APPENDIX B

ADVANCED HIV DISEASE

Community Pocket Reference

This Is a reference book for all communities, community health workers, and partners involved in the HIV response. It provides practical guide to support a holistic response to Advanced HIV disease in children and adults. Recommendations are guided by the WHO and informed by emerging lessons on community engagement on the IMPAACT4HIV project. This guide helps you recognise Advanced HIV Disease early, act quickly, and ensure people receive the care they need.

Informed communities strengthen the advanced HIV disease response.

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MARKET ACCESS AFRICA · IMPAACT4HIV IMPROVED ACCESS TO AHD CARE & TREATMENT 4 HIV · THRIVE Empower Locally, Catalyze Impact Globally · AFROCAB Treatment Access Partnership · match boxology

Contents

1. What Is Advanced HIV Disease (AHD)?

Definition

- CD4 count below 200 cells/mm³ in adults and children older than 5.
- OR they have a serious HIV-related illness (WHO Stage 3 or 4)
- **ALL children under 5 living with HIV not stable on ARTs**

Below 200

The lower the CD4 count, the higher the risk of life-threatening infections.

Below 100

Very high risk of cryptococcal meningitis

Below 50

Extremely compromised. Act urgently.

2. Warning Signs — Do Not Wait

If you see any of these signs, REFER URGENTLY to the nearest health facility. Do not wait.

A Adults & Adolescents

- ! Persistent fever
- ! Night sweats
- ! Severe weight loss
- ! Extreme tiredness
- ! Persistent cough
- ! Severe headache
- ! Confusion or vision changes
- ! Persistent diarrhoea
- ! Oral thrush
- ! Difficulty breathing

B Children

- ! Fast or difficult breathing
- ! Chest indrawing
- ! Severe weight loss
- ! Poor feeding
- ! Repeated infections
- ! Lethargy
- ! Convulsions
- ! Growth faltering
- ! Caregiver concern
- ! Missed clinic visits

Who Is Most At Risk?

Prioritise follow-up for:

- Newly diagnosed — assess immune status with CD4 cell count immediately
- People who interrupted ART
- Children under 5
- Lost to follow-up — trace and re-engage
- Recently discharged from hospital
- Adolescents / young adults (transition risk)

Red Flag Moments

act immediately when you see this:

- People with a new HIV diagnosis
- Baseline ART initiation
- Returns after stopping ART
- TB diagnosis + unknown CD4
- Discharged patient misses follow-up
- Discharged patient falls sick
- Adolescent repeatedly misses visits
- Child with growth concerns
- Children under 5 not stable on ARTs for up to 1 year
- ARTs are taken but don't seem to work
- Reoccuring illness or infections

3. WHO Recommended Advanced HIV Disease Care Package

This is what every person with Advanced HIV Disease should receive at the health facility.

Starting ART alone is not enough. The full package must be delivered together.

1 CD4 Testing

Identifies immune suppression. Essential even with viral load .

2 TB Screening

- TB is the leading cause of death in PLHIV.
- Clinical TB screening should be done at every clinical consultation.
- Lab testing TB screening (urine LAM-TB or PCR Xpert/Truenat) is done based on clinical indication and/or when CD4 cell count is <200 cells/mm3.

3 Serum CrAg Screening

For CD4 <100. Detects cryptococcal infection before meningitis develops.

4 Rapid / Optimised ART

Start or switch without delay. Assess for treatment failure if already on ART.

5 Preventive Therapies

Cotrimoxazole, TB preventive therapy, fluconazole for serum CrAg+.

6 Enhanced Follow-Up

- Clear hospital discharge plan.
- Community follow-up.
- Structured return visits.

Special Considerations

Children with Advanced HIV Disease need:

- Immediate clinical assessment
- Age-appropriate ART formulations and dosing
- Preventive therapies
- Nutritional support
- Pediatric routine vaccination schedule
- Caregiver counselling
- Structured follow-up

Even if viral load is controlled, a person can still be very weak and at risk. Some people achieve undetectable viral load but still have low CD4. They remain vulnerable. Always check both. Starting ART alone is not enough. The full Advanced HIV Disease care package must be provided.

Post-hospital discharge period carries high mortality risk:

Follow up within days of discharge (physically, phone call…).

Confirm medications

Check symptoms

Reinforce adherence

4. The 5-Step Community Action Flow

Use this process whenever a patient is at risk or a service gap is identified

When you see something that puts patients at risk, follow these steps.

1 NOTICE IT

1. Is there a missing test?
2. A stock-out?
3. A referral gap?
4. A child not gaining weight?
5. A missed screening?

Be specific. Write down what you see.

2 CHECK IF IT IS REPEATED

- ? Has this happened before?
- ? Are multiple patients affected?
- ? Is it happening to more than one patient?

If yes, it may be a system issue.

3 LOG IT

Record:

- Date
- What happened
- Who was affected.

Small notes prevent bigger crises. Use the Service Gap Log.

4 DISCUSS LOCALLY FIRST

Raise with the nurse in charge, facility manager, or supervisor.
Use facts, not blame.
Example: "In the last three weeks, three patients with CD4 below 100 were not screened for CrAg. Can we review the protocol?"

Many issues are resolved here.

5 ESCALATE IF

Escalate if:

- issue persists after discussion
- high-risk services affected
- multiple patients at risk
- child safety compromised
- preventable Advanced HIV Disease cases recurring.

Escalation Pathways:

- District review meetings
- Community monitoring reports
- Civil society forums
- National programme engagement

Escalation must always be:

- Evidence-based
- Respectful
- Focused on patient safety
- Solution-oriented

The goal is improvement, not confrontation.

Service Gap Log (Example of a Field Tool)

This tool can be used to track issues and follow up until they are resolved.

Date	What Happened?	Who Affected?	Repeated?	Who Informed?	Follow-Up Date
Example: 12 Feb	No CD4 testing available	3 patients	☑ ☐	Reported to nurse	
			☐ ☐		
			☐ ☐		
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5. Advanced HIV Disease Commodities & Services — Monitoring Checklist

This checklist is mainly for community monitors, supervisors, and facility visits

Use this checklist during facility visits. Document findings and escalate gaps. Focus on identifying missing tests, medicines, or delays that put patients at risk.

Diagnostics & Tests

Service / Commodity	Available?	Stock-outs?	Action Needed
CD4 Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Cryptococcal Antigen (CrAg) Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB Symptom Screening	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB-LAM (used for very weak patients who cannot produce sputum)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Viral Load Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Timely Return of Test Results	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Preventive Medicines

Service / Commodity	Available?	Stock-outs?	Action Needed
Cotrimoxazole	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB Preventive Treatment (TPT)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Pre-emptive Fluconazole (for CrAg+)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Treatment for Opportunistic Infections

Service / Commodity	Available?	Stock-outs?	Action Needed
First-line TB Treatment	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Amphotericin B	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Flucytosine	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Fluconazole (treatment dose)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Antibiotics for Severe Bacterial Infections	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Itraconazole	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

ART & Supportive Services			
Service / Commodity	Available?	Stock-outs?	Action Needed
Effective ART Regimens (TLD)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Paediatric ART Formulations (pALD)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Regimen Switching When Indicated	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Nutritional Assessment & Support	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Psychosocial Support	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Post-Hospital Discharge Follow-Up	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Clear Referral Pathways	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Escalate immediately when:

CD4 or CrAg testing is unavailable

TB diagnostics not functioning

OI preventive medicines are not available

OI treatment medicines missing

ART stock-outs

Post-discharge feedback is absent

Nutrition gaps are affecting recovery

Treatment modalities such as regimens are not accurate

Advocate for:

Medicine formulations that are child-friendly

Better availability of diagnostic tools

6. Integrated 4-Level Advanced HIV Disease Strengthening Framework

This section helps you understand how different levels of the system should function

Preventing unwanted deaths from Advanced HIV Disease requires every level to function. These indicators help identify whether Advanced HIV Disease is sufficiently captured or poorly prioritized

L1 Community

Must be in place:

- Active, supported CHWs
- Routine follow-up after discharge
- Treatment adherence support
- Monitoring of children & adolescents
- Community documentation of gaps (community observatories)

Warning signs:

- Patients returning very sick
- Children missing doses
- No feedback loop with facilities

L2 Facility

Must be in place:

- Functional CD4 testing
- Serum CrAg being done for people with CD4<100
- SBI testing
- Routine TB screening
- Paediatric ART in stock
- Treatment for CrAG, TB, histoplasmosis, SBIs
- Clear discharge plans

Warning signs:

- CD4 deprioritized
- CrAg not done
- Repeated stock-outs
- Advanced HIV Disease is only addressed when patients are very sick

Histoplasmosis test will be made available if prevalent in country, don't hesitate to ask for histoplasmosis testing

L3 District

Must be in place:

- Active commodity availability and supply monitoring
- Lab turnaround time oversight
- Review of Advanced HIV Disease indicators & mortality
- Paediatric Advanced HIV Disease and outcomes in district reviews
- Adolecsent Advanced HIV Disease in district reviews
- Response when facilities report gaps

Warning signs:

- No response to facility reports
- Delays in equipment repair
- Community findings not discussed

L4 National

Must be in place:

- Full WHO Advanced HIV Disease package in guidelines for primary and hospital care
- Dedicated budget for all commodities: CD4, CrAg (testing and treatment), TB (testing, treatment and TPT), paediatric ART, Histo LAM (if available) SBI testing
- Advanced HIV Disease indicators in performance frameworks
- Advanced HIV Disease prioritised in HIV strategic plans
- Advanced HIV Disease for children and adolescents explicitly prioritized
- Funding allocation alignment with Advanced HIV Disease delivery needs

Warning signs:

- CD4 removed without alternative risk screening
- CrAg not funded or procured
- TBLAM not funded or secured
- SBI testing not prioritized in children
- Prevention not prioritized – e.g cotrimoxazole for children
- Advanced HIV Disease reporting indicators are not tracked in national reporting systems
- Paediatric Advanced HIV Disease is not prioritized in funding or procurement provisions

7. Collective Call To Action

Use this to guide who to engage when issues are not resolved at facility level.

Knowing each person's role helps you target your communication and advocacy. It takes collaboration for these efforts to achieve our collective aim.

Communities:

- Identify early warning signs
- Support individuals to stay in care
- Follow up post-discharge
- Protect children & adolescents
- Document and report service gaps

Donors & Global Partners:

- Ensure access and availability of Advanced HIV Disease diagnostics & medicines
- Prioritise paediatric services
- Fund community monitoring efforts
- Focus evaluations on implementation gaps
- Foster cross-country learning

District & National:

- Monitor supply chains & lab systems
- Review of Advanced HIV Disease indicators performance and outcome tracking
- Use data from the field to inform priorities and allocation
- Include Advanced HIV Disease in national strategic plans
- Define Advanced HIV Disease packages both for primary health care and for hospital level
- Align Funding allocations (global and national grants with Advanced HIV Disease delivery
- Protect community-led monitoring

Health Workers & Facilities:

- Implement the full WHO Advanced HIV Diseasecare package
- Ensure CD4 & CrAg for all eligible patients
- Prioritise paediatric care
- Develop clear discharge plans
- Link feedback to communities
- Review Advanced HIV Disease cases and mortality

Advanced HIV Disease is preventable when it is recognised early and managed correctly.

IMPAACT4HIV
auruminstitute.org

THRIVE
thriveinfo.org

UNITAID
unitaid.org

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