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Community-led Monitoring: Learning from communities to improve service

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Monitoring for HIV Programs - Community-Led Monitoring in Kyrgyzstan

Presenter: Dina Masalimova
Organization: AFEW-Kyrgyzstan
Country: Kyrgyzstan



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Monitoring for HIV Programs (CLM in Kyrgyzstan)

AFEW-Kyrgyzstan

Dina Masalimova

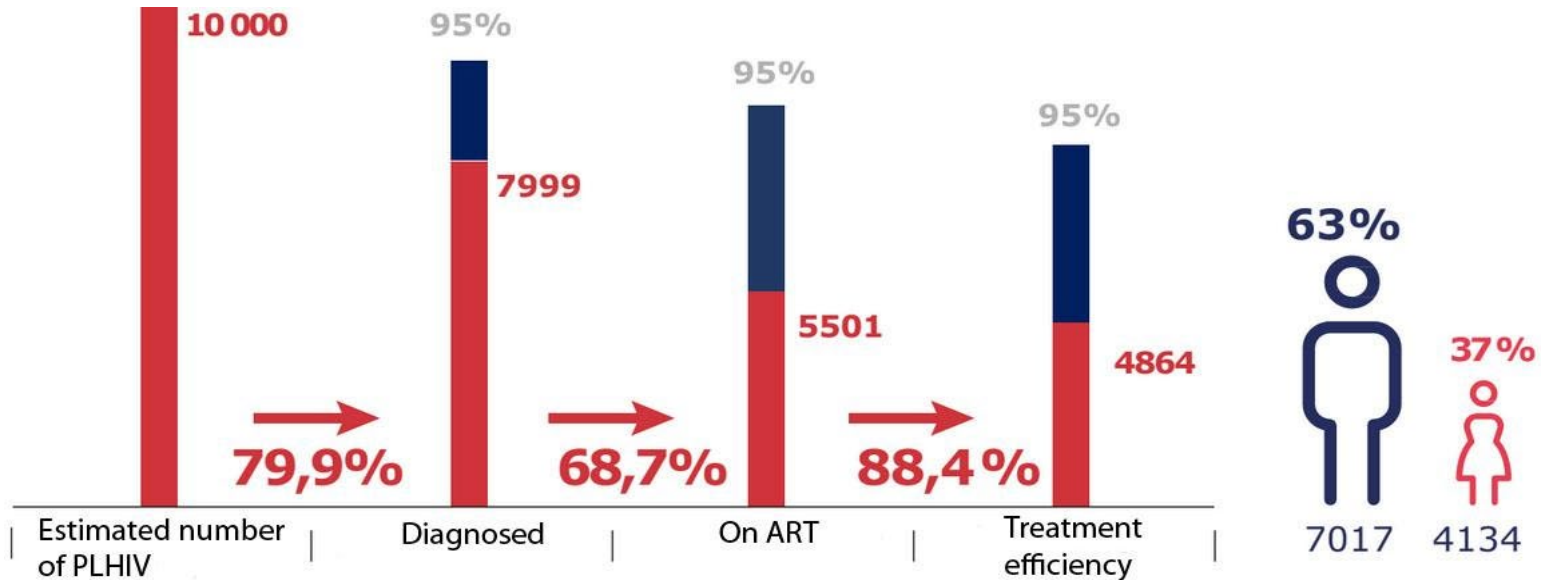


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Where we work?

Kyrgyzstan - Central Asian country with 7 mln population





Who are we?

- **CLM expert team:** 3 representatives of PLHIV, PWID and LGBT communities – data collection and analysis, drawing up reports and recommendations, communicating findings to the sites
- **AFEW-Kyrgyzstan** – technical support for the CLM team
- **Site level:** head of organization, project coordinator – recruiting of beneficiaries for monitoring visits, drawing up Action Plans for improving service delivery, implementation of Action Plans
- **Donor level:** EPIC, ICAP – technical support for the sites
- **National level:** reports are presented to the CCM



What are we doing?

- The first CLM Activity in Central Asia
- Timeline: October 2021 – September 2024
- Objective: to collect, analyze and utilize the community feedback on the “peer to peer” basis in order to improve access and quality of HIV services, as well as health outcomes in HIV service beneficiaries in Kyrgyzstan
- Project sites: PEPFAR-funded HIV service delivery sites: 4 sites (6 visits) in Y1, 6 sites (10 visits) in Y2 and Y3

What have we found?

Achievements

- Basic HIV services are highly accessible and acceptable;
- Key services are provided in accordance with the national standards;
- Level of beneficiary satisfaction with the PEPFAR-funded services is high;
- No interruption with supplies (condoms, lubes, ARVs and other medical items) were reported.

Gaps

- Low PreP awareness a both staff and beneficiaries, legal barriers to PreP access;
- Lack of social support and rights defending services to resolve complex problems of KPs;
- Gender issues: women are dependent on men who make decisions on their access to PreP, ART, and broader health issues;
- Migration: access to PreP, ART and other services for external migrants.



What are our guiding principles?

- Community-led at all stages;
- Quality data collection (in-depth interviews) at key areas of service delivery;
- Describing achievements and gaps fairly and objectively;
- “On the same side” with community sites: voicing their problems to the decision makers;
- No reports for the sake of reports.



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COMMUNITY-LED MONITORING: Community-Led Monitoring of HIV services in PEPFAR-supported sites in Burkina Faso

Presenter: Raga Valea
Organization: CORAB
Country: Burkina Faso



“Community monitoring of HIV services at PEPFAR-supported sites in Burkina Faso”

4th Annual USAID Global Health Local Partner Meeting: Panel on CLM



Presentation Plan

- I. **Brief overview of CORAB**
- II. **Introduction**
- III. **Methodology**
- IV. **Main activities**
- V. **Principles**
- VI. **How do we use CLM data to change your programs and make a national impact**
- VII. **Key findings**
- VIII. **Difficulties/Challenges**

I. Brief overview of CORAB

A coalition of Burkinabe Networks and Associations in the Fight against AIDS and the Promotion of Health abbreviated to CORAB.

Its Mission

Contribute to universal access to health care by promoting civil society leadership through active participation in national responses to major diseases.

Its Objectives :

- Strengthen advocacy and resource mobilization for health programs ;
- Capacities building of civil society organizations in the implementation of projects and programs integrating quality assurance standards ;
- Ensure the coordination of OSC interventions in the health sector;
- Promote good governance in the administration and management of resources.

Its geographical coverage

CORAB has coordination offices in the 13 administrative regions of the country.

II. Introduction

Community-Led Monitoring of services offered at sites supported by PEPFAR in Burkina is carried out by CORAB in Burkina Faso.

The implementation of the CLM-BF is justified by the observation of insufficiencies and the persistence of dysfunctions and barriers to access to HIV services despite the measures adopted and the means deployed by Burkina and its partners such as PEPFAR.

It aims at the efficient delivery of HIV services through the effective application of WHO recommendations and PEPFAR minimum requirements for access to HIV services ;

Ultimately, CLM-BF aims to increase access to quality health services for people living with HIV ;

III. Methodology



- The methodological approach consists of computerized data collection.
- It is done using a questionnaire on client satisfaction with the services offered by the health providers.
- Data collection is done through interviews with a sample of 5 clients per site and per quarter.
- The collected data are analyzed, processed, and documented.
- Corrective measures for identified barriers are proposed and submitted to the relevant sites for implementation.

IV. Main activities

- Meeting to present the project to the various stakeholders ;
- Training of officers on digital data collection using the Kobocollect application
- Data collection on client satisfaction,
 - ✓ stigma and discrimination cases,
 - ✓ gender-based violence ;
 - ✓ the elimination of formal and informal fees
 - ✓ the test and treat policy
 - ✓ the dispensing of ARVs for several months
 - ✓ The index testing application
- Organize quarterly mystery client surveys and client interviews to assess the availability, quality, and barriers to access to services;
- Monitor the implementation of index testing, including adverse effects at the site level
- Provide frequent updates to communities and other stakeholders on the results of the monitoring activities

Main activities 2/2

- Engage stakeholders to identify corrective actions ;
- Sensitize and educate clients and HIV service providers on recent HIV-related policy updates ;
- Translate existing policy guidance on HIV testing, treatment, and the prohibition of informal fees into local languages and easily accessible formats ;
- Advocate for increased domestic resources for HIV.

V. Principles

- Strengthening the meaningful engagement of populations and specific groups in decision-making forums ;
- Ensuring respect for Human Rights: the principle of non-discrimination, participation, gender equality, confidentiality, transparency and accountability, and sustainability of services ;
- The commitment of the actors to invest in the achievement of the objectives of improving the health and quality of life of the communities as stated in the ODDs, Universal Access, the PNDS, and the CSN-SIDA 2021-2025 ;
- Community activism built on a consensual approach to finding solutions involving all stakeholders through dialogue and consultation and not through unilateral denunciation or the use of aggressive means or approaches;
- The CLM-BF prohibits any unionist spirit in its actions and in its communication. It favors partnerships between the public sector and civil society in the quest for the well-being of the population. It is well aware that it is through complementarity and serenity that appropriate and sustainable solutions can be found to tackle the obstacles and concerns of vulnerable groups in accessing health services.
- The principles of equality and equity between field actors are sacred. They are the foundations of CLM-BF in all its actions.

VI. How do we use CLM data to modify your programs and have an impact at the national level?

- ✓ Call on decision-makers and stakeholders about the obstacles to the effectiveness of the rights of the populations and stigmatization and discrimination practices; gender-based violence ;
- ✓ Ensure citizen monitoring for the elimination of formal and informal fees in the provision of HIV-related services ;
- ✓ Provide strategic information to stakeholders for appropriate decision-making and ensure the monitoring and evaluation of corrective measures identified in the framework of the CLM-BF ;
- ✓ Propose solutions and undertake advocacy actions for the effectiveness of health rights for the population and particularly for specific groups ;
- ✓ Ensure the continuity of the proactive monitoring for the resolution of any conflict situation and violation of the rights to access to health;
- ✓ Extend the activities of the CLM-BF to the national level.



VII. Keyfindings

Cases of malfunction: Break in reagents (between April 2021 and March 2022) :

- 4 health service sites experienced a lack in testing reagents
- 4 sites experienced stock-out of ARVs during the indicated period
(CLM-BF Report: Routine data)

Elimination of formal and informal fees

- 11.15% of PLHIV interviewed stated that they had paid money for the services offered (CLM-BF Report: Client satisfaction survey)

Test and treat application

- 4% of people who tested positive for HIV were not immediately enrolled on ART (CLM-BF Report: Routine Data)

Index testing application

- 22/24 sites are implementing index testing
- 9% of new HIV cases did not benefit from index testing (CLM-BF Report : Client satisfaction survey)

Multi-month dispensing

- 39.8% of PLHIV interviewed stated that they receive ARVs for 3 months
- 47.8% of PLHIV interviewed stated that they were receiving ARVs for 6 months (*CLM-BF Report : Client satisfaction survey*)

Transition to TLD

All sites offer TLD to new HIV cases and gradually transfer cohort patients to TLD (*CLM-BF Report : Routine Data*)

Stigma and discrimination

- 4/339 PLHIV interviewed (1%) reported feeling stigmatized and/or discriminated against by health workers because of their HIV status (*CLM-BF N Report: Client Satisfaction Survey*)

Increased government resources for the fight against HIV

- 19% increase in national resources allocated to the fight against HIV (*Activities Report*)



VIII. Difficulties / Challenges

- Closure of health facilities in areas with high-security issues
- Inaccessibility of unsecured areas to conduct data collection monitoring and implement corrective measures
- Continuation of activities at high-security risk areas without endangering the lives of data collectors
- Expanded CLM-BF in FY22 to new security-challenged sites
- Scale up the CLM nationally in all health facilities to ensure that the population has access to quality health services in the current context,



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Community-Led Monitoring of HIV Services – Implementation Experience by NACOPHA in Tanzania

Presenter: Mathew Kawogo
Organization: NACOPHA
Country: Tanzania



NATIONAL COUNCIL OF PEOPLE LIVING WITH HIV IN TANZANIA

4th Annual USAID Global Health LOCAL PARTNER MEETING

*Nov 14 – 17, 2022
Johannesburg, South Africa*

Community -led Monitoring of HIV Services –
Implementation Experience by NACOPHA in Tanzania

Presented by Mathew Kawogo,



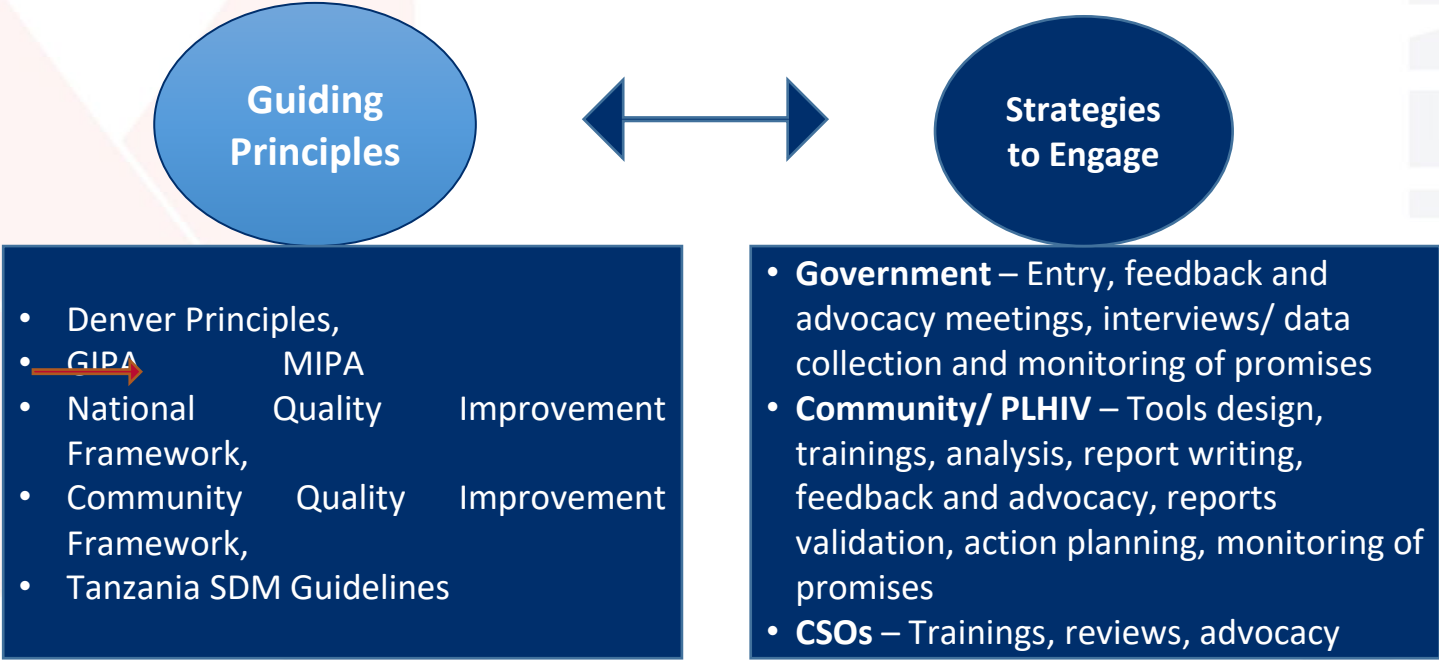
What is Community-Led Monitoring



- A service users'-centered monitoring approach that **seeks to improve access and quality services to PLHIVs**
- It is an **inclusive and systematic** approach whereby **service users take leadership** role in collecting data, providing feedback, and tracking HIV service provision and improvements
- A process that helps service users to **pinpoint** barriers to services, use evidence to engage with health service providers/ Government on **needed changes** to improve accountability and quality of HIV services
- Approach that helps service users to **monitor** the **5-As** (Availability, Accessibility, Acceptability, Affordability and Appropriateness)

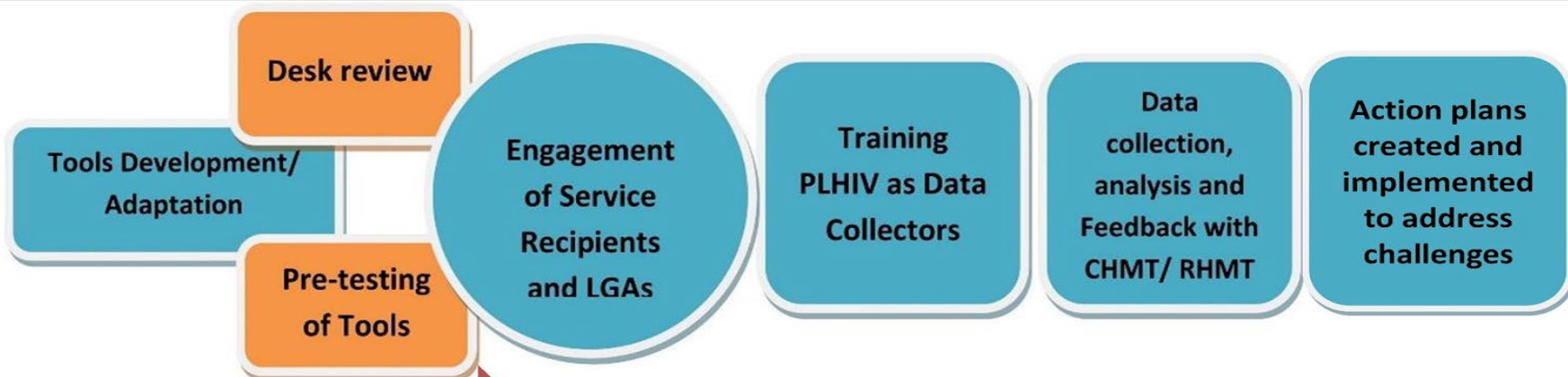
BACKGROUND AND SCOPE

- NACOPHA receives USAID/PEPFAR support to implement CLM in 65 councils through Hebu Tuyajenge Project



HEBU TUYAJENGE
TUFIKI 05-05-05

CLM METHODOLOGY



Questionnaire
for
"Community-led Monitoring"-
Service Recipients



Questionnaire for
"Community-led Monitoring" -
Health Facility Monitoring Tool



- KoboToolbox
- Excel

CLM Coverage todate

38

Number of district councils reached each with 5 wards

183

Number of health facilities reached todate

366

Number of health facility staff reached/ interviewed

380

Number of service recipients trained as service monitors

3,699

Number of service recipients interviewed

Piloted in 4 councils before scale up

Data collection, analysis and reports prepared in 34 scale up district councils

Feedback sessions conducted at district council levels, MoH and with PEPFAR

Monitoring of promised changes is ongoing in all 38 councils

SOME KEY FINDINGS AND ACTIONS

Service Area	Findings	Actions
Access to HTS	51% (n=2,984) access services within 2.5km 76% (n=1,134) accessing from facilities within their wards; 19% outside their wards 5% (n=1,134) from outreach	<ul style="list-style-type: none"> 3 facilities more facilities registered to provide CTC services; HTS outreach services established since Nov 2021
Availability, accessibility, and utilization of test and start services (ART initiation)	12.6% (n=2,904) reported challenges in ART uptake including side effects, ART stockout, long distance to facility, transport and unfriendly language from HWs.	<ul style="list-style-type: none"> Supportive supervision conducted by CHMT in 12 CTCs to mentor HCWs on stigma and discrimination
Prevention	18% of 69 facilities reported PrEP stock out during Nov 2021 – June 2022	<ul style="list-style-type: none"> Addressed following communication with MoH
Missed Appointments	21.81% (n=2,910) of recipients interviewed reported missed CTC appointments; due to travels/ moving to other areas and travel costs due to distance to facilities	<ul style="list-style-type: none"> Reminders are set through mobile texts and calls; Re-engagement through TAs and family treatment supporters
Turn-around time for HVL results	46% (n=2,749) of recipients interviewed received their HVL test results more than a month after testing	<ul style="list-style-type: none"> Follow up with facilities and HVL testing points; MoH in a process to convert existing 142 Gene Xpert machines to perform HVL test; 43
PLHIV less involved in feedback/ comments on service provision		<ul style="list-style-type: none"> 9 out of 10 facilities in Mbeya CC have set opinion boxes at CTCs level; and PLHIV involved in opening and reading

Plans to use CLM data

- Advocate for the integration of CLM data in the Tanzania Unified Community (data) System for wider impact and quality improvement
- Advocate for the review/ updating NQIF, CQIM and other national guidelines, strategies and plans
- Empower the community structures on evidence based advocacy
- Influence recognition and support to PLHIV who work closely with health facilities

GOING FORWARD – Tools review process





THANK YOU

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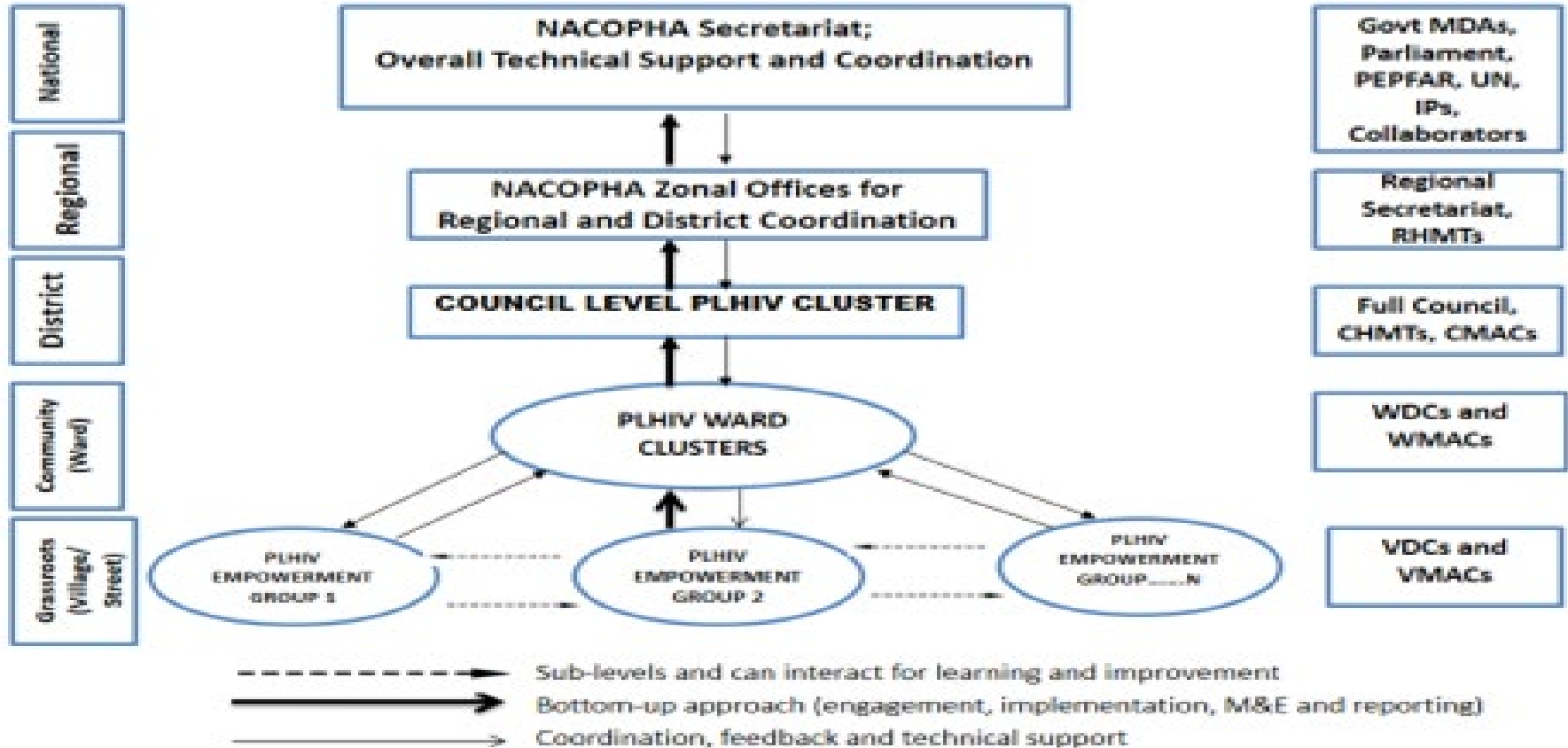
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CHALLENGE
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Strategic and Programmatic Focus

NACOPHA's five year Strategic Plan objectives, interventions and activities are ultimately focused to achieve the following 5 Strategic Result Areas (SRA):

1. Community Engagement and PLHIV Empowerment
2. Service Demand Creation and Retention
3. Advocacy and Policy Influencing
4. Strategic Information, Research and Communication
5. Organizational Strengthening

Our Approach to implementation of interventions and engagement



Key achievements by strategic areas

Area	Achievement
Capacity strengthening (Clusters and Secretariat)	<ul style="list-style-type: none">• Trained 1,675 Community Action Teams and 1,525 Treatment Advocates (TAs), 1,670 leaders of Cluster Coordination Teams, 4,572 PLHIV Support Groups leaders, 25 Master Trainers of Savings Groups• Improved Clusters management, governance , and coordination• Strengthened Financial and data management systems, digitalized data system• Implementation research – modeling community ART• Resources Mobilization ; Strategic plan review - 2012/2017 &2018/2023• Improved democracy through cluster elections and coordination of the Council (exponential growth in terms of coverage and membership)
Policy Influencing/ engagement	<ul style="list-style-type: none">• Active participation of f PLHIV /NACOPHA in the national reviews and development of policy, guidelines and strategies e.g NMSF-IV, HSHSP-IV, HIV management guidelines, HAPCA 2008 etc• Engaging PLHIV in the national dialogues forums- TNCM, JTWGs, NSAs• Engaging the Parliament in various key national TB and HIV priorities such as advocating for domestic financing for HIV and review of HAPCA 2008, participation of religious institutions, influencing age of Consent in 2019
Partnerships and collaboration	<ul style="list-style-type: none">• Enhanced collaboration, working relationships and support from the government (PM-Office, TACAIDS, PO-RALG, MoHCDGEC, etc)• Enhanced collaboration and engagement with other implementing partners

Where we want to go towards Epidemic control: 95 95 95 targets

- Investing more in community engagement with PLHIV and community structures
- Support improved coordination among implementing partners to engage PLHIV- working through NACOPHA structure-i.e PLHIV Clusters (acknowledging contribution of PLHIV where PEPFAR is supporting) and working as one constituency
- Continued support for collaboration with, Government , research institutions and implementing partners for learning, policy improvement and programming
- Support more CSOs in policy engagement for improved enabling environment

Opportunities for Future Engagement and Improvement

- Recognition and commitment for support from the Government, Members and leadership of the Parliament, Development partners (PEPFAR, UNAIDS, UNICEF, etc) and stakeholders.
- Existence of the Strategic plan and other operational strategic documents (e.g. Advocacy and communication strategy, resource mobilization and sustainability strategy etc.).
- Improved policy environment that provides PLHIV with recognition and space for engagement in the national HIV response.
- Strengthened capacity of PLHIV clusters to coordinate efforts of PLHIV at grassroots levels that can easily be tapped to complement the efforts to reach the community level beneficiaries.
- Committed staff and council leadership supporting cluster performance and mobilization of resources for sustainability.
- Extended geographical coverage of NACOPHA and grassroots reach to engage and serve more the PLHIV.

Potential areas for future improvement and growth

- Funding gap for enhanced capacity to support coordination and provision of technical assistance to PLHIV clusters
- Continue to address stigma and discrimination to increase access to HIV voluntary testing, disclosure, children identification, service uptake for prevention and treatment
- Low response from men, young people and children
- Demand creation not matching with available services at health facilities

Acknowledgement

- The Government of Tanzania (Prime Minister's Office, PO-RALG, TACAIDS, MOHs (NTLP and NACP), LGAs)
- The Parliament of Tanzania (High level leadership and Standing Committees)
- US Government (PEPFAR/USAID)
- UN Family (UNAIDS, UNICEF)
- Global Fund
- Other potential donors including AVAC, GNP+, TANROADS, etc
- Implementing partners – ICAP, FHI360, Pact Tanzania, AMREF, JHPIEGO, AGPAHE, EGPAF, KVP-led organizations, etc
- Networks of women and youth living with HIV

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