



THE AFRICAN NETWORK FOR THE CARE OF
CHILDREN AFFECTED BY HIV/AIDS

[ANECCA]

ASSESSMENT OF NATIONAL POLICIES & GUIDELINES RELATED TO PAEDIATRIC & ADOLESCENT HIV CARE IN UGANDA

REPORT



■ NOVEMBER 2016



 **The Global Fund**
To Fight AIDS, Tuberculosis and Malaria

CONTENTS

Acronyms and abbreviations	ii
Operational Definitions	iv
List of figures, tables, graphs and pictures	v
Acknowledgements	vi
Summary of consultancy ToR	vii
Executive Summary	viii
Section One: Introduction and Background	
1.1 Introduction to Paediatric and Adolescent HIV	1
1.2 Background to HIV/AIDS Response in Uganda	3
1.3 Problem Statement	4
1.4 Rationale for review of policies, guidelines and strategies	5
1.5 Objectives of the review	7
Section Two: Methodological Approaches	
2.1 Introduction	7
2.2 Study Design	7
2.3 Quality Assurance	10
2.4 Ethical Considerations	10
2.5 Study Limitations	11
Section Three: Results	
3.1 Introduction	12
3.2 Foundation for paediatric and adolescent HIV policies and guidelines	12
3.3 Stakeholder Awareness of and participation in Paediatric and Adolescent HIV policies	14
3.4 Strengths and Gaps in National HIV Policies, Guidelines and Strategies in Uganda for provision of quality services for children and adolescents living with HIV	15
4.0 Discussion and Conclusion	32
5.0 Recommendations	34
References	36
Annexes	37

LIST OF FIGURES & TABLES

Figure 1.1 Uganda Population Pyramid 2012/2013	1
Figure 2: Percent change in new HIV infections among children (0-14 years), Eastern and Southern Africa 2010-153	
Figure 3.1 Stakeholder Perception of Comprehensiveness of Uganda's Policy/Guidelines for Children and Adolescents living with HIV	20
Table 2.1 List of regions study districts and category of Key Informants	7
Table 3.1 Stakeholder perceptions of Key Strengths in Uganda's paediatric and Adolescent HIV Policies	19
Table 3.2 Key policy gaps and suggestions for Paediatric/adolescent HIV services in Uganda by thematic area	22
Table 3.3 Best Practices in policy implementation for Paediatric and Adolescent HIV services in Uganda	26
Table 3.4 Key policy implementation challenges for Paediatric and Adolescent HIV services in Uganda	27
Table 3.5 Opportunities to provision of quality services for children and adolescents living with HIV	31

Design/ Layout

tuchecommunication@gmail.com
+256 777 968 997, +256 706 135 361

ACRONYMS AND ABBREVIATIONS

ADFHS	Adolescent Friendly Health Services	IPV	Intimate Partner Violence
ADH	Adolescent Health	IYCF	Infant and Young Child Feeding
ADPs	AIDS Development Partners	LGDPG	Local Government Planning Guidelines
AIDS	Acquired Immunodeficiency Syndrome	M&E	Monitoring and Evaluation
AHSPR	Annual Health Sector Performance Report	MARPs	Most At Risk Populations
ANC	Antenatal Care	MCH	Maternal and Child Health
ANECCA	African Network for the Care of Children Affected by HIV/AIDS	MoH	Ministry of Health
ART	Antiretroviral Treatment	MTCT	Mother To Child Transmission
CDC	Centres for Disease Control	NDP	The National Development Plan
CSOs	Civil Society Organisations	NDP	National Development Plan
CSOs	Civil Society Organizations	NGOs	Nongovernmental organizations
DD	Demographic Dividend	NHP	National Health Policy
DFID	Danish Fund for International Development	NPAP	National HIV and AIDS Priority Action Plan
DNA	Deoxyribonucleic Acid	NSP	National Strategic Plan for HIV/AIDS
EAC	East African Community	NTLP	National Tuberculosis and Leprosy Program
ECD	Early Childhood Development	PC	Partnership Committee
eMTCT	Elimination of Mother to Child Transmission	PCR	Polymerase Chain Reaction
FANTA	Food and Nutrition Technical Assistance III Project	PHAs	People having AIDS
FBOs	Faith-Based Organizations	PITC	Provider Initiated Counselling and Testing
FGM	Female Genital Mutilation	PLHIV	People Living With HIV
FP	Family Planning	PM	Partnership Mechanisms
HBHCT	Home Based HCT	PMTCT	Prevention of Mother To Child Transmission
HCT	HIV Counseling and Testing	PTIP	prevention of Trafficking in Persons
HDPs	Health Development Partners	PWD	Persons With Disabilities
HIV	Human Immune Deficiency Virus	RH	Reproductive Health

RTC	Routine HIV Testing and Counseling
SCEs	Self-coordinating Entities
SDPG	Sector Development Planning Guidelines
SDPs	Service Delivery Points
SGBV	Sexual and Gender Based Violence
SMC	Safe Male Circumcision
SRH	Sexual and Reproductive Health
STIs	Sexually Transmitted Infections
TB	Tuberculosis
TWGs	Technical Working Groups
UAC	Uganda AIDS Commission
UAIS	Uganda AIDS Indicator Survey
UBOS	Uganda Bureau of Statistics
UCG	Uganda Clinical Guidelines
UMTAC	Uganda Medicines and Therapeutics Advisory Committee
UNICEF	United Nations Children Fund
UNMHCP	Uganda National Minimum Health Care Package
UPE	Universal Primary Education
UPHIA	Uganda Population HIV Impact Assessment
USAID	United Nations, U.S. Agency for International Development
VCT	Voluntary Counseling and Testing
VHTs	World Health Organization
WHO	Village Health team
GGE	General Government Expenditure
NHA	National Health Accounts



OPERATIONAL DEFINITIONS

○ Adolescents:

Adolescents are defined as persons between the ages of 10-19 years (WHO). This assessment focused on this particular population.

○ Health:

Refers to a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.



ACKNOWLEDGEMENTS

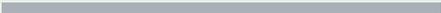


The report on **“Assessment of National Policies & Guidelines and Training Needs Related to Paediatric & Adolescent HIV Care in Uganda”** was made possible with support from the Ministry of Health, the African Network for the Care of Children Affected by HIV/AIDS (ANECCA), The Global Fund to Fight AIDS, Tuberculosis and Malaria and other partners in Adolescent and Paediatric Health.

We would like to register our appreciation to ANECCA team ANECCA team lead by Dr. Denis Tindyebwa, the consultants who compiled the report, Dr. Hizaamu Ramadhan and Dr. Rujumba Joseph. We further acknowledge the technical guidance provided by Dr. Cordelia Katureebe **from the** Ministry of Health. More gratitude extends to the field research team, the data management team and the respondents at national and district level for their efforts that saw this report materialize.

Finally, we acknowledge the financial support extended to ANECCA by the Global Fund to Fight AIDS, Tuberculosis and Malaria to actualize this study.

Professor Anthony Mbonye
Ag. Director General of Health Services



SUMMARY OF CONSULTANCY TOR

The main purpose of the assignment was to review and assess national policies and guidelines in Uganda and identify gaps in order to improve coverage and quality of services for children and adolescents living with HIV. The specific objectives were:



EXECUTIVE SUMMARY

Uganda's population continues to grow currently at rate of 3.0 percent and is estimated at 34.9 million where 70% of the total population is less than 25 years. Adolescents constitute 25.6% of the population, 10-14 years (14.2%), 15-19 years (11.4%) and children below 18 years constitute 56.7% of the total population. Uganda has one of the youngest and most rapidly growing populations in the world of which about 48.7 percent is made up of child dependents under 15 years. In line with the Sustainable Development Goals, Uganda Vision 2040 has pronounced harnessing the "demographic dividend" as one of the key strategies for realizing the social and economic transformation envisaged by the year 2040.

Despite the rapid scale-up of prevention of mother-to-child, transmission of HIV (PMTCT) programs in Uganda over the past 10 years, there are still an estimated 20,600 children throughout the country infected with the virus during pregnancy, childbirth and breastfeeding. Without effective anti-retroviral treatment (ART), an estimated one-third of infected infants will die by one year of age, and about half will die by two years of age. The positivity rate for EID has drastically reduced to 3.5% by June 2016 from 5.3% by March 2014 for all infant HIV tests. The number of Dry Blood Spot (DBS) samples tested also increased

from 13,277 in 2012 to 58,894 in 2016 and the prevalence of HIV positive samples has progressively declined from 9.5% in 2012 to 3.5% in June 2016. In Uganda, the estimated number of persons living with HIV in 2015 was still high at 1.5 million. Positive progress was noted in the further decline in AIDS-related deaths to 28,000 from 31,000 in 2014, further reduction in the number of New HIV infections among all age groups to 83,000 in 2015 from 95,000 in 2014 and the much more significant and drastic reduction in the number of new infections among children of 3500 by end of 2015.

There are still gaps in HIV testing/ diagnosis/ early infant diagnosis; gaps in linkage of the HIV positive children to care and ART initiation; and in retaining those on ART despite the roll out of paediatric ART to lower level facilities in Uganda. Of the children aged 2 to 5 years that tested HIV positive in 2015, those initiated on ART were only 60%. Among children under 2 years initiated on ART in 2015, 23% were lost to follow up in the first year. For children under 5 years, the viral suppression rates were only 69%. Only 39% of the health facilities had adolescent friendly services. Inadequate policy frameworks for paediatric and adolescent HIV care and treatment is one of the factors identified for the limited access to HIV treatment, care and support by children and

adolescents, in Uganda. This justified the need for a comprehensive policy analysis underpinned by this report.

Objectives of the review

1. To review and assess existing National Paediatric & Adolescent HIV Policies and Guidelines in Uganda with a view to identify strengths and gaps for provision of quality services for children and adolescents living with HIV
2. To document best practices and opportunities within National Policy Frameworks, Strategies and Guidelines for provision of quality services for children and adolescents living with HIV in the target countries
3. To make recommendations that inform the development of national plans to promote the adoption and implementation of policies that increase coverage and quality of paediatric and adolescent HIV care, treatment and support
4. To facilitate national stakeholder's consultations to develop national action plans to bridge the gaps in the policies and guidelines

Methodology

This was an exploratory cross-sectional study that employed qualitative methods of data collection conducted between the July and October 2016 in 10 districts distributed in 10 regions of Uganda. Forty key informants at health facility, district and national levels were selected using criterion sampling to provide information concerning policy and service delivery issues affecting adolescents and children living with HIV. Data collection used a mix of methods including desk-based review and key informant interviews. Key Informant Interviews were analyzed via content thematic approach and coding was done using NVivo software version 9. The findings from KIIs at different levels were triangulated. Selected quotations from respondents and tables reflecting issues of interest were used in presentation of study results. Quality assurance measures included training research assistants, pretesting tools and field supervision during data collection. Ethical approval for the study was obtained from the Makerere University School of Public Health Higher Degrees, Research and Ethics Committee and Uganda National Council of Science and Technology. All study participants read the informed consent form; their issues were responded to by the research assistant and signed the informed consent form.

Study Limitations

The study did not directly capture perspectives of children and adolescents living with HIV and their

caregivers who could have provided lived experiences on how policies are translated into action, major implementation challenges and suggestions for improvement. However, stakeholder perspectives we obtained in this study provide rich insights about the policies and the changes needed.

Key findings

Foundation for paediatric and adolescent HIV

legislation: The Uganda Constitution (1995), the *Penal Code Act (1995)*, the *Children's Act (1997)*, the *HIV and AIDS prevention and control act (2014)*, *Education Act (2008)*, *National Council for Children Act* collectively identify children and adolescents as important constituencies of the Uganda population critical in contributing to national development. They give prominence to protection and promotion of their health and well-being in order to enable them realize their potentials and participate in decisions that impact on their lives within the precincts of Government programs and policies.

Policies, guidelines and strategies that address adolescents and paediatric HIV:

The specific policy identified was the Uganda HIV Counseling and Testing policy 3rd edition (2010) and the Guidelines developed to operationalize policies, and with respect to adolescent and paediatric HIV included; National Antiretroviral Treatment Guidelines for Adults, Adolescents, and Children (2008), National Implementation Guidelines for HIV counseling and testing in Uganda (2010), Uganda Addendum-to-National-ART-Guidelines (2013), Uganda Clinical Guide-

There are still gaps in HIV testing/ diagnosis/ early infant diagnosis

60%

- HIV positive children 2-5 yrs initiated on ART

23%

- Children under 2 years initiated were lost to follow up in the first year

69%

- Viral suppression rates among children <5 years

39%

- Health facilities with adolescent friendly services

lines (2012), Adolescent Health Policy Guidelines and Service Standards (May 2011), World Health Organization, (2013) consolidated guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection; Recommendations for a Public Health Approach and Guidelines for the management of sexually transmitted infections (2003). The Strategies that guide programming for the different Government sectors included the National Development Plan II (2015), National HIV/AIDS Strategic Plan-2015/2016-2019-2020, Health Sector Development Plan (2015) and the National Adolescent Health-Strategy (2011).

Stakeholder Awareness of and participation in Paediatric and Adolescent HIV policies: Overall, most study participants noted that Uganda had most policies for the provision of HIV testing, care and treatment for children and adolescents and these were regularly updated. The most commonly mentioned policies/guidelines in relation to paediatric and adolescent HIV include: the Uganda HIV Counseling and Testing Policy, Prevention of Mother to Child Transmission of HIV policy, Uganda National Antiretroviral Treatment Guidelines and the Adolescent Health Policy. With exception of the Adolescent Health policy which has particular focus on adolescents, other policies and guidelines were general to HIV. Awareness of paediatric and adolescent HIV related policies was high among District Health Team members and national level informants directly involved in planning and provision of paediatric and adolescent HIV services. On the contrary, most narratives of health workers and officials from

education and community development departments reflected lack of awareness about paediatric and adolescent HIV policies and their provisions. The limited awareness among frontline health care workers raises questions on how such health workers can effectively translate policies to actions. In addition, the limited awareness of such policies by officials from other sectors like education and community development is a potential limitation to realizing the needed multi-sectoral contributions in the design and delivery of paediatric and adolescent HIV services in Uganda.

Policy development process: All national level stakeholders acknowledged that although the process of policy development involved major stakeholders such as the ministries of health, academia and UN agencies. There was minimal involvement of gender, education, justice sectors as well as health services the consumers.

Strengths in Paediatric and Adolescent HIV Policies, Guidelines and Strategies in Uganda: It was stated that Uganda has most policies needed for the delivery of integrated and effective paediatric HIV services. The major strength in Uganda's policies mentioned were; paediatric and adolescent HIV prevention, testing and care are integrated in national policy and strategy documents. Provision for test and treat especially for children and some adolescents (0-14 years) as well as decentralized service delivery was other strengths. These views were further supported by the findings of the desk review under the

specific policies, guidelines and strategy documents discussed hereunder.

Stakeholder Perception on Comprehensiveness of Uganda's Policy/Guidelines: Most national level stakeholders perceived Uganda's HIV testing and treatment policies and guidelines to be comprehensive. The most highly rated policy guidelines in terms of comprehensiveness were care and treatment guidelines for children at 83% while HIV testing and counseling guidelines for Children (74%) and for Adolescents (67%) had the least rating. Indeed, some study participants especially those at national level noted that the Uganda HTC policy and guidelines were being revised to align them with emerging evidence, new WHO guidance and address gaps in counseling and testing children for HIV.

Stakeholder perceived Policy gaps for provision of quality services: District and national level stakeholders identified critical policy gaps that need to be addressed to further strengthen Uganda's paediatric and adolescent HIV services. The health facility stakeholders identified mainly challenges related to implementation of policies and guidelines. Lack of clear guidance on disclosure of HIV status to children and adolescents as well as weak linkages between HIV testing and treatment services were key gaps identified by health workers in relation to paediatric and adolescent HIV services. In addition, lack of national and district specific targets for HIV testing and treatment services for children and adolescents; weak/no provisions for support at community, school and during transition from child to

adolescent and adult clinics were also identified as limitations. Lack of guidance on the appropriate age to disclose HIV status to children and adolescents as well the process of disclosure; lack of counselors in the ministry of health structure; unknown burden of stigma among children and adolescents as well as weak interventions to address it were key gaps in paediatric and adolescent HIV care policies.

Best practices in Implementation of National paediatric and adolescent HIV Policy Frameworks and Guidelines in Uganda: The main best practices in relation to implementation of paediatric HIV policies were; institutionalization of mother baby care points at health facilities to address needs of both the mother and baby under the eMTCT programme. The policy of test and treat involving initiation and continuation of ART treatment for pregnant and lactating mothers and children under 15 years living with HIV was another best practice which contributed to increased access to treatment for women and children, and reduction in mother to child transmission of HIV in Uganda. The 'know Your Child's HIV Status Campaigns' where parents and caregivers are sensitized and mobilized to take their children for HIV testing as another best practice. Continuing Medical Education and mentorships at health facilities were identified as good avenues used for policy dissemination. The major gap is that most of these promising initiatives are not implemented on scale, were largely donor dependent and implementers do

not have standard guidelines of how such initiatives are initiated and supported. The use of Adolescent support groups and peers in the delivery of HIV prevention, testing and support services especially at large HIV service providers were key promising initiatives.

Paediatric and Adolescent HIV Implementation challenges: Policies and guidelines were inadequately dissemination to frontline health workers and communities which was a major barrier to policy implementation. In addition, the policy documents were few, bulky and highly technical thus posing a challenge of interpretation by frontline workers. The frequent changes in policies and guidelines also made effective dissemination of policies a challenge. There was low demand and utilization of paediatric and adolescent HIV services by communities which was linked to limited community awareness about paediatric and adolescent HIV care and health facility challenges such as lengthy waiting time at health centres and stock-out of drugs. Stigma at family and community levels was another challenge to effective implementation of HIV policies. Other challenges included stock out of critical supplies for paediatric and adolescent HIV care, limited space and other facilities to ensure provision of adolescent HIV services was another challenge to effective policy implementation and inadequate staff, skill and knowledge gaps among health workers and lack of counselors in the Ministry of Health staff structure.

Opportunities within National Policy Frameworks, Strategies and Guidelines for provision of quality services for children and adolescents living with HIV:

- Availability of HIV implementers and donors willing to support
- National policies and guidelines are being updated (HTS, ART guideline)
- The Ministry of Health has developed an Adolescent HIV training Curriculum which can be used strengthening capacity of service providers
- Trainers of Trainers for Adolescent HIV training Curriculum
- Paediatric and Adolescent HIV coordination team at the Ministry of Health for coordination technical supervision and support
- Some Implementing partners such as Baylor Uganda, Mild May, TASO have expertise in use of peer support groups and use of peers in provision of adolescent HIV care services

- Implementing partners have developed training packages for building the capacity of community support structures
- M&E indicator framework being developed by MoH & ANECCA with support from UNICEF – can form a basis
- Ongoing National HIV survey can provide a basis for knowing the burden of paediatric and adolescent HIV as a basis for setting district and national targets
- Integrate sexual and gender-based violence (SGBV) prevention and human rights into HIV prevention and care programming.
- Work with partners to come up with clear national and district paediatric and adolescent HIV burden and targets to guide this process.
- Institutionalize the paediatric and adolescent HIV technical and coordination team to ensure continued visibility, leadership and coordination policy and guidelines implementation, monitoring, review and evaluation.
- Increase community awareness and advocacy for paediatric and adolescent HIV so as to increase demand for these services.
- Ensure that HIV and AIDS specifically paediatric and adolescent components are mainstreamed in the curriculum of all Education Institutions and at all levels in Uganda.
- Advocate for revision of public service structures and institutionalize critical staff and positions at health facilities, line ministries, departments, agencies and districts.

Recommendations

The ministry of health should:

- Update key policies and guidelines especially ART treatment and HIV Testing policies and guidelines to address the identified policy gaps along the HIV continuum.
- Widely disseminated HIV policies and guidelines beyond the health sector and in user friendly formats including summaries, policy pull-outs and job Aids.
- Strengthen the role of private health care providers in the design and implementation of paediatric and adolescent HIV policies and guidelines by promoting implementation of the public private partnership in the delivery of HIV and AIDS services.
- Advocate for allocation of more financial and human resources to the health sector to ensure availability of adequate health workers and supplies.
- Expand availability and capacity of laboratories at different levels for effective delivery of paediatric and adolescent HIV and AIDS services.

SECTION ONE

INTRODUCTION & BACKGROUND

1.1 Introduction to Paediatric and Adolescent HIV

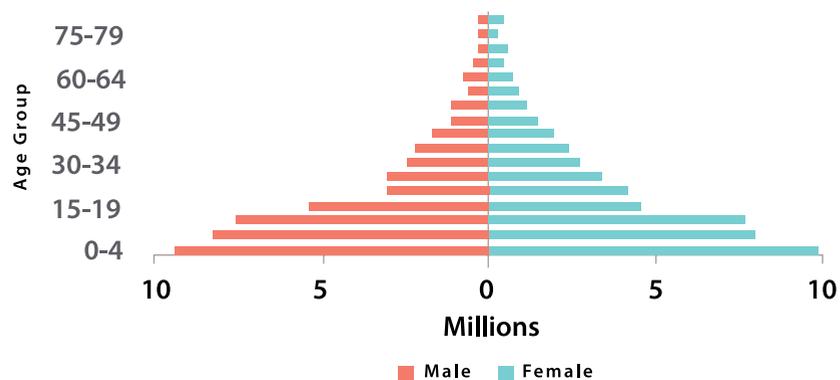
Uganda's population continues to grow currently at rate of 3.0 percent and is much higher than the region's average population growth of 2.8%. According to 2014 National Population and Housing Census (NPHC), Uganda's total population stood at 34.9 million, an increase of 10.7 million from the 24.2 million in 2002 Census. Of the total population, 70% is less than 25 years (Figure 1.1) and adolescents constitute 25.6% of the population, 10-14 years (14.2%), 15-19 years (11.4%). Overall, children below 18 years constitute 56.7% of the total population (NPHC, 2014)¹.

Children below 18 years constitute

56.7%

of the total Ugandan population

Figure 1: Uganda Population Pyramid 2012/2013



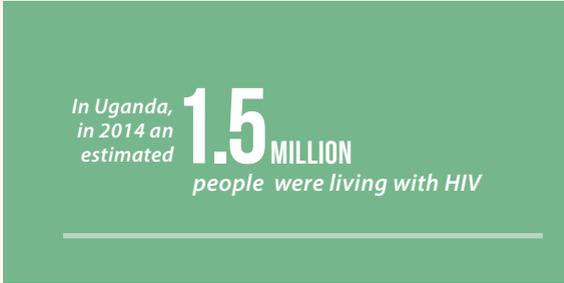
Source: Uganda Bureau of Statistics, (2014) National Population and Housing Census

With every Ugandan woman on average producing 6 children throughout her reproductive period, the country presents a scenario of one of the youngest and most rapidly growing populations of today's world². Consequently, close to half (48.7 percent) of Uganda's population is made up of child dependents (under 15 years), and 70 per cent less than 25 years of age (NPHC). This population structure of high dependency undermines the social transformation and sustainable development efforts of the Country as well as presenting serious challenges in addressing HIV and AIDS, which is among the leading cause of mortality and morbidity. Nevertheless, it is possible to turn the large youthful population that the country has achieved through years of high fertility into an opportunity by making appropriate policies and investments for adolescents (10-19 years), particularly with respect to Adolescent Health and HIV services. Uganda Vision 2040 has pronounced harnessing the "demographic dividend" as one of the key strategies for realizing the social and economic transformation envisaged by the year 2040. The other strategies are embedded in the recently adopted global Sustainable Development Goals (SDG), which Uganda has mainstreamed in her development planning frameworks, particularly goal 3 on good health and well-being for all and goal 4 on universal access to quality education and live-long learning. In order to convert the abundant youthful human resource

into appropriate human capital, it must be healthy, educated and properly skilled which underpin the need for appropriate policies and programs.

Despite the rapid scale-up of prevention of mother-to-child, transmission of HIV (PMTCT) programs in Uganda over the past 10 years, there are still an estimated 20,600 children throughout the country infected with the virus during pregnancy, childbirth and breastfeeding.³ HIV-infected infants often show clinical symptoms in their first year of life. Without effective anti-retroviral treatment (ART), an estimated one-third of infected infants will die by one year of age, and about half will die by two years of age.⁴ In 2010, the WHO released guidelines recommending that all children below 2 years of age receive ART as soon as diagnosed as HIV-infected. The positivity rate for EID has drastically reduced to 3.5% by June 2016 from 5.3% by March 2014 for all infant HIV tests. The number of Dry Blood Spot (DBS) samples tested also increased from 13,277 in 2012 to 58,894 2016 and the prevalence of HIV positive samples has progressively declined from 9.5% in 2012 to 3.5% in June 2016; again reflecting the effectiveness of Option B+⁵. Although the benefits to early infant HIV diagnosis and initiation on treatment are clear, children often access HIV services late or irregularly. Partly, this is a result of weak policy guidelines and their effective implementation for ensuring access to services by children.

In Uganda, in 2014 an estimated 1.5 million adults and children were living with HIV; of these, 680,514 (52%) adults compared to about 58,884 (32%) were on ART^{6,7}. There are still gaps in HIV testing/ diagnosis/ early infant diagnosis; gaps in linkage of the HIV positive children to care and ART initiation; and in retaining those on ART despite the roll out of paediatric ART to lower level facilities in Uganda. For example, only 51% of HIV exposed babies accessed the first DNA PCR by 6 weeks of age in the year 2015. Furthermore, of the children aged 2 to 5 years that tested HIV positive in 2015, those initiated on ART were only 60%. Also among those children under 2 years of age initiated on ART in 2015, 77% were retained in care at 1 year; implying that 23% were lost to follow up in the first year. For children under 5 years, the viral suppression rates were only 69%. In addition, in the support supervision activities conducted by the Ministry of Health in 2015, only 39% of the health facilities had adolescent friendly services.⁸ This is certainly not a favorable position, especially in light of the 90-90-90 treatment target set by UNAIDS;



In Uganda, in 2014 an estimated **1.5** MILLION people were living with HIV

1. Uganda Bureau of Statistics, (2014) National Population and Housing Census

2. World-Bank. Fertility rate, total (births per woman) 2014 [cited 2016 31st May]; Available from: <http://data.worldbank.org/indicator/SP.DYN.TFRT.IN/>

3. UNAIDS. Together We Will End AIDS. 2011.

4. WHO. Antiretroviral therapy of HIV infection in infants and children: towards universal access: recommendations for a public health approach - 2010 revision. 2010.

5. Uganda-AIDS-Commission. Uganda HIV and AIDS Country Progress Report. 2016

6. Ministry-of-Health-Uganda. Status of Antiretroviral Therapy Services in Uganda: Semi-Annual Report for January-June 2014. 2014.

7. UNAIDS. "15 by 15" – a global target achieved. 2015 [cited 2016 18th May]; Available from: <http://www.unaids.org>

8. Ministry-of-Health-Uganda. Update on Paediatric and Adolescent HIV care and treatment in Uganda. National Stakeholders Workshop for eMTCT, EID, Paediatric and Adolescent care and treatment Services. Kampala; 2016.

whereby 90 % of HIV infected individuals are tested, 90% are receiving ART and 90% are virologically suppressed.⁹ There have been several factors identified for the limited access to HIV treatment, care and support by children and adolescents, in Uganda among which are the inadequate policy frameworks for paediatric and adolescent HIV care and treatment. This is the basis for the review of policies on paediatric and adolescent HIV in Uganda.

This report therefore presents the findings of the assessment on paediatric and adolescent HIV care and treatment policies in Uganda and structured as follows. Section 1 provides the introduction and background, section 2 details out the methodological approaches, section 3 lays out the results, section 4 provides the discussion while section 5 gives the conclusions and recommendations.

1.2 Background to HIV/AIDS Response in Uganda

Guided by the National Strategic Plans for HIV and AIDS, Uganda has been implementing innovations in the HIV response leading to a decline in new HIV infections. The results of the 2016 Uganda Population HIV Impact Assessment (UPHIA) indicate that the current prevalence of HIV among adults aged 15 - 49 years in Uganda is 6% (this means that 6%

of adults aged 15-49 years in Uganda are living with HIV). Among children under age five years, HIV prevalence is 0.5%, while among those aged 5 - 14 years, it is also 0.5%. Based on the survey results, the total number of adults and children of all ages living with HIV in Uganda is estimated at 1.3 million. The HIV prevalence among young people 15 -24 years was 2.1% (0.8% in men and, 3.3% among women). Among adults, HIV prevalence is lowest in those 15-19 years¹⁰ . Some of the main achievements in HIV prevention in Uganda include reduction in new infections in young and adults (100,000 2014 to 83,500 in 2015); new infections have reduced among paediatric from 12,000 in 2013 to 3,500 in 2015; and there is a 86% reduction in new infections among exposed infants since 2011 (UAC, 2016). Lack of a more focused approach to target adolescents and young people remains a major gap in the current National HIV response. For example, in 2014 adult ART coverage was 52% while paediatric ART coverage was 32%.¹¹

Data from UPHIA identified existing gaps in HIV programmes and specific populations that need special focus. HIV prevalence among those aged 15-19 years was 1.1 % (1.8% in girls and 0.5% in boys), this increases to 3.3% among those aged 20-24 years (5.1% in young women and, 1.3% in young men). It then increases again to 6.3% among those aged 25-29 (8.5% in women and 3.5% in men). This



.....

Key sectors involved in delivery of adolescent health services include

- MINISTRY OF GENDER, LABOUR AND SOCIAL DEVELOPMENT
- MINISTRY OF EDUCATION AND SPORTS
- MINISTRY OF LOCAL GOVERNMENT
- JUSTICE AND UGANDA AIDS COMMISSION

9. UNAIDS. 90-90-90: An ambitious target to help end the AIDS epidemic. 2014 [cited 2016 24th May]; Available from: <http://www.unaids.org>

10. Ministry-of-Health-Uganda (2017). Preliminary results of the 2016 Uganda Population HIV Impact Assessment

11. Ministry-of-Health-Uganda (2017). Preliminary results of the 2016 Uganda Population HIV Impact Assessment

suggests new infections remain an issue in these age groups. This continuing infection risk necessitates innovative interventions to prevent new infections in young people beginning around age 20. Furthermore, women 15-24 and men under 35 years of age who are living with HIV have rates of Viral Load Suppression <50%. Viral load suppression is not uniform across ages. Children are found to have lower suppression rates at 70% compared to adults. This is coupled with a higher sample rejection rate of 7% compared to 5% for adults. Only 30,356 of the 350,369 (8.7%) patients were children less than 14 years. The figure 13 below shows that viral load suppression rates are lower among children than adults for both on first and second line ARVs.¹² While the new infections and AIDS related deaths have reduced, the number of People Living with HIV has continued to increase. There has been progressive decline in the AIDS related death since 2005 coinciding with the scale up of ART in the country.¹³

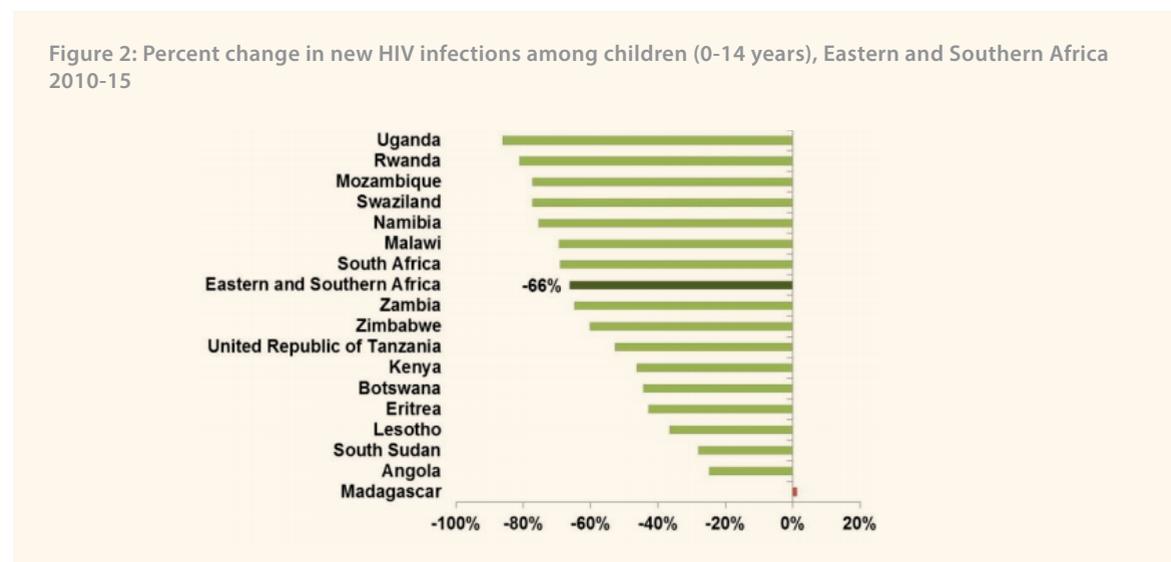
1.2.1 Adolescent and paediatric health services in Uganda

The Adolescent Policy Guidelines and Service Standards (2011)¹⁴ guide adolescent health services in Uganda. The policy provides essential package of interventions by level of health facility based on the availability of expertise and skills. The integrated National Guidelines on Antiretroviral Therapy,

prevention of mother to child Transmission of HIV and Infant and young child feeding 1st edition, the addendum to the National Antiretroviral Treatment Guidelines –January 2014 and the Uganda HIV Counseling and Testing policy 3rd edition Jan 2012 also support adolescent and paediatric HIV services. The Ministry of Health is responsible for adolescent health service delivery but some cross-sectoral adolescent interventions are offered through other sectoral ministries and departments. Key sectors involved in delivery of adolescent health services include; Ministry of Gender, Labour and Social Development (MoGLSD), Ministry of Education and Sports (MoESTS), Ministry of Local Government (MoLG),

Justice and Uganda AIDS Commission (UAC) among others. They have produced Sector plans to shape the direction and guide coordination of health and HIV services including adolescent services. Analysis shows that Uganda is leading by 86% reduction in new HIV infections among children (0-14 years), Eastern and Southern Africa.

The high rate of enrolment and retention into care and ART and the marked reduction in AIDS related deaths (from 46,000 in 2011 to 28,000 in 2015) explain the rise in prevalence¹⁵. Even as the world celebrates these victories and embarks on a historic effort to end the AIDS epidemic as a public health



12. Ministry-of-Health-Uganda. Status of Antiretroviral Therapy Services in Uganda 2014
 13. Uganda-AIDS-Commission. Uganda HIV and AIDS Country Progress Report. 2016
 14. Uganda-AIDS-Commission. Uganda HIV and AIDS Country Progress Report. 2016
 15. Ministry-of-Health-Uganda. Adolescent Health Policy and Service Standards. 2011

threat by 2030, the most vulnerable of all populations – children and adolescents – risks being left behind. Compared to adults, children are less likely to be diagnosed with HIV in a timely manner, and more likely to die of AIDS-related causes. Adaptation of the test and treat for all HIV positive children has continued to increase the number of children enrolled on ART to 60,124 by June 2016, from 54,000 by Dec 2014. Coverage for children has risen from 54% in 2014 to 66% (60,124/92,370) by end of June 2016, while the performance for end of June 2016 was over 93.4% (60,124/64,402) according to the projected program targets. Recent projections for children living with HIV indicated a decrease from 134,831 in 2014 to 95,637 in 2015 and 89,102 in 2016. As described earlier on, the program has put in place interventions to eliminate paediatric HIV through eMTCT and EID, where those found to be HIV positive are immediately started on ART. This has resulted in a rapid increase in coverage for children on ART from 31% in 2014 to 66 by end of June 2016.

There has been an increase in the number of sites providing ART for children from 869 in 2013 to 1,292 by December 2015. Coverage for paediatric ART provision was scaled up to over 66% of estimated HIV positive children. Out of 17,385 children who tested positive, 12,235 were started on ART. Implying

30% (5,147) did not receive ART. The enrolment of paediatric patients on ART almost tripled between 2010 and June 2016 due to improved access to EID services, rapid scale up of ART and the adaptation of the 2015 treatment guidelines to treat all HIV positive children up to 15 years of age. However, between April to June, 2016 the number of active ART clients was 898,197 where children under 15 years constituted only 6.8% compared to about 93.2% of adults in Uganda¹⁶. Some factors identified for the limited access to HIV treatment, care and support by children and adolescents include limited early infant diagnosis (EID) services, knowledge about PMTCT and ART for children and training on management of adolescents living with HIV. Other factors include insufficient number of trained service providers, inadequate health system infrastructure and socio-cultural factors such as stigma as well as lack of confidence among different cadres of health care workers in managing ART among adolescents living with HIV. The strong community belief in traditional birth attendant system further encourages pregnant mothers to seek antenatal care, birth assistance and postnatal care outside the health system^{18,19}. Unless children are linked to timely diagnostic services and life-saving HIV treatment, half of all children living with HIV will die before age two, with peak mortality occurring 6-8 weeks after birth.^{20,21}

1.3 Problem Statement

As Uganda transitions from the Millennium Development Goals (MDGs) to Sustainable Development Goals (SDGs), a key area of sub-optimal performance was sexual reproductive health with specific emphasis on adolescent and child health. Despite a range of program activities targeted to sexual and reproductive health in the country, the attendant indicators in Uganda still show substantial inadequacy. According to the 2017 Uganda AIDS Indicator survey (AIS), HIV prevalence among all young people 15-19 years was 1.1% (1.8% in girls and 0.5% in boys), this increases to 3.3% among those aged 20-24 years (5.1% in young women and, 1.3% in young men). There was an 86% (3,487) reduction in the number of new infections among children; close to the NPAP target of 95% by 2018 and a 3% HIV transmission rate from mother to child, including during breastfeeding²². In the same year, only 41,356 (25%) infants born to HIV positive mothers received ARV for eMTCT and new infections among the children were 5,200²³. The proportion of HIV-infected children and adolescents tested, on ART, and are virologically suppressed is still low. For example, only 51% of HIV exposed babies accessed the first DNA PCR by 6 weeks of age in the year 2015; only 32% of HIV-infected children were on ART in 2014; and among

16. Uganda-AIDS-Commission. Uganda HIV and AIDS Country Progress Report. 2016 17.

18. Ministry-of-Health-and-Social-Welfare-Tanzania. Rapid assessment of the paediatric HIV treatment service delivery in Tanzania. July 2014.

19. Ministry-of-Health-Uganda. Assessment of Adolescent HIV care and treatment services in Uganda. 2014.

20. Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet*. 2004 Oct 2-8;364(9441):1236-43.

21. THSHSP, editor. Tanzania Third Health Sector HIV and AIDS Strategic Plan (HSHSP – III), 2013 – 2017; 2013.

22. Uganda-AIDS-Commission. Uganda HIV and AIDS Country Progress Report. 2016

children under 2 years of age initiated on ART in 2015, 23% were lost to follow up in the first year^{24,25}. Of the factors that contribute to this unfavorable situation, those related to the limited capacity of healthcare workers to provide optimal paediatric and adolescent HIV care services are prominent. The contraceptive prevalence rate among the married young women 15-24 years of age is only at 11.4 per cent with a high Family Planning (FP) unmet needs: for 15-19 year old girls it is 31.3% and among those aged 20-24 years, it is 35.4% (UDHS, 2011). Teenage pregnancy rate among the 15-19 years olds stands at 24 percent, and the median age of sexual debut is only 16.7 years. Adolescent pregnancy contributes to 30 per cent to the primary school dropout ratio (AODI/UNICEF study, 2011). Uganda's abortion rate stands at 54 per 1,000 (World AIDS Report, 2015). Most abortions are unsafe, although over 50% are believed to be carried out by medical practitioners. Within the continuum of health challenges, adolescent and children still face substantial barriers to quality health services at individual, community and health system levels. However, despite various assessments conducted by different stakeholders on adolescents and children, evidence on adolescent and children HIV and AIDS related policy gaps in Uganda is fragmented, not adequately informative for policy review and planning. Many assessments do

not provide adequate disaggregation of adolescent and children HIV and AIDS issues by the different age groups. Studies point out that there is limited implementation of these policies occasioned by inadequacies in program design and their level of funding, the human resources available, and limited knowledge and enforcement of the existing policies and laws. These have perpetuated a continuation of poor service delivery to adolescents.²⁶ A comprehensive policy review was necessary to foster a better understanding of gaps that impair adolescents and children access and utilization of HIV and AIDS as well as other health services.

The Global Fund to Fight AIDS, Tuberculosis and Malaria through ANECCA supported the Government of Uganda to address key policy and capacity gaps through the "Catalyzing Improvement in the Policy Environment, Human Resources Capacity and Knowledge Management about Care, Treatment and Support for Children and Adolescents Living with HIV in Africa" project. This was a nation-wide study under the auspices of the Ministry of Health, targeted to informing efforts at addressing policy gaps to ensure that interventions are responsive to the needs of adolescents and children, in line with the anticipated benefit that this demographically important group will contribute to the Demographic Dividend. As part of achieving Uganda's aspirations

for socioeconomic transformation and transition into an upper-middle income country by 2040, the findings of policy review in areas of adolescent and child health will play a crucial role in harnessing sizable demographic dividends (National Planning Authority, 2014). The findings will further align adolescent and child health policies and programs to the National aspirations enshrined in the National Development Plan (2015), Sustainable Development Goals (2015), National Strategic Plan for HIV and AIDS (2015) and Uganda Vision 2040.

1.4 Rationale for review of policies, guidelines and strategies

There is generally insufficient evidence to facilitate policy and programmatic understanding of the policy and programmatic gaps with respect to the needs of adolescents and children service delivery needs. The current policies on adolescents and children are not aligned to the new local and international strategies and policies thus creating gaps in programming and implementation of adolescent and child health interventions. For example, UDHS and Health Management Information System (HMIS) provide statistics on some of the indicators but do not provide for a needs based analysis on the adolescent sub groups making it difficult to monitor and evaluate effectiveness of interventions and inform improvements.

23. Uganda-AIDS-Commission. *Uganda HIV and AIDS Country Progress Report*. 2014.

24. Ministry-of-Health-Uganda. *Status of Antiretroviral Therapy Services in Uganda: Semi-Annual Report for January-June 2014*. 2014.

25. Ministry-of-Health-Uganda. *Update on Paediatric and Adolescent HIV care and treatment in Uganda*. National Stakeholders Workshop for eMTCT, EID, Paediatric and Adolescent care and treatment Services. Kampala; 2016.

26. UNICEF. *Analysis of the 2014 UNAIDS estimates*. July 2015

Efforts were made to increase access to adolescent and child friendly services with support from development partners. However, information on policy gaps for adolescent and child health services and HIV and AIDS in particular from a countrywide perspective was not known. There was need for a comprehensive policy analysis with respect to adolescent and child health services to generate relevant evidence. The Global Fund to Fight AIDS, Tuberculosis and Malaria supported project aims to improve coverage of quality services for children and adolescents living with HIV by implementing interventions that remove policy bottlenecks, build capacity, and ensure access to appropriate information and services related to HIV testing, care and treatment for children and adolescent in Uganda.



The study findings will assist to identify strengths and gaps in national policies and identify best practices for purpose of developing national and regional plans to improve coverage and quality of services for children and adolescents living with HIV.

1.5 Objectives of the review

- To review and assess existing National Paediatric & Adolescent HIV Policies and Guidelines in Uganda with a view to identify strengths and gaps for provision of quality services for children and adolescents living with HIV .
- To document best practices and opportunities within National Policy Frameworks, Strategies and Guidelines for provision of quality services for children and adolescents living with HIV in the target countries .
- To make recommendations that inform the development of national plans to promote the adoption and implementation of policies that increase coverage and quality of paediatric and adolescent HIV care, treatment and support.
- To facilitate national stakeholder's consultations to develop national action plans to bridge the gaps in the policies and guidelines.

SECTION TWO

METHODOLOGICAL APPROACHES

2.1 Introduction

This section describes the methodology used in this assessment. It provides the study design, study setting and population, data collection methods, data management and analysis, quality assurance, ethical considerations and study limitations.

2.2 Study Design

This was an exploratory cross-sectional study that employed qualitative methods of data collection.

2.2.1 Study setting and population

The policy and guidelines review assessment was conducted in 10 regions of Uganda as defined by UBOS/UDHS. From each region, one district was randomly selected (Refer to table 2.1) below. From Kampala as a region, one division was randomly selected. In each of the selected districts and division, the study focused on health facilities with ART clinics within each level of the health care delivery system namely: Regional Referral Hospital, District /General Hospital, HCIV and HCIII. The study was conducted between July and October 2016.

40

key informants were interviewed [30 KIIs at District and Health facility levels] [10 at national level]

Table 2.1: List of regions study districts and category of Key Informants

Region	District/ Division	District Health Team	ART /Health facility In-charge	Community Development	Education	Total
District KIIs						
Kampala	Nakawa Division	-	2	1	-	3
Central 1	Mpigi	2	1	-	-	3
Central 2	Kiboga	3	1	-	1	5
East Central	Kamuli	1	1	1	-	3
Mid Eastern	Pallisa	2	1	-	-	3
North Eastern	Bukedea	1		1		2
West Nile	Nebbi	1	1	-	1	3
Mid North	Lira	2	1	-	-	3
South Western	Kanungu	1	-		1	2
Mid Western	Masindi	1	1	1	-	3
Sub-Total	10	14	9	4	3	30
National Level KIIs						
Government Ministries (MoH, MoE&S, MoGLSD)						4
Development Partners (UNICEF, UNAIDS, UNFPA)						4
NGOs (Baylor Uganda & Mildmay)						2
Sub-Total						10

2.2.2 Target population

Selected stakeholders at health facility, district and national levels supporting and/or providing children and adolescent centered services participated in the study as key informants and provided information concerning policy and service delivery issues affecting adolescents and children living with HIV. Key informant interviews targeted respondents from three levels; Representatives from development partners, paediatric and adolescent HIV implementing partners, representatives from government

sectors that have a stake in paediatric and adolescent health and representatives of district local governments. We used a criterion sampling (Dey I, 1999) method to select Key informants. We purposively selected respondents who were involved in the planning or delivery of services to children and adolescents. Informants were expected to be information-rich to reveal major system and policy strengths and weakness with respect to paediatric and adolescent HIV policy and service delivery.

Key informants were purposively selected depending on their position, deemed role and knowledge about paediatric and adolescent health. Overall, 40 key informants were interviewed (30 KIIs at District and Health facility levels and 10 interviews at national level). District level informants were members of the District Health Teams mainly District Health Officers (DHOs) and HIV focal point persons; District Education Officers (DEOs) and Community Development Officers (CDOs). Health facility in-charges and

heads of ART clinics constituted key informants at health facility level. At national level, key informants were Officials from the Ministry of Health involved in the design and implementation of paediatric and adolescent HIV services; Ministry of Education and Sports and Ministry of Gender Labour and Social Development; selected UN agencies mainly UNICEF, UNFPA and UNAIDS and selected paediatric and adolescent HIV implementing partners (Baylor Uganda and Mild May Uganda). The inclusion of informants at health facility, district and national levels provided an opportunity for data triangulation, but also, to assess stakeholder perspectives about paediatric and adolescent HIV policies at different levels.

2.2.3 Data Collection Methods

Data collection used a mix of methods including desk-based review and key informant interviews.

a) **Desk-based review and analysis**

This was part of the initial phase of data collection and continued throughout the entire study. Existing paediatric and adolescent HIV policies, guidelines, plans and strategies were reviewed against the World Health Organization 2015 guideline documents, which address the prevention, care, and treatment of HIV for children and adolescents. The key resource documents reviewed are annexed (Annex 1).

b) **Key Informant Interviews**

A pre-designed key informant interview guide with open-ended questions, followed with probes was used to explore study participants' views on issues related to awareness and existence of policies, and guidelines relevant to paediatric and adolescent HIV care in Uganda. The interviews also covered knowledge of policy provisions, policy development process, policy strengths and gaps; as well as policy implementation processes, challenges and suggestions to address the policy gaps identified. All interviews were conducted in English, were audio recorded and transcribed by research assistants. Research assistants were paired one as an interviewer and the other as a note taker.

2.2.4 Data Management and Analysis

Key Informant Interviews (KIIs) were analyzed using content thematic approach. The transcripts were read several times to identify themes and sub-themes in relation to objectives of the study. Coding was done using NVivo software version 9. The findings from KIIs at different levels were triangulated. Selected quotations from respondents and tables reflecting issues of interest were used in presentation of study results. The Health Policy Conceptual Model by Walt & Gilson provided a guide in analysis of

informants' perceptions of Uganda's national policies and guidelines related to paediatric and the adolescent HIV care. The assessment focused on awareness of **existence** of Paediatric and adolescent HIV policies by key stakeholders, the **process** of policy development including the role of various stakeholders (**actors**), **content** of policies and guidelines including comprehensiveness of the policy and the **implementation** of the policies.

2.3 Quality Assurance

The research assistants and research supervisors were recruited based on their level of skills and education as well as prior experience in research related to children and adolescent health. They were trained on use of the data collection tools. The tools were pretested prior to field data collection. During data collection, the national consultants supervised the field teams to ensure quality.

2.4 Ethical Considerations

Ethical approval for the study was obtained from the Makerere University School of Public Health Higher Degrees, Research and Ethics Committee (HDREC) and Uganda National Council of Science and Technology (UNCST). All study participants read the

informed consent form; their issues were responded to by the research assistant and signed the informed consent form. Research assistants were trained on study procedures including ethical considerations. Names and other identifiers of study participants were masked in the presentation of study findings to ensure confidentiality. Thus where quotations from participants are included in the report, we use Key Informant District Health Team; Key Informant District Education Officer, Key Informant Community Development Officer, Key Informant Health facility to indicate source of the quote. For National level key informants they are represented as Key Informant Government to denote all key informants from government agencies and Key Informant Development partner to reflect key informants from UN agencies and HIV implementing partners.

2.5 Study Limitations

The study did not directly capture perspectives of children and adolescents living with HIV and their caregivers yet these are critical stakeholders for HIV policy development and dissemination. Besides they could have provided lived experiences on how policies are translated into action, major implementation challenges and suggestions for improvement. However, given that we purposively

targeted actors involved in the design and implementation of paediatric and adolescent HIV services we are confident that stakeholder perspectives we obtained in this study provide rich insights about the policies and the changes needed. Given exploratory nature of the study, we are unable to quantify these perceptions. Nonetheless, we believe that the themes and sub-themes reflected in this study about stakeholder perceptions with regard to strengths, gaps, opportunities and implementation challenges for paediatric and adolescent HIV policies and guidelines in Uganda, can inform the design of a quantitative study to better monitor trends and changes in these perceptions. Due to time and resource constraints there is a wide range of other stakeholders who could have been involved in the study such as religious leaders, the media, business entities, other development actors and government departments. Given the country wide focus of our study and the fact that most stakeholder narratives did not vary greatly we are confident that the findings largely reflects what is obtaining on ground with regard strengths, gaps, opportunities and actions required to strengthen paediatric and adolescent HIV policies, guidelines and services in Uganda.



- *The research assistants & supervisors were recruited based on their level of skills, education & prior experience in research related to children and adolescent health*

SECTION THREE

RESULTS

3.1 Introduction

The synthesis in the findings section is informed by the desk review conducted prior to primary data collection to provide insight into development of data collection tools for the qualitative study. It included a number of legislation, policies, guidelines and strategies that relate to adolescents and pediatric health in general and HIV in particular. The desk review findings were triangulated with qualitative data derived from 40 key informants (30 at District and Health facility and 10 national levels KIs). The findings are presented on the basis of study objectives. The gaps identified under each policy, guideline, strategy and the qualitative data are reflected in the conclusions and form the basis for drawing recommendations.

3.2 Foundation for paediatric and adolescent HIV policies and guidelines

Uganda has several legislation, policies and strategies that provide the foundation upon which the paediatric and adolescent HIV policies and guidelines were developed. Review of literature identified a number of these guiding documents discussed infra.

18 YEARS

*the legal age for consent,
under sub section 2.4 on
HCT for children*

Legislation

The Uganda Constitution (1995) as the supreme law of the land provides the broad legal framework for the State to fulfill the fundamental rights of all Ugandans to social justice and economic development, the protection and promotion of human and property rights, and outlaws discrimination. Article 34 provides for the rights of children including among others the right to basic education and medical treatment. The Penal Code Act (1995) provides for sexual offences intended to protect vulnerable people including children and young people from sexual abuse, which is harmful to their health and development. The Children's Act (1997) states that every child has the right to education and guidance, immunization, an adequate diet, shelter, medical attention, and to protection from violence, abuse and good health. The Local Government Act (1997) provides for delivery of medical and health services including maternity and child welfare services, control communicable diseases like HIV/AIDS. The HIV and AIDS prevention and control act (2014) provides for promotion of adolescents and young people's health through prevention, care and treatment of HIV and AIDS. The Education Act (2008) provides for education and training of a child as the joint responsibility of the State, the parent or guardian and other stakeholders. The National Council for Children Act provides a structure and mechanism for the proper coordination, monitoring and evaluation of all policies and programmes relating to the

survival, protection and development of children in Uganda. The legislation collectively identify children and adolescents as important constituencies of the Uganda population critical in contributing to national development. They give prominence to protection and promotion of their health and well-being in order to enable them realize their potentials and participate in decisions that impact on their lives within the precincts of Government programs and policies.

Policies

The review of pediatric and adolescent HIV related policies was informed by the need to identify gaps in relation to their ability to address the needs of adolescents and children with respect to HIV and thereof provide recommendations for review. The specific policy identified was the Uganda HIV Counseling and Testing policy 3rd edition (2010) which was reviewed given its focus on the objectives of the review.

Guidelines

Guidelines were developed to operationalize policies, and with respect to adolescent and paediatric HIV, the following were reviewed; National Antiretroviral Treatment Guidelines for Adults, Adolescents, and Children (2008), National Implementation Guidelines for HIV counseling and testing in Uganda (2010), Uganda Addendum-to-National-ART-Guidelines (2013), Uganda Clinical Guidelines (2012), Adolescent Health Policy

Guidelines and Service Standards (May 2011), World Health Organization, (2013) consolidated guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection; Recommendations for a Public Health Approach and Guidelines for the management of sexually transmitted infections (2003).

Strategies

The development plans are strategy documents that guide programming for the different Government sectors. With respect to the health sector, adolescent, and paediatric HIV, the following strategies were reviewed; National Development Plan II (2015), National HIV/AIDS Strategic Plan-2015/2016-2019-2020, Health Sector Development Plan (2015) and the National Adolescent Health-Strategy (2011). The following section provides findings of stakeholders' awareness about paediatric and adolescent HIV policies.

Article

34 OF THE UGANDAN CONSTITUTION

provides for the rights of children including; the right to basic education and medical treatment

3.3 Stakeholder Awareness of and participation in Paediatric and Adolescent HIV policies

Overall, most study participants noted that Uganda had most policies for the provision of HIV testing, care and treatment for children and adolescents. Study participants noted that the policies are regularly updated in line with guidance from global guidelines especially from the World Health Organization. The most commonly mentioned policies/guidelines in relation to paediatric and adolescent HIV include: the Uganda HIV Counseling and Testing Policy, Prevention of Mother to Child Transmission of HIV policy, Uganda National Antiretroviral Treatment Guidelines and the Adolescent Health Policy. Most of the policies and guidelines were general to HIV but with specific provisions addressing concerns of children and adolescents the exception being the Adolescent Health policy with particular focus on adolescents.

Variations in awareness of policies were eminent among study participants. Overall, awareness of paediatric and adolescent HIV related policies was high among District Health Team members and national level informants directly involved in planning and provision of paediatric and adolescent HIV services. On the contrary, most narratives of health workers and officials from education and community development departments reflected lack of awareness about paediatric and adolescent HIV policies and their provisions. In response to questions about awareness of such policies, common in the narra-

tives were comments such as: 'I can't answer this question because I do not know any policy' and 'I am not sure' about health policies, you need to go to the health department ...'. Many respondents attributed this lack of awareness to inadequacies in the dissemination of health policies mainly confined to the health sector. Indeed, most study participants at health facility, district and national levels mentioned that other sectors such as community development and education though relevant and could aid effective implementation of paediatric and adolescent HIV policies/guidelines; they are rarely or minimally involved in health policy development and dissemination.

A mere mention of 'policies' and exploring about policy content made most informants uncomfortable. The discomfort with talking about health policies was linked to asking about unfamiliar issues but also the wide spread perception among some study participants that policies were highly technical and required specialized knowledge. The limited awareness of paediatric and adolescent HIV policies especially among frontline health care workers raises questions on how such health workers can effectively translate policies to actions. In addition, the limited awareness of such policies by officials from other sectors like education and community development is a potential limitation to realizing the needed multi-sectoral contributions in the design and delivery of paediatric and adolescent HIV services in Uganda.

Key informants from the education sector and community development were aware of policies and

strategies within their areas of jurisdiction such as the Orphans and Vulnerable Children Policy (OVC policy) and the Presidential Initiative on AIDS Strategy for Youth (PIASCY) an HIV prevention strategy targeting HIV prevention in primary and post primary schools in Uganda. These policies were rarely mentioned by mainstream health sector actors again reflecting sector specific interventions.

With regard to the policy development process, all national level stakeholders acknowledged that although the process of policy development involved major stakeholders such as the ministries of health, academia and UN agencies, there is need to make the policy making process more inclusive and participatory to involve other sectors such as gender, education, justice as well as the consumers i.e. the community/beneficiaries. In relation to the policy making process, some key informants noted:

When it comes to policies, another big stakeholder that tends to miss as they try to develop and disseminate these policies is the ministry of gender, yet as stakeholders develop these policies, you need to mainstream gender and rights in the design of whatever is being addressed, because adolescent girls have different problems from adolescent boys, but each one of them needs to be addressed in their respective gender perspective (Key Informant Development partner). The MoH policy development process is participatory ... what is lacking in involvement of other line sectors like the Social Development sector, the education sector and Justice Law and Order Sector all which play significant roles in adolescent

and paediatric HIV... (Key Informant Development partner). Beneficiaries are left out and Civil Society Organizations are left out. Donors and the Ministry of Health are the ones mainly involved in policy development. I have not attended any policy meeting where religious and cultural leaders are involved. But also other community members, artists...all are important (Key Informant Development partner)

In addition, most national level study participants mentioned frontline health workers, adolescents and other beneficiary groups as stakeholders that were often not involved in policy and guideline development processes as some informants noted.

Most stakeholders such as Ministry of Health, donors, HIV implementing partners and District Health Officers are involved in policy development. But we need more involvement of health workers beyond District Health Officers to include frontline health workers and other sectors beyond the health sector. Even expert clients could be involved more (Key Informant Development partner)

Some study participants believed that the process of involving stakeholders in formulation and revision of policies was improving especially with policies currently under revision in which wider consultations beyond the Ministry of health and donors were being made as one of the national level key informant noted.

These days more and more stakeholders are involved in policy development. There are a lot of consultations that take place. For instance during the revision of the HIV Testing policy, HIV implementing partners, health workers, members of parliament, adolescent, parents ...have been consulted and discussions are still going on before the policy revision is finalized (Key Informant Development partner).

Limited involvement of communities, the consumers of policies was linked to lack of organized consumer groups in the past. Community volunteers, health services consumer and advocacy groups are increasing in Uganda thus likely to create an avenue for more beneficiary involvement in policy development and dissemination in future.

3.4 Strengths and Gaps in National HIV Policies, Guidelines and Strategies in Uganda for provision of quality services for children and adolescents living with HIV

3.4.1 Strengths in Paediatric and Adolescent HIV Policies, Guidelines and Strategies in Uganda

Overall, District Health Team members and national level key informants mentioned that Uganda has most policies needed for the delivery of integrated and effective paediatric HIV services. The major strength in Uganda's policies mentioned were; pae-

diatric and adolescent HIV prevention, testing and care are integrated in national policy and strategy documents and they are regularly updated based on evidence and international guidance mainly from the World Health Organization. Provision for test and treat especially for children and some adolescents (0-14 years) as well as decentralized service delivery was other strengths mentioned in Uganda's HIV policies and guidelines. These views were further supported by the findings of the desk review under the specific policies, guidelines and strategy documents discussed hereunder.

We need more involvement of health workers beyond District Health Officers to include frontline health workers and other sectors beyond the health sector

The goal of the Uganda HIV Counseling and Testing policy 3rd edition (2010) is to contribute to reduction of HIV transmission and improving the quality of life by enabling persons to know their sero-status and linking them to prevention, care, treatment and support services. In terms of comprehensiveness of the policy, it elaborates systems for technical guidance at the national and subnational level to provide technical guidance to improve coverage and quality of care to optimize HIV prevention, care and treatment of women and children. These provisions are under sub section 6.13 and operationalized under the policy objective that ensures HCT services meet the required minimum standards and policy statements a), b), c) and d). The policy has provision for the integration of HIV prevention, care and treatment services with maternal, newborn and child health and reproductive health programs (Section 6.0, Thematic Area 2: part c and d, Sub sections 6.2, 6.7 and 6.8). It further emphasizes the important of HIV testing that is respectful, nondiscriminatory and ethical in manner (sub section 6.1 and policy objectives i) and ii). It has specific provision for special groups (sub section 6.2) that include but not limited to most at risk populations (MARPs), Couples, persons with disabilities (PWD), health workers, mentally impaired and children. The HIV testing policy recognizes the importance of disclosure to family members and sexual partners and provides specific strategies adopted to encourage disclosure to adolescent couples.

These provisions (sub section 6.2, policy statements e, f, g and i). The policy builds strong linkages to prevention, care and treatment services after testing within the overall goal (5.1) and thematic area 2 (sub section 6.5). There is emphasis on adolescent posttest counselling as well as concrete provisions and practical measures outlined for appropriate and successful linkage to prevention, treatment and care services (sub section 5.1). There are provisions for privacy and confidentiality (sub section 6.10, 6.1 and policy objectives i, ii) which are not necessarily specific for adolescents and children.

The policy defines the age for consent for HTC (sub section 6.2) and has provisions for community based testing and counselling (sub section 6.3, policy statements a & b). There are provisions on linking all categories of clients and not specifically children to other care and support services (under sub section 6.5). The policy has clear provisions for linking adolescents testing HIV positive to care.

The ***National Implementation Guidelines for HIV counseling and testing in Uganda (2010)*** provide for facility, community based HIV testing services for children, and adolescents (sub section 2.2). These are expounded under HCT at community settings which include a free-standing site; outreach HCT services and home based HCT (HBHCT) services which provide the advantage of reaching couples, men and eligible children in households. The guidelines

further emphasize the important of HIV testing that is respectful, nondiscriminatory and ethical in manner under section one on ethical-legal issues in HCT. The provisions include the right to accurate information and access to HCT and related services; the right to quality services delivered under ethical requirements . They also provide for special groups which include adolescents, youth and children (section 1.4). Persons within these special populations may have a concentration of risk behaviours for HIV transmission.

The guidelines recognize the importance of disclosure to family members and sexual partners. Whereas this is not mandatory (sub section 1.4), the guidelines provide for privacy and autonomy of the couple and individual and in situations where a partner has tested alone, disclosure of HIV status, partner(s) notification and testing shall be encouraged. Where individual members of a couple receive pre-test counselling and testing separately, the service provider should reinforce the benefits of, and support the disclosure of test results to the spouse or sexual partner. The national HTC guidelines recognize the importance of early identification of persons with HIV with early successful linkage to prevention, care and treatment services and for those who test negative link to prevention services. The specific strategies for early identification of children and adolescents include service integration are under sub section 2.6 and 2.7.

In order to ensure universal and equitable access to HIV testing and counselling for children and adolescents, the guidelines recommend design of HIV/AIDS programs, which ensure that special populations have equitable access to HCT service. Section 2 on HCT service delivery further elaborates HCT as a core intervention in the comprehensive strategy of the government and its partners to address HIV/AIDS in Uganda. As such and in line with universal access, HCT services will be promoted and provided at convenient locations for all eligible populations.

There are strong linkages between HCT with prevention, care and treatment services after testing. Sub section 2.4 states that appropriate information about services to which the client is referred and linked should be provided; and mechanism for documentation, feedback and monitoring put in place. They also provide for monitoring systems to measure uptake and coverage of HIV testing (sub section 3.6). There is emphasis on posttest counselling for all clients in the HCT protocol although it is not specific to adolescents.

The guidelines give provision for adolescent privacy and confidentiality which is emphasized in section 1 on ethical-legal issues in HCT. They further define the age for consent for HTC for adults as those aged 18 years and above. Under sub section 2.4 on HCT for children, child consent considers the legal age for consent as 18 years. The guidelines have clear

provisions for linking adolescents testing HIV positive to care.

The **strategies** reviewed relate to all components of PMTCT Paediatric HCT, Paediatric Prevention, Care and Treatment, Adolescent HCT and Adolescent Prevention, Care & Treatment. Among the areas of focus include target setting and provisions, measures for appropriate assessment of successful linkage to prevention, care and treatment services. The main strategy documents that address Paediatric HCT which were reviewed include **National Development Plan II (2015)**, **National HIV/AIDS Strategic Plan-2015**, **Health Sector Development Plan (2015)** and the **National Adolescent Health-Strategy (2011)**. The findings under this section cut across all sub sections for adolescents and paediatrics.

The **National Development Plan II (2015)** prioritizes investment in five (5) areas with the greatest multiplier effect on the economy one of which is the human capital development where the health sector falls. The thrust is on investments in early-childhood development and improving the quality of education, training and healthcare at all levels. Being a strategic document, it provides a global perspective of adolescent health under which HIV is premised. Chapter 12 on Human Capital Development, sub section 12.1 on health, objective 1 and under maternal, neonatal and child health part vi), ii), iv) and vi) is where one of the provisions establishes and ensures

access to HIV prevention and management programs for adolescent boys and girls. These provisions were the basis for developing the National HIV and AIDS strategic plan 2 and the Health Sector Development Plan 2015.

The **National HIV & AIDS Strategic Plan-2015** has its overall goal as Zero new infections, Zero HIV and AIDS related mortality and morbidity, and Zero discrimination. This is operationalized through four sub goals 1), 2), 3) and 4). The NSP has systems for technical guidance at the national and subnational level to provide technical guidance to improve coverage and quality of care to optimize HIV prevention, care and treatment of the target populations, which among others include women and children (sub section 4.5.1). The NSP provides for the integration of HIV prevention, care and treatment services with maternal, newborn and child health and reproductive health programs. This is expounded in the Investment Case for Uganda upon which development of the NSP was premised. It provides recommendations for increased integration of HIV with TB and other programs including maternal and child health (MCH), Sexual and Gender Based Violence (SGBV), among others. In country partnership is identified by the NSP as critical in providing HIV prevention, care and treatment for women, infants and young children (sub section 5.2.2).

The strategy prioritizes youth, adults and paediatric under the prevention thematic goal and objectives. This is reflected in strategic action 1.1.8 under care and treatment in sub section 4.3. The strategy puts primary emphasis on efforts that rapidly increase enrollment, better retention in chronic care, and early initiation of ART, effective HIV treatment, and greater adherence to HIV treatment.

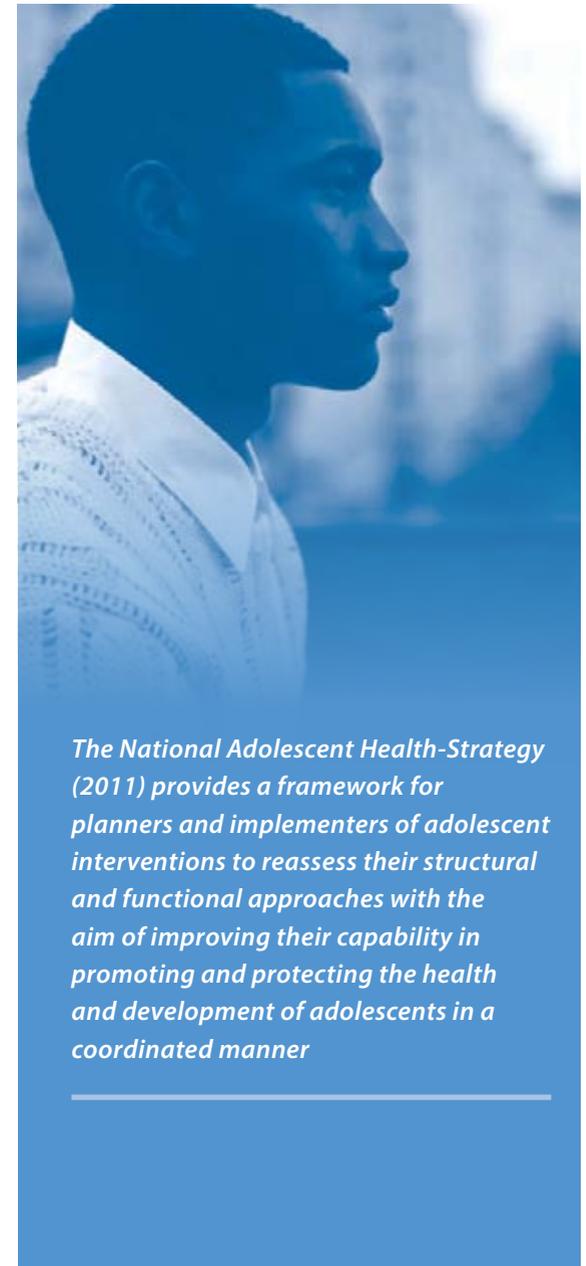
Adolescents and children are also prioritized in the strategic plan (sub section 4.3, strategic actions 1.1.1, 1.1.2 and 1.1.3; Strategic Objective 2, strategic actions 2.2.1, 2.2.2, 2.2.3, 2.2.4, 2.2.5, 4.4.2, 4.4.3 and 4.4.4). The NSP promotes and supports health systems interventions to improve the delivery of HIV prevention, care and treatment services for all including women and children (sub section 4.5.1), which are identified as critical in guiding the national response.

The **Health Sector Development Plan (2015)** is part of the overall health sector planning framework. Guided by its goal of accelerating **movement towards Universal Health Coverage with essential health and related services needed for promotion of a healthy and productive life**, it provides the strategic focus of the sector in the medium term. The Plan's strategic intents, which address adolescent and paediatric health, are under sub section 3.2 HSDP innovations and investment case and sub section 3.2.1 on HSDP innovations. The specific area that addresses adolescent and paediatric health is sub section 3.3.1 on health promotion across the life course. The program areas corresponding to the life cohorts and are: Reproductive, Maternal (15 - 49

years) and New-born Health (up to 28 days of life); Child Health (29 days – 5 years); School age and adolescent health (6 – 24 years); and adult health (25 – 59 years). Against this background, the plan does not specifically prioritize adolescent and paediatric HIV.

The **National Adolescent Health-Strategy (2011)** provides a framework for planners and implementers of adolescent interventions to reassess their structural and functional approaches with the aim of improving their capability in promoting and protecting the health and development of adolescents in a coordinated manner. The goal of this strategy is to improve the quality of life and well-being of young people in Uganda. It creates an enabling policy environment and legal framework that will facilitate adolescent health and development programmes. The provisions of the strategy address the major aspects that affect access to and utilization of ADH services. These include meaningful participation of adolescents/young people; generation and use of information; coordination, collaboration, partnerships and networking; addressing adolescent and young people's rights; delivery of quality adolescent health friendly services; ensuring availability of resources for adolescent services and; providing enabling policy, socio-cultural environment and legal framework. The strategy prioritises adolescent HIV where one of the priority areas is STI/HIV/AIDS and Adolescents. A number of strategic objectives reflect the general provisions for adolescent health services.

For **HIV testing and counselling**, section 1.2, the strategy quotes the Sexual Offences Act (2011), a policy setting the minimum age for sexual consent



The National Adolescent Health-Strategy (2011) provides a framework for planners and implementers of adolescent interventions to reassess their structural and functional approaches with the aim of improving their capability in promoting and protecting the health and development of adolescents in a coordinated manner

for HCT at 18 years. Under Chapter five on indicators for adolescent-friendly service provision, one of the health facility characteristics is privacy and confidentiality honoured measured as percent of facilities with space set aside to provide health care to the youth. The other provision is adequate space and sufficient privacy measured as proportion of health facilities with an adolescent health corner. Under Chapter five which outlines indicators for assessing adolescent-friendly services, one of the health facility characteristics is privacy and confidentiality. The provisions for adolescent friendly HTC services are expounded in Chapter 1, Section 1.9 under Guiding Principle number 5, provides for integrated and sustained delivery of adolescent friendly service. Sub section 1.11 on priority areas and components has a component for provision of Adolescent Friendly Services. Output 2 under sub section 1.12 measures the

minimum package for adolescent friendly services and service delivery standards developed; output 5 focuses on service providers trained on young people's health issues and adolescent friendly service delivery; output 7 looks at service delivery points provided with appropriately trained staff and relevant materials for provision of adolescent friendly services. Strategy 5 provides for capacity building for delivery of quality adolescent health services at all relevant levels. It further states that provision of adolescent friendly health services is paramount to the demand and utilisation of the services by the young people. Strategy 6 looks at improvement of access to adolescent-friendly health services with emphasis on sexual and reproductive health. Part (ii) provides the minimum basic package for adolescent friendly services and ensures equity and quality. Strategy 7 on research on adolescent health states

that carrying out research/studies on documented barriers to provision of adolescent friendly services (accessibility, affordability, privacy and confidentiality, staffing including age and skills of service providers; availability of supplies; IEC materials for behavioural change; timing (days and hours of operation); community perception and support. Chapter three on institutional/implementation framework provides for local governments and authorities to build capacity to implement adolescent friendly services and Chapter five sets out indicators for AFHS provision. It is important to note that in all cases, the provisions are not exclusive to adolescent HCT. The desk review findings above were further supported by the stakeholder perception about the strengths of existing paediatric and adolescent HIV policies presented in table 3.1.

Table 3.1: National Level Stakeholder perceptions of Key Strengths in Uganda's paediatric and Adolescent HIV Policies

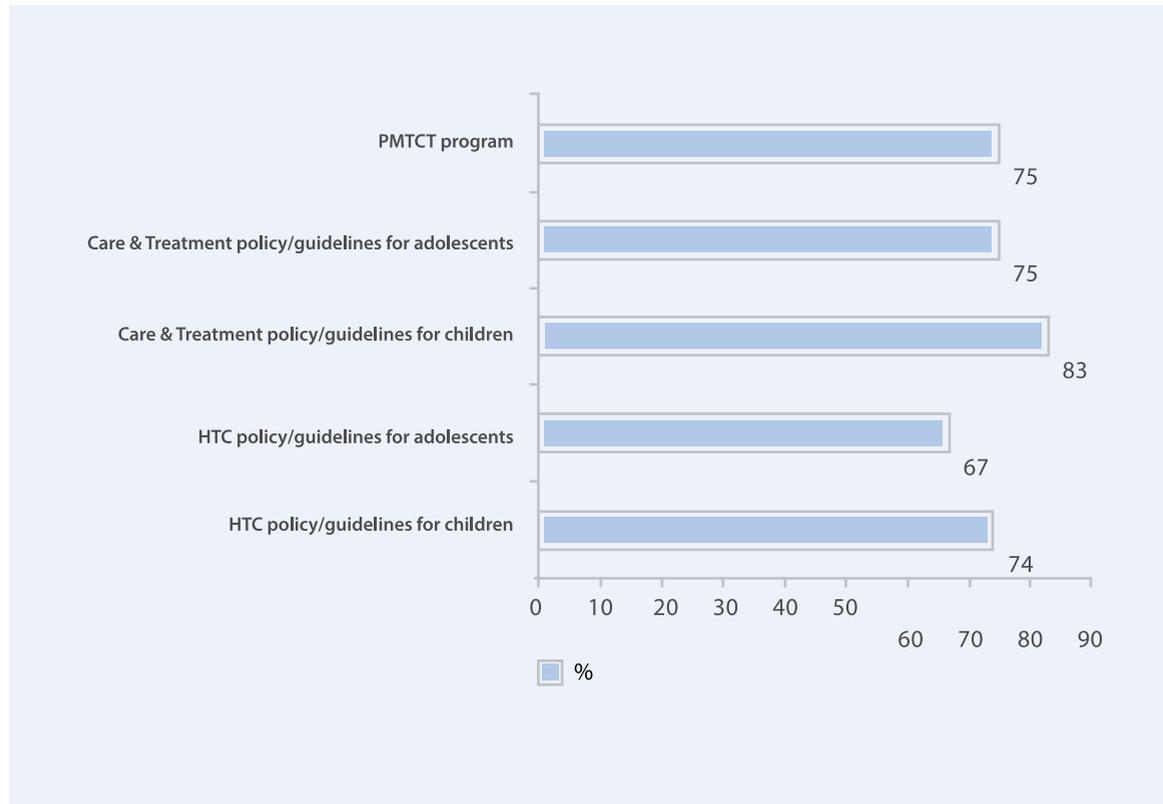
Strength of Uganda's paediatric and adolescent HIV Policies	Paediatric	Adolescents
HIV prevention integrated in national HIV policies and strategies	Yes	Yes
HIV testing integrated in national HIV policies and strategies	Yes	Yes
HIV care integrated in national HIV policies and strategies	Yes	Yes
HIV services integrated in maternal, newborn and child health (MNCH), TB and other health services	Yes	Yes
Policies regularly updated in relation to WHO recommendations	Yes	Yes
Provides for test and treat for mothers under eMTCT, children and adolescents	Yes	Partly – up to 14 years
Provides for decentralized HIV testing, treatment and monitoring services	Yes	Yes

3.4.1.1 Stakeholder Perception on Comprehensiveness of Uganda's Policy/Guidelines for paediatric and Adolescent HIV

Save for the gaps identified through the desk review and discussed in the subsequent section of the report, most national level stakeholders perceived Uganda's HIV testing and treatment policies and guidelines to be comprehensive (Figure 1). The most highly rated policy guidelines in terms of compre-

hensiveness were care and treatment guidelines for children at 83% while HIV testing and counseling guidelines for Children (74%) and for Adolescents (67%) had the least rating. Indeed, some study participants especially those at national level noted that the Uganda HTC policy and guidelines were being revised to align them with emerging evidence, new WHO guidance and address gaps in counseling and testing children for HIV.

Figure 3: Stakeholder Perception of Comprehensiveness of Uganda's Policy/Guidelines for Children and Adolescents living with HIV n=10



While most stakeholders mentioned that Uganda's paediatric and adolescent HIV policies and guidelines were in general comprehensive and regularly updated in line with international recommendations, the country was poor at implementing those policies. As some informants noted:

Uganda has very good policies. The challenge is to translate policy into action. Having paediatric and adolescent HIV policies and other policies on paper we are mature the challenge is poor implementation (Key Informant Development partner). Uganda has the documents, some may need to be updated but we have more challenges with implementation (Key Informant Government).

Several impediments to policy implementation dominated narratives of study participants at health facility, district and national levels and these are presented in a separate section of this report.

3.4.2 Stakeholder perceived Policy gaps for provision of quality services for children and adolescents living with HIV in Uganda

District and national level stakeholders identified critical policy gaps (table 3.2) that need to be addressed to further strengthen Uganda's paediatric and adolescent HIV services. The health facility stakeholders identified mainly challenges related to implementation of policies and guidelines. Lack of clear guidance on disclosure of HIV status to children and adolescents as well as weak linkages between HIV testing and treatment services were key gaps identified by health workers in relation to paediatric and adolescent HIV services.

District and national level stakeholders highlighted lack of national and district specific targets for HIV testing and treatment services for children and adolescents; weak/no provisions for support at community, school and during transition from child to adolescent and adult clinics. Lack of guidance on the appropriate age to disclose HIV status to children and adolescents as well the process of disclosure; lack of counselors in the ministry of health structure; unknown burden of stigma among children and adolescents as well as weak interventions to address it were key gaps in paediatric and adolescent HIV care policies.

These gaps were further reflected in the desk review for adolescents and paediatric HIV services where it was identified that the **National Implementation Guidelines for HIV counseling and testing in Uganda (2010)** were not specific on counselled adolescents about potential benefits and risks of disclosure of their HIV status, empowered to determine when, how and to whom to disclose.

For HIV testing and counselling, the **National Adolescent Health-Strategy (2011)** does not have exceptions for adolescents HTC below defined age of consent and does not exclusively state clear provisions for privacy in delivery of HTC services but only provides measurements. In addition, the strategy does not exclusively have provisions for confidentiality in provision of HTC services but only lays out indicators for measurements. The **National Antiretroviral Treatment Guidelines for Adults, Adolescents, and Children (2008)** are silent on provisions for confidentiality in provision of HTC services to adolescents. They do not have clear provisions for adolescent friendly HTC services and linking adolescents testing HIV positive to care. The **Uganda Addendum to National ART Guidelines (2013)** do not have any provisions for privacy in provision of HTC services but only note that adolescents prefer to be seen by the same providers for reasons of trust and confidentiality, both of which are essential for the provision of comprehensive care.

It is important to note that some of the policy gaps are already being addressed in policies being revised. For instance, most national level stakeholders mentioned that the Draft HIV Testing Services (HTS) policy provides for children above 12 years to access HIV testing services without requiring consent from their parents/guardians. As one informant noted:

Under HIV Testing and Counseling policy adolescents could not access HIV testing services without the consent of their parents or guardians and this was a barrier. This has been addressed in the policy being revised. Once the policy is approved, adolescents who are 12 years and above will be able to test for HIV on their own. This is likely to increase access to testing services for adolescents (Key Informant Development partner).

The other policy gaps are summarized in table 3.2 and further discussed under the views of stakeholder in the subsequent part of this section.

Table 3.2: Key policy gaps and suggestions for Paediatric/adolescent HIV services in Uganda by thematic area

Thematic Area	Policy Gap for Children living with HIV	Policy gap for Adolescents living with HIV	Suggestion for improvement
HIV Counseling and Testing	Not clear guidance on age and process of HIV status disclosure No national and district targets	Not specific on testing adolescents 12 years and above without parental consent No age segregated national and district targets	Finalize revision of HTS policy/ guidelines & provide for: Testing adolescents, disclosure of HIV status and age specific targets for children and adolescents
Linkages/ referral	Weak linkage to care	Weak linkage to care	Strengthen linkages for HIV testing, care and other support services

Thematic Area	Policy Gap for Children living with HIV	Policy gap for Adolescents living with HIV	Suggestion for improvement
Treatment	No District and national HIV treatment targets for children	<p>Test & treat does not cover all adolescents (only covers 10-14 bundled with children, 15 years and above are bundled with adults)</p> <p>No District and national treatment targets for adolescents</p> <p>Weak linkages between HIV testing and care</p>	<p>Update treatment policy guidelines as per 2016 WHO guidelines to allow initiation of all children and adolescents living with HIV on treatment regardless of CD4 count & clinical stage & on prevention of Opportunistic infections among all children and adolescents living with HIV</p> <p>Set child and adolescent national and district treatment targets</p> <p>Strengthen linkages between testing –care and other support services</p>
Follow-up and monitoring	<p>No age segregated national/district data on burden & targets for Paediatric HIV</p> <p>Viral load monitoring weak & not updated</p> <p>No provision for professional counselors and coordination team at MoH for paediatric and adolescent HIV</p>	<p>No age segregated national/district data on burden & targets for adolescent HIV</p> <p>Viral load monitoring weak & not updated</p> <p>No provision for professional counselors & Coordination team for paediatric and adolescent HIV at MoH</p>	<p>Work with HMIS to establish district and national paediatric and adolescent HIV burden and segregate monitoring data for children, young and older adolescents from adults.</p> <p>Ensure regular and timely review of progress across all districts and develop targeted interventions to accelerate progress.</p> <p>Initiate use of M&E tools such as dashboard for Paediatric and adolescent HIV.</p> <p>Strengthen viral load monitoring & align to WHO 2016 recommendations</p>

Thematic Area	Policy Gap for Children living with HIV	Policy gap for Adolescents living with HIV	Suggestion for improvement
			Liase with ministry of public services to consider inclusion of professional counselors in MoH structure of health workers & to institutionalize paediatric and adolescent HIV coordination and support team at MoH.
Community demand and support for paediatric & adolescent HIV care	Weak	Weak	Interventions to create/strengthen community demand & support for children and adolescents living with HIV
School support for children & adolescents living with HIV	Weak	Weak	Liase with ministry of education to educate teachers & build support for children and adolescents living with HIV
Stigma and discrimination	Burden un known Weak interventions to reduce stigma and discrimination	Burden un known Weak interventions to reduce stigma and discrimination	Measure stigma in children and develop interventions to address it among children and adolescents living with HIV
Support to transition child to adolescent and adolescent to adult clinics	Weak	Weak	Provide guidelines and support for managing transmission between child-adolescent and adolescent to adult HIV clinics
Address SGBV and child protection issues	Weak	Weak	Enhance capacity of actors engaged in HIV care for children & adolescents to prevent, identify & address SGBV Strengthen collaboration with other actors such as police, gender, legal, probation & welfare, community development and education

Thematic Area	Policy Gap for Children living with HIV	Policy gap for Adolescents living with HIV	Suggestion for improvement
Role of private health facilities in HIV testing and care	<p>Limited role of private health care facilities in HIV testing, treatment and support for children</p> <p>Limited capacity of health workers in the private sector on Paediatric HIV</p> <p>Gaps in collection, processing and inclusion of HIV data in HMIS</p>	<p>Limited role of private health care facilities in HIV testing, treatment and support for adolescents</p> <p>Limited capacity of health workers in the private sector on adolescent HIV</p> <p>Gaps in collection, processing and inclusion of HIV data in HMIS</p>	<p>Revise national HTC and Treatment policies/guidelines to clarify and strengthen the role of private health care facilities in provision of paediatric and adolescent HIV services</p> <p>Strengthen private-public partnerships including provision of policies, guidelines training and mentorship of private sector health workers on paediatric and adolescent HIV</p> <p>Work with HMIS team to ensure better inclusion of data on paediatric and adolescent HIV from the private sector in national monitoring and reporting.</p>

Key policy gaps

1. No provision for Professional Counselors

Study participants at health facility, district and national levels noted that whereas HTC and ART policies and guidelines provide for pre and post-test HIV counseling as well as adherence counseling including for children and adolescents living with HIV, the Ugandan Ministry of Health structure does not provide for employment of professional counselors. Thus counseling is an add-on task done by other health workers mainly nurses and midwives. Most informants believed that such health workers are inadequately equipped for the task especially when dealing with children and adolescents living with

HIV. The lack of professional counselors also raises questions on the quality of provider initiated counseling services for children and adolescents.

In the Ministry of Health setting, we do not have professionally trained counselors to handle these issues of adolescents (Key Informant Government). We lack professional counselors; it is the health workers that do the counseling part of it. So you find they (clients) are not given enough time. They are not given enough time because of the over whelming numbers of clients that they normally attend to. So we are mainly using expert clients to do the counseling part of it (Key Informant Health Facility). Structures (MoH)

do not allow us to recruit trained counselors. We are just using the general nurses who did not do enough training in counseling and the patient load you know HIV care requires a lot of time,... client load at the facilities really affects some of these services particularly for children (Key Informant District Health Team).

From the above narratives, it is clear that lack of policy provisions to institutionalize professional counselors within the Uganda's Ministry of Health System coupled with the heavy client load constrains the provision of quality HIV and adherence counseling especially among children and adolescents living with HIV.

2. Lack of standards and guidance on HIV status Disclosure

Lack of standardized methodologies and guidance on when and how to disclose HIV status to children was another policy related gap mentioned by study participants.

Disclosure is also a gap. Some people say at 5 years, it is not very clear when a child should be told and how. ...we find this (disclosure) challenging of course the assumption is that once you tell this child, the child gets traumatized... (Key Informant District Health Team). It is important that the current policy review processes address issues like disclosure to adolescents growing up with HIV, what to tell them and at what age. ...issues of mental health like depression for adolescents with HIV e.t.c. (Key Informant Development partner).

Other policy gaps mentioned mainly by District and National level stakeholders, in relation to paediatric and adolescent HIV services were: lack of guidance and interventions to support children and adolescents living with HIV in school, assessing and addressing stigma and discrimination among children and adolescents living with HIV and how to effectively address Sexual and Gender Based Violence as well as other child protection concerns of children and adolescents.

..of course we need to involve school teachers as well if a child is in a boarding school, how should a matron handle this? How should a matron disclose this information? Who should handle the drugs at school? These are the things we need to improve

upon mainly the ministry of education and the ministry of health. Can the child keep the medicine in the box? Can the matron keep the drugs? These are policy gaps that need to be addressed (Key Informant District Health Team).

3. Lack of age segregated data for children and adolescents in HIV testing and care

For instance, under Health Management Information System (HMIS) children on treatment and several assessments are grouped as 0-14 years and 15-49 year olds. The implication here is that data for children, adolescents and adults is mixed up yet different groups have different needs and require differentiated care models.

4. Limited role played by private health care facilities in paediatric and adolescent HIV care

Most national level study participants were concerned about the limited role played by private health care facilities in the delivery of paediatric and adolescent HIV services yet many people seek services from these facilities as noted in the following narratives.

Many people including adolescents don't like to come in a place where everybody knows it is an HIV care place but a private clinic everybody goes there. So we (Government) need to work with the private sector in order to reach more adolescents and children with HIV testing and care services. That means the private sector also needs to be sensitized, their health workers need to be trained and provided with policy and guidelines because it takes the two, if you create

demand on the other side that they can reach the private sector and then they can't find the service then the problem remains ... (Key Informant Development Partner).

Another one added:

We need as a country to reach out to the private sector, give them the skills and make sure those that get commodities like HIV test kits they get are not sold. And for those (children and adolescents) who go to the private sector we expect the minimum to be done in terms of HIV care e.g. HIV testing should be done whether you have paid or not. Health workers should be able to provide the drug and this should be done appropriately but also most importantly knowledge about referral like where drugs can be obtained if the patients are not able to buy the ARVs from the private sector. If we need to have the private sector participate in all these things, get them trained and if the ministry of health doesn't have money to train the private sector then they should reach out to development partners to provide support... There should be purposeful skill and knowledge transfer even in ... policies, pull outs, job aides otherwise the private sector I think does better in terms of adult care you know adults take care of themselves but for children and adolescents am not sure what they are doing because they are never targeted.

Underlying the above narratives is the need for the Ministry of health to reach out, engage and capacitate the private sector to enable it play an active and effective role in the implementation of paediatric and adolescent HIV services in Uganda.

3.4.3 Best practices in Implementation of National paediatric and adolescent HIV Policy Frameworks and Guidelines in Uganda

The study explored perspectives of study partici-

pants with regard to best practices in implementation of policies, frameworks and guidelines for the provision of paediatric and adolescent HIV services in Uganda and the findings are summarized in table 3.3.

Table 3.3: Best Practices in policy implementation for Paediatric and Adolescent HIV services in Uganda

Best Practices for Paediatric HIV policies	Best Practices for Adolescent HIV policies
<ul style="list-style-type: none"> • Mother-baby Care points • Test and Treat for children (0-14 years) • Know Your Child's Status Campaign • Policy dissemination integrated in CMEs • Integrated support supervision includes policies • Mentorship training an avenue to disseminate policies and guidelines • HIV Implementers help in policy dissemination 	<ul style="list-style-type: none"> • Youth Friendly Corners • Adolescent support groups • Use of peers led models of care • Test and treat for some adolescents (up to 14 years) • Policy dissemination integrated in CMEs • Mentorship training an avenue to disseminate policies and guidelines • HIV Implementers help in policy dissemination

The main best practices in relation to implementation of paediatric HIV policies were; institutionalization of mother baby care points at health facilities to address needs of both the mother and baby under the eMTCT programme. Stakeholders mentioned that most health facilities run joint baby-mother points of care where services for monitoring mothers and testing HIV exposed babies are provided in an integrated manner within maternal and child health clinics. Under this arrangement, children who test HIV positive are linked to HIV care, thus increasing the number of children in care but also reducing losses to follow-up for such children.

The policy of test and treat involving initiation and continuation of ART treatment for pregnant and

lactating mothers and children under 15 years living with HIV was another best practice mentioned by most study participants. To most informants this has increased access to treatment for women and children but also contributed to a reduction in mother to child transmission of HIV in Uganda.

In addition, HIV implementing partners such as Baylor Uganda, Uganda Cares and some health facilities especially regional referral hospitals were reported to carryout 'know Your Child's HIV Status Campaigns' where parents and caregivers are sensitized and mobilized to take their children for HIV testing as another best practice. Those found HIV positive, are enrolled or linked to care thus increasing the number of children tested for HIV and those enrolled in care.

Continuing Medical Education and mentorships at health facilities were mentioned as good avenues used for policy dissemination. However, most of these promising initiatives are not implemented on scale, were largely donor dependent and implementers do not have standard guidelines of how such initiatives are initiated and supported. Different implementers use different approaches to offer support services for children and adolescents. With regard to adolescent HIV policies, initiation of Youth Friendly Corners, use of Adolescent support groups and peers in the delivery of HIV prevention, testing and support services (peer led models) especially at large HIV service providers were key promising initiatives.

At some health facilities where we have youth friendly corners, health workers attend to these adolescents. The services which they get range from family planning, HIV counseling and testing, and in case some of the adolescent are positive they are referred to ART clinics ... (Key Informant District Health Team). There are many implementers like TASO, Baylor, Reach-Out Mbuya with several programmes supporting adolescents in HIV care such as adolescent support groups, use of peers in counseling, adherence support, HIV testing and health education (Key Informant Government)

National stakeholders mentioned that health facilities where adolescent support groups and peer educators have been used, they have contributed to increasing the number of adolescents tested and linking those found to be living with HIV.

3.4.4 Paediatric and Adolescent HIV Implementation challenges

The study explored implementation challenges with regard to paediatric and adolescent HIV policies and guidelines and the findings are summarized in table 3.4.

Table 3.4: Key policy implementation challenges for Paediatric and Adolescent HIV services in Uganda

Policy implementation challenge	Suggestion to improve policy implementation
Inadequate Dissemination of policy and guidelines documents	Ensure adequate policy dissemination to all stakeholders including health workers and the public
Unfriendly policy formants - bulky and not easy to read	Package policies in user friendly formats (summaries, pull-outs, job aids) Engage more with print, electronic and social media for dissemination of key policy messages Come-up with summary policy documents with key provisions on paediatric and adolescent HIV for health workers and leaders
Negative attitude of health workers towards policies and poor reading culture	Strengthen use of Continuing medical education and support supervision to disseminate and discuss key policy messages
Human resource challenges (few staff, lack of counselors in MoH skill and knowledge gaps on paediatric and adolescent HIV)	Lobby for more health workers Lobby and advocate for inclusion of counselors in Ministry of Health structure Training, mentorship and regular CMEs to improve health worker knowledge and skills on paediatric and adolescent HIV Engage, train and supervise adolescent peers
Stock out of Critical supplies (HIV testing kits, ARVs and other drugs for prevention of Opportunistic infections)	Advocate for sufficient allocation of resources to ensure constant availability of critical supplies for paediatric and adolescent HIV services
Limited community awareness and demand for paediatric and adolescent HIV services	Strengthen community awareness and advocacy to test link and retain children and adolescents in care
Over dependence on donor funding – (service discontinuity when projects end, non standardized delivery of services)	Advocacy for Government to fund Paediatric and Adolescent HIV programmes MoH strengthen coordination, monitoring and accountability mechanisms and enforce use of standardized training, mentoring, monitoring and result tracking tools.

Inadequate dissemination of policies and guidelines

Study participants at health facility, district and national levels often mentioned inadequate dissemination of policies and guidelines especially to frontline health workers and communities as a major barrier to policy implementation. Many informants noted that often the policy documents are few and do not reach health workers as some informants observed.

...health policies... are developed at the Ministry of Health; when it comes to dissemination normally the dissemination stops at the district level(Key Informant Health Facility). The other issue with dissemination was that you know the policies are developed in Kampala, they have disseminated them at various levels up to the district level but the documents/ materials for the lower units such as health facilities (HC III) that offer these services are not available (Key Informant District Health Team).The deficiencies is in the dissemination...because it means down there not many people are aware of what they are supposed to be doing, and at the implementation level where its most important many of the health workers don't have access to the policies... (Key Informant District Health Team).

Most informants expressed need to be provided with sufficient copies of policies to distribute to health care workers. It was noted that some times the Ministry asks District Health Officers to print and distribute policies and guidelines but districts are financially constrained to fulfill this role.

Dissemination, I think the ministry needs to own up the challenge... they call us and talk to us about policies but we need hard copies because sometimes

when they give us soft copies then the idea is that we go back to the district, print and disseminate them which is not possible because of lack of resources (Key Informant District Health Team).

Unfriendly formats and bulky policies and poor reading culture

The challenge of policy dissemination was further compounded by policy documents being bulky and highly technical thus not easy to read and comprehend especially by busy frontline health workers and other stakeholders outside the health sector as some informants observed.

Being a big book like this, people will not pick interest in reading it (Key Informant District Health Team).

We need key messages for each policy and guidelines to enable the target audiences internalize them (Key informant Development partner). The general lack of a reading culture and negative attitude of some health workers also emerged as a barrier to policy internalization thus limiting policy implementation.

Knowledge is a gap because we have policies but do we read these policies, do we know what these policies are talking about you see (Key Informant Community Development Officer) ... the attitude of service providers to reading some of these things (policies), they don't like reading, you may even bring a book and press it there and tell them please there is a book on this, they may tell you too many stories, but what I have realized, few people who provide services are always interested in reading these policies (Key Informant District Health Team).Government is good at producing those policies but they don't reach

the public so if someone can come and disseminate them through workshops and go on radio creating of awareness so that people can understand what is taking place (Key Informant District Education Officer).

The frequent changes in policies and guidelines also made effective dissemination of policies a challenge.

Low community awareness and demand for paediatric and adolescent HIV services

Study participants highlighted low demand and utilization of paediatric and adolescent HIV services by communities. Low community demand for services was linked to limited community awareness about paediatric and adolescent HIV care and health facility challenges such as lengthy waiting time at health centres and stock-out of drugs. Stigma at family and community levels was another challenge to effective implementation of HIV policies as one participant noted.

Even when we test, the groups that will be less likely to be linked to HIV care are children and adolescents because they create additional stigma to the family. We need to train health workers to know that but also to advocate at family level and in communities to know that if you have tested positive, your children also have a right to be tested and linked to care (Key informant Development partner).

Community sensitization should also include provision of information on children's rights and where services are offered. Use of adolescents as peer service providers was also recommended to reduce stigma among adolescents.

Shortage of Supplies

Stock out of critical supplies for paediatric and adolescent HIV care was another challenge to effective implementation of paediatric and adolescent HIV policies and guidelines. Study participants at health facility, district and national levels mentioned that supplies such as HIV test kits, ARVs and drugs for treatment and prevention of opportunistic infections often run out and limit effective delivery of HIV testing and treatment services for children and adolescents.

We have also had issues with supplies, you may find a health facility going without anti TB drugs for two or three months or even HIV test kits ... (Key Informant Health facility). We still experience stock-out of drugs and supplies such as HIV test kits yet these are important in translating policies into action. This is because of the low budget allocated to the health sector. The health sector budget allocation in Uganda is 8% of

the national budget instead of the recommended 15%... (Key Informant Government). Health workers still suffer with stock outs, so they call and say what do I do this drug is not here? So you know, sometimes there are no alternatives or health workers do not know them (Key Informant Development Partner).

Stock-out of supplies meant that children and adolescents miss out or encounter delays in access of the services even when they may be provided for in policy and treatment guidelines. Study participants also noted that most of the HIV funding for Uganda's HIV programme is from donors and this threatens sustainability and effective implementation of policies. Limited financial resources also hindered district health teams from conducting regular support supervision at health facility levels.

Limited funding ... you need to move down to lower level facilities and provide onsite mentorship but sometimes this supervision instead of being frequent

it is irregular because of limited funds (Key Informant District Health Team).

Limited space and other facilities to ensure provision of adolescent HIV services was another challenge to effective policy implementation.

Human resource related challenges

The main human resource challenges limiting paediatric and adolescent HIV policy implementation were; inadequate staff, skill and knowledge gaps among health workers and lack of counselors in the Ministry of Health staff structure.

3.4.5 Opportunities within National Policy Frameworks, Strategies and Guidelines for provision of quality services for children and adolescents living with HIV

Several opportunities were mentioned that can be tapped to enhance paediatric and adolescent HIV care. These are summarized in table 3.5:

Table 3.5: Opportunities to provision of quality services for children and adolescents living with HIV

- Availability of HIV implementers and donors willing to support
- National policies and guidelines are being updated (HTS, ART guideline)
- The Ministry of Health has developed an Adolescent HIV training Curriculum which can be used strengthening capacity of service providers
- Trainers of Trainers for Adolescent HIV training Curriculum
- Paediatric and Adolescent HIV coordination team at the Ministry of Health for coordination technical supervision and support
- Some Implementing partners such as Baylor Uganda, Mild May, TASO have expertise in use of peer support groups and use of peers in provision of adolescent HIV care services
- Implementing partners have developed training packages for building the capacity of community support structures
- M& E indicator framework being developed by MoH & ANECCA with support from UNICEF – can form a basis
- Ongoing National HIV survey can provide a basis for knowing the burden of paediatric and adolescent HIV as a basis for setting district and national targets

It was noted that several HIV implementers and donors exist and are willing to support provision of HIV services for children and adolescents. With support from implementing partners, the Ministry of Health is leading processes to update key HIV policies and guidelines including the HIV testing policy and treatment guidelines. These present opportunities to ensure that the policy gaps identified in this report such as lack of clarity on age of consent/assent for HIV testing and disclosure of HIV status; and the need to enroll all children and adolescents living with HIV on care to be addressed. At the time of the study, the Ministry

of Health with support from Baylor Uganda had developed an Adolescent HIV training Curriculum which can be used for standardized capacity building of service providers in adolescent HIV care. In addition, trainers or trainers at national level had been trained and these can help to rollout and monitor adolescent HIV training in the country. Another opportunity identified by national level stakeholders for strengthening paediatric and adolescent HIV services was the initiation of Paediatric and Adolescent HIV coordination team at the Ministry of Health. Although, HIV implementing partners were supporting this team, most stake-

holders mentioned that it was performing critical coordination and technical support supervision roles. It was noted that the technical coordination team had improved the visibility of paediatric and adolescent HIV services in the country.

Some Implementing partners such as **Baylor Uganda, Mild May, TASO** have expertise in use of peer support groups and use of peers in provision of adolescent HIV care services. These partners can support expansion of these initiatives and provide space for others actors to learn. National stakeholders also mentioned that the **Ministry of Health** and **ANECRA** with support from **UNICEF** was developing an M & E indicator framework for paediatric and adolescent HIV . The M&E framework can form a basis for setting clear targets and monitoring progress on paediatric and adolescent HIV services. Indeed, the ongoing Uganda National HIV survey is expected to provide statistics on the current national and district specific burden of paediatric and adolescent HIV to inform district and national targets.

SECTION FOUR

DISCUSSION AND CONCLUSION

This national qualitative study provides key insights on stakeholders' perspectives with regard to the status of paediatric and adolescent HIV policies in Uganda. Overall, the study revealed that most stakeholders in Uganda perceive the country to have mature and well developed and regularly updated paediatric and adolescent HIV policies and guidelines mainly informed by experience, research and guidance from global actors mainly the World Health Organization. The most commonly mentioned policies/guidelines in relation to paediatric and adolescent HIV include: the Uganda HIV Counseling and Testing Policy, Prevention of Mother to Child Transmission of HIV policy, Uganda National Antiretroviral Treatment Guidelines and the Adolescent Health Policy. Most of the policies and guidelines were general to HIV without specific provisions addressing concerns of children and adolescents the exception being the Adolescent Health policy which specifically focuses on adolescents.

Study findings revealed a relatively high awareness of paediatric and adolescent HIV related policies among District Health Team members and national level informants. This is not surprising given that these actors are directly involved in planning and provision of paediatric and adolescent HIV services and are often targeted by the Ministry of Health during policy formulation and dissemination. On the contrary, most frontline health workers and officials from other departments such as education and community development generally had limited awareness about paediatric and adolescent HIV policies and their provisions. These findings reflect limited dissemination of paediatric and adolescent HIV related policies and guidelines likely to limit effective service delivery. The limited awareness of these policies and guidelines by actors in education and community development sectors shows that more efforts are needed to realize the desired multi-sectoral HIV response as reflected in the Uganda HIV and AIDS Strategic plan (UAC 2015).

Stakeholder insights from this study have revealed that Uganda has several policies and guidelines to address paediatric and adolescent

HIV

The results indicated that the process of policy development and revision was participatory and consultative but mainly involved actors from the Ministry of Health, the academia, UN agencies and other development partners involved in paediatric and adolescent health. Despite this strength, there is need to widen consultations especially to include other sectors and stakeholders outside the health sector including gender, education, community development and policy beneficiaries in this case adolescents, children and their caregivers. The involvement of frontline health care providers should also be prioritized. Widening stakeholder involvement in policy formulation is critical to increase policy relevancy and better fit in context (Gill Walt G, Shiffman J et al. 2008). Multi-sectoral involvement can open up new opportunities for better implementation of services to children and adolescents. Collaboration with the education department would open opportunity for advocacy to address support needs of children and adolescents living with HIV in school and the possibility of offering HIV counseling and testing services at school. Involving beneficiaries in formulation of policies and development of guidelines can help to improve policy acceptability and is likely to increase service utilization.

Other strengths of Uganda's paediatric and adolescent HIV policies mentioned by stakeholders were; paediatric and adolescent HIV prevention, testing and care are integrated in national policy and strategy documents, policies are regularly updated often informed by WHO guidance and policies and guidelines provide for test and treat especially for children and some adolescents (0-14 years) as well as decentralized service delivery.

Study findings revealed lack of clear guidance on disclosure of HIV status to children, lack of national

and district specific targets for HIV testing and treatment services for children, weak linkages between HIV testing and treatment and weak/no provisions for support at community, school and during transmission from child to adolescent clinics as some of the critical paediatric HIV policy gaps. With regard to adolescent HIV care, lack of clear guidance on disclosure of HIV status to adolescents, lack of national and district specific age segregated targets for HIV testing and treatment services for adolescents, weak linkages between HIV testing and treatment and weak/no provisions for support at community, school and during transmission from adolescent to adult clinics; unknown burden of stigma among adolescents and weak interventions to address it were key policy gaps. The lack of guidance on how to address sexual and gender based violence especially among the adolescents and the limited role of private health care providers in the delivery of HIV services to children and adolescents in Uganda were other key policy gaps. It is important that these gaps are addressed in the ongoing HIV testing services policy and ART guidelines review. As noted earlier Uganda is currently revising several policies to align them with recent recommendations (WHO, 2016).

Study findings revealed that despite having good and regularly updated paediatric and adolescent HIV policies, there were major implementation challenges that limited the effectiveness of these policies to deliver the needed actions for children and adolescents living with HIV. Inadequate Dissemination of policies and guidelines, unfriendly policy formants, negative attitude of health workers towards policies and poor reading culture, human resource challenges (few staff, lack of counselors in MoH structure, skill and knowledge gaps on paediatric and adolescent HIV), insufficient financial resources leading to

stock out of critical HIV supplies; limited community awareness and demand for paediatric and adolescent HIV services and over dependence on donor funding were key policy implementation challenges mentioned by stakeholders. These challenges are not particular to paediatric and adolescent HIV but rather typical to other health policies in Uganda and other African settings the major driver being inadequate financial and human resources.

Overall, stakeholder insights from this study have revealed that Uganda has several policies and guidelines to address paediatric and adolescent HIV. However, several gaps revealed in this study should be addressed to further strengthen these policies. This process should take into consideration emerging national experience with policy implementation as well as the recent WHO guidance.

From the policy review findings, one can draw an overarching conclusion that there is no standard format for developing policies and guidelines which ensures prioritization of adolescents and paediatric HIV services yet these constitute a sizable proportion of the country's population which is sexually active and prone to HIV infection. All policies do not express renewed commitment and leadership to achieving full coverage of PMTCT services. Some of the gaps that thread across most of the policies and guidelines are the lack of targets and program performance measurements for linking adolescents to HIV treatment and other care and support services; ensuring adolescent retention to care and clear provisions for linking adolescents testing HIV positive to care. In fact the component of monitoring and evaluation is missing in most policies and guidelines but this is provided for in the strategies.

SECTION FIVE

RECOMMENDATIONS

Update key policies and guidelines especially ART treatment and HIV Testing policies and guidelines to address the identified policy gaps along the HIV continuum. The process of policy revision should involve wider consultations including with frontline health workers and consumers services.

- Widely disseminated HIV policies and guidelines beyond the health sector and in user friendly formats including summaries, policy pull-outs and job Aids.
- Integrate sexual and gender-based violence (SGBV) prevention and human rights into HIV prevention and care programming. There is need to strengthen the capacity of health, legal and social service providers to manage

SGBV cases among women, adolescents and children.

- Strengthen efforts against stigma and discrimination. This requires assessing the burden of stigma and discrimination among children and adolescents to match guide prevention and response.
- Strengthen policy monitoring, review and evaluation. The ministry of health should work with partners to come up with clear national and district paediatric and adolescent HIV burden and targets to guide this process. The ministry of Health should initiate and institutionalize use of paediatric and adolescent HIV monitoring and evaluation dash boards to measure and display changes and inform the development of tailor made plans to reach the set targets.

- Institutionalize the paediatric and adolescent HIV technical and coordination team at the Ministry of Health to ensure continued visibility, leadership and coordination policy and guidelines implementation, monitoring, review and evaluation. This is also important to ensure that responses are well designed, implemented and evaluated in a standardized manner by all actors.
- Strengthen the role of private health care providers in the design and implementation of paediatric and adolescent HIV policies and guidelines. For this to happen, there is need to promote the implementation of the public private partnership in the delivery of HIV and AIDS services including providing health workers from the private sector with policies and guidelines; training, monitoring, support



supervision and inclusion of data from such facilities in analysis and in national reports and other systems.

- Government should allocate more financial and human resources to the health sector to ensure availability of adequate health workers and supplies to turn policies and guidelines into sustainable actions for children and adolescents living with HIV.
- Increase community awareness and advocacy for paediatric and adolescent HIV so as to increase demand for these services.
- Ensure that HIV and AIDS specifically paediatric and adolescent components are mainstreamed in the curriculum of all Education Institutions and at all levels in Uganda. This should be augmented by Continuing Profes-

sional Development and mentorship programmes to ensure availability of skilled and competent health workers.

- Advocate for revision of public service structures and institutionalize critical staff and positions at health facilities, line ministries, departments, agencies and districts. These include paediatric and adolescent HIV coordination team at MOH and counselors to be formally included in the health care cadres.
- Expand availability and capacity of laboratories at different levels for effective delivery of paediatric and adolescent HIV and AIDS services. In addition there is need to increase the number of accredited health facilities providing comprehensive HIV and AIDS and TB services including for children and adolescents.

here is need to promote the implementation of the public private partnership in the delivery of

HIV/AIDS
SERVICES

REFERENCES

- Uganda Bureau of Statistics (2014), National population and housing census
- Gill Walt G, Shiffman J et al. (2008), 'Doing' Health Policy Analysis: Methodological and Conceptual Reflections and Challenges. Health Policy Plan. 23 (5): 308-17 doi:10.1093/heapol/czn024
- Global Country Report (2013)
- Government of Uganda (2014), The state of Uganda population report
- Government of Uganda (2015), National Budget
- Ministry of Health (2013), Baseline Assessment of Access to HIV Testing, Care and Treatment Among Adolescents in Uganda, December 2013
- Ministry of Health (2014a), National spectrum estimates
- Ministry of Health (2015a), Health Sector Development Plan
- Ministry of Health (2015b), Annual Health Sector Performance Report (APRR) 2014/15
- Ministry of Health (2014b), Central Public Health Laboratories, September 2014.
- Ministry of Health (2015c), Draft National TB strategic plan 2015/16-2019/20
- Uganda AIDS Commission (2015), Joint Annual Review Report
- Uganda Bureau of Statistics (2014), Statistical Abstract
- UNICEF (2014) 'country programme of cooperation between the Government of Uganda and UNICEF 2016–2020'. Draft. Kampala: UNICEF
- Uganda World Health Organization (1995), A picture of health? A review and annotated bibliography of the health of young people in developing countries Geneva, [WHO/FHE/ADH/95.4]

ANNEXES

Annex 1: List of documents reviewed

Policies

Uganda HIV Counseling and Testing policy 3rd edition (2010)

Guidelines

National Antiretroviral Treatment Guidelines for Adults, Adolescents, and Children (2008)

National Implementation Guidelines for HIV counseling and testing in Uganda (2010)

Uganda Addendum-to-National-ART-Guidelines (2013)

Uganda Clinical Guidelines (2012)

Adolescent Health Policy Guidelines and Service Standards (May 2011)

World Health Organization, (2013) consolidated guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection; Recommendations for a Public Health Approach

Guidelines for the management of sexually transmitted infections (2003)

Strategies

National Development Plan II (2015)

National HIV/AIDS Strategic Plan-2015/2016-2019-2020

Health Sector Development Plan (2015)

National Adolescent Health-Strategy (2011)



African Network for Care of Children Affected
by HIV and AIDS [ANECCA]

Plot 1 Kololo Hill Drive,
P.O Box 7484, Kampala Uganda
Tel: +256 039 3516266
Website: www.anecca.org