

Reimagining Community Engagement: Redefining the vision in an evolving landscape



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Tuesday 10th June 2025

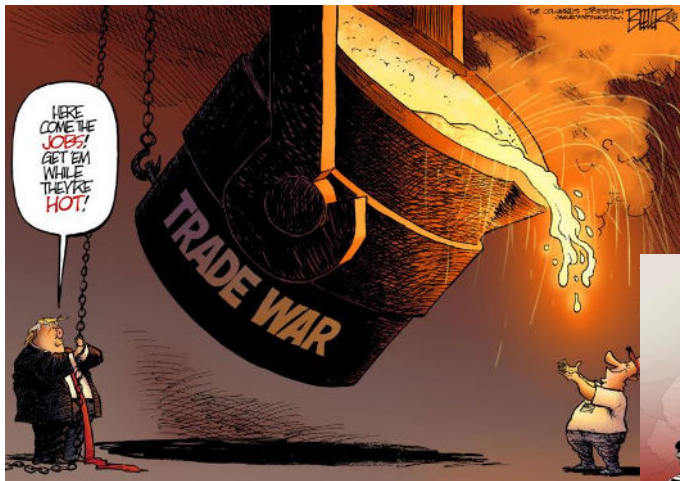
Session 3: State of the Response: The Community Experience



CQUIN Network Meeting | June 10-12, 2025 – Johannesburg, South Africa

EVOLVING LANDSCAPE

OUR OPERATING CONTEXT



RISK-SATURATED FUTURE

Global Risks Report 2025 [World Economic Forum]

FIGURE D Global risks landscape: An interconnections map³

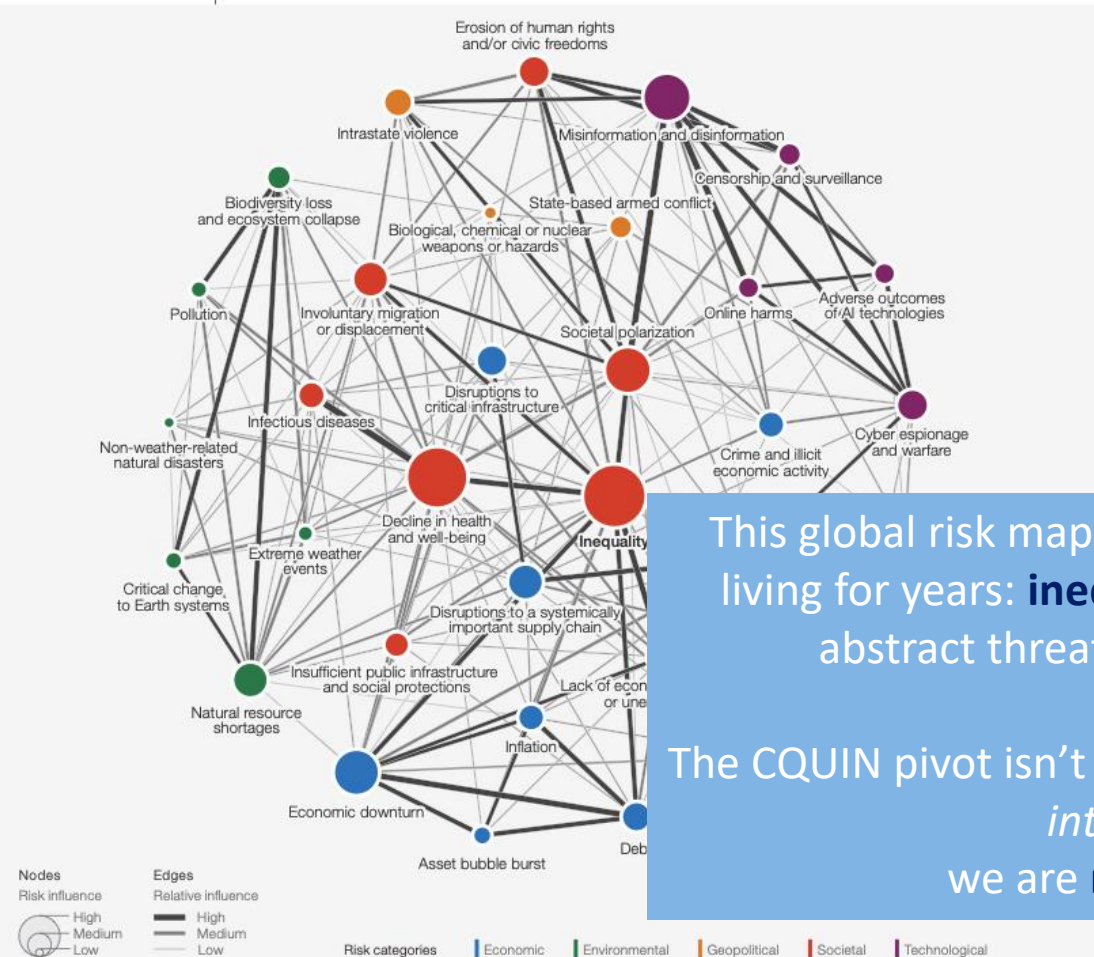


FIGURE 1.7 Global risks over the short term (2 years), by stakeholder group

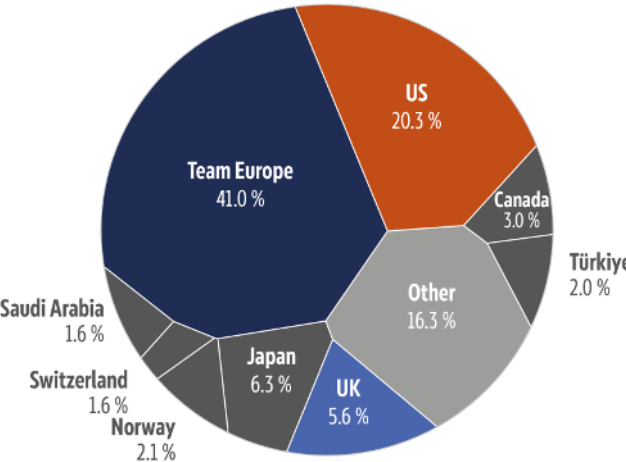


This global risk mapping confirms what communities have been living for years: **inequality, misinformation, and conflict** aren't abstract threats—they are everyday barriers to care.

The CQUIN pivot isn't just timely—it's necessary. We are *not just* integrating HIV into systems, we are **reimagining systems** to survive.

IMPACT ON GLOBAL PUBLIC HEALTH & HIV RESPONSE

Main donors of ODA worldwide
Disbursements, 2023, share of total (%)



Source: EPRS, OECD.

EPRS | European Parliamentary Research Service



UNAIDS will need to reduce the current number of staff from 608 to approximately 280 over time, according to a communique from the UNAIDS cabinet, seen by Devex.

By *Jenny Lei Ravelo* // 06 May 2025

Cuts have eliminated more than a dozen US government health-tracking programs

By *MIKE STOBBE* The Associated Press, Updated May 4, 2025, 6:03 p.m.

14



UNAIDS will also reduce its country presence from 75 to 36 countries. Photo by: dieBildmanufaktur / Alamy

Facing a major funding crisis, UNAIDS is cutting its workforce by more than half and scaling back its country presence — a shakeup that staff fear could weaken the global HIV response at a critical time.

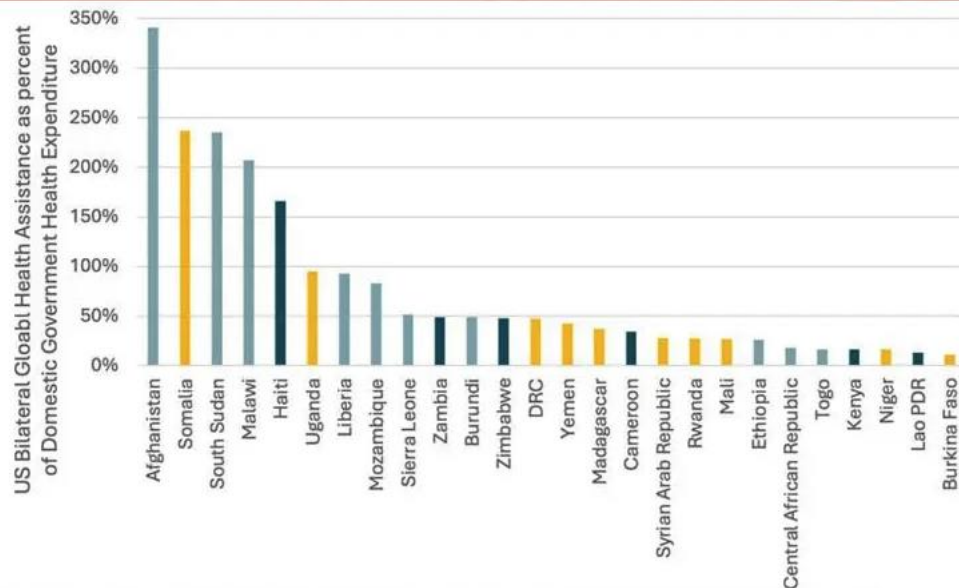


CQUIN's relevance and essential pivot

11/03/25

Human costs of US aid cuts laid bare as UK follows
<https://www.scidev.net/global/scidev-net-investigates/human-costs-of-us-aid-cuts-laid-bare-as-uk-follows/>

Twenty-six countries most vulnerable to US global health



KEY:

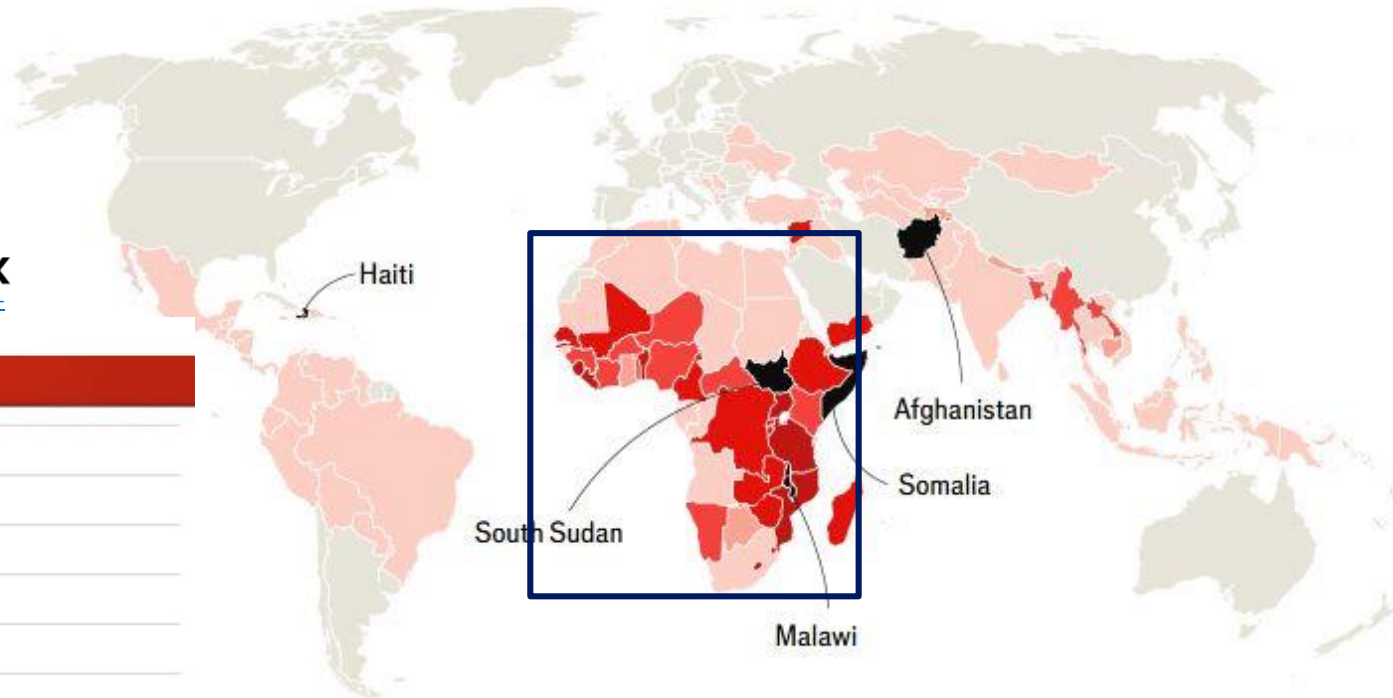
DRC = Democratic Republic of Congo; Lao PDR = Lao People's Democratic Republic
 Teal Grey = low-income country and in/at high risk of debt distress
 Yellow = low-income country, not at high risk of debt distress
 Teal = Lower-middle-income country in/at high risk of debt distress

Source: Center for Global Development

Big shoes to fill

<https://www.economist.com/graphic-detail/2025/03/11/which-countries-are-most-vulnerable-to-donald-trumps-aid-cuts>

US health aid as % of government health spending, 2022-23 average*



1	Afghanistan	341%	6	Uganda	95
2	Somalia	237	7	Liberia	93
3	South Sudan	235	8	Mozambique	83
4	Malawi	207	9	Tanzania	59
5	Haiti	166	10	Sierra Leone	52

*Government health spending data from 2022 only

Source: Centre for Global Development

WHAT IS THE IMPACT?

DIRECT & IMMEDIATE IMPACT ON PEOPLE LIVING WITH HIV

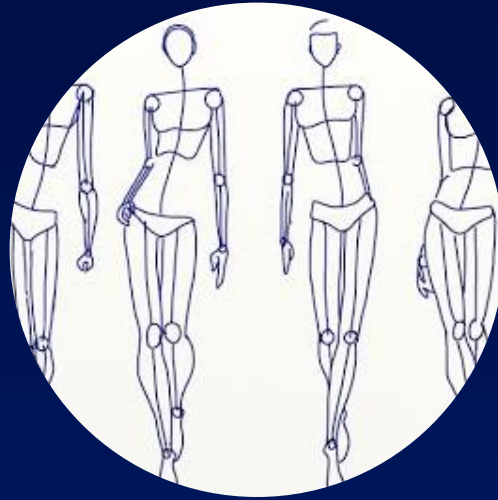


"THROWING THE BABY OUT WITH THE BATH WATER"

<https://wordhistories.net/2018/11/23/throw-baby-bathwater/>

- No PrEP services unless or pregnant or breast-feeding
- No viral load testing services
- No resistance testing
- ARV supplies restricted and spotty
- Closure of drop-in centers
- No outreach workers
- Closed data systems
- No funding for community-led interventions including CLM

**Years of gains
reversed overnight!**

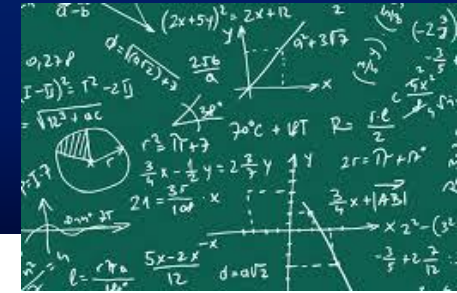


WHAT DO WE KNOW AND PREDICT?

Community Intelligence x National Data x Mathematical Models = WHOLE PICTURE



CLM & Predictive Models



Highlights from CAN rapid assessments & preliminary early warning CLM data

65% of countries reported significant **budget cuts** and major disruptions

78% of organizations reported **disruptions to CLM**

72% of organizations reported **disruptions in HIV treatment, care, prevention, service delivery services**

65% of organizations reported **disruptions in community systems strengthening, policy and advocacy initiatives**

100% of organizations reported a **neg impact on data management systems**

75% of organizations reported **operational disruptions and loss of staff**



ACCESS TO HIV TREATMENT

(Malawi)

“A client came to this facility for emergency supply. The client is originally from Mchinji but came to Dedza for a short visit. But because of the government directive in the circular we could not give him the emergency supply as he did not bring a transfer in. This was the most challenging thing for us, sending back a client when we had plenty of supplies.”

— HEALTHCARE WORKER, DEDZA, MALAWI,
27 FEBRUARY 2025

“For us, we want to be able to accommodate key population friendly services. We are preparing about four facilities to be able to have key pops coming into those facilities and getting services with the mainstream, but in a friendly environment.”

— DROP-IN CENTRE NURSE, MANGOCHI,
MALAWI, 27 FEBRUARY 2025

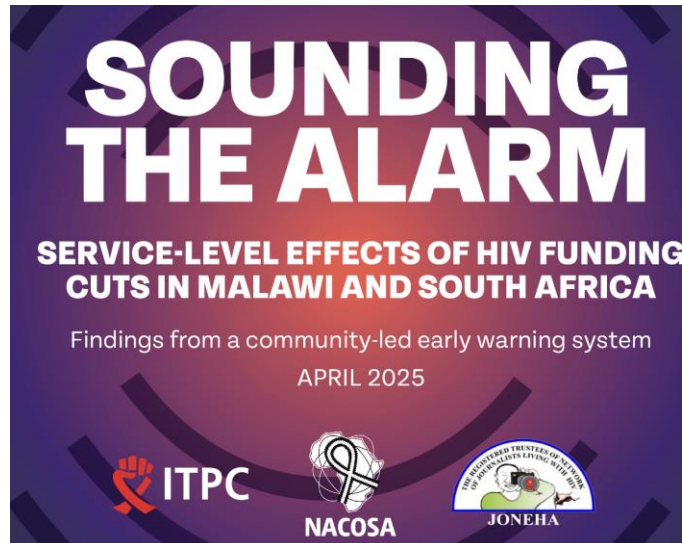
- **300,000 global deaths projected**—more than 200,000 among **children**—due to U.S. funding cuts, mainly from preventable causes like malnutrition, pneumonia, and HIV-related illness [2025, Brooke Nichols, Boston University]
- **South Africa could face 601,000 excess HIV deaths and 565,000 additional new infections** within a decade if PEPFAR is withdrawn abruptly [2025, Dr. Lind-Gail Bekker, The Guardian]
- The **HIV care continuum would deteriorate** from 95-85-90 to **92-73-88 in South Africa**, undermining decades of viral suppression progress. [2025, Reuters, Financial Times]
- **Viral load testing dropped by 21%** in South Africa post-cuts, **affecting early detection and treatment among pregnant women and youth** [2025 NICD South Africa]
- Across Africa, **up to 2.9 million additional HIV-related deaths** are predicted by 2030 **due to donor withdrawals** [2025 Lancet HIV model]
- Even a **90-day PEPFAR aid freeze** could cause **60,000–74,000 excess HIV deaths** in Eastern and Southern Africa alone [2025, PEPFAR and UNAIDS]

<https://www.imperial.ac.uk/news/162709/researchers-develop-more-reliable-method-working/>

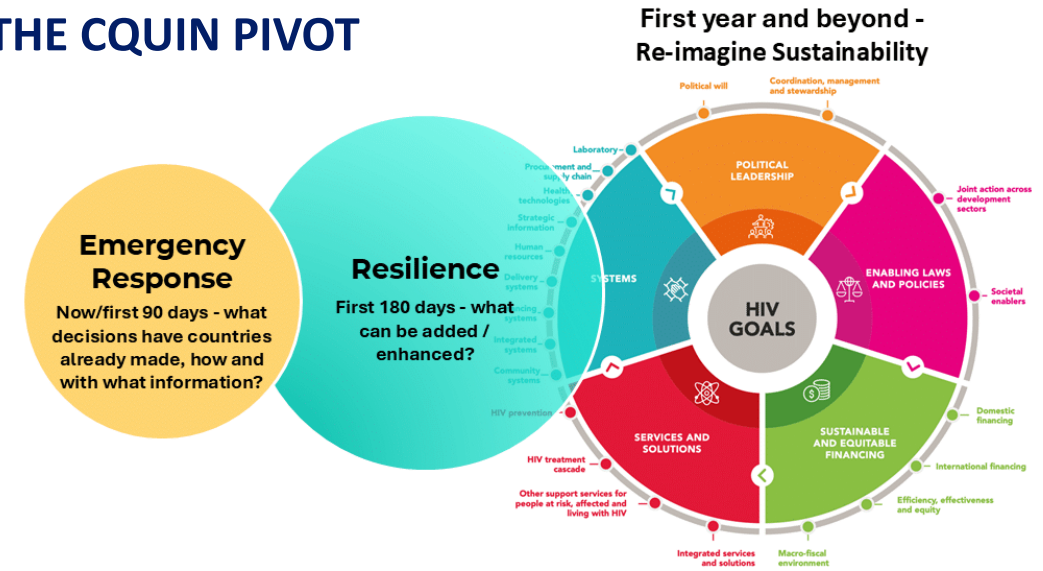


WHAT DO WE DO?

COMMUNITY RESILIENCE, INNOVATION AND ACTION



THE CQUIN PIVOT



COMMUNITIES:

- As first and early responders: communities on the frontlines for COVID-19, US Funding Stop Work Order & funding cuts
- Producing rapid data on impact: early warning community-led monitoring & response

WHAT COMMUNITIES ARE *actually* DOING ON THE GROUND?

- **Coordinating Crisis Response:** PLHIV networks are *convening multi-stakeholder meetings* with Ministries of Health, donors, and partners to coordinate responses and scenario planning.
- **Pushing for Policy Adjustments:** *Advocating for multi-month dispensing (MMD)* of ARVs and emergency mitigation measures from governments to *protect continuity of care*.
- **Real-Time CLM-Based Monitoring:** Using CLM *to track access disruptions and treatment gaps*, ensuring grounded, rapid visibility into what is collapsing.
- **Sustaining Treatment Literacy:** Delivering prevention and treatment *education to prevent disengagement* from care despite systemic breakdowns at facility and community levels.
- **Mobilizing Domestic Resources:** Advocating for *increased domestic HIV funding and local resource mobilization* to sustain programs—especially for commodities and HRH.
- **Expanding National & Global Partnerships:** *Communities are not isolating—they're organizing*. Across the CQUIN network and beyond, PLHIV and community-led organizations are **strategically expanding alliances**, not just within HIV, but across movements—health systems, climate justice, gender equity, and accountability.

Charting the HIV response in an increasingly fragmented, crisis-prone world



From **Stopgap** to **Systemic**

Moving beyond temporary fixes (like emergency ARV access) to structural reforms in supply chains, labs, governance, and data systems.



From **HIV-Centric** to **Health System-Wide**

Integrating HIV services **into routine, chronic care models**—not dismantling HIV responses, but leveraging their strengths for broader health gains.



From **Donor-Driven** to **Country-Owned**

Empowering Ministries of Health to lead, plan, and finance HIV programs as part of their national systems—with **community and civil society meaningfully at the table**.



From **Fragmented** to **Harmonized M&E**

Creating unified service quality assessment tools and guiding frameworks that work across diverse programs and contexts.



VISION FOR ENGAGING COMMUNITIES



VISION FOR COMMUNITY ENGAGEMENT

Anchored in inclusion and voice, the original vision focused on ensuring communities were *engaged partners* in program design, monitoring, and accountability—especially in the HIV response. It emphasized:

- **Community-led monitoring (CLM)** as a quality improvement and feedback mechanism.
- **Equity and access** for key populations and people living with HIV (PLHIV).
- **Strengthening community systems** to complement health systems.

CE was framed as a **strategic enabler**—important but often positioned as complementary to "core" systems like labs, supply chains, or data systems.



“Community engagement and community-led monitoring must be an integral part of our global response...not just a mere exercise.”

Anele Yawa, CAN SA

WHY WAS THE VISION STALLED?

- **Donor Convenience Often Drove Parallel Systems**

Vertical HIV programs, while effective in the short term, were often easier to fund, manage, and measure separately. This led to fragmentation—separate supply chains, data systems, even workforce streams.

- **Integration Was Talked About, But Not Urgent**

As long as external funding flowed, the pressure to structurally integrate HIV into national systems remained low. Integration was often framed as a long-term aspiration, not a present necessity.

- **Country Ownership Was Partial**

Despite rhetoric, many national programs remained donor-dependent—not just financially but in terms of agenda-setting, M&E frameworks, and implementation models.

- **Community Engagement Was Box-Checked, Not Power-Sharing**

While CE was recognized as valuable, it was often treated as advisory—not as a governing force with decision-making power or control over budgets, data, or program direction.



WHAT HAD HAPPENED
WAS...

STRATEGIC IMPLICATIONS

- The vision must evolve from “engagement” as a *method*...to “**community power**” as a *goal*.
- There is a growing need to **institutionalize** community roles within national health governance structures (e.g., through formal roles in accountability, co-creation, and resourcing).
- There’s an urgent call for **new financing models**—beyond U.S. government aid—including domestic resource mobilization, south-south cooperation, and alternative donor frameworks.

WHAT HAS CHANGED IN THE VISION?

1. **From Partnership to Defense:** Previously, community engagement was about *partnership*—now it’s about *survival and resistance*. Communities are mobilizing to protect hard-won gains in health, rights, and access as donor commitments erode. **Engagement is now a more political act.**
2. **From Consultation to Accountability Power:** Where community involvement used to be seen as an *input for programs*, it’s increasingly framed as a mechanism for **holding systems accountable**. Community-Led Monitoring (CLM), for instance, is not just a feedback tool—it’s becoming **a frontline defense** against collapsing service delivery.
3. **From Funded Voice to Unfunded Mandate:** As funding shrinks, especially for civil society, communities are asked to do *more with less*. This has created a paradox: expectations of engagement are growing (e.g., in policymaking, monitoring, response design), but the **resources to support it are vanishing.**





WHAT IS THE VISION FOR CE *Now*?

- **A Frontline Defense:** Communities are now the **early warning system** for collapse in service delivery (e.g., PrEP, viral load testing, resistance surveillance, DIC closures). CLM has shifted from “monitoring quality” to **sounding the alarm** on life-threatening disruptions.
- **An Innovation Engine:** In the absence of donor-led responses, communities are **driving adaptive, low-cost solutions**, from multi-month dispensing to decentralized service models.
- **A pillar of sustainability:** Integration efforts across CQUIN now emphasize not just merging services, but embedding **community structures into system architecture**, ensuring CE is not “tacked on” but **institutionalized**.

Community engagement can now be understood as a frontline force for accountability, innovation & sustainability—embedded within health systems as both an early warning system & as a driver of adaptive, community-led solutions.



COMMUNITY CAUTIONS

If this is the vision, what must follow?

- Community power must be **funded**, not just *praised*.
- Engagement must be **built into** systems—not *layered on top*.
- Accountability must be **bi-directional**—communities are not *just watchdogs*, they are *co-pilots*.



Thank You!



RELEVANT CITATIONS

Slide 2: OUR OPERATING CONTEXT

- **Microplastics**

<https://news.stanford.edu/stories/2025/01/what-s-the-deal-with-microplastics-the-material-that-never-goes-away>

- **I hate my X**

<https://timesofindia.indiatimes.com/world/us/trump-vs-musk-how-did-american-media-cover-breakup-check-major-headlines-/articleshow/121669671.cms>

- **Indo-Pakistan war**

<https://www.istockphoto.com/photos/india-pakistan-conflict>

- **War in Ukraine**

<https://www.bbc.com/news/articles/c0l0k4389g2o>

- **Drill baby drill**

<https://www.npr.org/2024/11/13/nx-s1-5181963/trump-promises-more-drilling-in-the-u-s-to-boost-fossil-fuel-production>

- **Access to clean water**

<https://www.wateraid.org/au/articles/wateraid-report-reveals-nations-with-lowest-access-to-water>

- **Bottom trawling**

https://only.one/explore?notify_error=Sorry,%20that%20page%20didn't%20exist

- **Tariffs**

<https://www.dailynews.com/2018/03/08/trumps-steel-tariffs-could-start-a-trade-war-political-cartoons/>

- **Drought**

<https://www.wfpusa.org/articles/countries-most-affected-by-climate-change/>

- **Gaza**

<https://www.cartooningforpeace.org/en/editos/111-days-of-war-between-israel-and-the-hamas/>

- **Wildfires**

<https://blog.worldweatheronline.com/usa/california-wildfires-2025-unprecedented-devastation-and-the-rising-threat/>

Slide 4: IMPACT ON GLOBAL PUBLIC HEALTH AND HIV RESPONSE

- **From the American People – USAID**

<https://issafrica.org/iss-today/data-modelling-reveals-the-heavy-toll-of-usaid-cuts-on-africa>

- **Dr. Tedros**

<https://news.un.org/en/story/2025/02/1160081>

- **WHO won't give up**

<https://www.facebook.com/dw.africa/posts/the-world-health-organization-who-acknowledged-the-us-freeze-on-foreign-aid-fund/1037116901785535/>

RELEVANT CITATIONS

Slide 7: WHAT DO WE KNOW AND PREDICT

- Models

<https://za.pinterest.com/pin/429249408207048273/>

Slide 8: PREDICTIVE MODELS

- Math on green board

<https://www.imperial.ac.uk/news/162709/researchers-develop-more-reliable-method-working/>

Slide 13: VISION

- Binoculars

https://www.flaticon.com/free-icon/binoculars_8241132

Slide 17: WHAT IS THE VISION FOR CE NOW?

- Caution

<https://www.freepik.com/free-photos-vectors/caution-symbol>

- Icing on the cake

<https://butternutbakeryblog.com/how-to-frost-a-cake/>