in the discussion. Refreshments will be served thereafter.

## 9.10 APPENDIX X: KEY INFORMANT INTERVIEW GUIDE TOOL

**STUDY TITLE:** Prevalence, Barriers and Facilitators of Age Appropriate Transition from Pediatric to Adult care among HIV infected Adolescents/Youth at Kenyatta National Hospital.

Study Number:..... Key Informant Category.....

Site: .....

Moderator..... Note-taker.....

Date..... Start time..... End time.....

**Introduction:** before beginning the interview, I will present myself and the reason of this investigation. Thank the respondent to agree to be interviewed. Assure them their responses will be kept confidential.

### **SECTION A: GUIDE QUESTIONS FOR KIIs FOR THE HEALTH CARE WORKERS TAKING CARE OF THE HIV INFECTED ADOLESCENTS AND YOUTH AT KNH CCC.**

1. What is the process of transition in your clinic?
2. What is the appropriate age of transitioning to adult care?
3. What parameters do you look at when deciding on transitioning an adolescent?
4. What are the barriers to successfully moving out of pediatric clinic?
5. What are the facilitators to successful moving out of pediatric and going to adult clinic?
6. Usually what amount of time does transition take at your centre?
7. Are there any guidelines/ criteria or checklist for transition that you are aware of in your centre?
8. What needs to change to improve successful transition?

**Closing session:** ask for any final comments or any additional information they would like to share. Thank them for participating in this interview.