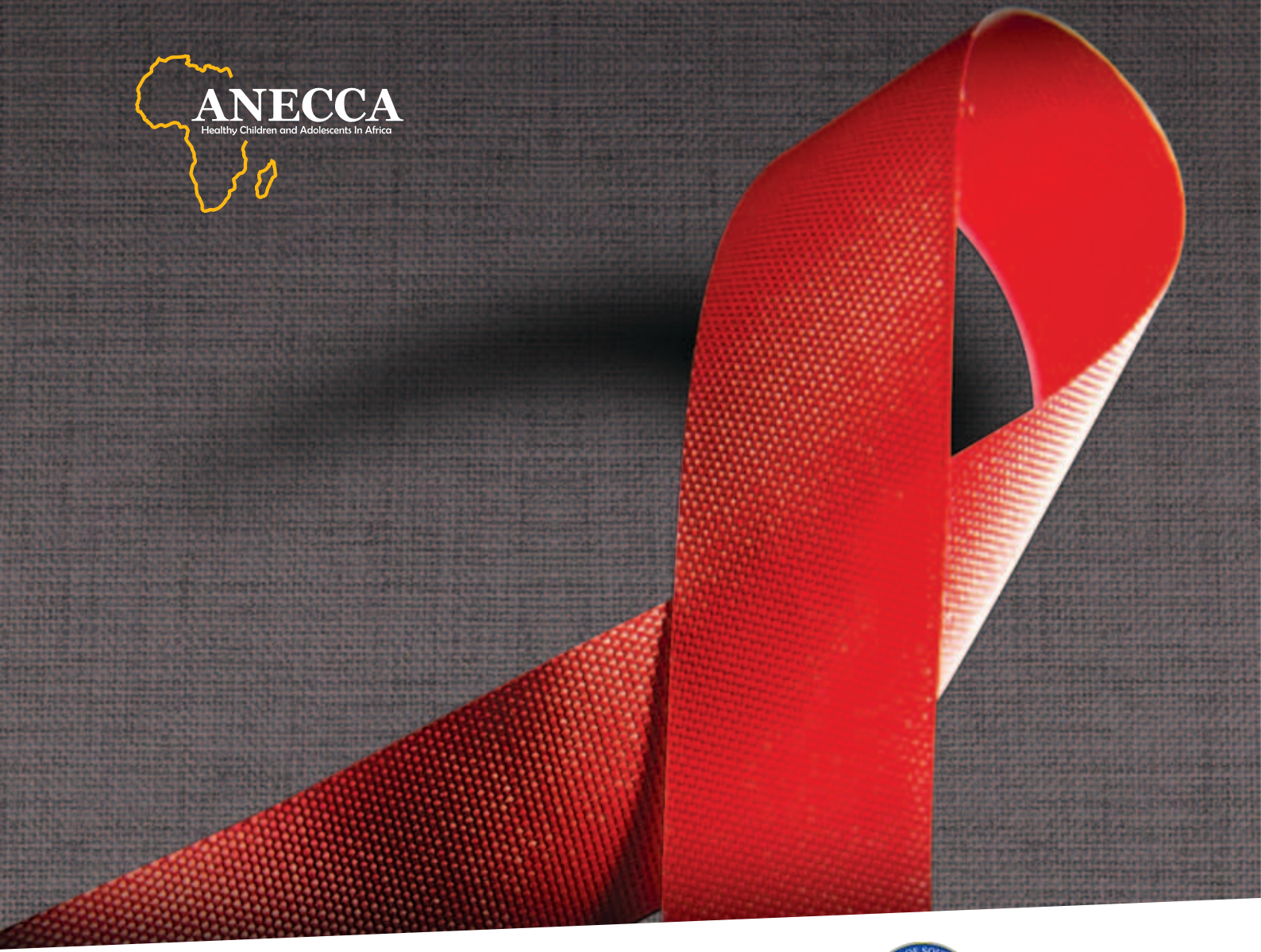
RAPID ASSESSMENT OF POLICY GAPS

for Children and Adolescent HIV Services in South Sudan

ANECCA
Healthy Children and Adolescents In Africa



The Global Fund
To Fight AIDS, Tuberculosis and Malaria

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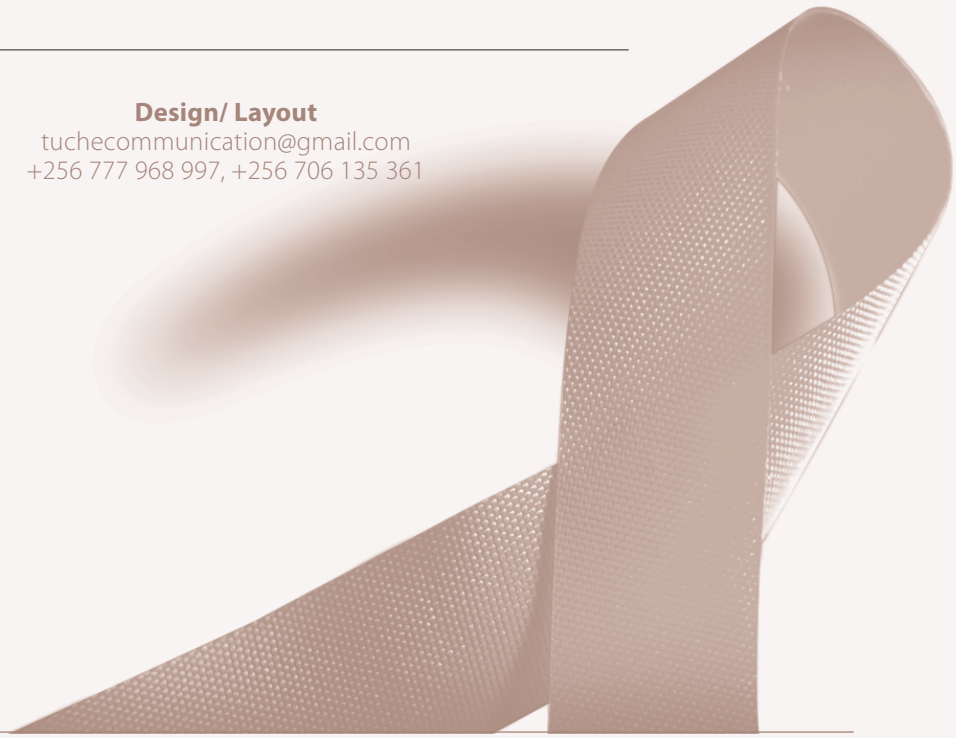

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The world currently holds the largest generation of young people in history: 1.8 billion adolescents and youth make up one quarter of the world's population.

Fulfilling young people's right to health care can create a powerful force for economic development and positive change in South Sudan.

Abbreviations

ANECCA	African Network for Care of Children Affected by HIV/AIDS
ART	Antiretroviral therapy
HIV/AIDS	Human immunodeficiency virus/ acquired immunodeficiency syndrome
GARPR	Global AIDS Response Progress Reporting
UN HLM	United Nations High Level Meeting
MCH	Maternal and child health
NTD	Neglected tropical diseases
NSP	National strategic plan
PEFPAR	President's Emergency Plan for AIDS Relief
PITC	Provider-initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission
SPLA	Sudan People's Liberation Army
TB	Tuberculosis
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNICEF	The United Nations Children's Fund
UNFPA	The United Nations Population Fund
USAID	U.S. Agency for International Development
WHO	World Health Organization

Executive Summary

This rapid assessment of gaps and strengths in HIV policies and guidelines in South Sudan is part of a seven-country grant from the Global Fund to fight AIDS Tuberculosis and Malaria implemented by the African Network for Care of Children Affected by HIV/AIDS ANNECA to improve coverage of quality services for children and adolescents living with HIV. The study aimed to review and assess existing national paediatric and adolescent HIV policies and guidelines in South Sudan to identify strengths and gaps in provision of quality services for children and adolescents living with HIV; to document best practices and opportunities within national policy frameworks strategies and guidelines in the provision of quality services for children and adolescents living with HIV in South Sudan; and 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.

This assessment is a descriptive study. Primary research was through qualitative research, i.e. in-depth interviews with stakeholders at national, state and facility levels. Secondary research was primarily through a desk review to assess content of policy documents, guidelines, strategic documents and action plans. The WHO-defined standard of care for children and adolescents living with HIV was used as the gold standard to assess the various documents. The desk review also facilitated mapping of key country stakeholders.

This review reveals that South Sudan does not have policies and guidelines specific to children and adolescents. However, there are specific training materials on children. Strengths of the existing policies and guidelines are that these documents have largely been adopted from WHO guidelines, but they have been modified to suit local situations and limitations. Their provisions place infants, children and adolescents as priority populations for HIV testing services (HTS) and HIV care and treatment. The ***2015 HIV prevention strategy*** focuses on young people at risk, particularly girls and young women as a priority group. The country has adopted Re-test before starting treatment, Test and Start, and 90–90–90 targets in the ***South Sudan 2016 HTS draft guidelines***. The policy and guidelines give explicit guidance along the continuum of care for children especially for HIV-exposed infants diagnosis (EID) , presumptive diagnosis of HIV (testing and treatment schedule).

Some gaps in the policies include: lack of flexibility in consenting to HIV testing for those below 18 years, who have not been classified as being at risk of HIV infection; and provisions on HTS do not promote age-appropriate disclosure, an important aspect for adherence and retention particularly for adolescents living with HIV. South Sudan HIV guidelines are not up to date with the latest WHO guidance on initiation of antiretroviral therapy, which requires that every person diagnosed with HIV should be initiated on treatment, regardless of immunological status. The age cut-off in children is not defined in the consolidated HIV guidelines in terms of age-appropriate antiretroviral therapy (ART) regimens. The actual ART regimen for children age < 3 years does not conform to the latest WHO guidelines that recommend use of lopinavir/ritonavir (LPV\r) . South Sudan still uses nevirapine as part of the treatment regimen. The challenges of judgment, stigma and discrimination, confidentiality and privacy that adolescents face are not adequately addressed in the policy or the guidelines, and the multi-sectorality of HIV prevention is not well recognized and strategized. The policy and guidelines emphasize treatment monitoring supported by CD4 testing and viral load start-up plan, but very little is being done to implement treatment.

Other gaps include data disaggregation by age not being responsive to adolescent HIV programming (current options are < 15 years or ≥ 15 years); MOH does not have specific targets for adolescent testing and treatment at national, state, county and facility levels.

Results of the qualitative research, i.e. in-depth interviews with stakeholders at national, state and facility levels, reveal that most study participants were aware that HIV policies and guidelines exist, though most could still not mention any of the guidelines or policy by name, and had very little knowledge of their content. Most respondents also noted that there were no

specific policies and guideline documents for adolescents and children only, but recommendations on HIV care and treatment for children and adolescents are incorporated in the main national HIV policies for adults. Respondents were of the view that most of these documents were general to HIV but with specific provisions addressing concerns of children and adolescents. Most study participants reported that South Sudan follows a participatory process in the development or adoption of HIV-related policies and that HIV policies are adapted from international and regional documents.

Most key informants reported on the whole, the guidelines are being implemented since HIV prevention, care and treatment are being offered. However, the extent to which these guidelines and policies are being implemented differs between counties and facilities. Other informants were of the opinion that HIV policies and guidelines are not being implemented, or if they were then it was not according to the set standards. The commonest challenge mentioned hindering implementation of the guidelines was lack of a separate room or arrangement for children and adolescents. Others reported the lack of specific guidelines for children and adolescents; lack of laboratory services especially for dried blood spots (DBS), CD4 and viral load tests; an inadequate number of qualified staff; and shortage/interruption in provision of commodities such as HIV test kits and drugs.

Recommendations

- Update key policies and guidelines especially on antiretroviral therapy and HIV testing in line with the latest WHO guidelines
- Lower the age of consent for HIV testing for adolescents to suit the South Sudan context (Uganda/ South Africa 12 years and above)
- Be explicit on the recommended age of disclosure of HIV status for children and adolescents (school-going age 6–12 years) according to the latest WHO guidelines
- Ensure policies and guidelines for children and adolescents are available and disseminated to health workers and HIV programme staff in summarized format—especially the key provisions and statements
- Implement the EID programme scale up plan
- Integrate sexual gender-based violence into HIV policies and guidelines—screening at HIV counselling and testing, and care and treatment including post-exposure prophylaxis
- Integrate issues of orphaned and vulnerable children into HIV policies and guidelines, and design a strategy for reaching adolescents—create appropriate messages taking into account age, culture and religion, conduct awareness activities in the community to create demand for services.

1 INTRODUCTION

1.1 Status of the Health Care System in South Sudan

Despite the Republic of South Sudan having attained Independence in 2011, after decades of civil war that left over 2 million people dead, the health infrastructure remains rudimentary and fragmented. Decades of neglect by the Sudan government and years of devastation from civil war have contributed to the poor health status of South Sudanese people. Rates of access to antenatal and obstetric care are among the lowest in the world

Data from the 2006 ***Sudan household and health survey*** revealed that South Sudan had the highest rates of maternal mortality at 2,054 per 100,000 live births, child mortality at 135 per 1,000 live births, neonatal mortality at 52 per 1,000 live births and infant mortality at 84 per 1,000 live births. Recent statistical estimates from the 2015 Population Reference Bureau show some improvements but the indicators show the country is still facing major health problems—maternal mortality ratio: 730 per 100,000; child mortality rate: 40 per 1,000; and infant mortality rate: 67 per 1,000.

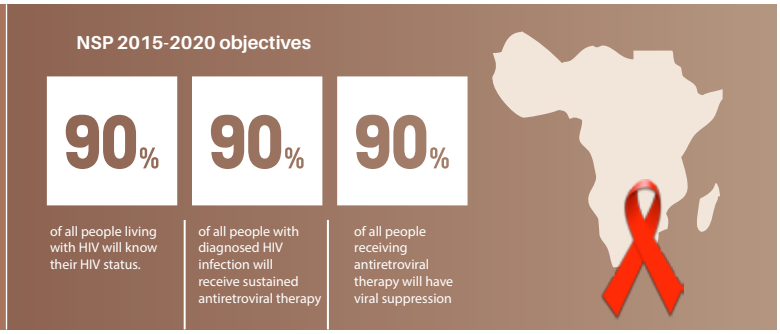
Approximately 12 percent of deliveries occur in a health facility, and only 17 percent of women receive the fourth visit of antenatal care (RoSS 2010). Only 34 percent of South Sudanese have access to improved water supply, while only 14 percent have access to improved sanitation. The contraceptive prevalence for modern methods is extremely low at 1%. The quality of maternal and child health care available sometimes does not reach acceptable standards. Malaria is the leading cause of morbidity and mortality, accounting for 20–40 percent of morbidity, with over 20 percent of deaths reported at health facilities and 30 percent of all hospital admissions (Pasquale et al. 2013). The World Health Organization (WHO) estimates the incidence of tuberculosis (TB) disease in South Sudan to be 79 per 100,000 for new sputum smear positive TB and 140 per 100,000 for all forms of TB cases.

Children particularly suffer poor health. Approximately 25 percent of under-fives are stunted due to inadequate nutrition while only one in five children aged 1 year or below is immunized against measles. Most of the population does not have access to clean water. Of the 17 neglected tropical diseases recognized by WHO, all are present in South Sudan. They include dracunculiasis or guinea worm, which is spread through contaminated water. South Sudan had 99 percent of the world's documented cases of guinea worm in the first half of 2012. Low levels of health awareness among the general public coupled with rudimentary systems of disease surveillance and prevention make it difficult to control disease outbreaks when they occur.

South Sudan's dire health outcomes are closely linked to a lack of access to health care. South Sudan has a total of 1,147 functioning health facilities serving a population believed to be in excess of 12 million. Buildings are ill-equipped and unhygienic, often consisting of no more than a one-room structure with thatched roof and dirt floor. More than half of the population live more than a 5-km walk from the nearest primary health care unit, the most basic health facility. The per capita number of outpatient visits to health facilities is just 0.2 each year.

There is a chronic shortage of health professionals at all levels, from nurses and midwives to laboratory technicians, doctors and surgeons. There are 1.5 doctors and 2 nurses for every 100,000 citizens. The personnel gap is partially filled by less qualified staff, such as community health workers and home health promoters, but they do not have the ability to deal with cases beyond the most routine. The government cannot afford to pay the salaries of the existing labor force. Nearly half the people working in South Sudan's health service are employed by international NGOs. In addition, many NGOs top up the

To reach the 90-90-90 global target in high HIV prevalence areas such as sub-Saharan Africa, more has to be done at the national and regional levels towards improving coverage and quality of care to children and adolescents living with HIV.



salaries of health workers on the government payroll, who receive lower wages.

The human capacity deficit extends to planning, policy, and oversight functions of the health system. Sufficiently qualified staff are almost entirely absent from the county health departments, and the situation is little better at either the state ministries of health or at the national ministry of health. Planning capacity is particularly weak, meaning that predictable seasonal outbreaks of diseases like malaria rapidly turn into full-blown health crises because stockpiles of drugs and mosquito nets are not ordered and distributed in advance. Capable and dedicated individuals are dotted across the health system, but they find themselves overburdened and unsupported, or placed in settings where they are supervised by people less qualified than themselves. Demoralization can quickly set in, and as a result, staff retention is a problem.

To address the new country's poor health indicators, the Ministry of Health has set priorities for many health areas. Several key policies provide important strategic direction and guidance to engage with the health sector and, in particular, in efforts to ensure access to primary health care. The ***Basic package of health and nutrition services*** sets guidelines for essential health services to be made available at primary health care centers and units. Similarly, the ***National reproductive health strategic plan,*** 2011, highlights the goal of reducing maternal and neonatal morbidity and mortality, and improving the reproductive health status of the people of South Sudan through the provision of a comprehensive, universally accessible, quality, integrated, equitable and sustainable comprehensive reproductive health package.

1.2 Status of HIV epidemic in South Sudan

South Sudan has a mixed HIV epidemic, with pockets of hyperendemicity and concentration among key populations and within the country's southern region, while the epidemic is generalized within the wider population. Antenatal clinic surveys reported national prevalence of 2.6 percent in 2012 (MoH 2012), from 3.0 percent in 2009 and 3.7 percent in 2007. According to the Global AIDS Response Progress Report (SSAC 2015) the estimated prevalence for 2015 was 2.7 percent.

About 180,000 people, including 14,000 children, were estimated to be living with HIV in 2015 (spectrum estimates). Higher prevalence has been estimated among women than men, and in certain age groups including 20–24 and 25–29 years. This variance is explained by a range of social, cultural, economic and risk factors disfavoring women and girls. About 12,000 people died from AIDS-related causes in 2015 including about 1,400 children below 15 years (UNAIDS spectrum estimates, 2015).

Sex workers and their clients, including the military, account for at least 63% of new adult infections (RoSS 2013). Prevalence within the military is 5 percent (RoSS 2012), about twice that of the general population. For sex workers, it is at least five times higher than the general population.

While much progress has been made in responding to HIV epidemic in South Sudan, such as improving coordination (SACC 2013), the number of AIDS-related deaths is rising. Service coverage levels are strikingly low: less than 5 percent of all adults and 3 percent of all children living with HIV are on treatment.

1.3 Paediatric and adolescent HIV

To reach the 90–90–90 global target in high HIV prevalence areas such as sub-Saharan Africa, more has to be done at the national and regional levels towards improving coverage and quality of care to children and adolescents living with HIV. Much as there has been progressive improvement on the prognosis for HIV infection in the world, South Sudan lags behind. The country has high levels of poverty, limited infrastructure and capacity for service provision in all sectors, and some of the lowest socio-economic and health indicators in the world.

By June 2016, only 27 sites across the country were offering comprehensive HIV treatment, care and support to people living with HIV. The estimated percentage of people living with HIV on antiretroviral therapy (ART) for all ages is 11 percent, and 5 percent for children below 15 years. The estimated prevention of mother-to-child transmission (PMTCT) coverage in the country is 41 percent (SACC, 2015). The ratio of newly HIV-

infected adults to those newly on treatment—or the tipping point—was calculated at 10 for 2011. This tipping point shows that South Sudan is one of the countries furthest behind in the region, if not globally, in turning back the HIV epidemic and its coverage for treatment and targeted prevention interventions (unpublished South Sudan operational plan report, 2014).

The world currently holds the largest generation of young people in history: 1.8 billion adolescents and youth make up one quarter of the world's population. Fulfilling young people's right to health care can create a powerful force for economic development and positive change in South Sudan. A wide-lens perspective on health and development is needed to address the social determinants that put young people at risk of HIV and other sexually transmitted infections (UNAIDS 2013).

The new global target prioritizes equity. The world will not end the AIDS epidemic unless all communities affected by HIV have full and equitable access to life-saving treatment and other prevention services. In particular, the ambitious 90–90–90 target demands dramatic progress in closing the treatment gap for children, adolescents and key populations, using a rights-based approach. South Sudan must therefore remain committed to early diagnosis of HIV infection in infants and treatment for children in order to continuously improve and provide high-quality treatment, and care services must reach more children and adolescents especially as they transition from child to adult services.

1.4 Problem Statement and Rationale to the Policy and Guidelines Assessment

South Sudan has put in place a policy and guidelines that facilitate HIV care and treatment among adults and children living with HIV. These include the ***South Sudan national HIV and AIDS strategic plan, 2013–2017; Prevention of mother-to-child scale-up plan; South Sudan HIV policy 2015, Consolidated clinical guidelines on use of antiretroviral drugs for HIV treatment and prevention, 2014; South Sudan national prevention strategy, 2015–***2017; as well as specific guidelines on HIV counselling and testing including provider-initiated testing and counselling. However, several gaps exist in the policy environment for care of HIV-infected children and adolescents. South Sudan does not have national specific plans (policy documents) on paediatric and adolescent ART. This assessment will investigate whether the available guidelines in use are comprehensive, particularly in the areas of HIV testing as well as linkage, initiation and retention on ART of infected children and adolescents.

In other countries, the literature review on this subject reveals a lack of clear targets and strategies for identifying and linking, initiating and retaining HIV-infected children and adolescents on ART. Other countries have put in place a policy of provider-initiated testing and counselling (PITC), but the guidelines and training curricula they have are mainly for adults, with minimal content on children and adolescents. Therefore, implementation of PITC for children and adolescents is minimal in most health facilities. Several unresolved questions remain regarding policy on testing and counselling of children and adolescents. Besides the variation in the age of consent for testing young adolescents across the countries, there is disharmony and uncertainty on how to deal with children and adolescents who seek HIV services on their own. Policy mix-up is preventing some adolescents from seeking and getting sexual reproductive health and HIV services, because adolescents tend to visit health facilities without the knowledge and company of their parents or guardians.

1.5 Study Objectives

- To review and assess existing national paediatric and adolescent HIV policies and guidelines in South Sudan with a view to identifying strengths and gaps in the 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 South Sudan.
- 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 stakeholders' consultations to develop national action plans to bridge the gaps in the policies and guidelines.

2 METHODOLOGY

2.1 Study Design

This research is a descriptive study. Primary research was through qualitative research, i.e. in-depth interviews with stakeholders at national, state and facility levels. Secondary research was primarily through a desk review to assess content of policy documents, guidelines, strategic documents and action plans. The WHO-defined standard of care for children and adolescents living with HIV was used as the gold standard to assess the various documents. The desk review also facilitated mapping of key country stakeholders.

2.2 Study Area

The review and assessment of policy and guidelines was carried out in all the 10 regions (former states) of South Sudan. The study was designed to identify policy gaps, opportunities to improve policy and to document best practices that will increase coverage and quality of care for children and adolescents living with HIV. The study was conducted by ANECCA in partnership with the South Sudan Ministry of Health. The South Sudan Research Ethics Committee granted ethical approval and the Ministry of Health granted institutional clearance including national and state HIV departments.

2.3 Study Population

The population or respondents for this policy review and assessment were selected at two levels—national and health facility. Purposive sampling was used to select study respondents for the two levels.

2.3.1 National Level

In collaboration with the Ministry of Health and ANECCA ministerial focal persons, the national consultant carried out a stakeholder analysis and identified the various stakeholders in paediatric and adolescent HIV care. These included UN bodies, professional associations, civil society organizations and relevant government programs, departments or units (Box 1). Purposive targeted sampling was used to identify two or three respondents per organization, who are directly involved in paediatric and adolescent HIV policy and guidelines, for key informant interviews.

Box 1. National level Respondents

a. Ministry of Health; South Sudan AIDS Commission
b. Ministry of Health Reproductive and Child Health departments
c. UNICEF, UNFPA, WHO and UNAIDS
d. USAID/PEFPAR
e. Civil society organizations
f. Global Fund—HIV/AIDS

2.3.2 Health Facility Level

Participating health care facilities were selected through purposive sampling. Out of the 27 sites providing antiretroviral therapy in South Sudan, 10 health care facilities were selected to participate in the study. The selection criteria for the facilities was based on comprehensiveness of HIV care package, staff population and accessibility of the facility.

In each of the randomly selected health facilities, health workers were purposively sampled from service delivery points that provide paediatric and adolescent HIV care services. To understand integration and provision of services such as provider-initiated testing and counselling, the health facility in charge was also sampled for interview.

Table 1. Participating health facilities

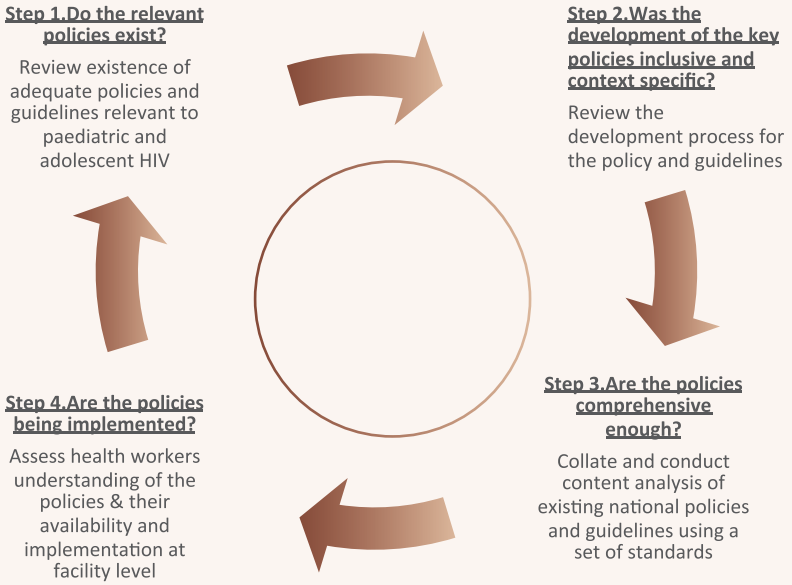
State	Facility
Jubek State	Juba Military Hospital
Imatong State	Nimule Hospital
Gbudwe State	Yambio State Hospital
Jonglei State	Bor Hospital
Eastern Lakes State	Mapuordit Hospital
Eastern Lakes	Yirol Hospital
Yei River State	Yei Hospital
Aweil State	Aweil State Hospital
Gogrial State	Kuajok Hospital
Eastern Nile State	Renk Hospital

2.4 Data collection methods and analysis

2.4.1 Policy review method – Content analysis

The review and assessment of existing national policies and guidelines related to paediatric and adolescent HIV care was based on the Health policy conceptual model (Figure 2) and was adapted so that four critical policy issues were reviewed: 1) existence of paediatric and adolescent HIV care policies, 2) process of policy development including the role of various stakeholders (actors), 3) content of the policy and guidelines including comprehensiveness of the policy, and 4) the implementation of the policies.

Figure 2. Health policy conceptual model: Key questions to answer in the policy review and assessment. (Adapted from Walt & Gilson 1994)



Box 2. Minimum listing of policy documents for review

a. The national HIV strategic plan
b. The national HTC strategy or guidelines
c. ART / Treatment policy/strategy/guidelines
d. Paediatric HIV care and treatment guidelines
e. Early Infant Diagnosis policy/guidelines, where these exist
f. PMTCT/EMTCT guidelines/policy/strategy
g. Adolescent HIV guidelines/strategy/ policy

The desk review of the various policies, guidelines, strategic documents and action plans assessed content of the documents and used the Walt & Gilson policy review process (Figure 2). All national policies that made reference to paediatric and adolescent HIV were included for consideration. The policies reviewed belonged to South Sudan and had been approved by the national ministry of health as the official policy documents (Box 2).

For this review, a policy includes any document that provides the official government position on a thematic area under study. These included policies, plans, guidelines, curriculums, legislation, and strategy documents among others.

Content analysis started with collating and cataloguing the relevant policy documents for review. Subsequently, the content was reviewed against the WHO guideline documents, which address prevention, care, and treatment of HIV for adolescents, i.e. the consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection (WHO 2016), and the ***Adolescents: guidance for testing and counselling for adolescents and care for adolescents living with HIV*** (WHO 2013).

2.4.2 Key Informant Interviews

Selected stakeholders at health facility and national levels supporting 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. Informant interviews targeted respondents at 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 from regional governments. We purposively selected respondents who were involved in the planning or delivery of services to children and adolescents, thus were expected to have enough information to reveal major system and policy strengths and weakness with respect to paediatric and adolescent HIV policy and service delivery.

State and county informants were State MoH director generals, MoH State HIV coordinators and the South Sudan Aids Commission (SSAC) state and county coordinators. Health facilities in-charge 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; select UN agencies, mainly UNICEF and UNAIDS, and select partners implementing paediatric and adolescent HIV services. The inclusion of informants at health facility, state and national levels provided an opportunity for data triangulation, but also to assess stakeholder perspectives about paediatric and adolescent HIV policies at different levels.

Key informants were purposively selected depending on their position, deemed role and knowledge about paediatric and adolescent health. A pre-designed key informant interview guide with open-ended questions followed with probes was used to explore study participants views on issues concerning awareness and existence of policies and guidelines relevant to paediatric and adolescent HIV in South Sudan, knowledge of policy provisions, policy development process, policy strengths and gaps, policy implementation process, challenges and suggestions to address policy gaps identified. All interviews were conducted in English, and were audio recorded and transcribed by research assistants. Research assistants were paired, one as an interviewer and the other as a note taker.

2.5 Data Analysis

Using the policy review guide template, detailed findings of the policy assessment were documented. Current policy provisions were summarized and any gaps or opportunities were highlighted using descriptive narratives and schematic diagrams.

Recordings of the key informant interviews were transcribed within hours by the field assistants or by the ANECCA project officer who facilitated the interview. The transcriptions were compared with the manual notes, and gaps in the recordings filled.

The final consolidated documents were then analysed by the national consultant, using a simple descriptive narrative and paying particular attention to emerging themes, content of the discussions and issues that generated consensus. The major themes and issues identified were then compared across categories of respondents and geographic location.

2.6 Quality Assurance

To promote the rigor and quality of the research, the study team ensured that data were authentic and methods of data analysis were trustworthy. The lead consultant together with the ANECCA secretariat supported the national consultant and ANECCA in-country team to carry out this review and assessment.

For the field assessment, the national consultant selected competent field assistants with experience in qualitative research. The study team underwent training in qualitative research techniques, ethical issues pertaining to confidentiality and informed consent.

The research team was also trained in qualitative methods, specifically key informant interviews, and in data tools to ensure understanding was standardized. The research team also used a standard research guide; data were triangulated to enhance understanding of the theme. Key informant interviews were carried out by the national consultant, national ANECCA project officer and study assistants.

2.7 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 to interview, we are confident that the stakeholder perspectives we obtained in this study provide rich insights about the policies and the changes needed.

2.8 Ethical Issues – Consent Process and Documentation

The national consultant trained the study team in research ethics, study tools, obtaining participant consent, maintaining confidentiality and security of all collected data. The study team then trained the data collectors for 3 days and covered the following: study tools, proper techniques for conducting key informant interviews, study protocols and secure data storage while in the field, and ethical issues of maintaining confidentiality and obtaining informed consent.

The study assistants were instructed to explain to each participant, in the main local language, the following before obtaining oral consent from the participant: the purpose of the study, procedures, risks, benefits, rights of the participant, and protecting data confidentiality. The research assistants were to answer questions to the satisfaction of the study participants before obtaining consent and proceeding with the interview. Privacy and confidentiality of participants were maintained during the interviews through ensuring records were kept in safe storage, and interview locations were convenient and private. All interviews had anonymous study IDs and were used on all documents. Completed questionnaires were stored in a locked cabinet accessible only by the study team.

2.9 Risk

Participants in this study faced minimal to no risk. However, participants might have felt a little uncomfortable discussing the services received and satisfaction with these services while they were still in the health facility premises. This was mitigated though assuring the participants of confidentiality of information provided. Furthermore, no personal identifiers were collected, further ensuring confidentiality. No sensitive questions that may have caused the respondents' discomfort were asked in this survey.

2.10 Expected Outcome of the Policy Assessment Study

The outcomes of this study will foster improved understanding of the strengths and gaps in national policies and guidelines. This will help South Sudan to develop country-specific action plans, leading to improved coverage and quality of services for children and adolescents living with HIV. Each country process will add to the development of a regional position paper that promotes the adoption and implementation of policies that increase coverage and quality of paediatric and adolescent HIV care, treatment and support.

2.11 Plan for Reporting Unanticipated Problems

The national consultant was the principal investigator (PI). The lead consultant, ANECCA director, ANECCA coordinator, ANECCA M&E specialist as well as the in-country ANECCA project officer were co-investigators. The PI reported to the ANECCA Technical Advisory Committee and the National Research Institutional Review Board Committee if any unanticipated problems, abuse or illegal activity that might occur during the study. Each participant also received an information sheet and a copy of the consent form with contact information of the local IRB so that they can report individually any breach of protocol or ethics directly.

3 RESULTS OF THE DESK REVIEW

The review of HIV policies and guidelines in South Sudan revealed that the country does not have children and adolescent-specific policies and guideline documents. However, there are specific training materials for children living with HIV. The policies in the South Sudan HIV guidelines have largely been adopted from the WHO guidelines, but they have been modified to suit local situations and limitations. The adolescent minimum package of services is listed but there is no strategy in place to ensure its implementation. There is no minimum package of services for children age 2–9 years.

3.1 Key Points from the Desk Review

The key points of the South Sudan HIV policies and guidelines are:

3.1.1 Strengths of policies and guidelines

- The provisions of the policy and guidelines–
  - are largely consistent with WHO guidance and standards (WHO 2013 treatment guidelines and 2015 HTS recommendations)
  - prioritize infants, children and adolescents as priority populations for HTS and HIV care and treatment
  - advocate integration of services, i.e, provider-initiated testing and counselling, TB and sexual reproductive health
  - give explicit guidance along the cascade of care for children, especially for Exposed Infant Diagnosis (EID), presumptive diagnosis of HIV (testing and treatment schedule)
- The 2015 HIV prevention strategy–
  - focuses on young people at risk, particularly girls and young women as priority group
  - has adopted a combination prevention approach to HIV prevention
- The country has adopted Re-test before starting treatment, Test and Start, and 90–90–90 targets in the *South Sudan 2016 HTS draft guidelines*.
- The EID algorithm captures and recommends testing for viral load at birth. This is in line with the latest WHO guidelines.

3.1.2 Gaps in the policy and guidelines – HIV Testing Services

- The provisions of the policy and guidelines do not:
  - provide for flexibility in consenting to HIV testing to those below age (18 years) who are not classified as having risk of HIV infection
  - promote age-appropriate disclosure, which is an important aspect for adherence and retention particularly for adolescents living with HIV
  - offer concrete strategies to promote emerging HIV diagnostic technologies if contextual evidence emerges
- There is no guidance on HIV self-testing.
- Implementation of strategies to get children and adolescents to attend HIV testing services is weak.
- In relation to the WHO guidelines—
  - the South Sudan HIV guidelines are not up to date with the latest WHO guidelines on ART initiation, which stress that every person diagnosed with HIV can be initiated on treatment regardless of immunological status, and which effectively eliminated eligibility criteria with the CD4 cell count test (WHO, 2016)
  - the actual ART regimen for children less than 3 years does not conform to the latest WHO guidelines that recommend use of LPV\r. South Sudan is still using nevaripine as part of the regimen.

- The South Sudan policy and guidelines—
  - do not have an M&E framework to capture adolescent-specific ART indicators
  - lack clear definition of age stratification in adolescents regarding treatment modules and change of regimen
  - cut-off age for children is not defined in the consolidated HIV guidelines for age-appropriate ART regimens
  - have not adequately addressed linkage to care after diagnosis for children and adolescents. Implementation of guidelines such as those on EID is yet to take off on large scale
  - have not adequately addressed the challenges of judgment, stigma and discrimination, confidentiality and privacy issues facing adolescents
  - their implementation is hampered by inadequate funding and inadequate technical skills of providers and other health workers, such as laboratory personnel
  - have not recognized and strategized for multi-sectorality of HIV prevention.
- Other strategies needed—
  - a national youth strategy to guide adolescent testing and linkage to care
  - a clear implementation strategy on linkage of services, because many children and adolescents are lost in the cracks.
- Some sites have limited or no access to viral testing; thus, viral testing at birth is not practised in all sites. This is a draw back to identifying HIV-positive children.

3.1.3 Gaps in policies and strategies – Care and Treatment

- South Sudan does not have specific guidelines and policy documents targeting children and adolescents in HIV care and treatment except Integrated management of adolescents and adults illnesses /Integrated management of pregnancy and childbirth training materials.
- The HIV care and treatment guidelines are yet to be revised according to WHO (2016) recommendations on treatment guidelines.
- The provisions of the policy and guidelines emphasize treatment monitoring supported by CD4 testing and Viral load start-up plan, but little is being done on its implementation.

3.1.4 Gaps in policies and strategies – Children and Adolescents

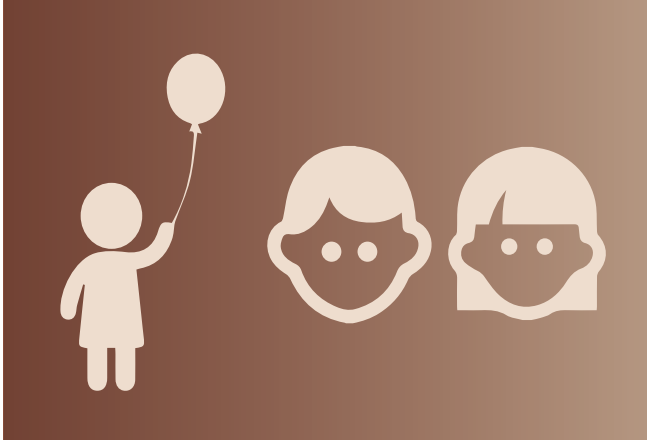
The provisions of the policy and guidelines:

- do not explicitly give MOH guidance on setting up, managing and the minimum service package for adolescents
- offer little in addressing specific factors affecting HIV service delivery in South Sudan such as:
  - psycho-social factors: knowledge, beliefs and motivation within a given social context, lack of understanding of why it is important to enroll in care, stigma and fear of disclosure of HIV status and use of herbal medicine
  - structural factors related to underlying economic conditions of daily life, accessibility of care (distance from home), lack of transportation, food insecurity
  - health care delivery factors: quality of care at the point of contact with the patient (long waiting time).

3.1.5 Gaps in policies and strategies – Strategic Information

- Data disaggregation by age does not correspond to adolescent HIV programming (current options are < 15 or ≥ 15 years).
- Specific MOH targets for adolescent testing and treatment at national level are lacking.
- Specific MOH targets for children and adolescents at state, county and facility levels are lacking.

One of the provisions of the policy and guidelines is to prioritize infants, **children and adolescents** as priority populations for HTS and HIV care and treatment prioritize infants, children and adolescents as priority populations for HTS and HIV care and treatment



3.2 Detailed Findings of the Desk Review

3.2.1 Age disaggregation

A desk review of the South Sudan HIV policy documents and guidelines reveals that persons living with HIV are either categorized as children (age 0–14 years) or adults (15 years and above). However, adolescents have been re-categorized as a subset from these two groups and are defined as the age group 10–19 years. Within this subset, adolescents are further stratified as

- adolescents who acquired HIV prenatally, and
- adolescents who acquired HIV during childhood or adolescence

These categories are in line with the WHO guidance that children constitute the category from birth to 14 years, and adults from15 years and above. However, adolescents are further classified according to the antiretroviral regimen they are taking. The treatment recommendations for adolescents weighting ≥ 35 kg is the same as that for adults while the regimen for adolescents weighing < 35 kg is the same as that for children 3–9 years.

The policies in South Sudan HIV guidelines have been adopted from the WHO guidelines in many aspects, but they have been modified to suit local situations and limitations. The adolescent minimum package is listed but there is no strategy in place for its implementation.

3.2.2 Prioritizing adolescents and children in HIV testing and age of consent

The WHO consolidated guidelines on HIV testing services (HTS) identify adolescents and infants and children among the priority populations for HTS focus. A review of the HTS guidelines and corresponding documents for South Sudan shows that adolescents and young children are also prioritized as population groups of focus in the policy context for HTS.

Age of consent is one the most prominent areas of policy content for HTS guidelines and the corresponding HTS implementation plan that is specific to adolescents and children. The WHO guidelines have not been prescriptive and explicit on the optimal age for children or adolescents to give consent for HIV testing. However, in the 2013 ***WHO HIV testing and counselling guidelines for adolescents*** and the subsequent ***WHO HIV testing services guidelines*** for 2016, the WHO recommends a review of age of consent policies and practices so that they do not pose barriers to HIV testing for adolescents and children (WHO 2013, 2015)). The current HTS guidelines for South Sudan have pegged age of consent for accessing HTS at 18 years, and those younger than 18 years require consent from the parent or guardian, or to be accompanied by either one. An exception under this rule of parental/guardian consent is adolescents under 18 who are exposed to risk of HIV infection through marriage, are pregnant, are parents, are engaged in behaviour that puts them at risk, or are child sex workers. Another exception is adolescents who do not have parents.

The South Sudan HIV guidelines stipulate that:

> *"Anyone 18 years of age and above requesting HTC should be considered able to give full, informed consent. Young people under age 18 years of age who are married, pregnant, parents, engaged in behaviour that puts them at risk, or are child sex workers are considered capable of giving their own consent for HTC, and do not need a parent or guardian's consent. HTC for those who are under 18 years and do not have the above-mentioned risk factors, should be done with knowledge and consent of a parent or guardian. Verbal consent is sufficient. For those under 18 years of age who have no parents or guardians, parental/ guardian consent will not be required before testing is done but the young person will be asked to sign a declaration that they have no parents or guardians. HTC services will be provided in consultation with social services' providers or institutional heads."*

This policy is inflexible and could be a barrier to testing for some young people as it is hard to establish the level of risk that each young person is under. Others could have acquired HIV prenatally and currently are not under any risk of HIV infection. Other countries in the region have lowered the age of consent to 12 and 13 years.

Other issues identified in regard to HIV testing for adolescents and children include:

- an implementation plan for HTS is lacking
- there is no clear demonstration of how to track down adolescents to come for HTS
- the challenges of judgment, stigma description, confidentiality and privacy issues facing adolescents are neither addressed in the policy nor in the guidelines.

3.2.3 HIV status disclosure to adolescents and children

The WHO recognizes that HIV disclosure to children and adolescents remains an integral part of HIV testing services. The WHO recommends that:

> *"Children of school age (6–12 years) should be told their HIV-positive status and their parents' or caregiver's status; younger children should be told their status incrementally to accommodate their cognitive skills and abilities".*

The South Sudan HIV policy and guidelines acknowledge issues of disclosure, but after reviewing all policies a clear-cut strategy on how to address disclosure issues is lacking. This recommendation is especially important because the success of HIV care and treatment services has resulted in an increasing number of children born with HIV are still alive and on treatment, though some do not know their HIV status.

South Sudan HIV guidelines are not explicit on the age of the disclosure, though they stipulate that information about the HIV status of a child should be given only if necessary in the interest of the child with his parents'/guardian's consent, which is consistent with WHO recommendations.

The South Sudan HIV guidelines stipulate that:

> *"Giving information about the HIV status of a child should be done only if necessary in the interest of the child with his/her parents'/guardian's consent; and only to trustworthy teachers who have received training in HIV counselling. Adolescents should be disclosed to at the time of HIV testing as their understanding of the HIV test results is critical for successful linkage and retention in care and treatment services. HTC counselors should be trained on a child developmental approach to gradual disclosure of HIV status for younger children. Young children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure."*

Further analysis of the policy and guidelines reveals that these documents acknowledge the issues of disclosure, but there is no clear-cut strategy on how to address them.

- For example, there's no strategy for training home care workers on disclosure, and care givers' role in disclosure has not been specified.
- Issues of stigma at the community level and in school after disclosure are not covered.
- A policy on youth friendly services and how to implement it has not been articulated.

3.2.4 HIV testing and linkage to care as part of the prevention of mother-to-child transmission cascade focusing on children and adolescents

- Have specified testing at antenatal clinics at regular intervals, consistent with the WHO guidelines.
- The WHO recommendation on testing of HIV-exposed infants at the earliest from birth has been recognized. However, this is not followed due to considerable program limitations. The South Sudan algorithm takes long before an infant exposed to HIV is tested and linked to treatment. All sites do not test for viral load.
- Consistent with WHO recommendations, the South Sudan policy provisions stipulate: HIV testing services to be offered as part of routine antenatal care and in childbirth settings; retesting of pregnant women with HIV to be performed in the third trimester or during labour and childbirth; and periodic HIV testing for lactating mothers.

A recent WHO Treat All guidance entails that every person diagnosed with HIV can be **initiated on treatment** regardless of immunological status, and which effectively eliminated eligibility criteria with CD4 cell count test

3.2.5 ART treatment issues for children and adolescents

The recent WHO Treat All guidance that entails that every person diagnosed with HIV can be initiated on treatment regardless of immunological status, and which effectively eliminated eligibility criteria with CD4 cell count test (WHO 2016), has settled the discourse on when to start ART for all populations including adolescents and children. South Sudan HIV guidelines are not up to date with this new recommendation, and still refer to pre-eligibility criteria.

The actual ART regimen for children age less than 3 years does not conform to the latest WHO guidelines that recommend use of LPV\r. South Sudan is still using NVP as part of the regimen. While WHO recommends a LPV/r-based regimen as first line for children below 3 years, there are still challenges with the use of this regimen in South Sudan mainly due to its requirement for cold chain conditions during transportation and lack of available treatment options for 2nd line should a child fail this regimen. For these reasons, a nevaripine-based regimen has been recommended. It is anticipated that the LPV/r regimen will be adopted in future, when new heat-stable sprinkle formulations become available.

The cut-off age in children for age-appropriate ART regimens is not defined in the South Sudan guidelines. ART formulation remains a challenge: children above 6 years can be given ATV/r, but currently child-friendly formulations of ATV/r are not available. Most ART regimens for children and adolescents are administered twice daily, posing a challenge in adherence for school-going children. The guidelines still mention the use of d4t, which is no longer recommended. The guidelines have not given directions on how to transition patients on d4T to a substituted therapy. ART regimens for TB/HIV co-infection are in line with the WHO recommendation; however, the use of EFV in children less than 3 months weighing more than 3.5 kg has not been considered, as recommended by the US Food and Drug Administration.

3.2.6 Linkage to other services and retention in care

The South Sudan consolidated HIV guidelines clearly articulate the challenges facing linkage to care as stipulated below. However, the policies or guidelines do not have strategies to address them.

- Psycho-social factors related to knowledge, beliefs and motivation within a given social context. The main factors affecting linkage to care under psycho-social factors are–
    - lack of understanding of why it is important to enroll in care
        - stigma and fear of disclosure of HIV status
        - use of herbal and other alternative medicine
- Structural factors, such as related to underlying economic conditions of daily life
    - accessibility of care
    - lack of transportation
    - work responsibilities
    - food insecurity
- Health care delivery factors:
    - quality of care at the point of contact with the patient (long waiting times, conflict with staff, coordination of care, stigma)
    - service inaccessibility (distance from home)

The South Sudan HIV guidelines have outlined the following strategies to address some of the gaps in linkage:

- integrating HTC with other services such as provision of provider-initiated testing and counselling in antenatal clinics, the TB clinic or outpatient department
- using triplicate referral forms
- providers actively tracking lost-to-follow-up patients
- using linkage facilitators and other community support groups and client reminders and follow-up using mobile telephony
- Implementing a good strategy on linkage to and from TB services.

3.2.7 Treatment adherence and monitoring

- WHO recommends viral load testing as an essential part of HIV management for persons of all age groups living with HIV. The viral load testing algorithm entails that every person living with HIV and on antiretroviral therapy should undergo a viral load test at 6 months following ART initiation and every 12 months thereafter.
- The South Sudan HIV policy provides clear levels of a HIV patient's treatment monitoring. The levels are classified as clinical and laboratory monitoring. Clinical monitoring is comprehensive and has included nutritional assessment and management, opportunistic infection management, STI management and cervical cancer. However, the clinical and laboratory monitoring of HIV patients is not in line with the latest WHO guidelines.

4 ASSESSMENT

OF NATIONAL POLICIES AND GUIDELINES RELATED TO CHILDREN AND ADOLESCENT HIV CARE

4.1 Qualitative study analysis and results

4.1.2 Stakeholder awareness of paediatric and adolescent HIV policies

"Overall, most study participants were aware of the existence of HIV policies and guidelines. Most of them also noted that there were no specific policies and guidelines for adolescents and children but recommendations on HIV care and treatment for pediatrics and adolescents are incorporated in the main national HIV policies for adults. Respondents were of the view that most of the policies and guidelines were general to HIV but with specific provisions addressing concerns of children and adolescents. " … Unfortunately, we do not have any policy and guidelines on pediatric HIV. All we have re guidelines for use of ARVs, the main guidelines, within main guidelines, we have also pediatric ARVs incorporated. We have not established policy itself on pediatrics by its own." - Department director, National Ministry of Health

"Yes, we have ART document, we have ARV guideline, we have VCT guideline, which is HIV testing and counselling guideline, we have PMCT, prevention of mother to child transmission guideline… the PMCT document for children and the ART guideline need to be harmonized. I order the drugs, this prophylaxis drug can be given to the mothers …, so the care can be done in the hospital and also at home…." - Director General, State Ministry of Health

One respondent though reported that there is training material that focuses on children.

"Strategic polices and guidelines are in place but not for children and adolescents exposed or affected by HIV. The current guidelines need to be updated to handle children and adolescents living with HIV…. No, there is none in the country. No stand-alone, only training… [materials]." - WHO Zonal Representative

Some of the reasons advanced by the key informants for the lack of policies for adolescents and children included that the country is young just coming out of decades of civil war, the current conflict and inadequate funding for HIV programmes.

…..Well. We are still struggling as a country to put in attention, to put in leadership, to put in political will, to put in funding for HIV. The South Sudan Aids Commission since its establishment in 2006 has struggled to exist, the current volatile situation in the country, the tensions… have also prevented our only opportunity of securing … [Funding]…. - South Sudan AIDS commission Coordinator , County Level

Most of the key informants though had vague knowledge of the identities and titles of the policies and guidelines on HIV. Key informants from the national level were more knowledgeable than stakeholders, officials and health providers at state and facility levels. Awareness of HIV policies, including paediatric and adolescent HIV-related policies, was high among informants at the national and state levels, who were directly involved in planning, drafting and implementing the policies. On the contrary, most responses of health workers and officials from county health departments reflected lack of awareness about paediatric and adolescent HIV policies and their provisions. Many respondents attributed this lack of awareness to inadequacies in involving them in the process of drafting and disseminating the HIV policies.-

Only a few key informants mentioned the actual policies and guidelines. This reveals the low level of knowledge of South Sudan policies and guidelines considering that more than 18 policies, strategies and guidelines have been drafted and disseminated in South Sudan since 2008 (see Box 1). During interviews key informants mentioned South Sudan national HIV and AIDS strategic plan, Consolidated clinical guidelines on use of antiretroviral drugs for HIV treatment and prevention, and Guidelines for prevention of mother-to-child-transmission.

Box 4. HIV Policies Strategies and Guidelines developed and disseminated in the last 8 years in South Sudan

a. HIV/AIDS behavior change and communication (BCC) strategy, 2008
b. HIV/AIDS monitoring and evaluation (M&E) framework, 2008
c. Guidelines for ART use in adults and children, revised 2010
d. Guidelines for syndromic management of STIs (plus training manuals), 2009
e. National blood safety strategy, 2009
f. Guidelines for voluntary counselling and testing (VCT), 2008
g. Guidelines for Prevention of mother-to-child-transmission (PMTCT), 2010
h. PMTCT training curriculum for trainers and trainees, Job aids and training slides, 2010
i. National condom strategy
j. Maternal, neonatal and reproductive health (MNRH) strategy
k. 5 year Health Sector response work plan
l. South Sudan national HIV/AIDS policy, 2007
m. South Sudan national HIV policy, 2015
n. South Sudan national HIV and AIDS strategic plan, 2013–2017
o. South Sudan national HIV strategic information plan, 2013–2017
p. South Sudan HIV Department strategic information plan, 2013–2017
q. South Sudan national HIV prevention strategy, 2015–2017
r. Consolidated clinical guidelines on use of antiretroviral drugs for HIV treatment and prevention, 2014
s. South Sudan draft HTS guidelines, 2016

Other key informants through their responses revealed they had different understanding of what a policy meant. The responses revealed that they could not differentiate between what is a guideline, policy or manual. This made it difficult for them to mention the exact names of the policy or guidelines, or to differentiate between the different versions of the guidelines or policies. They also could not differentiate between national and WHO guidelines.

> *… We have many National HIV and AIDs strategic policies and guideline these include: M&E, Guidelines for the use of antiretroviral drugs for adults … children, PMTCT and participants Manual for comprehensive HIV/AIDs care. … I think there is no specific prioritization for pediatric and adolescent in these guidelines*
> *- Ministry of Health State HIV coordinator*

> *"…Yes, we do have policies surrounding HIV programmes and one particularly I will bring attention to is the latest National strategic framework or strategic plan for 2013–2017, which was recently developed prior to the country's efforts to lobby for global funds. So this document was developed and I think by large it has not been disseminated and still implementation may be far from happening. And we also have previously had HIV counselling guidelines that were developed… . We also have PMTCT guidelines that were also developed and these ones helped us to highlight basically the question of pediatric and adolescents HIV care…."- County South Sudan AIDS Commission, HIV/AIDS coordinator*

Some of the reasons advanced by the key informants about their poor knowledge of policies and guidelines were that they had not read through the guidelines and therefore were not aware of their contents or provisions. "I don't think so because I did not go through then basically [policies], I don't think so because I did not go through them I am not really sure" - Ministry of Health, Director general, State level

4.1.3 Policy development process

With regard to the policy development process, most study participants reported that South Sudan follows a participatory process in the development or adoption of HIV-related policies. However, participants had contrary views such as inadequate participation of counties and facility staff in problem identification and policy development. Others reported that the counties' context and the available data should be given due consideration when developing guidelines and policies.

"The involvement of stakeholders was not enough because the representation at the counties level was not there in problem identification or in the development of these pediatric and adolescent policies …." - Ministry of Health, State HIV coordinator

4.1.4 Adapting from international documents and policies

Most of the key informants interviewed were of the opinion that HIV policies in South Sudan are adapted from international and regional documents. Study participants noted that the policies are regularly updated in line with global guidelines, especially from the World Health Organization, and in consideration of experiences from the East African region, as South Sudan and other neighboring countries have similarities.

"Yes, most definitely. I think most guidelines comes from WHO, yes WHO … We also look at regional policies because our problem in South Sudan may not be different from our neighbors…. We are in the East Africa region our neighbors they must have some similarities, we are in sub-Saharan Africa our policies must have some particular areas of commonalities. - County South Sudan AIDS Commission (SSAC), HIV/AIDS coordinator

4.1.5 Key strengths, opportunities and weaknesses

Most of the key informants were of the opinion that the South Sudan HIV/AIDS policy recommendations for children and adolescents are good, but some themes are not well addressed such as feeding policy, separate clinics for children and adolescents, and how to ensure there are qualified staff to implement activities. Other policy or HIV guidelines mentioned by key informants as strengths included good HIV technical working group at national level that ensures documents and policies are in place, commitment of donors and non-governmental organizations acting as implementing partners.

Key informants also reported on the weakness in the HIV policies, guidelines and the general HIV program. They reported poor implementation plans and strategies as affecting the national program. Also cited was poor infrastructure such as roads electricity, etc., in South Sudan.

"Our infrastructure is not good. For example, to get DBS from Tambura to Juba, it takes time. I was thinking if we had hubs for EID in different regions in South Sudan that can facilitate things. Collecting all DBS from all over and then try to get it to a reference laboratory in Juba, it takes time." - National NGO HIV/AIDS program Advisor

Key informants reported that some opportunities that can be used to improve policies include review meetings, training and government commitment.

"…. We usually have quarterly review meetings where we review ourselves. … these issues have to be addressed during the meeting. Training the staff, training them in new tools, the development process … people have to be trained to create awareness about HIV…" - DG State Ministry of Health

4.1.6 Implementing policy and guidelines

Most key informants reported that on the whole the guidelines are being implemented since HIV prevention, care and treatment are being offered. However, the extent to which these guidelines and policies are being implemented differs between facilities. In some facilities only some aspects of the guidelines are being implemented. Others are not (such as the key programme of EID).

"In some places, yes, in some places like the biggest hospital …I am sure they are doing the implementation but only in some primary health care centers. … but in the biggest hospitals like El-Sabah Children's Hospital, they are doing these kinds of things because we are working in collaboration with HIV programmes." - DG, State Ministry of Health

Others were of the opinion that HIV policies and guidelines

are not being implemented, or if they are being implemented, then it is not according to the set standards.

> *No, the pediatric and adolescent HIV/AIDS policy is not being implemented … according to the desired standard - Ministry of Health State HIV coordinator*

4.1.7 Barriers to policy and guidelines implementation

Several barriers and challenges that hinder implementation of the policies and guidelines were presented. The common challenge mentioned was lack of a separate room or an arrangement for children and adolescents. Others reported that one of their key barriers was lack of specific guideline for children and adolescents, lack of laboratory services especially for blood specimens, CD4 and viral load tests, and inadequate qualified staff, shortage/interruption of commodities such as HIV test kits and drugs. Another barrier mentioned was inadequate funding for the HIV programme.

> *"One of the barriers is funding, it is the major challenge we have in our efforts country-wide to mitigate the HIV situation in the country. Right now, government's funding for HIV is as low as less than 3% out of the total funds, yes. Less than 3%; if less than 3% for HIV in general how do we start paying attention to that small component unless we get funding from somewhere, otherwise …" - County South Sudan AIDS Commission (SSAC) HIV/AIDS coordinator*

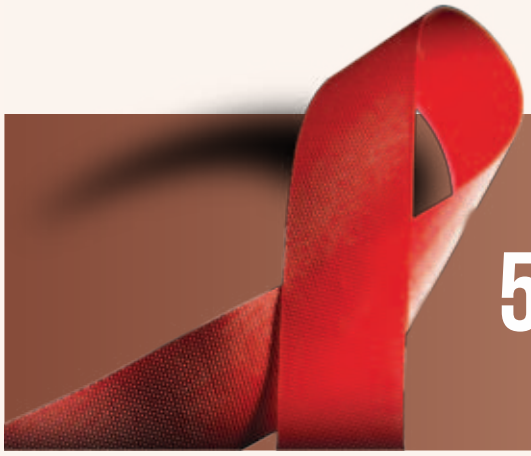
> *"… That's why I was saying that addressing these important steps by training the people who are working on the programmes, the pediatricians. You need to call them for training because usually, when we have training we train our staff who are working in the programme. We don't train the staff who could be involved in testing and counselling like the paediatricians. We really need them both to be trained by…" - DG, State Ministry of Health*

The key informants mentioned other barriers to implementation of HIV policies and guidelines for adolescents and children:

- Lack of critical equipment
- Poor infrastructure
- No incentives
- Inadequate mentorship
- Few trained personnel to handle children and adolescents
- Poor uptake of technology
- Inadequate funding
- High staff turnover
- Low remuneration
- Stigma and discrimination

> *"… Yes, the problem is that we need to avoid discrimination of children or adolescents living with HIV. If there is no trained caretaker to explain to the child why they are taking the drugs, we will continue to lose children or adolescents with HIV …. One child committed suicide last time because the parents did not tell him why he was taking those drugs… ." - ART In-charge, State Hospital*

With regard to the policy development process, most study participants reported that South Sudan follows a participatory process in the **development or adoption** of HIV-related policies



5 RECOMMENDATIONS

- Update key policies and guidelines especially on ART treatment and HIV testing in line with the latest WHO guidelines.
- Lower the age of consent for HIV testing for adolescents, to suit the South Sudan context (Uganda/South Africa, 12 years and above).
- Be explicit on the recommended age of disclosure of HIV status for children and adolescents (school-going age, 6–12 years), according to the latest WHO guidelines.
- Ensure policies and guidelines for children and adolescents are available and disseminated to health workers and HIV programme staff in summarized format– especially key provisions and statements:

"Policy documents should be found at the lowest level possible…. even health facilities should have a copy because it is only there that you can now ensure their implementation. That's what I would say." - *County South Sudan AIDS Commission (SSAC) HIV/AIDS Coordinator*

- Enhance resource mobilization to ensure the provisions in the policy and guidelines are implemented.
- Scale-up HIV care and treatment services including for children and adolescents.
- Implement the ART/PMTCT scale-up plan.
- Implement the EID programme scale-up.
- Integrate sexual gender-based violence into HIV policies and guidelines (screening at HCT and care and treatment including post-exposure prophylaxis).
- Integrate issues of orphans and vulnerable children into HIV policies and guidelines.
- Design a strategy for reaching adolescents:
    - Create messages appropriate to the age, culture and religion
    - Conduct awareness activities in communities to create demand
- Revise routine data collection and reporting tools to capture appropriate age disaggregation including for adolescents.
- Identify outcomes for adolescent service provision and performance, and plan on programme response.
- Assign HIV service targets to state, county and facility levels to be able to track performance.
- Ensure children and adolescents who are part of key and priority populations are addressed in policies and guidelines.
- Deploy qualified staff to all health facilities
- Install appropriate laboratory infrastructure.
- Supply drugs regularly.
- Ensure more commitment by government and implementing partners.

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Annex 1: Informed consent form

KEY INFORMANTS AND HEALTH WORKERS

Good morning/ Good afternoon, my name is _____

About the study

This study involves conducting analysis of policies and guidelines on children and adolescents living with HIV, and the training needs assessment for service providers in South Sudan. The Ministry of Health (MoH) in partnership with the African Network for the Care of Children Affected by HIV/AIDS (ANECCA) who commissioned it. The information you will provide shall help them to understand the policy gaps in service delivery, access and utilization by children and adolescents, and training needs of health service providers to better plan health services for them. You have been selected because you are involved in provision of HIV services to children and adolescents in South Sudan. Your participation is voluntary and will incur you no cost. It will also not affect your appointment at your present or future job. The principal investigators are Dr Dhuor Andrew Makur and Mr Gerald Kimondo, who are in-charge of the study. The co-investigators are Dr Makeba Shiroya-Wandabwa, Dr Chidi Victor Nweneka, Dr Denis Tindyebwa and Dr Robert Iriso. This study was approved by the Ministry of Health Ethical Oversight committee under the chairperson of Dr. Richard Lako Lino.

The interview will take 30–45 minutes.

Risks

Although the study involves collecting data from you, the design of the study does not include procedures relating to taking any biological samples. Minimal risks are expected and these could be from distress arising from questions that may be considered sensitive.

Benefits

There are no direct benefits to participants themselves at the time of the study. However, there are indirect social benefits that include the fact that this data will help ANECCA and MoH to review relevant policies and guidelines as well as develop a training strategy for service providers with respect to paediatric and adolescent health and HIV services.

Voluntary participation

In case you are not interested in the study, you do not have to participate and no benefits will be lost. One of your rights to participate in this study is that you can withdraw from this study at any time.

Confidentiality

The answers you give us will be known only to us and will be kept confidential. For all study participants, names shall not be taken; instead, anonymous identifiers will be used, and referred to during the discussions, so that no names shall be tagged to particular responses. All answers provided shall only be known to the research team and will be kept confidential.

Authorization to use and disclosure of your information

Signature: Signing below indicates that: you have been informed about the study in which you volunteer to participate; that you have asked the questions about the study and that information given to you has permitted you to make a fully informed decision about participating in the study. By signing this consent form, you do not waive any legal rights. A copy of this consent form will be provided to you. In case of any questions regarding the study, please contact the Principal Investigators, Dr. Dhuor Andrew Makur (0956266214) and Mr Gerald Kimondo. In case of any questions regarding your rights, please contact Dr. Richard Lako Lino, the chairperson of the Ministry of Health Ethical Oversight committee.

Respondent's signature: _____ Date: _____

Interviewer's name: _____ Telephone Contact: _____

Signature: _____ Date: _____

Annex 2: Structured Questionnaire

Rapid Assessment of Training Needs for Children and Adolescent HIV Services and Mentorship Approaches for Children and Adolescent HIV Services in South Sudan

Structured Questionnaire

Name of the health provider_____

Name of the health facility_____

Sex_____

Age_____

Demographic information *(For All Health Care Worker Respondents)*

1. Health facility: _____
2. Type of facility
   - a. Primary [ ] 1
   - b. Secondary [ ] 2
   - c. Tertiary [ ] 3
3. Respondent's job role
   - a. HIV-trained physician (in-service) [ ] 1
   - b. Non-HIV-trained physician (in-service) [ ] 2
   - c. Physician assistants – HIV trained [ ] 3
   - d. Physician assistants – non-HIV trained [ ] 4
   - e. Nurse/midwife – HIV trained [ ] 5
   - f. Nurse/midwife – non-HIV trained [ ] 6
   - g. Clinical officer – HIV trained [ ] 7
   - h. Clinical officer – non-HIV trained [ ] 8
   - i. Community health worker [ ] 9
   - j. Social worker [ ] 10
   - k. HIV Counsellor-tester [ ] 11
   - l. Others [ ] Please specify: _____ 12
4. Sex: Male [ ] (1) Female [ ] (2}
5. Age (years): _____
6. No of years in profession: _____
7. No of years working on HIV: _____
8. No of years working in this facility: _____
9. Marital status
   - a. Single – never married [ ] 1
   - b. Married [ ] 2
   - c. Divorced [ ] 3
   - d. Separated [ ] 4
   - e. Co-habiting [ ] 5
   - f. Widowed [ ] 6
10. Sexual orientation
    - a. Heterosexual only [ ] 1
    - b. Bisexual [ ] 2
    - c. Homosexual [ ] 3
    - d. Others [ ] Please specify: _____ 99

HIV Educational Background *(For All Health Care Worker Respondents)*

11. Have you ever received any formal of training on HIV medicine, excluding pre-service training?
Yes [ ] (1) No [ ] (2) (If No, go to question 14)
12. If yes to question 11 above, approximately how many training sessions have you received?
13. If yes to question 11 above, what is the cumulative duration of the training?
14. Have you ever received any formal training on care and support of children living with HIV?
Yes [ ] (1) No [ ] (2) (If No, go to question 17)
15. If yes to question 14 above, approximately how many training sessions have you received?
16. If yes to question 14 above, what is the cumulative duration of the training?
17. Have you ever received any formal training on care and support of adolescents living with HIV?
Yes [ ] (1) No [ ] (2) (If No, go to question 20)
18. If yes to question 14 above, approximately how many training sessions have you received?
19. If yes to question 14 above, what is the cumulative duration of the training?
20. Have you ever received any formal of training on HIV counselling? Yes [ ] (1) No [ ] (2) (If No, go to question 23)
21. If yes to question 17 above, approximately how many training sessions have you received?
22. If yes to question 17 above, what is the cumulative duration of the training?
23. Have you ever received any formal training on HIV counselling for children living with HIV?
Yes [ ] (1) No [ ] (2) (If No, go to question 26)
24. If yes to question 20 above, approximately how many training sessions have you received?
25. If yes to question 20 above, what is the cumulative duration of the training?
26. Have you ever received any formal training on HIV counselling for adolescents living with HIV?
Yes [ ] (1) No [ ] (2) (If No, go to question 30)
27. If yes to question 20 above, approximately how many training sessions have you received?
28. If yes to question 20 above, what is the cumulative duration of the training?
29. Have you ever received any form of formal **mentoring** on treatment, care and support of people living with HIV?
Yes [ ] (1) No [ ] (1) (If No, go to question 31)
30. If yes to question 17 above, approximately how many times have you been mentored in the last 24 months?
31. Have you ever received any form of formal **mentoring** on treatment, care and support of people living with HIV?
Yes [ ] (1) No [ ] (2) (If No, go to question 33)
32. If yes to question 17 above, approximately how many people have you mentored in the last 24 months?
33. Which of the following scenarios applies to you (Mark True or False as appropriate)?
    a. I did self-training on HIV medicine using journals and other literature (1)
    b. I did self-training on paediatric HIV using journals and other literature (2)
    c. I did self-training on adolescent HIV using journals and other literature (3)
    d. I got instructions on HIV medicine through conferences on HIV/AIDS (4)
    e. I got instructions on paediatric HIV through conferences on HIV/AIDS (5)
    f. I got instructions on adolescent HIV through conferences on HIV/AIDS (6)
    g. I took courses on HIV medicine during pre-service training (7)
    h. I took courses on paediatric HIV as pre-service student (8)
    i. I took courses on adolescent HIV as a pre-service student (9)
    j. I took courses on HIV medicine as part of a continuing professional development programme (10)
    k. I took courses on paediatric HIV as part of a continuing professional development programme (11)
    l. I took courses on adolescent HIV as part of a continuing professional development programme (12)
    m. I attended a formal training session on HIV medicine and received certificate (13)

n. I attended a formal training session on paediatric HIV and received certificate (14)
o. I attended a formal training session on adolescent HIV and received certificate (15)
p. I used web-based learning to get instructions on HIV medicine (16)

HIV Educational Background *(For only Clinicians)*

34. Have you ever received any formal training on treatment of children living with HIV? Yes [ ] (1) No [ ] (2) (If No, go to question 37)
35. If yes to question 14 above, approximately how many training sessions have you received?
36. If yes to question 14 above, what is the cumulative duration of the training?
37. Have you ever received any formal training on treatment of adolescents living with HIV
Yes [ ] (1) No [ ] (2) (If No, go to question 40)
38. If yes to question 37 above, approximately how many training sessions have you received?
39. If yes to question 37 above, what is the cumulative duration of the training?

Attitudes and opinions about paediatric and adolescent HIV *(For All Health Care Worker Respondents)*

40. A child living with HIV can be effectively managed by HIV clinician whether or not that clinician has specific training on management of HIV positive children

a. Strongly agree 1
b. Agree 2
c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

41. An adolescent living with HIV can be effectively managed by HIV clinician whether or not that clinician has specific training on management of HIV-positive adolescents

a. Strongly agree 1
b. Agree 2
c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

42. Children with HIV should ideally only be managed by an HIV-trained paediatrician because children are too complicated

a. Strongly agree 1
b. Agree 2
c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

43. Children/adolescents living with HIV deserve special treatment compared to adults

a. Strongly agree 1
b. Agree 2
c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

44. Anti-HIV drugs are too strong for child's young body

a. Strongly agree 1
b. Agree 2
c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

45. The parents of an adolescent with HIV should be notified of the patient's status even without their consent

a. Strongly agree 1
b. Agree 2

c. Disagree 3
d. Strongly disagree 4
e. No opinion 5

46. Pregnant adolescents with HIV attending an antenatal clinic should be used to illustrate to the rest of the antenatal clinic attendees why pre-marital sex should be avoided
    a. Strongly agree 1
    b. Agree 2
    c. Disagree 3
    d. Strongly disagree 4
    e. No opinion 5
47. A sexually active14-year-old female attending your clinic should be offered condoms
    a. Strongly agree 1
    b. Agree 2
    c. Disagree 3
    d. Strongly disagree 4
    e. No opinion 5
48. I will feel uncomfortable offering condoms to a sexually active 15-year-old female attending my clinic
    a. Strongly agree 1
    b. Agree 2
    c. Disagree 3
    d. Strongly disagree 4
    e. No opinion 5

Knowledge of paediatric and adolescent HIV *(For clinicians only)*

49. According to the 2013 WHO recommendations on management of children with HIV, HIV-positive children below five years of age should be commenced on ARVs once their CD4 count falls below 500 cells/mm^3 True [ ] (1) False [ ] (2)
50. According to the 2013 WHO recommendations on management of adolescents with HIV, HIV-positive adolescents should be commenced on ARVs once their CD4 count falls below 500 cells/mm^3 True [ ] (1) False [ ] (2)

For Questions 51–65, indicate whether the statement is true (1) or false (2)

51. Concerning HIV infections in children:
    a. When using CD4 estimation to monitor disease progression and treatment response in infants, it is better to use the absolute number rather than CD4 cell percentage
    b. Virologic set-point occurs early in infection when CD4 cells are produced and the HIV is actively replicating
    c. The presence of HIV antibody in a child less than 12 months of age defines HIV infection
    d. Infection before 4 months of life increases HIV disease progression in infants
    e. Breastfeeding accounts for more than 50% of HIV transmission in children
52. Concerning paediatric HIV counselling and testing:
    a. For effective counselling all relevant information should be given at first contact or visit
    b. Counselling should not include nutritional support and growth monitoring
    c. It is right to test a critically ill child whose parent refuses to consent for HIV testing for the purpose of immediate clinical management
    d. Post-test counselling should be provided by the same care provider who conducted the pre-test counselling
    e. In provider-initiated testing and counselling, HIV testing is offered to all in-patient and out-patients seen in health facilities
53. Regarding mother-to-child transmission (MTCT) of HIV
    a. More than 95% of paediatric HIV infections are due to MTCT of HIV
    b. All HIV-infected women transmit HIV to their babies
    c. Sexually transmitted diseases increase risk of MTCT of HIV
    d. Babies are at risk of breast milk transmission of HIV only in the first 6 months of life
    e. Mixed feeding does not pose a higher risk for infants of HIV-infected women
54. Ngozi was diagnosed with HIV during pregnancy and gave birth to a daughter 6 weeks ago. Today she brings her to the under-5 clinic for her first immunization visit. There is no access to virologic tests available at your clinic. In addition to giving her immuniza-

tions, what else should you do?

a. Prescribe single-dose nevirapine only
b. Prescribe zidovudine for 6 weeks only
c. Prescribe Cotrimoxazole if her growth and development are appropriate
d. Prescribe Cotrimoxazole when the child is 3-month old
e. Developmental assessment should be performed at every visit

55. A 3-year-old HIV-infected child presents with lymphadenopathy, severe oral candidiasis and severe pneumonia. Her CD4 is 20%

a. She has WHO stage II disease
b. She is severely immunosuppressed
c. Defer starting her on antiretroviral therapy
d. The priority here is to manage opportunistic infections first
e. Screen the child for tuberculosis

56. Regarding immunological and virological assessment

a. A CD4 percentage of 12 in a 4-year-old girl is suggestive of severe immunosuppression
b. Advanced immunosuppression in a child less than 1 year is defined as CD4 percentage of 25 – 30
c. Severe immunosuppression in a child older than 5 years is defined as CD4 count < 200
d. At 1 year old with a CD4 count of 700 is not immunosuppressed
e. An HIV virologic test is necessary to make a diagnosis of HIV in children of all ages

57. In a TB/HIV co-infected child:

a. There is an increased risk of developing primary progressive infection
b. Most diagnostic criteria would have higher sensitivity and specificity
c. NNRTIs are absolutely contraindicated
d. It is possible to have a deteriorating clinical condition despite improving CD4+ count and suppression of viral load
e. If TB develops while a child is on AZT, NVP and 3TC a possible option is to substitute NVP with EFV or ABC

58. In management of OIs;

a. Cotrimoxazole prophylaxis lowers the risk of ***Pneumocystis jirovecii pneumonia*** (PCP), toxoplasmosis, salmonella species and malaria
b. LIP occurs in less than 5% of HIV-infected children
c. Prednisolone is useful in treating LIP
d. In a child with white patches in the mouth, retrosternal pain on swallowing, refusal of food and excessive salivation; oral nystatin should be the drug of choice

59. Aisha is a 3-year-old girl who was recently diagnosed with HIV infection in a private hospital. She has been having recurrent illness with pneumonia, oesophageal candidiasis and recurrent diarrhoea. Her weight is 10 kg with a CD% of 15. Aisha lives with grandma as she lost her mother to HIV last year. The following statements are true:

a. Aisha is in WHO clinical stage 3
b. Prior to initiation of ART, identification of a secondary care giver is not desirable
c. The following regimen is best recommended as first line AZT/3TC/NVP
d. The following regimen is best recommended as first line D4T/3TC/NVP

60. Tayo is a five-old-boy with HIV infection that was commenced on ZDV/3TC/NVP about 6 weeks ago. The following statements are true:

a. If his Hb is 7g/dl all his ARVs should be stopped
b. If his haemoglobin is 7g/dl, zidovudine should be substituted with an alternative drug
c. If he develops a severe rash all over his body, it should be treated with hydrocortisone and antifungals, and he should continue ART
d. If his mother reports that most of his time he vomits out the ARV drugs, the ARVs should be withdrawn immediately
e. If after 6 months of ART with good adherence his CD4 has dropped, he should continue on the same ARV drugs

61. Supportive care for infected and affected children includes:

a. Psychosocial support in homes and communities
b. Disclosure to all children at the age of 5 years
c. Administration of BCG vaccine to all HIV-exposed infants
d. Administration of measles vaccine twice at 6 and 9 months to all HIV infected/ exposed children
e. Basic essential services identified by the National Plan on Action on OVC focuses on health and psychosocial support only

62. About nutrition and HIV

a. Exclusive breastfeeding for the first 3 months of life is an option for babies of HIV-infected mothers
b. Breast milk substitutes can be used if AFASS, which means affordable, feasible, adaptable, secure and safe
c. Low birth weight is a common manifestation of HIV in the new born
d. Nausea in HIV-infected children may be managed with feeding small meals frequently and avoiding high-fat and greasy diets
e. A 3-year-old weighing 11 kg is well nourished

63. The following statements are true about the care of adolescents with HIV and AIDS
a. Adherence to care and treatment can be a challenge
b. Relationship with peers and family is developmental stage dependent
c. Obtaining consent for medical treatment is easy
d. Are unable to appreciate the long-term implications of diseases
e. They often lack social skills

64. Concerning care of adolescents with HIV:
a. Those in Tanner Stages I & II are managed using paediatric ARV guidelines, while those in Stage III and above are managed using adult ARV guidelines
b. Pill burden and lifestyle may be barriers to adherence
c. Having treatment partners may not be useful to adolescents
d. Life skills training should be part of any adolescent care programme
e. Developing self-awareness and managing emotions are components of life skills

65. The minimum health services package for paediatric HIV and AIDS care should include the following:
a. Confirmation of HIV status as early as possible
b. Advocacy to policy makers
c. Monitoring growth and development
d. Diagnosis and early treatment of other infectious (Malaria, TB and ARI)
e. Appointment of a paediatrician for paediatric OPD care

Knowledge of paediatric and adolescent HIV *(For All Health Care Workers except Clinicians)*

66. According to the 2013 WHO recommendations on management of children with HIV, HIV-positive children below five years of age should be commenced on ARVs once their CD4 count falls below 500 cells/mm^3 True [ ] (1) False [ ] (2)

67. According to the 2013 WHO recommendations on management of adolescents with HIV, HIV-positive adolescents should be commenced on ARVs once their CD4 count falls below 500 cells/mm^3 True [ ] (1) False [ ] (2)

•

For Questions 68–75, indicate whether the statement is true (1) or false (2)

68. Concerning paediatric HIV counselling and testing:
a. For effective counselling, all relevant information should be given at first contact or visit
b. Counselling should not include nutritional support and growth monitoring
c. It is right to test a critically ill child whose parent refuses to consent for HIV testing for the purpose of immediate clinical management
d. Post-test counselling should be provided by the same care provider who conducted the pre-test counselling
e. In provider-initiated testing and counselling, HIV testing is offered to all in-patient and out-patients seen in health facilities

69. Regarding mother-to-child transmission (MTCT) of HIV
a. More than 95% of paediatric HIV infections are due to MTCT of HIV
b. All HIV-infected women transmit HIV to their babies
c. Sexually transmitted diseases increase risk of MTCT of HIV
d. Babies are at risk of breast milk transmission of HIV only in the first 6 months of life
e. Mixed feeding does not pose a higher risk for infants of HIV-infected women

70. Ngozi was diagnosed with HIV during pregnancy and gave birth to a daughter 6 weeks ago. Today she brings her to the under-5 clinic for her first immunization visit. There is no access to virologic tests available at your clinic. In addition to giving her immunizations, what else should you do?
a. Prescribe single-dose nevirapine only
b. Prescribe zidovudine for 6 weeks only

c. Prescribe Cotrimoxazole if her growth and development are appropriate
d. Prescribe Cotrimoxazole when the child is 3-months old
e. Developmental assessment should be performed at every visit

71. Supportive care for infected and affected children includes:

a. Psychosocial support in homes and communities
b. Disclosure to all children at the age of 5 years
c. Administration of BCG vaccine to all HIV-exposed infants
d. Administration of measles vaccine twice at 6 and 9 months to all HIV infected/exposed children
e. Basic essential services identified by the National Plan on Action on OVC focuses on health and psychosocial support only

72. About nutrition and HIV

a. Exclusive breastfeeding for the first 3 months of life is an option for babies of HIV-infected mothers
b. Breast milk substitutes can be used if AFASS, which means affordable, feasible, adaptable, secure and safe
c. Low birth weight is a common manifestation of HIV in the new born
d. Nausea in HIV-infected children may be managed with feeding small meals frequently and avoiding high fat and greasy diets
e. A 3-year-old weighing 11 kg is well nourished

73. The following statements are true about the care of adolescents with HIV and AIDS

a. Adherence to care and treatment can be a challenge
b. Relationship with peers and family is developmental stage dependent
c. Obtaining consent for medical treatment is easy
d. Are unable to appreciate the long-term implications of diseases
e. They often lack social skills

74. Concerning care of adolescents with HIV:

a. Those in Tanner Stages I & II are managed using paediatric ARV guidelines, while those in Stage III and above are managed using adult ARV guidelines
b. Pill burden and lifestyle may be barriers to adherence
c. Having treatment partners may not be useful to adolescents
d. Life skills training should be part of any adolescent care programme
e. Developing self-awareness and managing emotions are components of life skills

75. The minimum health services package for paediatric HIV and AIDS care should include the following:

a. Confirmation of HIV status as early as possible
b. Advocacy to policy makers
c. Monitoring growth and development
d. Diagnosis and early treatment of other infectious (malaria, TB and ARI)
e. Appointment of a paediatrician for paediatric OPD care

Thank you for your time.

Annex 3: Key Informant Interview Guide for National and State Level Policymakers

Thematic area	Key questions	Probes
Existence of the policy	Please tell me about existing national HIV and AIDS strategic policies, guidelines and documents and whether these documents prioritize paediatric and adolescent HIV?	Probe and get a listing of general HIV and AIDS documents in the country including strategic plans, policies, guidelines
Policy development process	Does the country have stand-alone paediatric and adolescent HIV and AIDS policies and documents?	Probe and get specific HIV and AIDS documents such as HTC guidelines and policy, HIV prevention policies, ART policies, PMTCT/EMTCT policy documents, HIV treatment and care guidelines
Policy content & gaps	What are other paediatric and adolescent HIV and AIDS relevant documents in the country?	Probe for specific paediatric and adolescent HIV documents for example EMTCT policy documents, paediatric ART documents, adolescent ART documents, early infant diagnosis guidelines
Policy implementation	Do you think the country has all the necessary policy documents / guidelines to address paediatric and adolescent HIV policy issues?	Probe for other policies such as child health policies, adolescent policies, and see whether these include paediatric and adolescent HIV issues
Recommendations for addressing identified gaps and concluding remarks	How were the stakeholders involved at the various stages in the development of paediatric and adolescent focused HIV and AIDS policies and guidelines?	Using the policies reported, ask whether the respondent feels the country has adequate policies/guidelines for paediatric and adolescent HIV response
	What do you think are the gaps in the engagement / involvement process and how do you think this can be addressed in future?	Probe what the respondents thinks may be additional guidelines/policies, etc. that are required
	What informed the development of the various policies? Were these adopted from international documents / policies?	Probe on adequacy of the involvement at the various stages including problem identification and prioritization, contextualization of the issues
	What were the gaps in the process of identification of the policy problem? What about in the contextualization of the policies?	Probe on the involvement of critical groups such as involvement of adolescents in the development of adolescent HIV policies, involvement of professional associations like paediatric associations
	Do the general HIV and AIDS policies discussed earlier prioritize paediatric and adolescent HIV? If yes what are the issues prioritized (both for paediatric and for adolescent)?	Probe process of policy problem identification
	Are there areas where you think the HIV and AIDS general policies/ strategic documents could be strengthened to ensure better prioritization of paediatric and adolescent HIV? For the specific paediatric and adolescent HIV and AIDS documents reported, what do you think are the key strengths, opportunities and weaknesses? How do you think this could be addressed?	If policy was adopted, probe on the process of contextualizing the policy to the country, were there any gaps and challenges?

Thematic area	Key questions	Probes
	Are the policy provisions on paediatric and adolescent HIV being implemented?	
	What are the barriers to the implementation of the various policy provisions?	Using the mentioned general documents, probe respondents opinions on whether they prioritize paediatric and adolescent HIV, probe on the respondents response to get the reasons for their response (Will be good if possible to read the documents in advance)
	How can the barriers be addressed?	Probe on what respondents think should be done to the general documents to ensure they prioritize paediatric and adolescent HIV
	As we close, what would be your general recommendations for addressing policy-related gaps on pediatric and adolescent HIV response in this country?	Some possible areas for probing include: consent to HIV testing, age criteria for self-consent, and exceptions for HIV testing below the age of consent for the general population or a stipulated subpopulation. Other themes will include initiation to ART for those testing HIV positive, targets, retention in care and treatment, approaches to care and treatment.
	Are there any other pediatric and adolescent HIV and AIDS issues that you may wish to share with me?	See also a separate WHO guidelines on some standards
		Probe whether for adolescents and children testing HIV positive there are policy provisions for: linkage, initiation to treatment and retention, and clear strategies and targets for each
		Use information on policy provisions to probe whether the policies are being implemented at the various levels
		Probe evidence of the implementation of the policy provisions
		Probe challenges/ barriers to implementation including: Lack of knowledge on the policy provisions among implementers, lack of availability of the policy documents at the implementation points, e.g. health facilities, etc.
		Probe ways of addressing the various barriers to policy implementation identified

Annex 4: Policy Key information interviews Guide for Health Workers

Thematic area	Key questions	Probes
Knowledge of policy provisions for paediatric and adolescent HIV care and treatment	Please tell me about national policies promoting paediatric and adolescent HIV care in this county? What are some policy provisions in these policy documents? Have these documents been disseminated to the health workers? Do you this could be improved?	Probe to get a listing of all the paediatric and adolescent HIV care policy documents mentioned Using the policy documents mentioned, probe to see whether the health workers understand the policy provisions Probe to see whether the reported policy documents have been disseminated
Best practices in policy implementation		
Opinions on policy gaps for pediatric and adolescent HIV care and treatment	What would you say are the policy gaps on paediatric HIV care? How has this affected access to HIV care by children in this facility? Would you give examples of policy gaps for adolescent HIV care? How has this affected access to HIV care by adolescents?	Use the various standard policy provisions for paediatric HIV care to probes the gaps under each Probe how each of the identified policy gaps impacts HIV care by children Use the various standard adolescent HIV care policy provisions to probe policy gaps under each For each policy gap mentioned, probe how it impacts on access to HIV care by adolescents
Availability of policies/guidelines on paediatric and adolescent HIV at facility level	How is access to various adolescent and paediatric HIV care policies/guidelines by health workers in this facility? Are there policy/guidelines /tools that are not available at this facility level? If yes, which ones? How has that affected provision of services to children and adolescents? What would be your suggestions for improving this situation?	Using knowledge of the various national paediatric and adolescent HIV policies and guidelines, probe their availability at facility level Probe whether the facilities have the most up-to-date policies and guidelines Probe how unavailability of the guidelines/policies has impacted service delivery
Policy practice	In general, how is the implementation of the various paediatric HIV policy provisions in this facility? What are some policy provisions that have been implemented successfully and why? What challenges do you face in implementing those policy provisions What are your suggestions for addressing those policy practice barriers?	
Recommendations on policy gaps and practice	As we conclude what would be your advice for ensuring implementation of paediatric HIV care policy provisions at facility level? What about adolescent HIV care policy provisions?	

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