Advanced HIV Disease (AHD) in Children & Adolescents

IMPAACT4HIV Baseline Survey Consolidated Findings: South Africa/Mozambique/Nigeria

1 Introduction and Rationale

This consolidated summary synthesizes baseline survey findings from South Africa, Mozambique, and Nigeria under the IMPAACT4HIV programme. The assessments aimed to identify AHD knowledge gaps, barriers to care, service delivery weaknesses, and opportunities to strengthen paediatric AHD outcomes.

2 Sample Size and Methodology

Data collection included mixed qualitative and quantitative methods across community and facility settings:

Nigeria:

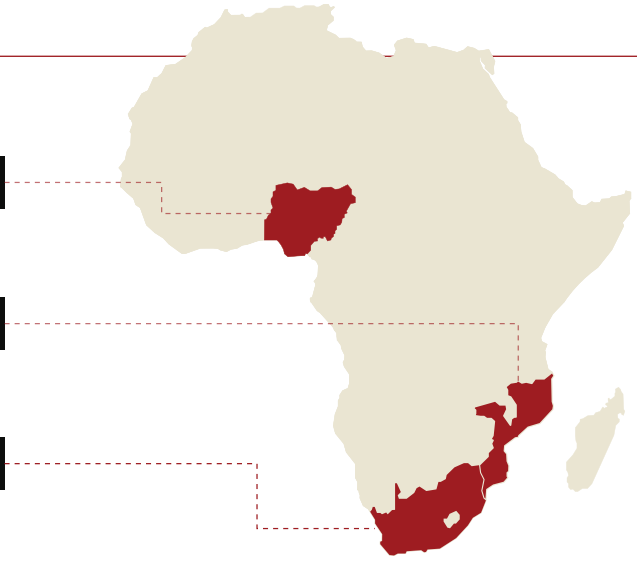
147 FGD participants + 20 KIIs across four states (Kano, Gombe, Rivers, Lagos).

Mozambique:

50 participants (parents/caregivers, community leaders, and peer educators) in Matola and Manhiça.

South Africa:

95 survey participants + 10 FGDs across three districts (Dr Kenneth Kaunda, Bojanala, and Ngaka Modiri Molema).



Themes explored included:

AHD knowledge

Stigma

Adherence challenges

Referral pathways

Diagnostic access

Health system constraints

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3 Key Findings

Knowledge of HIV & AHD

- Across all countries, awareness of AHD was extremely low among caregivers, adolescents, and even service providers.
- AHD was often confused with AIDS or general illness. Misconceptions were common, for example Spiritual causes cited in Mozambique (where outcomes were left to "*God*") and Nigeria (where HIV was viewed as a "*spiritual attack treatable with prayers*").

Adherence & Disease Progression

- Despite low AHD knowledge, participants generally understood that poor ART adherence leads to deterioration.
- Progression drivers included treatment lapses, malnutrition, late diagnosis, caregiver fatigue, stigma, and economic strain.

IEC Materials

- AHD-related IEC materials were scarce or absent across all settings.
- In South Africa, 84% of respondents had not seen AHD materials.
- Communities in Mozambique and Nigeria had almost no exposure to AHD information.

Stigma & Mental Health

- Self stigma, community gossip, bullying, and discrimination significantly affected health seeking behaviour.
- Mozambique highlighted specific gaps in mental health services, noting that HIV providers often do not engage with mental health issues.
- Stigma delayed disclosure, treatment uptake, and contributed to late AHD presentation.

System-Level Gaps

- **Diagnostic Shortages:**
  Critical shortages of CD4, CrAg, and TB LAM were reported, particularly in Nigeria and South Africa.
- **Human Resources:**
  Challenges include limited AHD training for providers, HR shortages, and the 'japa syndrome' (emigration of health workers) in Nigeria.
- **Service Delivery:**
  Weak referral systems (unidirectional with poor feedback) and inadequate integration with TB/PMTCT/nutrition services were common barriers.

Community Barriers

- Caregiver fatigue, economic hardship (transport costs, food insecurity), and low health literacy hinder adherence and timely care.
- Adolescents expressed frustration with long term medication ("tired of taking drugs") and a lack of youth friendly support.

Opportunities

- **Community Leaders:** Traditional and religious leaders expressed willingness to support awareness and combat stigma.
- **Existing Structures:** Strong Community Health Worker (CHW) networks and peer clubs can be leveraged for tracking and support.
- **Digital Health:** High mobile penetration offers opportunities for digital communication channels targeting adolescents.

4 Call to Action

A coordinated, cross country response is urgently required. Key priorities include strengthening AHD awareness, improving diagnostic access, re engaging community structures, reducing stigma, addressing economic barriers, and expanding youth friendly services.

5 Recommendations

Strengthen AHD Literacy & Caregiver Support	• Co-create IEC campaigns in local languages with caregivers and adolescents. • Test child-friendly AHD explanations with families before rollout. • Use participatory training methods that build on existing caregiver knowledge.
Build Provider & CHW Capacity	• Design AHD training through consultation with frontline workers. • Develop job aids for ease of use in resource-limited settings. • Conduct rapid assessments to understand workflow constraints.
Improve Diagnostics & Treatment Access	• Prioritize CD4, CrAg, TB-LAM based on community-identified needs. • Map supply chain gaps with facility staff input. • Pilot point-of-care innovations with end-users before scaling.
Strengthen Community Engagement	• Co-design stigma reduction campaigns with religious and traditional leaders. • Structure support groups based on member preferences. • Engage people living with HIV as advisors throughout programme design.
Enhance Referral Systems & Integration	• Design two-way referral systems with input from both sending and receiving facilities. • Use process mapping with staff to identify practical integration points. • Pilot, gather feedback, and refine before scaling.
Reduce Economic Barriers	• Tailor economic support to local realities through empathy interviews with caregivers. • Allow communities to identify which support options work best. • Design flexible, context-responsive mechanisms.
Expand Youth-Friendly Services	• Co-design adolescent spaces with youth advisory panels. • Use rapid feedback cycles to continuously improve services. • Ensure spaces, schedules, and approaches meet adolescent preferences.