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**SOCIAL AND CLINICAL OUTCOMES OF ADOLESCENTS AND YOUNG ADULTS
WITH HIV TRANSITIONED FROM PEDIATRIC TO ADULT-CENTERED CARE AT
THE UNIVERSITY TEACHING HOSPITAL OF KIGALI (CHUK)**

Investigator: Joselyne Uwinkesha, MD

College of Medicine and Health Sciences

School of Medicine and Pharmacy

Department of Pediatrics and Child Health

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UNIVERSITY TEACHING HOSPITAL OF KIGALI (CHUK)

By

Joselyne Uwinkesha

Registration number: 1111244

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In the college of Medicine and Health Sciences

Supervisors: Dr. Febronie Mushimiyimana

Dr. Aimable Kanyamuhunga

University of Rwanda

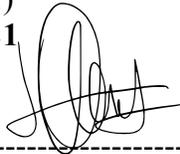
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CERTIFICATION FOR AWARD

The undersigned certify that they have read and hereby recommend for acceptance by the University of Rwanda a dissertation entitled “**Social and clinical outcomes of adolescents and young adults transitioned from pediatric to adult centered-care at University Teaching Hospital of Kigali (CHUK)**” in partial fulfillment of the requirements for the Degree of Master of Medicine (Pediatrics and Child Health) of the University of Rwanda.



Dr. Aimable Kanyamuhunga
(Supervisor)
Date: **21/12/2021**



Dr. Febronie Mushimiyimana
(Supervisor)
Date: **21/12/2021**-----

DECLARATION

I declare that this dissertation is the result of my own work except where specifically acknowledged, and has not been submitted for any other degree at the University of Rwanda or any other institution.

Joselyne Uwinkesha

Registration number: 11111244

Signature:



Date: December 20, 2021

DEDICATION

This research is lovingly dedicated to my treasured husband and daughter, Dr. Fiacre Byiringiro Mugabe and Lenah Perla Mugabe, whose affection cheered me on when I was discouraged.

To my beloved mother Illuminée Umurungi and to the memory of my late father Emmanuel Murenzi, who are the reason of what I become today.

To my sisters Josiane Umulinga, Josine Umuhire, and Josette Uwera, whom I have always been able to count on.

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ABSTRACT

Background: HIV is a health burden globally. With the introduction of HAART, many HIV-infected children are surviving up to adulthood, necessitating transition from pediatric to adult care.

Aim: The purpose of this study was to determine the social and clinical outcomes of HIV-infected adolescents and young adults (YA) transitioned from pediatric to adult care at CHUK.

Methods: We did a cross-sectional study at CHUK. We targeted HIV-infected adolescents and YA transitioned from pediatric to adult HIV clinic from January 2016 to December 2019. We used descriptive statistics to characterize the study population and paired T-test to compare pre-and post-transition viral loads.

Results: During the study period, 85 adolescents and YA were transitioned from pediatric to adult HIV clinic at CHUK. Among them, 57 consented to the study.

At the time of transition, The median age was 19. More than half (56.1%) of participants were male, and 43.9% were female. Most of them (82.4%) were still having at least one parent alive. Seventy-seven percent were still in a school setting, more than half (61.4%) had no job and only 14% had no health insurance.

More than half of the youth (69.6%) confirmed that they were sexually active. Among females, only 8% stated that they had ever been pregnant. Only 8.8% of the participants confirmed that they had become parents, 7% stated that they had STI (s) other than HIV since the time of transition and 15.8% stated that they had opportunistic infection (s) since the time of transition.

At 3 years post-transition, the VL suppression had increased from 82.5% to 94.7% and the mean VL had decreased from 4454.3 to 3867.9. The difference in means of viral loads was not proven to be statistically significant. The majority of our population (96.5%) were still engaged in care.

Conclusion: The high rate of retention in care among our participants is likely due to the emphasis of the government of Rwanda on HIV prevention and management. More work is needed to determine the post-transition outcomes of HIV-infected adolescents and YA at a national level.

Keywords: *outcomes, adolescents, young adults, HIV, transition.*

GLOSSARY OF TERMS

%.: Percentage

ART: Antiretroviral Therapy

CBHI: Community-Based Health Insurance

CHUK: University Teaching Hospital of Kigali

CMHS: College of Medicine and Health Sciences

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

IRB: Institutional Review Board

MD: Medical Doctor

MMed: Master of Medicine

OI (s): Opportunistic Infection (s)

PI: Primary Investigator

RDHS: Rwanda Demographic and Health Survey

REC: Research Ethics Committee

STI (s): Sexually Transmitted Infection (s)

UNICEF: United Nations International Children's Fund

UR: University of Rwanda

USA: United States of America

VL: Viral Load

YA: Young Adults

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CHAPTER I. INTRODUCTION

I.1. Background

Globally, Human Immunodeficiency Virus (HIV) prevalence is estimated at 0.8% in the age group of 15-49 years (1)(2). As stated by UNICEF, in 2014, approximately 2 million adolescents were HIV infected worldwide (3)(4)(5). Almost 25% of them were living in 3 countries (South Africa, Kenya, and Nigeria). Whereas around 2.8 million young adults were HIV-infected, 82% of them were living in Sub-Saharan Africa, and most of them (71%) were female (3)(4).

As stated by the Rwanda Demographic and Health Survey (RDHS 2014-2015), the prevalence of HIV has been stable since 2005 (3% among adults 15-49 years, 4% among women, and 2% among men) (6). Children are not spared. 0.8% of children 0-14 years are living with HIV (7). According to United Nations Program on HIV/AIDS (UNAIDS), the HIV prevalence remains low among the youth in Rwanda, but there is an increase from 2010 and 2015 in the age range of 20-24 years (from 1.8% to 2.4% in women and 0.5% to 1% in men) (8)(9).

The institution of Highly Active Antiretroviral Therapy (HAART) had a great impact on the outcome of patients living with HIV in general, many children with HIV are surviving up to adulthood (10)(11). This represents the necessity for transition from pediatric to adult care (12). Healthcare transition is a planned and purposeful movement of adolescents and young adults (YA) with chronic medical and physical conditions from pediatric to adult-centered health care systems (12)(13).

According to World Health Organization (WHO), an adolescent is any person with age between 10 and 19 years (14). As maintained by Erik Erikson's stages of human development, a young adult is any person with age between 20 and 39 years.

The transition into adulthood is a censorious phase of human evolution during which young individuals take on new responsibilities (12). To be successful, it requires early participation and engagement of the youth and his or her family with the collaboration of both pediatric and adult health care teams (15)(16). The median age at transition is 18 years in many countries (9)(12), but getting to this age does not guarantee the possession of an adult way of behaving (12).

The transition period has been associated with high drop-out rates with resultant substandard retention in care and a rise in morbidity and mortality (12)(13).

Few kinds of research have been done in Sub-Saharan Africa, and none in Rwanda to assess the outcomes of HIV-infected adolescents and YA after transition. This study will identify those outcomes, both social and clinical.

I.2. Problem statement

HIV is a global health burden. With the introduction of HAART, many children with HIV are getting through adulthood, necessitating transition from pediatric to adult care. Worldwide, some studies have been done to evaluate the outcomes of HIV-infected adolescents and YA post-transition, few in Sub-Saharan Africa and none in Rwanda. Since 2016, the pediatric HIV clinic at CHUK has been transferring adolescents and YA to the adult-centered clinic, but no evaluation of their outcomes has been done. This study has determined those outcomes, both clinical and social and results will be available to the health care providers for evidence-based medical practice.

I.3. Research question

What are the social and clinical outcomes of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK?

I.4. Aims and objectives

I.4.1. Main objective

- To find out social and clinical outcomes of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK

I.4.2. Specific objectives

- To evaluate the socio-economic status of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK
- To assess sexual and reproductive health of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK
- To determine clinical and biological outcomes of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK: occurrence of opportunistic infections, comparison of viral loads before and after transition
- To assess the retention in care of HIV-infected adolescents and YA transitioned from pediatric to adult care at CHUK

CHAPTER II. LITERATURE REVIEW

HIV-infected adolescents and YA are a rising generation of the HIV-infected population (15)(17).

Priscilla Idele et al. conducted a review on the epidemiology of HIV among adolescents in Sub-Saharan Africa. They found that, in 2012, 82% of approximately 2.1 million HIV-infected adolescents were living in Sub-Saharan Africa, and 58% of them were female. They highlighted that the awareness of HIV, HIV testing, condom use, and antiretroviral therapy (ART) coverage are still low in most countries and that early sexual commencement is more common among girls than boys in low and middle-income countries (18).

It is only in the adolescent age group that HIV-related mortality is increasing (15)(17)(19)(20). They face a period of immature physical, mental and sexual development, with denial of illness, vulnerability, and resultant poor adherence (15)(17).

Transitioning is a planned and purposeful movement of adolescents and young adults from pediatric to adult-centered care (2). To be successful, it requires early participation and engagement of the youth and his or her family with the collaboration of both pediatric and adult health care personnel (15). The goal of transition is to provide excellent care and developmentally suitable HIV health care services (2).

A cross-sectional survey done in Rwanda, Kenya, Burundi, Tanzania, Uganda, and Ethiopia identifying the gaps in transition services of HIV-infected adolescents showed that almost half of facilities did not plan before transition and a similar proportion of health care providers did not receive training to support transition (4).

Challenges to transition include providers without expertise in adolescent medicine, lack of agreement on time for transitioning, and deficiency of formal transition program (11)(19).

There are differences between adult and pediatric care practice styles and youth has difficulty adapting (21).

A cross-sectional study on social support needs among 328 randomly selected HIV-infected adolescents in transition from pediatric to adult care in Cambodia showed that most had at least one parent departed (mother 50.9%, father 60.5%), and most of them were leaving with relatives

(49.3%) or biological parents (40.8%). A third came from impoverished families and 21% were working for pay. Among them, 46.6% stated that their family had been given sustenance for their health care including school fees (62.1%), food support (76.5%), transport payment to ART clinics (53.6%), vocational training (22.9%), psychosocial counseling (35.3%), or home visits (11.1%). 55% of them were supported by health equity funds or health insurance and 32% of them reported experiencing HIV stigma (22).

Scovia Nalugo et Al. in Uganda conducted a study on the reproductive health of perinatally HIV infected adolescents. They found that more than a third (34.1%) of perinatally infected youth were sexually active (23). Maria Trent et Al. in the United States of America (USA) studied new sexually transmitted infections (STIs) among HIV-infected adolescent girls. They found that 1.4% of the participants had STIs (24).

Fatima Kakkar et al conducted a study to evaluate health outcomes of HIV-infected adolescents after transition to adult care in Québec, Canada. They found that 22% of youth were single, 25% had become parents (21).

A study done by Mamaru Wubale Melkamu et al. in Ethiopia determining the prevalence of opportunistic infections (OIs) in HIV-infected children revealed that 9.7% of those children had OIs. (25). Another study done by Nebiyu Dereje et al. in Ethiopia demonstrated that the prevalence of OIs among HIV-infected adults on HAART was 29.2% (26).

Retention in care and viral load suppression are low in adolescence and young adulthood after transition, especially among youth with low educational level and lack of independence regarding their medical care. A study done in the USA in 2012 showed that only 21% of HIV-infected adolescents and YA had been prescribed HAART and only 16% were virologically suppressed (viral load <200 copies).

This population is more at risk of psychiatric illnesses. In a study of 172 youth of 11 to 24 years perinatally acquired HIV, 48% had the diagnosis of psychiatric disease (27).

A study done in the United Kingdom (UK) to compare clinical outcomes of HIV-infected adolescents, pre-and post-transition to adult care revealed that 74% of the population were on ART in pediatric care, increasing to 84% at last visit in adult care (28). In the 12 months before

transition, 47% had two successive viral loads >400 copies/ml or one viral load > 1000 copies/ml contrary to 52% in 12 months post-transfer. 3% died in adult care (28).

A single-center retrospective cohort study done in America among HIV-infected subjects showed that adolescents and YA who were newly received in the adult clinic had the lowest rates of viral load suppression (58.7%) compared to adults (78.3%) (10).

Hussen SA et al. conducted a retrospective cohort study in Atlanta, Georgia. They compared the outcome of HIV-infected young adults whose transition had been planned and those who experienced a gap in care. The first group had a higher rate of retention (65% versus 27%) and a higher rate of viral load suppression at the time of the last adult care visit (54% versus 35%) (29). Brian C. Zanoni et Al. in South Africa also found a high rate of retention in care (95%) of the youth attending adolescent clinics (30).

A study done by Hansudewechakul et al. on transition of HIV-infected adolescents to adult care in Thai found that 76% of them were virologically suppressed in the first year post-transition. They thought transitioning youth in groups builds a support system and facilitates peer interactions. All four patients that died were virologically unsuppressed at the time of transition (4.500 to 149.00 copies/ml) and had poor adherence (31).

Dahourou DL et al. conducted a review of evidence on transition outcomes of adolescents and YA with HIV in Africa, they observed high attrition rates in this age group compared to others (4).

In a randomized controlled trial done in Nigeria to measure the comparative efficacy of organized transition and usual practice of abrupt transfer of adolescents and YA with HIV, they found that coordinated transition significantly increases retention in care, and viral load suppression, and psychological wellbeing (19).

CHAPTER III. METHODOLOGY

III.1. Study design and description

This was a cross-sectional study using chart review and information from participants.

III.2. Study site

The study was conducted at the University Teaching Hospital of Kigali (CHUK), which is a public referral tertiary level hospital located in Kigali, the capital city of Rwanda, and it is affiliated to the Ministry of Health. As a tertiary level hospital, CHUK is mandated to improve patient care across the hospitals under its catchment area through supervision and mentorship programs. For HIV-related care, the mentorship activity is done in the 15 district hospitals in 13 administrative districts out of the 30 administrative districts in the country. CHUK has both pediatric and adult HIV clinics. From a pilot study done, the CHUK pediatric HIV clinic takes care of 183 children currently. 155 (84.7%) of them are adolescents and 2 (1%) are young adults. It has a team of trained health care providers composed of 1 medical doctor, 1 nurse, 1 social worker, and 1 psychologist. On the contrary, the CHUK adult HIV clinic follows 2873 people, of whom 284 (9.9%) are adolescents and 664 (23.1%) are young adults. It is a team of skilled health care providers consisting of 4 medical doctors, 6 nurses, 1 social worker, and 1 psychologist.

Since 2016, HIV-infected adolescents and YA are being transitioned from CHUK pediatric to adult care. The above-described team of health care providers at the pediatric HIV clinic provides contact sessions of education on HIV/AIDS tackling the transition to adult care for at least 2 months to the subjects aged above 15. After those sessions, the adolescents and YA who are willing to be transitioned are accompanied by a nurse to the adult clinic and presented to the team taking over.

III.3. Study population

HIV-infected adolescents and YA that were transitioned from pediatric to adult HIV clinic at CHUK from January 2016 to December 2019. During this period, 106 adolescents and YA were

transitioned including 85 referred to the CHUK adult HIV clinic. The criteria for transition were age above 15, and willingness to be transitioned.

III.4. Selection of the study population

III.4.1. Inclusion criteria

Every HIV-infected adolescent and YA who moved from pediatric to adult HIV clinic at CHUK from January 2016 to December 2019.

III.4.2. Exclusion criteria

- Anyone who refused to participate in our study
- Anyone who was not able to communicate (verbally or written)

III.5. Study procedures

III.5.1. Procedure at enrollment

We reviewed clinical records to identify all adolescents and YA who had been transitioned from pediatric to adult HIV clinic at CHUK during the study period. We got patient or parental listed phone numbers through Medical Record System or open clinic. Thereafter, we called them to ask when their appointment in the adult HIV clinic was planned. Using a developed, pre-tested structured questionnaire, after giving explanations on the purpose of the study and getting informed consent, we collected data from eligible participants by an in-person interview on their due appointment. Thereafter, we reviewed their charts to retrieve their last viral load before transition and their three consecutive viral loads taken after transition. Data were collected after getting the Institutional Review Board (IRB) approval.

III.5.2. Outcomes and confounders

Social and clinical outcomes of adolescents and YA with HIV transitioned from pediatric to adult-centered care were determined. Independent variables include socio-demographic data: age, sex, place of residence, nationality, parents alive, lives with, presently in a school setting, the highest level of education, employment, ubudehe category, medical insurance. Dependent variables

include: marital status, sexually active? ever pregnant?, became a parent?, had sexually transmitted infection (s) other than HIV since the time of transition?, had opportunistic infection (s) since the time of transition?, viral loads, last physician follow up.

III.5.3. Sample size

According to the RDHD 2014-2015, the prevalence of HIV has been stable since 2005 (3% among Rwandans aged 15 to 49) (6). Note that the recent RDHS of 2019 does not include the prevalence of HIV.

By calculating our sample size, the following formula has been used:

$$n = Z^2 \times P (1-P)/d^2$$

Z = 1.96 = statistic value corresponding to the confidence level of 95%

P = proportion or expected prevalence of HIV according to RDHS 2014-2015 (0.3%)

d = standard error (5%).

$$n = (1.96)^2 \times 0.03 \times (1-0.03) / (0.05)^2 = 44.7$$

n = 45 participants

From a pilot study done at CHUK pediatric HIV clinic, 106 HIV-infected adolescents and YA had been transitioned between 2016 and 2019. Among them, 85 were transitioned to CHUK adult HIV clinic and 21 were moved to other hospitals.

Our calculated sample size (45 participants) is small compared to 85 adolescents and YA who have been transitioned to CHUK adult clinic.

To have more accurate results, all those HIV-infected adolescents and YA who had been transitioned from CHUK pediatric to CHUK adult HIV clinic, meeting our inclusion criteria were enrolled in our study and constituted our sample size.

III.5.4. Data management and analysis

We entered collected data through Google form and the analysis was done using SPSS 25.0 version. We used descriptive statistics to characterize the study population and paired T-test to compare pre-and post-transition viral loads. The significance of a difference of means of viral loads was taken for a P-value <0.05.

III.6. Ethical considerations

III.6.1. Confidentiality

Participant confidentiality was maintained by keeping all data in a secured area and in a password-protected computer. Each participant was given a code, no name or other identity was disclosed.

III.6.2. Informed consent

We got written informed consent from all participants before being enrolled in this study.

III.6.3. Ethical approval

The research proposal was presented to the IRB of the College of Medicine and Health Sciences (CMHS), University of Rwanda (UR), and approval notice number 062/CMHS IRB/2021 was provided. It was then submitted to the ethics committee of CHUK and ethical clearance number EC/CHUK/026/2021 was issued. Thereafter, the study was conducted.

III.6.4. Funding and sponsors

No funding was sought for this study.

III.6.5. Risks to subjects

There were no physical, legal, or financial risks identified during enrollment and data collection.

-Social risks:

Participants might disclose information that is socially private to them. To mitigate this, we gave a very good debriefing at the start of data collection and every information was kept confidential.

-Emotional risks:

Being HIV positive is a difficult experience. Participants might have emotional distress while giving information about it. To mitigate this risk, the PI collected data together with the psychologist. They ensured good preparation before starting data collection and kept compassionately and morally supporting participants. If a participant showed any sign of significant emotional distress, data collection was immediately terminated, and support was given to the participant.

CHAPTER IV: RESULTS

IV.1. Recruitment chart flow of our participants

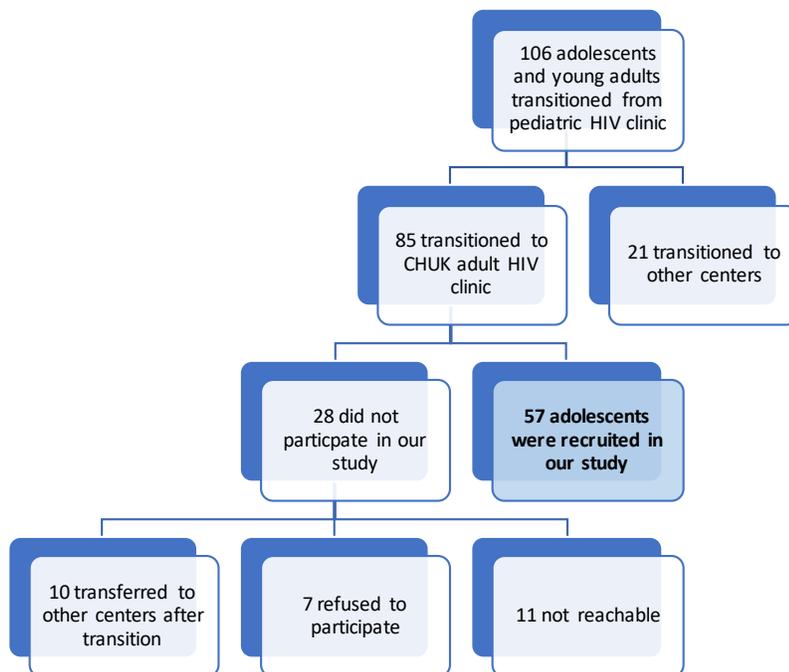


Figure 1: Recruitment chart flow for our participants

106 participants were transitioned from CHUK pediatric HIV clinic during the study period. Among them, 85 were transitioned to the CHUK adult HIV clinic and were eligible for our study, and 21 were transitioned to other centers. Of those 85 eligible participants, 57 successfully completed the study, 10 had been transferred to other centers, 7 refused to participate and 11 were not reachable. No one was confirmed deceased, and all of them were Rwandese.

V.2. Participant’s demographic and socio-economic data

Table 1: Participant’s demographic and socio-economic data

Characteristics		n	%
Age range	Adolescent (10-19)	1	1.7

(Mean: 23)	Young Adult (16-39)	56	98.3
Sex	Male	32	56.1
	Female	25	43.9
Residence	Kigali City	51	89.5
	North	4	7
	East	1	1.7
	West	1	1.7
	South	0	0
Parents alive?	Both parents alive	20	35.1
	Mother alive	17	29.8
	Father alive	10	17.5
	No parent alive	10	17.5
Lives with	Biological parents	35	61.4
	Relatives	16	28.1
	Alone	6	10.5
Presently in a school setting	Yes	44	77.2
	No	13	22.8
Highest level of education	University	21	36.8
	Secondary	34	59.6
	Primary	2	3.5
	Illiterate	0	0
Employment	Job	22	38.6

	No job	35	61.4
Ubudehe category	One	2	3.5
	Two	2	3.5
	Three	43	75.4
	Four	10	17.5
Medical insurance	CBHI	46	80.7
	Other insurance	3	5.3
	No insurance	8	14

57 participants were recruited in our study. The median age of participants was 23 (range 19-30 years), and the median age at the time of transition was 19 (range 15-26 years). At the time of the interview, only one of the participants was an adolescent, representing 1.7%, 98.3% were young adults. More than half (56.1%) of participants were male, and 43.9% were female. The majority (89.5%) were living in Kigali City, no one was living in Southern province.

Our participants were living in different socio-economic conditions. Most (82.4%) were still having at least one parent alive and the majority (89.5%) were still living with at least one parent or relatives. Seventy-seven percent were still in a school setting and most of the participants (96.4%) had obtained a secondary school degree or higher. More than half (61.4%) had no job and the majority (75.4%) were in Ubudehe category three. Only 14% of the youth had no health insurance. However, 80.7% were using community-based health insurance (CBHI).

IV.3. Sexual and reproductive health

Table 2: Sexual and reproductive health

Characteristics		n	%
Sexually active?	Yes	34	59.6

	No	16	28.1
	No response	7	12.3
Marital status	Single	55	96.5
	Married/cohabitate	2	3.5
	Widow	0	0
	Divorced	0	0
Ever pregnant?	Yes	2	8
Females (N:25)	No	22	88
	No response	1	4
If ever pregnant, was the pregnancy intended?	Yes	1	50
	No	0	0
(N: 2)	No response	1	50
Became parent?	Yes	5	8.8
	No	36	63.2
	No response	16	28.1
Had STI other than HIV since the time of transition?	Yes	4	7
	No	47	82.5
	No response	6	10.5

More than half of the youth (69.6%) confirmed that they were sexually active at the time of the interview and 12.3% of the participants did not respond to this question. The majority (96.5%) were single, 3.5% were married or cohabitating with their partners. Among females (n=25), only 8% stated that they had ever been pregnant, 88% stated that they had never been pregnant and one (4%) did not respond. Among those who had ever been pregnant (n=2), one (50%) stated that the pregnancy was intended and the other one did not respond. Only 5 participants (8.8%) confirmed

that they had become parents (3 men and 2 women). 63.2% stated they had not become parents and 28.1 gave no response. Only 7% of the participants stated that they had STI (s) other than HIV since the time of transition, 82.5% stated that they did not, and 10,5% gave no response to this question.

IV.4. Clinical outcomes and retention in care

Table 3: Clinical outcomes and retention in care

Characteristics		N	%
Had opportunistic infection since the time of transition?	Yes	9	15.8
	No	46	80.7
	No response	2	3.5
Last viral load taken in pediatric HIV clinic before transition	≤ 20	42	73.7
	20-200	5	8.8
	≥ 200	10	17.5
First viral load after transition	≤ 20	41	71.9
	20-200	4	7.0
	≥ 200	12	21.1
Second viral load after transition	≤ 20	44	77.2
	20-200	2	3.5
	≥ 200	11	19.3
Third viral load after transition	≤ 20	48	84.2
	20-200	6	10.5
	≥ 200	3	5.3

Last physician follow-up	Within the past 3 months	38	66.7
	Within the past 6 months	17	29.8
	Within the past 12 months	0	0
	Not for over 1 year	2	3.5

At the time of the interview, the minority of the population (15.8%) stated that they had opportunistic infection (s) since the time of transition. 80.7% stated that they did not and 3.5% did not disclose this information.

Prior to transition, 82.5% of the youth were virologically suppressed (Viral load VL \leq 200 copies/ml), and 17.5% were not. Among those who were suppressed, 73.7% had an undetectable VL (\leq 20 copies/ml). With regard to the first VL taken in CHUK adult HIV clinic (taken 1 year after transition), 78.9% were virologically suppressed and 21.1% were not. Among those who were suppressed, 71.9% had an undetectable VL. With respect to the second viral load taken in adult care (taken 2 years after transition), 80.7% were virologically suppressed and 19.3% were not. Among those who were suppressed, 77.2% had an undetectable VL. Regarding the third viral load taken in the adult clinic (taken 3 years after transition), the large majority (94.7%) were virologically suppressed and only 5.3% were not. Among those who were suppressed, 84.2% had an undetectable VL.

At the time of the interview, the majority (96.5%) had last seen their physicians within the past 6 months and only 2 (3.5%) did not see their physicians for over 1 year.

Table 4: Comparison of means of viral loads using paired T-tests

	Mean	SD	95%CI		t value	P-value
			Lower	Upper		
Last viral load taken in pediatrics	4454.3	13975.7				

First viral load after transition	14855.7	86297.2	-32854.2781	12051.5283	$t_1: -0.928$	$P_1: 0.357$
Second viral load after transition	7110.4	27498.5	-10317.4762	5005.2036	$t_2: -0.695$	$P_2: 0.490$
Third viral load after transition	3867.9	14739.3	-4125.0324	5297.8826	$t_3: 0.249$	$P_3: 0.804$

Prior to transition, the mean of initial VL was 4454.3 (SD 13975.7). The mean of first VL taken in CHUK adult care had more than tripled up to 14855.7 (SD 86297.2), started decreasing again to near double of the initial mean of VL on the second testing up to 7110.4 (SD 27498.5), then came back to below the initial one at the third testing up to 3867.9 (SD 14739.3). The difference in means of viral loads was not found to be statistically significant using a paired sample t-test ($t_1=-0.9208$, $t_2=-0.695$, $t_3=0.249$; 56 df; P_1, P_2 and $P_3>0.05$).

CHAPTER V: DISCUSSION

With the introduction of HAART, many HIV-infected children are surviving till adulthood, warranting transition from pediatric to adult care. Since 2016, the pediatric HIV clinic at CHUK has been transferring adolescents and YA to the adult-centered clinic, but no evaluation of their outcomes has been done. Using a developed questionnaire, that was filled by participants during the semi-structured interviews, this study has determined those outcomes, both clinical and social. Even if only 57 youth participated (just 67% of those eligible), the results underline various general points in post-transition care.

V.1. Demographics and socio-economic status of the participants

This study showed that at the time of transition, the median age was 19, which is nearly the same as 18 found in many countries including Nigeria (19), Brazil (9), and Canada (21). We found that more than half of the participants (56.1%) were male. Studies done in Cambodia and Thailand found similar results with male predominance at 55.2% (22) and 54% (32), respectively. On the other hand, this is different from what was found in many other studies. According to UNICEF in 2014 (4)(9), HIV was more prevalent in adolescent females than males in Sub-Saharan Africa. The same applies to Rwanda, according to RDHS 2014 (6). In 2012, globally, and mainly in Sub-Saharan Africa, nearly two-thirds of all new HIV infections in adolescents were among females (18). This discrepancy may be explained by the fact that our population is made up of the youth that probably was perinatally infected, that has been followed up since early childhood till the time of transition.

The majority (89.5%) were living in Kigali City where our study site (CHUK) is located possibly because the follow up is easier when done near the place of residency, and no one was living in Southern province probably because CHUB (University Teaching Hospital of Butare), another tertiary level hospital operating as CHUK is located there, easing the follow up of the population.

At the time of the interview, the majority of the participants (89.5%) were still living with at least one parent or relatives. Although we have no corresponding data in Africa, Fatima Kakkar et al. in Canada (21) and Graham Toth in Cambodia (22) found very close results (92% and 89.9%, respectively). Most of the participants (96.4%) had obtained a secondary school degree or higher.

This differs from what was found in the aforementioned studies, where 52% (21) and 51.3% (22) of the respondents had obtained at least a high school degree, respectively. This high education rate can be attributable to the fact that Rwanda has implemented the compulsory “12 Years Basic Education” program, which facilitates all children to cover primary and secondary education.

More than half of the respondents (61.4%) had no job. Even though we have no similar studies in our settings for comparison, this unemployment rate is higher than the one found by Fatima Kakkar et Al. in Canada, where only 17% of the youth had no job. This dissimilarity may be explained by the high unemployment rate in low- and middle-income countries like Rwanda.

We found that only 14% of the youth had no health insurance. These results are alike the ones reported in a policy statement by the American Academy of Pediatrics, where 15% of the transitioned youth had no health insurance (15).

V.2. Sexual and reproductive health

In our study, more than half of the youth (69.6%) confirmed that they were sexually active. Scovia Nalugo et Al. in Uganda found that more than a third (34.1%) of perinatally infected youth were sexually active (23). We could not find an explanation for this dissimilarity.

Among females, only two (8%) stated that they had ever been pregnant, and 4% did not respond. Among those who had ever been pregnant, 50% stated that the pregnancy was planned. Kakkar et Al. in Canada found the same proportion (21).

Only 7% of the participants stated that they had STI (s) other than HIV since the time of transition. This is nearly the same as the results of Maria Trent et Al. in the USA where 1.4% of the participants had STI (24), although this study was done in settings different from ours and the participants were only females.

V.3. Clinical outcomes and retention in care

The minority of our population (15.8%) stated that they had opportunistic infection (s) since the time of transition. This rate is higher than the one found in a study done by Mamaru Wubale Melkamu et al. in Ethiopia (9.7%), determining the prevalence of OIs in HIV-infected children (25). Another study done by Nebiyu Dereje et al. in Ethiopia demonstrated that the prevalence of OIs among HIV-infected adults on HAART was higher (29.2%) than the one found in our study

(26). Unfortunately, we could not get data demonstrating the prevalence of OIs in HIV-infected adolescents and YA. The dissimilarities in the above results may be due to the difference in age of the population.

Prior to transition, 82.5% of the youth were virologically suppressed compared to 78.9% and 80.7% who were virologically suppressed on first and second testing in HIV adult clinic, respectively. This decrease in VL suppression at the first testing in the HIV adult clinic can be explained by the fact that the youth might have had difficulties adapting to a new environment. At the second testing in the adult HIV clinic, the VL suppression started to increase again, reaching 94.7% at the third testing. Similar to our study, M. Mburu et Al. in Kenya found an increase of VL suppression from 65% to 72% (33).

We found that prior to transition, the mean of initial VL was 4454.3 (SD 13975.7). The mean of first VL taken in CHUK adult care had more than tripled up to 14855.7 (SD 86297.2), started decreasing again to near double of the initial mean of VL on the second testing up to 7110.4 (SD 27498.5), then came back to below the initial one at the third testing up to 3867.9 (SD 14739.3). Unfortunately, the difference in means of those viral loads was not found to be statistically significant, which is similar to findings of the study done by M.Mburu et. Al in Kenya (33).

The retention in care, defined as at least one physician follow up within 6 months of the interview was high (96.5%) in our study as it was in a study done by Brian C. Zanoni in South Africa, where 95% of the youth attending the adolescent clinic were still engaged in care (30). Only two participants (3.5%) were lost to follow-up.

CHAPTER VI: CONCLUSION AND RECOMMENDATIONS

VI. 1: Conclusion

Our study demonstrated that the median age at transition was 19. Most of the participants had obtained a secondary school degree or higher probably because Rwanda has implemented the compulsory “12 Years Basic Education” program and the minority had no health insurance. More than half of the youth confirmed that they were sexually active and among females, only 8% stated that they had ever been pregnant. The viral load suppression decreased at 1-year post-transition possibly because the youth has had difficulty adapting. It then started to increase so that at 3 years post-transition, it was higher than before transition. We found a low rate of STIs and opportunistic infections, and a high rate of retention in care among our participants. Only 3.5% of the participants were lost to follow-up, likely due to the emphasis of the government of Rwanda on HIV prevention and management.

VI. 2: Strength and limitations

From what we know, this is the first study done in Rwanda looking at the outcomes of HIV-infected adolescents and YA post-transition from pediatric to adult care.

This study was done in only one health facility and may not reveal the whole country’s situation.

If the viral load is below 20, the precise number is not reported. In our study, 20 was taken for each viral load below or equal to 20. This would have given wrong numbers; hence it is hard to conclude on the null hypothesis found on the difference in means of viral loads before and after transition.

VI. 3: Recommendations

-Recommendation to CHUK

To train health care providers working in pediatric and adult HIV clinics for better success of transition, and hence, good outcomes post-transition.

-Recommendation to the Ministry of Health

To develop a transition protocol including the follow-up process which will be used by health care providers taking care of HIV-infected adolescents and YA.

To train health care providers working in pediatric and adult HIV clinics on the transition process for better success.

-Recommendations to the researchers

To conduct a study on outcomes of HIV-infected adolescents and YA at a national level, which will help to have more information.

To conduct a study determining the factors associated with a low rate of viral load suppression in HIV-infected adolescents and YA post-transition.

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APPENDIX

Appendix 1: DATA COLLECTION SHEET

Topic: “Social and clinical outcomes of HIV-infected adolescents and young adults transitioned from pediatric to the adult clinic at CHUK”

1. Participant identification and demographic data

Date:/...../.....

Participant code:

Age (in year):

Age range: Adolescent (10-19 years) Young adult (20-39 years)

Sex: Male Female

Place of residence: Kigali North South East
 West Other: specify

District:

Nationality: Rwandese Other: specify.....

2. Socio-economic data

Parents alive?: Both parents alive Mother alive Father alive
 No parent alive

Lives with: Alone Biological parent(s) Relative(s)
 Partner Others: specify

Presently in school setting: Yes No

Highest level of education: Illiterate Primary Secondary
 University

Employment: Job No job

Ubudehe category: One Two Three Four

Medical insurance: Community based Health Insurance Other insurance
 No insurance

3. Sexual and reproductive health

Sexually active?: Yes No No response

Marital status: Single Married/cohabitate Widow Divorced

Ever pregnant? (females): Yes No No response

If yes, was the pregnancy intended? Yes No No response

Became parent? Yes No No response

Had sexually transmitted infection (s), other than HIV, since the time of transition: Yes
 No No response

4. Clinical outcomes

Last viral load taken in pediatric HIV clinic before transition: copies/ml

First viral load after transition: copies/ml

Second viral load after transition: copies/ml

Third viral load after transition: copies/ml

Had opportunistic infection (s) since the time of transition? Yes No
 No response

Last physician follow up: Within past 3months Within past 6 months
 Within past 12 months Not for over 1 year

Appendix 2: CONSENT FOR PARTICIPATION IN A STUDY ON “Social and clinical outcomes of adolescents and young adults with HIV transitioned from pediatric to adult-centered care at CHUK”

This Informed Consent Form has two parts:

- Information Sheet (to share information about the research with you)
- Certificate of Consent (for signatures if you agree to take part)

PART I: Information Sheet

I am Joselyne Uwinkesha. We are doing research on social and clinical outcomes of adolescents and young adults (YA) transitioned from pediatric to adult HIV clinic at the University Teaching Hospital of Kigali (CHUK). I am going to give you information and invite you to be part of this research.

HIV is a global burden. With the use of Highly Active Antiretroviral Drugs, many HIV-infected adolescents and YA are surviving till adulthood, necessitating transition from pediatric to adult-centered care. The reason we are doing this study is to determine the social and clinical outcomes of adolescents and YA post-transition to adult care.

This research will involve an in-person structured interview and participant chart review.

We are inviting all HIV-infected adolescents and YA who were transitioned from CHUK pediatric to adult care between January 2016 and December 2019 to participate in this study.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Whether you choose to participate or not, all services you receive at this clinic will continue and nothing will change.

If you choose to participate in this study, you will receive no money or other benefits. This study will cause no harm to you. The information you will give will be kept confidential. No one but the researchers will be able to see it, and your identification will be coded.

You do not have to take part in this research if you do not wish to do so. You may also stop participating in this research at any time you choose. It is your choice and all your rights will still be respected.

If you have questions, you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact any of the following:

Dr. Joselyne Uwinkesha, lynejojo.ju@gmail.com, +250788636312

Dr. Febronie Mushimiyimana, mushime@gmail.com, +250788752779

This proposal has been reviewed and approved by the IRB of CMHS/UR and the Research Ethics Committee (REC) of CHUK, which are committees whose task is to make sure that research participants are protected from harm. If you wish to find more about the IRB of CMHS/UR, contact “Dr. Stefan Jansen, sjansen.ur@gmail.com, +250784575900”. For REC of CHUK, you may contact “Dr. Emmanuel Rusingiza, erkamanzi@gmail.com, +250785466254”.

PART II: Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Name of Participant

Signature of Participant

Caretaker’s name (if the participant is below 18 years)

Signature of the caretaker

Date

If illiterate

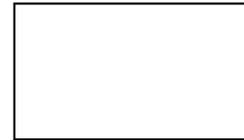
I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness

Thumbprint of
participant

Signature of witness.....

Date



Statement by the researcher

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the aspects of our research.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability.

I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Name of Researcher

Signature of Researcher

Date

Appendix 3: AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI KU BUSHAKE

Inyito y’ubushakashatsi: Social and clinical outcomes of adolescents and young adults with HIV transitioned from pediatric to adult-centered care at CHUK.

Aya masezerano afite ibice bibiri:

- Ibisobanuro bihabwa abasabwa kujya mu bushakashatsi
- icyemezo cyo kwemera kujya mu bushakashatsi

IGICE CYA 1: Ibisobanuro

Nitwa Joselyne Uwinkesha. Turi gukora ubushakashatsi ku mibereho y’urubyiruko rwanduye agakoko gatera SIDA rwavanywe ahakurikiranirwa abana rukajyanwa ahakurikiranirwa abakuze ku bitaro bikuru bya kaminuza bya Kigali (CHUK). Ngiye kubasobanurira hanyuma mbasabe ko mwajya muri ubwo bushakashatsi.

Agakoko gatera SIDA ni icyorezo cyugarije isi. Gukoresha imiti igabanya ubukana bwa SIDA byatumye benshi mu rubyiruko rwanduye agakoko gatera SIDA babasha gukura, bigasaba ko babohereza aho bakurikirana abakuze. Turi gukora ubushakashatsi kugira ngo tumenye imibereho y’urubyiruko rwanduye agakoko gatera SIDA rwavanywe ahakurikiranirwa abana rukajyanwa ahakurikiranirwa abakuze ku bitaro bikuru bya kaminuza bya Kigali (CHUK).

Muri ubu bushakashatsi tuzaganira n’abazabujya mo ndetse turebe no mu mafishi yabo.

Turabasa urubyiruko rwose rwanduye agakoko gatera SIDA rwavanywe ahakurikiranirwa abana rukajyanwa ahakurikiranirwa abakuze ku bitaro bikuru bya kaminuza bya Kigali (CHUK) hagati ya Mutarama 2016 n’Ugushyamba 2019 kujya muri ubu bushakashatsi.

Kujya muri ubu bushakashatsi ni ubushake. Ufite uburenganzira bwo kubujya mo cyangwa kutabujya mo. Wahitamo kubujya mo cyangwa kutabujya mo, serivisi hahabwaga kuri ibi bitaro uzakomeza kuzihabwa nta gihindutse.

Nuhita mo kujya muri ubu bushakashatsi, nta mafaranga cyangwa ikindi gihembo uzahabwa. Ubu bushakashatsi nta ngaruka buzakugira ho. Amakuru tuzakura mo azagirwa ibanga. Usibye abakora ubu bushakashatsi, nta wundi uzayabona kandi nta bikuranga bizagaragara.

Ntutegetswe kujya muri ubu bushakashatsi niba utabishaka. Ushobora kubuva mo igihe cyose ubishatse. Ni amahitamo yawe kandi uburenganzira bwawe buzubahirizwa.

Uramutse ufite ibibazo, wabibaza ubu cyangwa nyuma, kabone n'iyi ubushakashatsi bwaba bwaratangiyeye. Wifuje kubaza ibibazo nyuma wakwitabaza aba bakurikira:

Dr. Joselyne Uwinkesha, lynejojo.ju@gmail.com, +250788636312

Dr. Febronie Mushimiyimana, mushime@gmail.com, +250788752779

Imbanzirizamushinga y'ubu bushakashatsi yaseseguwe ndetse yemezwa na komite ishizwe ubuziranenge bw'ubushakashatsi (IRB) muri Kaminuza y'u Rwanda, Ishuri ry' Ubuvuzi (UR/CMHS) hamwe na komite ishinzwe ubuziranenge bw'ubushakashatsi (REC) mu bitaro bya CHUK. Izi komite ziharanira uburenganzira bw'abemeye kugira uruhare mu bushakashatsi.

Wifuzaga ibindi bisobanuro kuri IRB ya UR/CMHS wakwitabaza "Dr. Stefan Jansen, sjansen.ur@gmail.com, +250784575900". Ku bijyanye na REC ya CHUK yakwitabaza "Dr. Emmanuel Rusingiza, erkamanzi@gmail.com, +250785466254

IGICE CYA 2: Kwemera kujya mu bushakashatsi

Nasomye neza amakuru yatanzwe haruguru, cyangwa se nayasomewe. Nabonye umwanya wo kubaza ibyo ntasobanukiye kandi ibisobanuro nahawe byanyuze. Nemeye ku bushake kujya muri ubu bushakashatsi.

Amazina y'uwinjijye mu bushakashatsi

Umukono

Amazina y'umuhagarariye (niba ari munsu y'imyaka 18)

Umukono

Italiki

Niba uwinjiye mu bushakashatsi atazi gusoma no kwandika

Ndemeza ko uyu ugiye kwinjira mu bushakashatsi yasomewe neza aya masezerano, kandi ko yahawe umwanya wo kubaza ibibazo. Ndemeza ko yemeye kwinjira mu bushakashatsi ku bushake.

Amazina y’umuhamya

Igikumwe cy’uwinjiye

mu bushakashatsi

Umukono



Italiki

Ijambo ry’ukora ubushakashatsi

Nasomeye neza kandi nakoze uko nshoboye kose kugira ngo uwinjiye muri ubu bushakashatsi asobanukirwe ibikubiye muri aya masezerano.

Ndemeza ko uwinjiye mu bushakashatsi yahawe umwanya wo kubaza ibibazo kandi ko yabonye ibasonuro by’ukuri mu bushobozi bwanjye. Ndemeza ko uyu agiye kwinjira mu bushakashatsi ku bushake.

Amazina y’ukora ubushakashatsi

Umukono

Italiki

Appendix 4: IRB of CMHS/UR approval



UNIVERSITY of
RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES
DIRECTORATE OF RESEARCH & INNOVATION

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 1st /March /2021

Dr. Joselyne UWINKESHA
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 062/CMHS IRB/2021

Your Project Title "*Social And Clinical Outcomes Of Adolescents And Young Adults With HIV Transitioned From Pediatric To Adult Centered Care At Kigali University Teaching Hospital (CHUK)*" has been evaluated by CMHS Institutional Review Board.

Name of Members	Institute	Involved in the decision		
		Yes	No (Reason)	
			Absent	Withdrawn from the proceeding
Prof Kato J. Njunwa	UR-CMHS	X		
Dr Stefan Jansen	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS	X		
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS		X	
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 29th January 2021, **Approval has been granted to your study.**

Please note that approval of the protocol and consent form is valid for **12 months**.

Email: researchcenter@ur.ac.rw

P.O Box 3286 Kigali, Rwanda

www.ur.ac.rw

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 1st March 2021

Expiration date: The 1st March 2022



Dr Stefan Jansen
Ag. Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR

Email: researchcenter@ur.ac.rw

P.O Box 3286 Kigali, Rwanda

www.ur.ac.rw

Appendix 5: CHUK REC approval



CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Ethics Committee / Comité d'éthique

5th Mar,2021

Ref.:EC/CHUK/026/2021

Review Approval Notice

Dear Joselyne UWINKESHA,

Your research project: **"Social and clinical outcomes of adolescents and young adults with HIV transitioned from pediatric to adult centered care at University Teaching Hospital of Kigali (CHUK) "**

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 5th Mar,2021 to evaluate your request for ethical approval of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your research project.

You are required to present the results of your study to CHUK Ethics Committee before publication by using this link:www.chuk.rw/research/fullreport/?appid=326&&chuk.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

Dr Emmanuel Rusingiza Kamanzi
The Chairperson, Ethics Committee,
University Teaching Hospital of Kigali



Scan code to verify.

" University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations "