Build Resilient Communities

Community Data in Action: Community – Led Monitoring for Diagnostic & Laboratory services: Results from a pilot project in Burkina Faso, the Democratic Republic of Congo, and Sierra Leone in 2025

Pragashnee Murugan, ITPC

ITPC

UCOP+

NETHIPS Network of HIV Positives in Sierra Leone

RAME Réseau Accès aux Médicaments Essentiels

Welcome/Bienvenue/Bem-vindos

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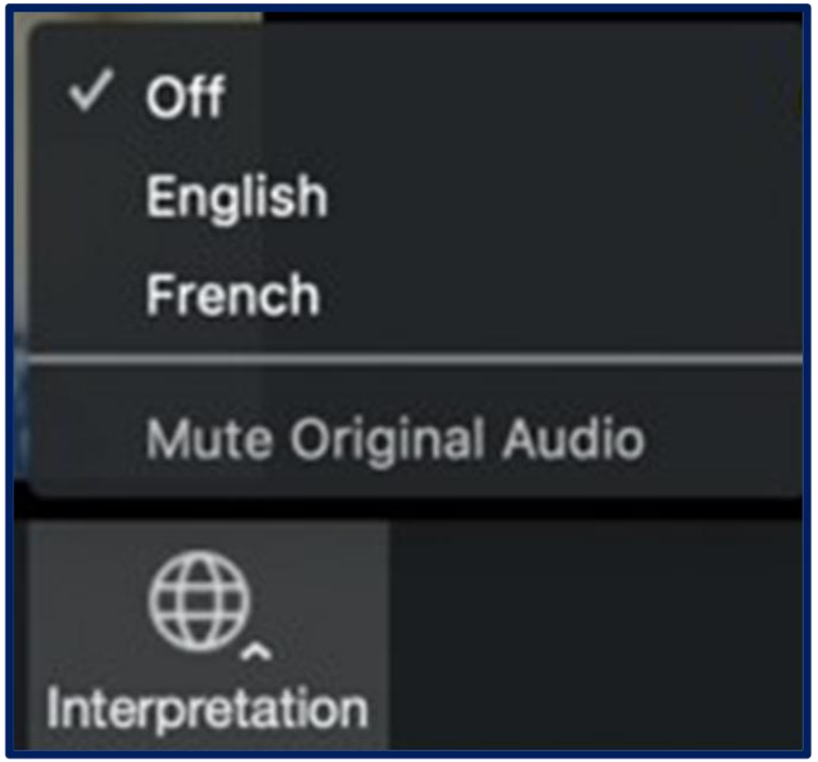

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Agenda

Time (EAT)	Session	Facilitator
4:00 – 4:05pm **(5 minutes)**	**Meeting Logistics & Introductions**	Pragashnee Murugan (ITPC)
4:05 – 4:15pm **(10 minutes)**	**Framing Remarks**	Nadia Rafif (ITPC) & Collins Otieno (ASLM)
4:15 – 4:35pm **(20 minutes)**	**WHO recommendations on diagnostics**	Tracy Swan (Clinical Advisor)
4:35 – 5:15pm **(40 minutes)**	**Case Studies: Country Findings** • Overall summary of findings • Insights from country partners -Country context -Key findings -Monitoring impact of funding cuts -Key takeaways	Pragashnee Murugan (ITPC) Ange Mavula UCOP+, DRC Christian Niessan RAME, Burkina Faso Martin Ellie NETHIPS, Sierra Leone
5:15 – 5:25pm **(10 minutes)**	**Q & A Discussion**	Participants
5:25 – 5:30pm	**Closing Reflections and Wrap up**	Nadia Rafif and Pragashnee Murugan (ITPC)

About ITPC & Our Partners

ITPC is an issue-based global organization working to achieve health and social justice for all through robust community engagement

OUR VISION

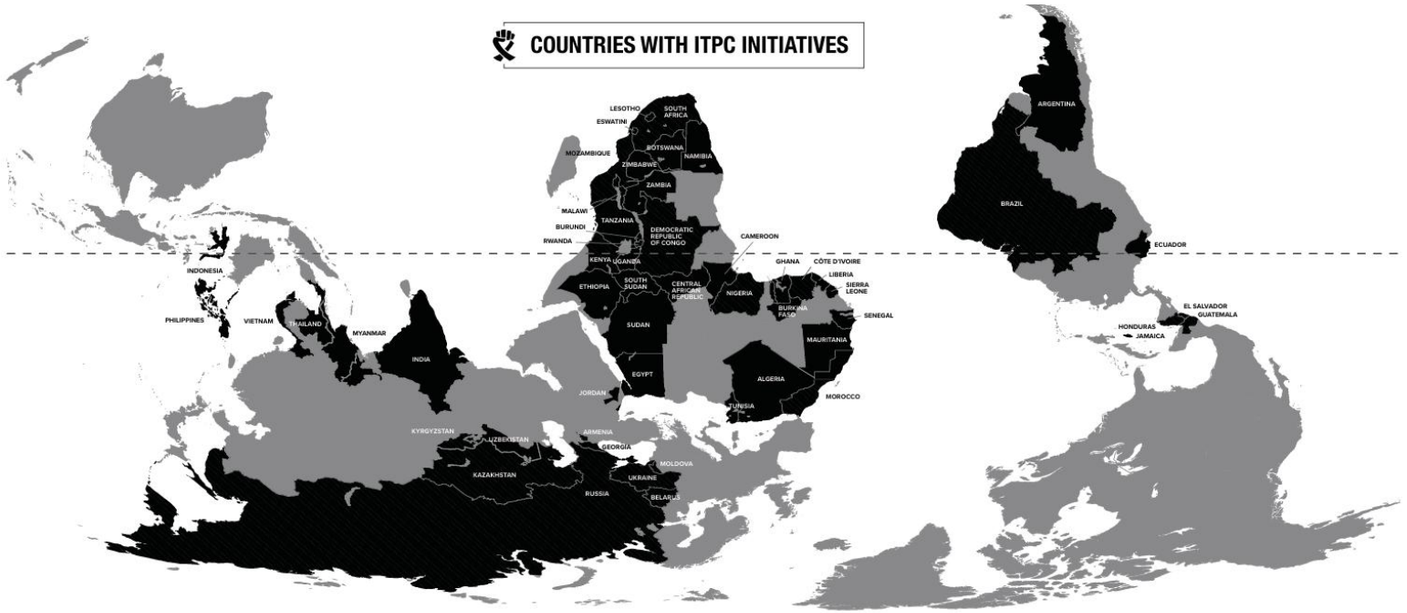
All people realize their right to a long, healthy and fulfilling life.

OUR MISSION

To achieve health and social justice through robust community engagement.

OUR VALUES

- Communities of people most affected by a particular issue are at the center of the response.
- We work in solidarity as a global movement.
- Equity and justice drive our solutions.
- We are transparent about our finances and how we work.
- We are accountable to communities.



ASLM
AFRICAN SOCIETY FOR LABORATORY MEDICINE

NETHIPS
Network of HIV Positives in Sierra Leone

UCOP+

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ITPC’s CLM defined:

ITPC’s CLM model: ***A science*-based accountability *innovation that puts “communities first”***

CLM is a process where communities take the lead to routinely monitor **issues that matter to them**

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Background

- Access to Viral Load (VL) testing and CD4 cell count is critical for people living with HIV (PLHIV) on antiretroviral treatment (ART).
- HIV-related diagnostics are essential for managing treatment and achieving positive health outcomes
- 2022 – Pilot Community – Led Monitoring (CLM) of routine viral load and CD4 cell count testing (Kenya and Sierra Leone)
- Purpose was to identify gaps in the availability of VL and CD4 testing, including adapting the CLM model to assess the impact of Covid-19
- Pilot project (2025) in CLM for diagnostic laboratory & laboratory services – (Burkina Faso, DRC, Sierra Leone) Continue addressing the gaps beyond the VL cascade and CD4 testing, include TB screening, adapt the CLM model to assess the impact of US funding cuts on HIV testing & Early Infant Diagnosis (EID)

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Objectives

Monitor availability and accessibility of **TB screening**, **HIV viral load** and **CD4 cell count testing**

Monitor availability and accessibility of **HIV self-testing** and **early infant diagnostics**

Demonstrate any **impact of the 2025 US funding cuts** on the provision of these services

Use the CLM data to **advocate for improved laboratory efficiencies**

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Methodology

- **Desk review and capacity – Review** of local framework and guidelines and capacity-building on HIV diagnostic informed the choice of indicators, co-developed by communities
- Trained **60 community data collectors** on the objective and use of the tool
- Roll - out in Sierra Leone (**NETHIPS**), Burkina Faso (**RAME**) and Democratic Republic of Congo (**UCOP+**)
- 34 health facilities monitored: 18 US funded 16 non - funded **Conducted 59 interviews with healthcare personnel** and feedback obtained from **481 Recipients of Care**
- Data collection between June-August 2025; information collected retrospectively for the **period of 1 July 2024 – 30 June 2025 – paper – based & electronic version (Alchemer)**
- **ITPC**, supported by **LabCoP** and **LabMap** initiatives by **ASLM**, provided the framework and guidance for the implementation of the pilot project

Snapshot of Tool

CLM for LABS indicator framework
Data collection period (TBC): 1st July-31st December 2024 and 1st January-30th June 2025

Area	Quantitative indicator	Baseline questions	Disaggregation	Data source
1. HIV testing	• # of HIV tests performed • # of HIV self-tests offered	• Do you offer HIV self-testing? • Do you perform confirmatory testing for people with a positive HIV self-test result? • Were there stockouts or shortages of HIV-related testing supplies, reagents, etc. during any of the reporting period? (if yes, details on item, duration and reasons) • Were any machines malfunctioning during the reporting period? (if yes, details on machine and time taken to repair) • What issues or challenges did you face while providing these testing services, and how can this site improve these testing services? • Has the US funding freeze and cuts impacted on the delivery of this test in your health facility? If so, please explain.	By age and gender	Health facilities records HCW interviews
	QUALITATIVE QUESTIONS • Why did you seek an HIV test? • How is HIV testing available in your area? (Public/private healthcare center, pharmacy, Drop-in Centres and/or other NGO-run sites, Mobile testing caravans/sites, through peer educators etc.) • Do you have access to HIV self-testing? • If you tested for HIV during the reporting period, what was the process to get the test (level of ease/difficulty for physical access to testing site, operating hours, clinic waiting times, welcoming/respectful and age/gender sensitive attitudes of health personnel free from stigma and discrimination)? • If you did do an HIV self-test during the reporting period, where do you go for the confirmatory test (same/other health facility)? • If you tested for HIV during the reporting period, what were costs associated with the confirmatory test? At the facility? Outside (e.g transport, other facility) • Overall, are you satisfied with the overall HIV testing experience?			RoC interviews/FGD
2. Early infant diagnosis	• # of infants born from HIV positive mothers • # of infants born from HIV positive mothers receiving POC NAT at 4-6 weeks from birth	• Do you offer POC NAT for infants? • When is POC NAT performed on infants? • Were there stockouts or shortages of early infant diagnosis testing supplies, materials reagents, etc. during any of the reporting period? (if yes, details on item, duration and reasons)	By gender	Health facilities records HCW interviews

Area	Quantitative indicator	Baseline questions	Disaggregation	Data source
4. CD4 cell count	• # of people eligible for a CD4 cell count at time of HIV diagnosis • # of people eligible for a CD4 cell count when re-entering HIV care • # of people eligible for a CD4 cell count as part of adherence counselling for unsuppressed VL • # of people who received a CD4 count at time of HIV diagnosis and received their results • # of people who received a CD4 count when re-entering care and received their results • # of people who received a CD4 count as part of adherence counselling for unsuppressed VL and received their results • # of people who had CD4 cell count below 200 cells/mm^3 • # of people who were given special care after CD4 test (CD4 cell count was <200 cells/mm^3)	• Do you provide POC CD4 count? • If not, how long do the results take? • When is CD4 cell count performed? • Do you explain why the test is being done, and what the results mean? • What is done if a person has a CD4 count below 200 cells/mm3? (adjustments to ART initiation/re-initiation, referral system for PLHIV with AHD etc.) • Were there stockouts or shortages of CD4 testing supplies, materials reagents, etc. during any of the reporting period? (if yes, details on item, duration and reasons) • Were any machines malfunctioning during the reporting period? (if yes, details on machine and time taken to repair) • What issues or challenges did you face while providing these testing services, and how can this site improve these testing services? • Has the US funding freeze and cuts impacted on the delivery of this test in your health facility? If so, please explain.	By age and gender	Health facilities records HCW interviews
	QUALITATIVE QUESTIONS • Have you ever had a CD4 cell count? If so, when? • Did anyone explain why the CD4 cell count was done? • What was the process to get the test (level of ease/difficulty)? • What were costs associated with the test? At the facility? Outside (e.g transport, other facility) • When was your most recent CD4 cell count? • If the most recent CD4 count was after January 2025, was there any change in this service compared to preceding years? Did you observe any adverse impact of the US funding freeze and cuts when doing your CD4 cell count? If yes, which ones? • How long did it take to get your result? • Did you get the test result during a separate visit or was it combined with another visit? • Did anyone explain what your result meant?			RoC interviews/FGD

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Using Community Data to drive Change

1. HIV TESTING
2. TB SCREENING
3. EARLY INFANT DIAGNOSIS
4. CD4 CELL COUNT
5. VIRAL LOAD TESTING
6. STOCKS OUTS AND EQUIPMENT MALFUNCTIONS

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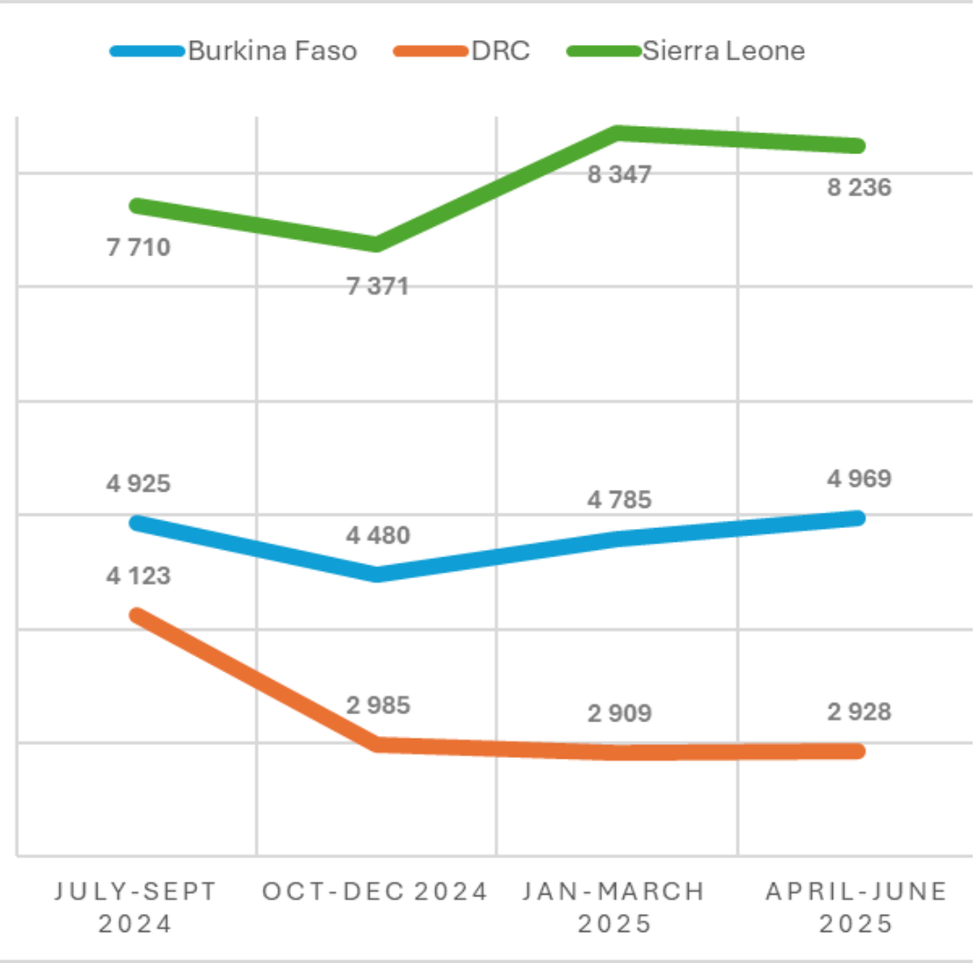
HIV testing



- 63,768 HIV tests were performed (Burkina Faso: 19,159; DRC: 12,945; Sierra Leone: 31,664
- Burkina Faso: 19,159 HIV tests
- DRC: 12,945 HIV tests 28% drop from 4,123 in July-September 2024 to 2,985 in October-December 2024
- Sierra Leone: 31,664 HIV tests

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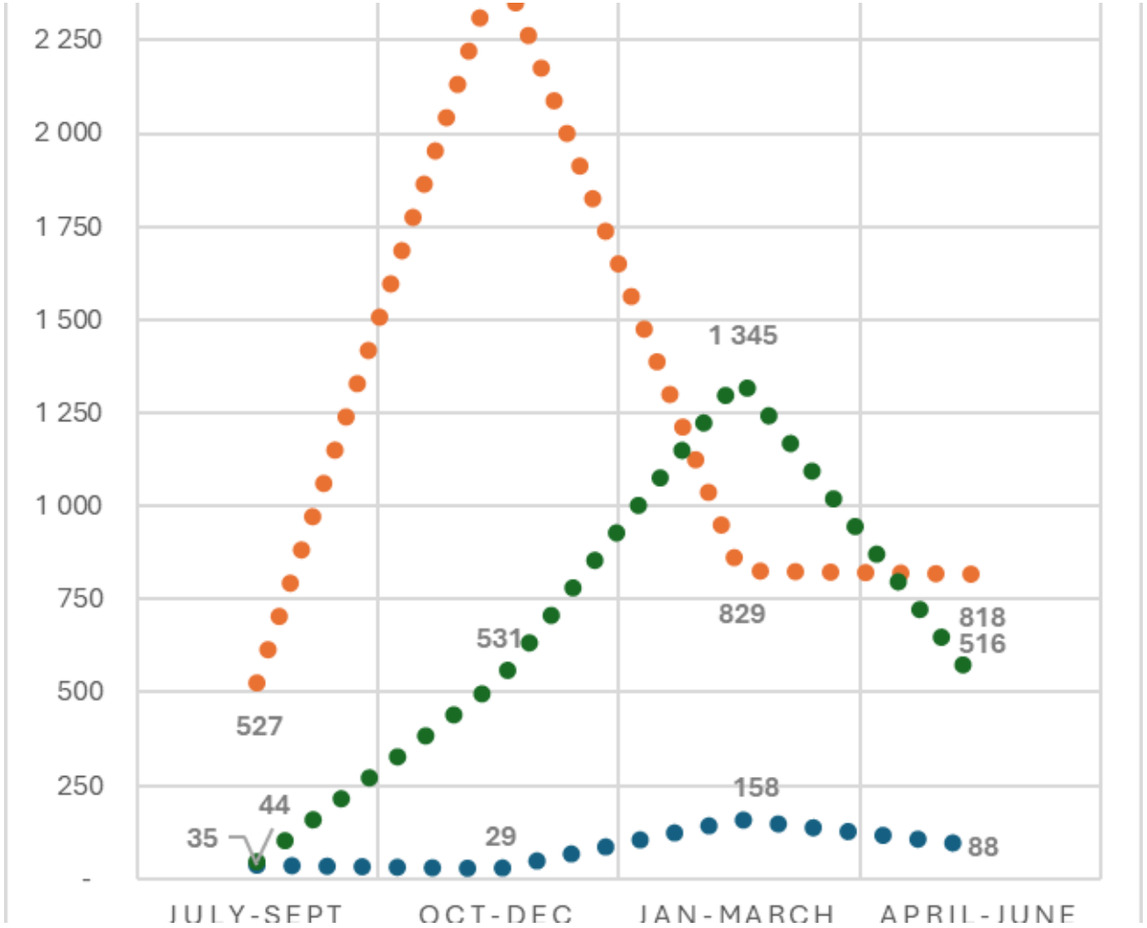
Self – Testing



- Low uptake of self – testing with a total of 7385 across 3 countries
- 42% (5/12) of the monitored health facilities in Burkina Faso, 50% (5/10) in the DRC, and 42% (5/12) in Sierra Leone do not offer HIV self-testing
- Barriers to self-testing: stockouts of self-test kits and a common perception that self-testing belongs exclusively under community outreach rather than under facility-based services.

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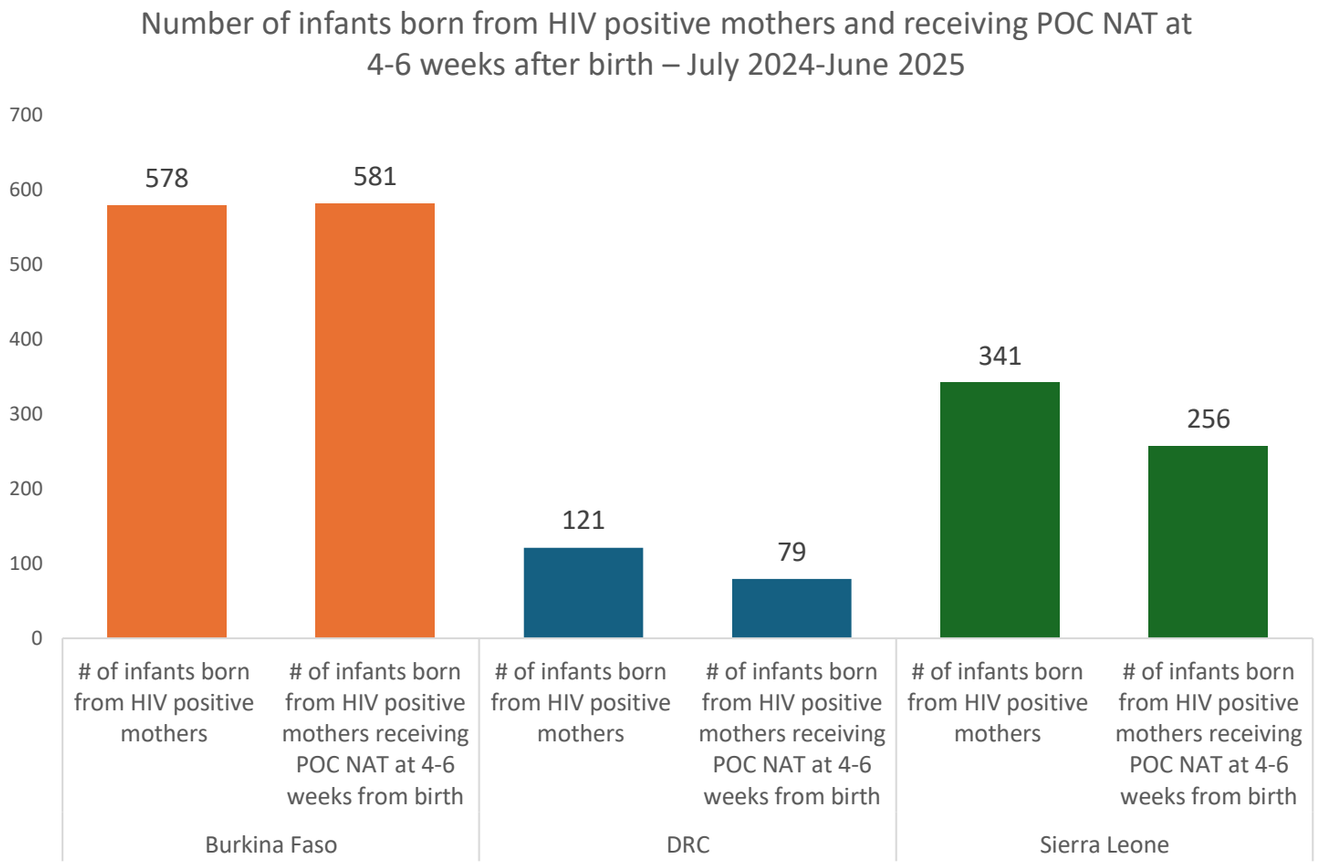
Early infant diagnosis – Nucleic Acidic Amplification (NAT) testing

- Differences in number of infants who received the NAT potentially due to infants born before or at the end of the reporting period
- All health sites in Sierra Leone and Burkina Faso declare performing POC NAT at birth, at first contact and/or between 4-6 weeks from birth, compared to 70% in DRC
- DRC ➜ US funding cuts have caused long-term stock outs of pediatric ARVs (Abacavir and Nevirapine)



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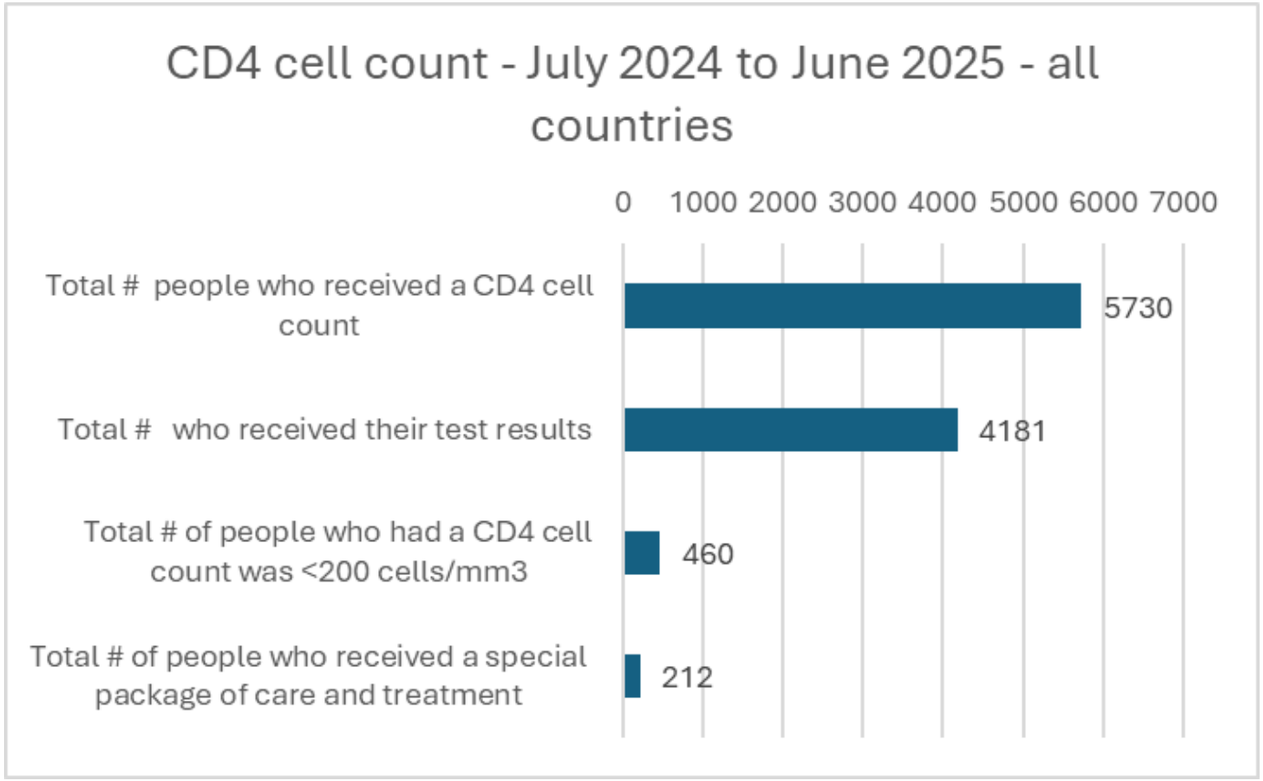
Overall Findings: CD4 Cell Count



- Across the 34 health facilities monitored, 65% (22/34) offer CD4 cell count testing, and 73% of them (16/22) have POC capacity
- Total of 5,730 CD4 cell count tests were performed over the reporting period across the three countries
- 4,181 RoCs (73%) received their test results; 460 RoCs (11%) had a CD4 cell count below 200 cells/mm³
- Of RoCs needing a special package of care and treatment, only 46% (212/460) received it

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Overall Findings: VL Testing

- Across all countries, 88% (30/34) of the monitored health facilities provide viral load monitoring
- All 12 health facilities in Burkina Faso and all 12 facilities in Sierra Leone provide viral load monitoring either on site or through sample referral systems
- In DRC, six of the 10 facilities assessed offer VL monitoring – five primary healthcare sites and one secondary district hospital

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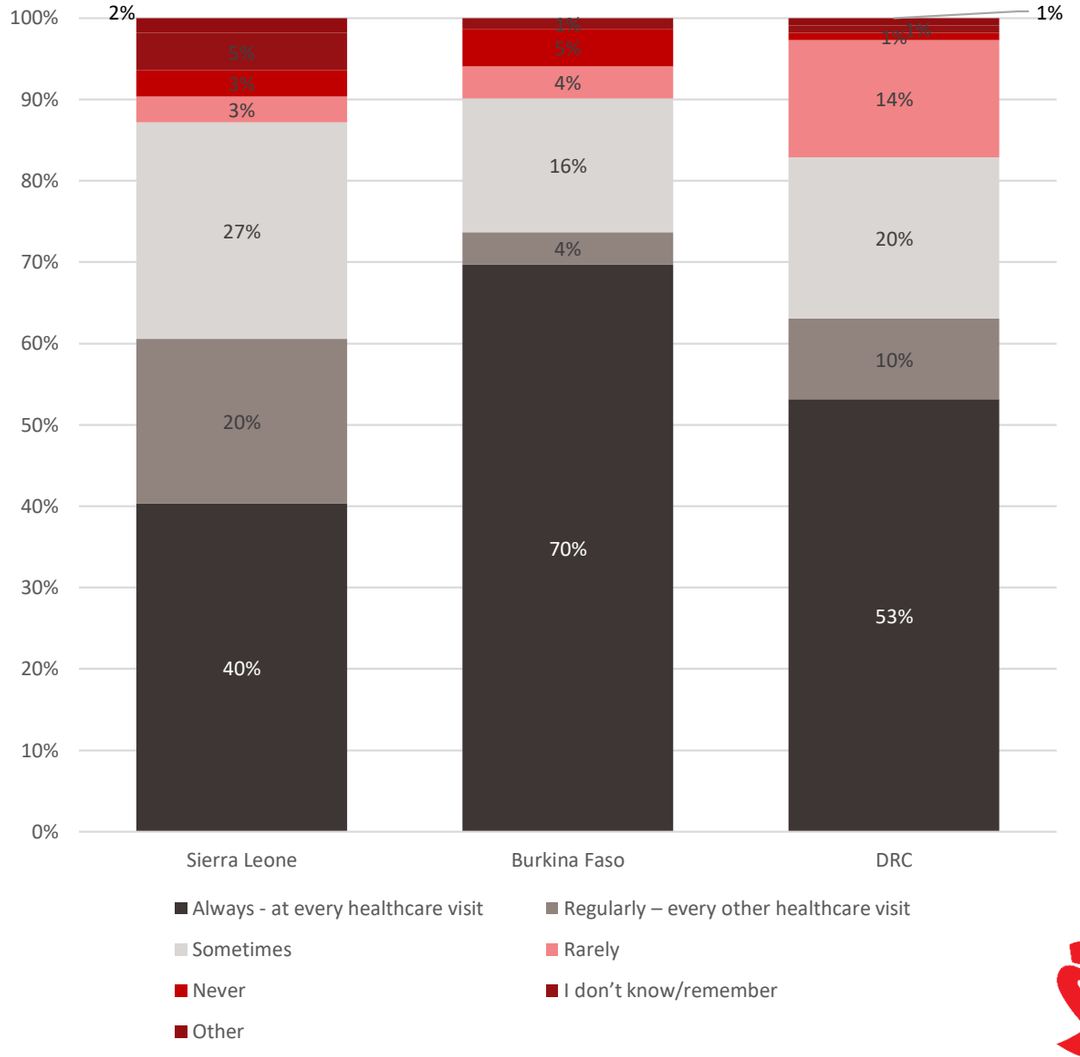
Tuberculosis (TB) screening

- 54% of RoC confirm that they are asked TB screening questions at every or every other healthcare visit – highest rates are in Burkina Faso (70%)
- 42% of respondents report that TB screening questions are never, rarely or only sometimes asked – highest rates are in DRC (45%) and Sierra Leone (53%)



Barriers: Stockouts and equipment malfunctions

Stockouts are systemic across the region, revealing fragile procurement and logistics systems

- **DRC** faces the most acute and prolonged supply gaps: structural failure of both Global Fund and PEPFAR distribution channels.
- **Burkina Faso** experiences recurrent reagent shortages and machine downtime due to administrative delays and incomplete supplies.
- **Sierra Leone** shows better continuity but remains vulnerable to procurement delays and machine failure

Country	Duration of stockouts	Underlying causes	Equipment malfunctions	Overall impact on services
Burkina Faso	Recurrent, localised shortages lasting 5 to 365 days	- National-level shortages and delayed procurement - Unfulfilled central orders - Slow administrative processes	- Frequent long breakdowns of COBAS and GeneXpert (up to 365 days) - Lack of maintenance, missing UPS, air-conditioning or memory cards	Moderate but multi-level disruption: EID and VL most affected; routine testing continued intermittently
DRC	Chronic, system-wide stockouts lasting up to 365 days in multiple facilities (both PEPFAR & GF-funded)	- Failure of national supply (PR/GF & PEPFAR) - Poor quantification and under-delivery - No district-level redistribution	PIMA CD4 non-functional since 2022 - No maintenance or replacement cartridges	Severe disruption: all HIV services (testing, EID, CD4, VL) affected; some sites without reagents all year
Sierra Leone	Repeated short stockouts (7-60 days) across public and US-funded hospitals	- No or delayed supply from central store - Under-supply to facilities	PIMA CD4 machine in Bo Hospital down for more than 1 year	Moderate disruption: HIV testing continuity maintained, but diagnostics and follow-up slowed

Achievements & reflections

1. EXAMPLES OF ADVOCACY ACHIEVEMENTS
2. REFLECTIONS ON THE IMPACT OF US FUNDING CUTS
3. NEXT STEPS

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Reflections & Recommendations

Reflections	Recommendations
2025 US funding cuts exposed donor dependence for core functions and exacerbated existing fragile procurement systems	Institutionalize national procurement budgets and mechanisms to reduce donor dependency
Stockouts and equipment malfunctions are the main disruptors of diagnostic and laboratory service continuity	Strengthen national supply chains and maintenance systems to end recurrent stockouts
Results of viral load monitoring are delayed and clinical management is weak	Strengthen viral load result management and clinical follow-up systems
Strengthen viral load result management and clinical follow-up systems	Reprioritize CD4 testing to strengthen advanced HIV disease management
Community-led monitoring revealed gaps across the diagnostic cascade that are not captured by routine national monitoring sys	Institutionalize CLM in national monitoring systems and ensure strong community engagement in the design, implementation, and monitoring of laboratory services

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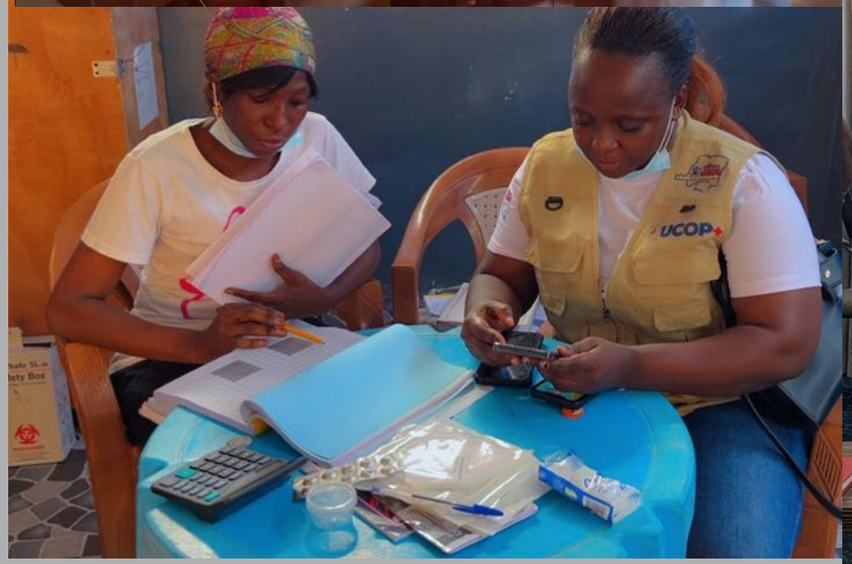
Thank you



[To know more: https://brc.itpcglobal.org/our-work/community-engagement/](https://brc.itpcglobal.org/our-work/community-engagement/)

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