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Advancing HIV Monitoring: Community Leadership, Big Data Science and Systems Integration

Intelligent Health Monitoring: Why community data must be part of the system



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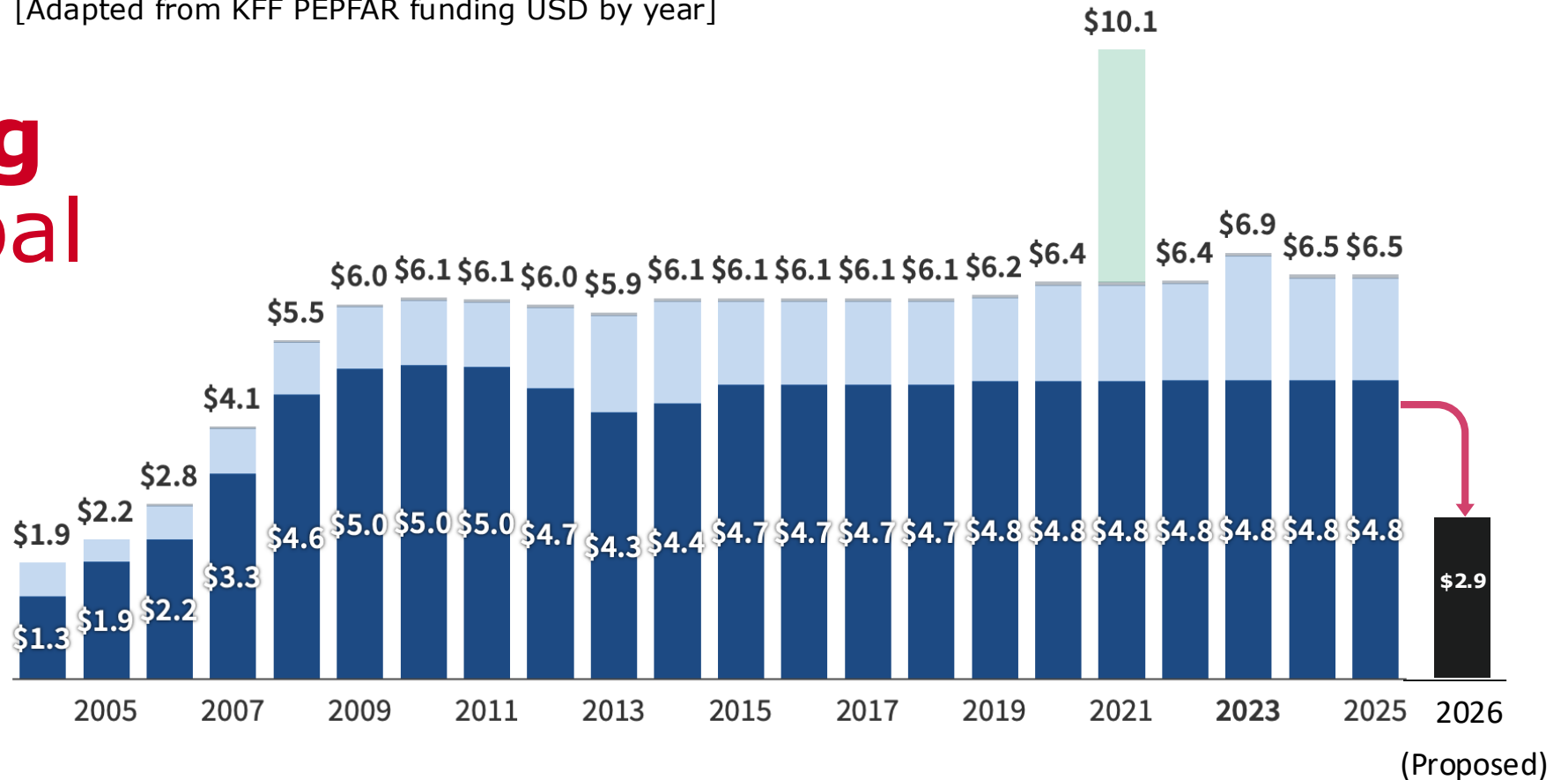
U.S. Funding for the President's Emergency Plan for AIDS Relief (PEPFAR), FY 2004 - FY 2025

(In Billions)

■ Bilateral HIV ■ Global Fund ■ UNAIDS ■ Emergency Funding

[Adapted from KFF PEPFAR funding USD by year]

HIV Funding Cuts: A Global Retraction in Motion

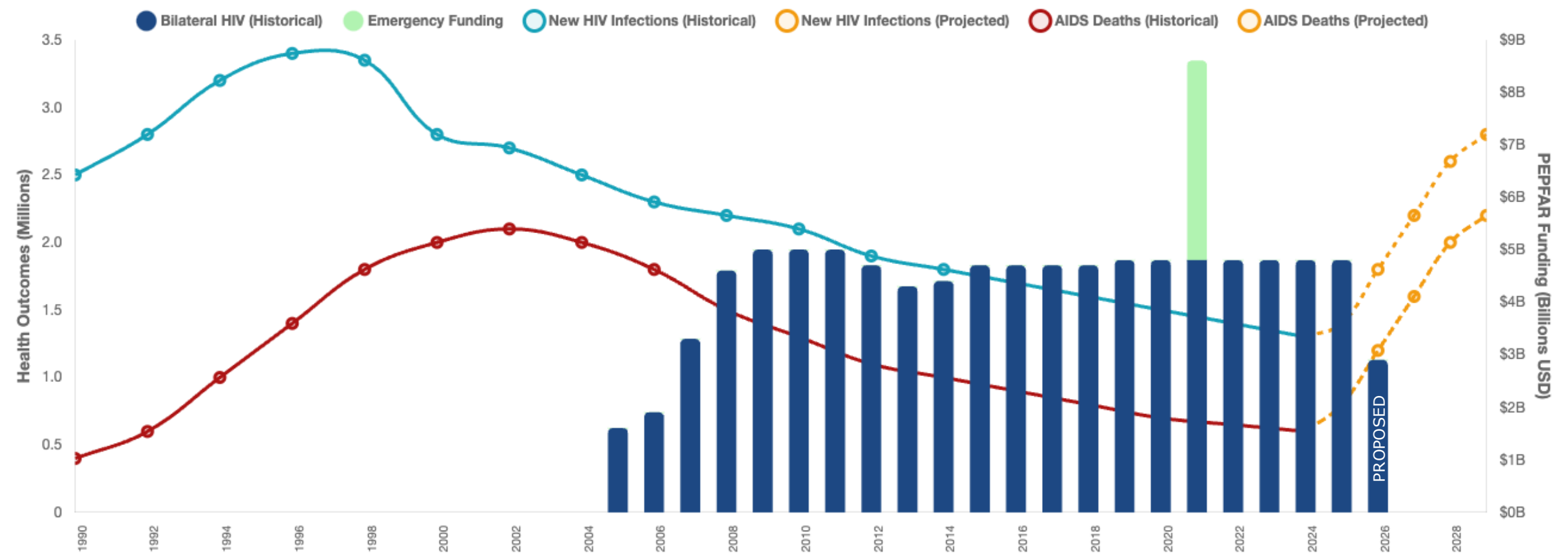


The Cost of Cuts: HIV Funding vs Health Outcomes



[A composite of UNAIDS epidemiological estimates 2025 and KFF PEPFAR funding USD by year]

PEPFAR Funding vs HIV/AIDS Global Outcomes (1990-2029)





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The Rise of AI: Promise, Pitfalls and Problem

Promise:

- AI helps process massive volumes of health data, faster than any human expert can.
- It can **identify patterns, predict outbreaks, optimize supply chains, personalize care.**
- In theory, it can increase efficiency and precision, especially with limited resources.

Pitfalls:

- But AI is only as good as the data it's trained on.
- Biases in data = biases in care.
- Most community realities are **underrepresented or missing** in national datasets.
- Without context, predictions risk being inaccurate or unjust.

Problem:

- Data poverty: Structural underinvestment in community data systems means **many populations are invisible to AI.**
- “No data” does not mean *no need*, it means *no one paid to listen*.
- If we don't include lived experience, AI will **reproduce the blind spots** of existing systems — faster.

Without community leadership, AI risks becoming just another **top-down system** — faster at replicating inequities that persist.



What is the goal of Big Data?

INTELLIGENCE

The ability to turn vast, diverse data into timely, **actionable insight that improves decisions, outcomes and equity.**

Which means:

- **Seeing the unseen** (dropout risk, stockout signals, service breakdowns)
- **Responding early** (fixing issues before they become crises)
- **Allocating wisely** (protecting what matters most under budget cuts)
- **Empowering communities** (making sure the data improves lives, not just systems)

The real value of big data is not about having more numbers, it is in knowing

what those numbers mean, when those numbers matter and who those numbers serve.



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Data without **people**
isn't **intelligence.**

It's noise.

What Real Intelligence Requires: Scale + Speed + Context



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Component	Role	Without it...	Status
Program & Strategic Intelligence (includes Big Data, HMIS)	Scale, breadth	You miss the full picture	Existing, compromised & increasingly fragmented and politicized
Artificial Intelligence (AI)	Speed, pattern detection	You are slow to respond	Rising exponentially
Community Intelligence (e.g. CLM)	Context, grounded prioritization	You act on the wrong assumptions	Under-invested and often invisible

Community Data: The Intelligence Layer the System Forgot



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Intelligence Type	Source Examples	Current Status	CLM Role
Program Intelligence	HMIS, DHIS2, PEPFAR/DATIM	Under strain, underfunded	CLM fills reporting blind spots with real-time evidence
Financial Intelligence	Costing models, budget tracking	Fragmented, often donor-driven	CLM data supports better value-for-money decisions
Operational Intelligence	Logistics, procurement, supervision	Weak feedback loops, stockouts rising	CLM tracks last-mile failures, informs reallocation
Strategic Intelligence	Forecasting, big data, AI, Grok 4 etc.	Underdeveloped, biased, lacks ground truth	CLM provides the " why " behind the " what "
Political Intelligence	Policymaker and donor insights	Decoupled from local accountability	CLM empowers advocacy and alignment with community need



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Community Intelligence: *A look into community-led monitoring*

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CLM Outcomes (2023) SOUTH AFRICA



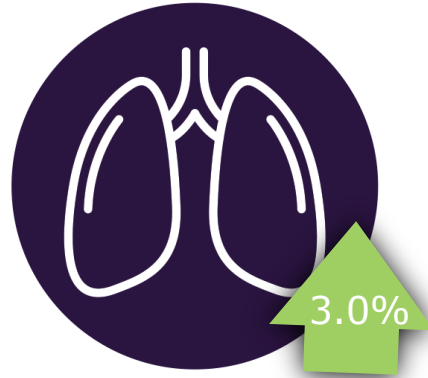
Proven
Impact



Following PrEP-related CLM feedback sessions with facility managers, people who visited our 19 monitored sites were **32% more likely to initiate PrEP** following an HIV test compared to the other 70 West Rand health facilities (1.32 OR 95% CI 1.27-1.38).



The percentage of older **men living with HIV who know their status increased** from 86.8% in 2022 to 88.9% in 2023, following a CLM data-driven campaign to increase community-led HIV testing from 20.4% in 2022 to 33.6% in 2023 (UN target achieved).



After using CLM data to alleviate stockouts of TB medicines, the **treatment success rate at our CLM sites increased** from 88% in 2022 to 91% in 2023, surpassing the End TB target of 90% by 2025 as well as South Africa's national treatment success rate of 79%.



Enhanced patient tracking for pregnant foreign nationals was implemented based on CLM insights. In 2023, women at our monitored sites were **twice as likely to deliver in the health facility** as compared to other West Rand facilities (1.99 OR 95% CI 1.51-2.62), reducing risk of vertical transmission.



When CLM data suggested HIV/SRHR service integration would increase HIV testing uptake ($r = 0.36, p = < 0.001$), we promoted this approach. In 2023, the **cost to diagnose one AGYW living with HIV was cheaper** at our CLM sites, at \$2,852, compared with \$4,154 at non-CLM sites (in terms of numbers needed to test).



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Insights from Early Warning CLM Data – Malawi June 2025



- 117 stakeholders interviewed across 11 health facilities in Malawi
- 24.6% reported **difficulty** accessing follow-up **appointments**; 13.1% reported **ARV access issues**
- Clinic records show 26% drop in HIV testing, 24% **drop in new ART initiations**, 36% **decline in viral load testing**
- Viral load suppression **down** 20%; TB cases among PLHIV **more than doubled** from 14 to 32 cases
- 40.6% of people said they **lack clear info on where** to access HIV services previously supported by USAID
- Community **fear and confusion** reported; reduced ART refills and halted outreach by expert clients

SERVICE	June 2024	June 2025
HIV Testing	9954	7412 ▼
New ART Initiations	71	54 ▼
Viral Load Testing	1447	926 ▼
Viral Load Tests with Suppressed Results	969	498 ▼
TB Infections (HIV+)	14	32 ▲

Table 1: Clinic records survey results from 11 health facilities in Malawi (Mimosa, Mpala, Chisitu, Mataware, Naisa, Milonde, Mwangi, Kalinde, Nambazo, Nkhwayi, Mwangi Health center).



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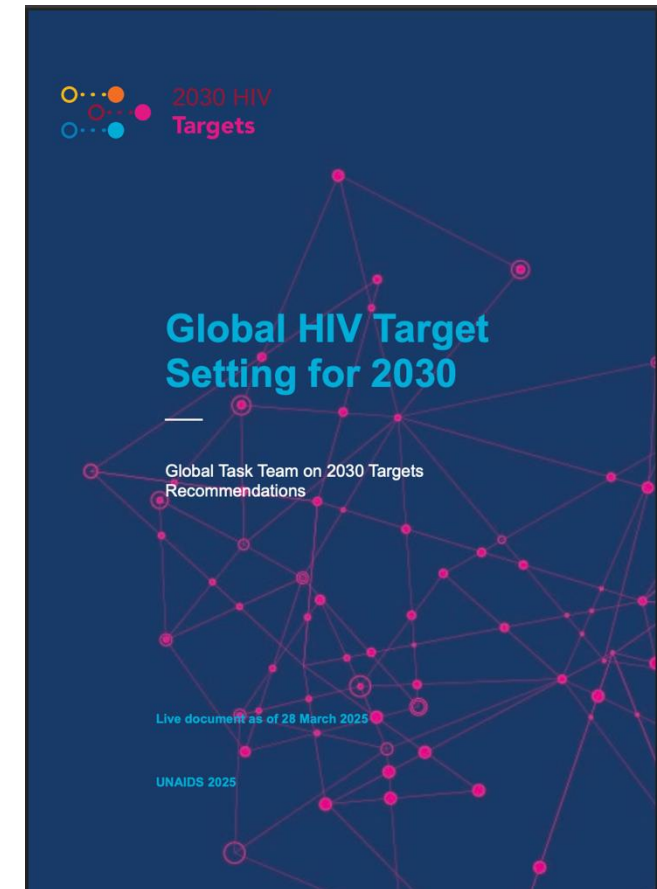
CLM is Now A Global Standard: 2030 UNAIDS Global Targets

Area 5. Ensure community leadership in the HIV response

5.3 - 90% of countries **incorporate** community-led monitoring **data** into national decision-making processes to strengthen accountability in HIV and TB programmes.

Area 6. Ensure sustainable financing for a people-centered national and global HIV response

6.2 - Countries **monitor and report on resources allocated** to community-led and other civil society organizations to deliver: community-led monitoring (CLM); programmes addressing societal enablers; and HIV prevention, testing and supportive services to treatment and care from both national governments and international sources. **All high-burden countries must have functional CLM systems in place.**





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True National Health Systems Intelligence: *What could the future look like?*

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- Cuts have **severely impacted M&E systems** in HIV, leading to loss of staff interrupted data entry, data reporting, aggregation and analysis.
- MoH in 13 countries across Africa report being **locked out of their own national M&E systems**.

Realities of Integration

Assessment finding: M&E System Components Impacted by USG Stop Work Order, 13 CQUIN countries, February 2025

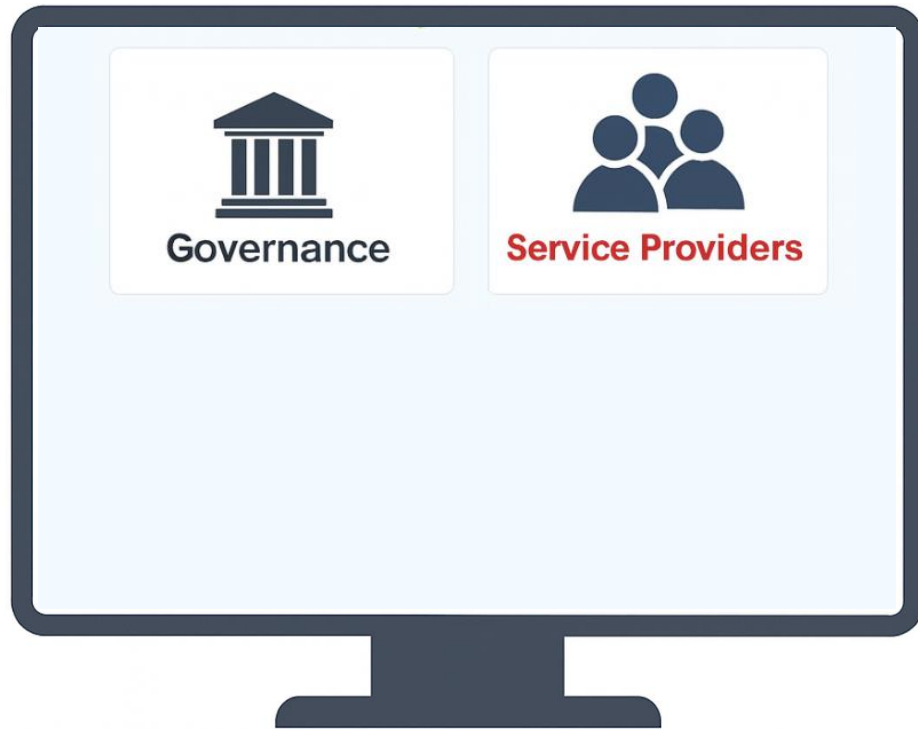
Component		Countries												
		A	B	C	D	E	F	G	H	I	J	K	L	M
Data collection	M&E Tools Availability	Partial	Partial	Partial	None	Partial	High	Partial	Not reported	Not reported	Not reported	Not reported	Not reported	High
	Data Quality and Completeness	Partial	High	High	Partial	Partial	High	High	High	High	High	High	High	Partial
	Community Based Monitoring	High	High	High	Partial	High	High	Partial	High	High	High	High	High	Not reported
	Retention Monitoring and Follow Up	High	High	High	Not reported	High	High	Partial	High	High	High	High	High	Not reported
	Commodity Tracking Systems	High	Partial	Partial	Not reported	Partial	High	Partial	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Databases, reporting, and use	HMIS reporting	High	Partial	Partial	Partial	High	High	Partial	Not reported	Partial	High	High	None	Partial
	EMR Functionality	High	Partial	High	None	High	High	High	Not reported	High	High	High	High	Partial
	Data Dissemination and Data Use	High	High	High	Partial	High	High	Partial	High	High	High	High	High	High
HRH capacity	M&E HRH Capacity	High	High	High	High	High	High	High	Not reported	High	High	High	High	High
	Supervision and Mentorship for HRH	Partial	Partial	Partial	Partial	High	High	High	High	High	High	High	High	High
	Capacity Building for M&E Staff	High	High	High	Not reported	Partial	High	Partial	Not reported	High	High	High	High	Not reported

Impact: ■ High ■ Partial ■ None ■ Not reported

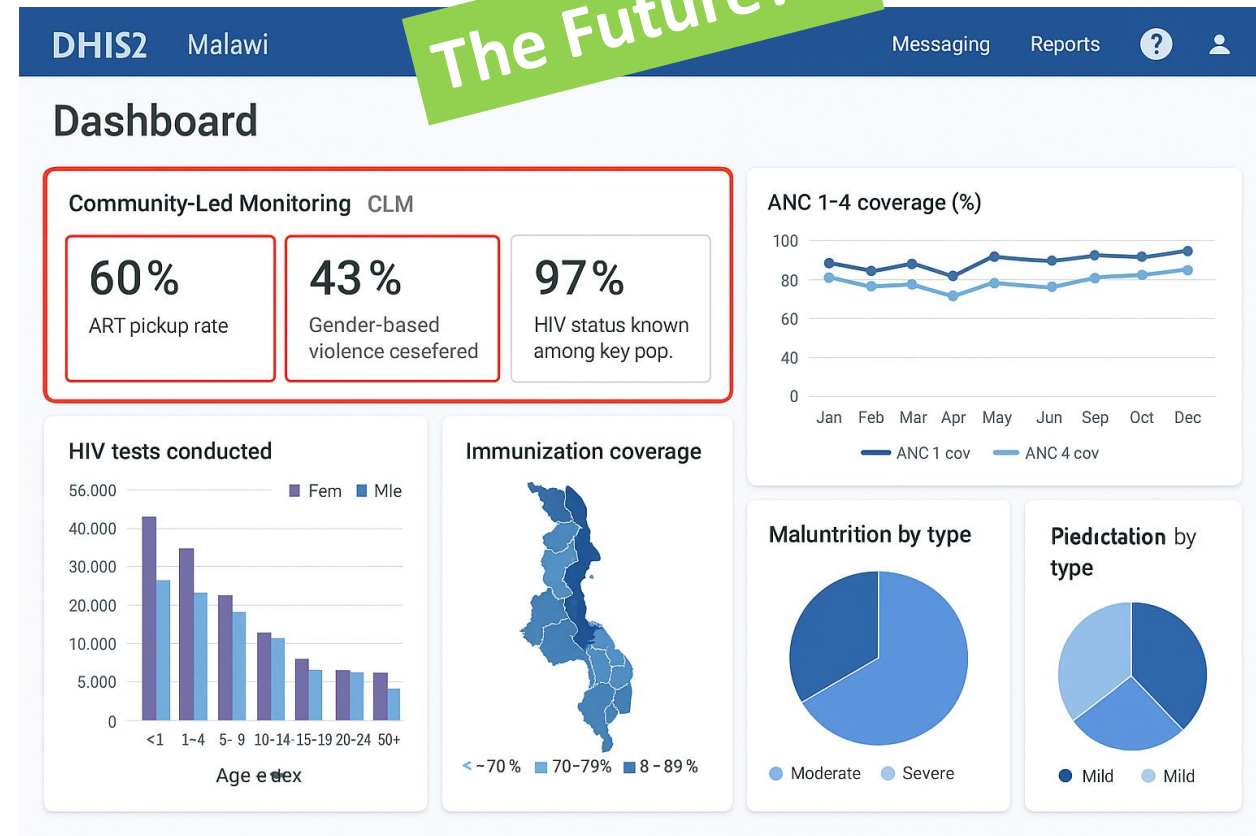
Source: Ministries of Health (CQUIN landscaping analysis)

Crisis or Opportunity?

From Fragmented to Future-Ready: Rethinking HMIS



**This isn't just a tech challenge
— it's a design opportunity**



**Mockup: AI-Generated DHIS2 platform with CLM indicators integrated into the interface. With visual inspiration from: <https://dhis2.org/cold-chain-management-malawi/>*



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Final Reflections

- The goal is not just to centralize data; it is to **integrate perspectives**.
- Monitoring systems must evolve to **match the reality** of **integrated service delivery**.
- AI and DHIS2 are **not enough** without **community-generated signals**.
- CLM is not a separate stream; it's a grounding layer for **real-time course correction** (early warning) and systems feedback.
- If communities don't live in silos, our **data systems shouldn't either**.

Health systems
without
community data
are **ineffective**
and **incomplete**.
Let's fix this!



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THANK YOU!



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