

# Recipient of Care Voices: Enhancing Satisfaction in HIV Services

A CQUIN Webinar: September 3, 2024



# House keeping

- 90-minute webinar with framing presentations followed by a panel discussion with Q&A
- Please type questions in the Q&A box located on the toolbar at the bottom of your screen
- If you would prefer to speak, please use the “raise hand” function on the toolbar and we will unmute you so that you have control of your microphone
- If you are a French or English speaker, please ask your question in your language of choice and the interpreters will translate as needed
- Slides and recording will be available on the CQUIN website ([www.cquin.icap.columbia.edu](http://www.cquin.icap.columbia.edu))



# Webinar Objectives



Enhance understanding of approaches to monitoring recipient of care satisfaction with a focus on best practices for data collection, analysis, and interpretation to drive program improvement.



Provide case study examples from diverse panel of experts for integrating recipient of care feedback into program planning and execution, with the goal of improving service delivery and client outcomes in HIV programs across diverse contexts.

# Agenda

## Framing Remarks

### Case Study Presentations:

1. Measuring Satisfaction to Improve NCD Integration in Zambia
2. Understanding Satisfaction with Services to Improve Quality in Nigeria
3. The Community Led Monitoring Approach

### Moderated Panel Discussion:

1. Patrick Akpan, Network of People Living with HIV, Nigeria
2. Eric M. Akoji MOH, Nigeria
3. Anthony Mutiti, ICAP Zambia
4. Adebola Adekogbe, CIHP Nigeria
5. Jelena Bozinovski, ITPC

# Framing Remarks

Onyekachi Ukaejiofo, MD

CQUIN Regional Clinical & QI Advisor ICAP in Nigeria





# CQUIN CoP Co-Created a Recipient of Care Satisfaction Toolkit in 2023

- In response to increasing requests from recipients of care, donors, MoH leaders, and other stakeholders, three of CQUIN's communities of practice (Quality Management, Community Engagement and Differentiated M&E), partnered with CQUIN's Community Advocacy Network to jointly identify resources and best practices related to recipient of care satisfaction (RCS).
- This collaborative process led to the development of an RCS toolkit which highlights key decisions related to RCS assessment and improvement and includes case study examples and resources for illustrative tools and methods.
- The RCS toolkit is designed to be a dynamic resource that evolves and expands over time.
- Please see the webinars recording here: <https://cquin.icap.columbia.edu/event/centering-recipients-of-care/>
- The RCS toolkit is available here: <https://cquin.icap.columbia.edu/cquin-resources/>



CQUIN  
RECIPIENT OF CARE  
SATISFACTION TOOLKIT

# Defining “satisfaction” within health care services

There is no gold standard definition of satisfaction within healthcare

- RCS is a measure of the extent to which an individual is content with the healthcare they received.
- RCS is a construct that is driven by an individual's expectations, perceived quality, and perceived value.
  - Satisfaction is the state of being content or fulfilled with a service or intervention based on one's needs and desires (Proctor, 2011; Giese and Cote, 2000; Rothschild, 2021).
  - It is a multidimensional and subjective concept – an emotional evaluation shaped by expectations and prior experiences (Batbaatar, Dorjdagva, Luvsannyam, and Amenta, 2015).

# Measurement Challenges

- The absence of an accepted definition of recipient of care satisfaction makes it challenging to assess
  - What is the standard for satisfaction? How is it defined? How is it measured?
  - Can subjective assessments be robust and valid?
  - Can recipients of care accurately assess the quality of the services they receive?
- Disagreements may arise when discussing ‘the who’ should be doing the measurement, where assessments should occur, how assessments should occur and what should be measured.
- A common approach is to identify *dimensions* of health services which are assumed to lead to satisfaction or its opposite



# Example: Dimensions of Satisfaction

Ng and Luk, 2019

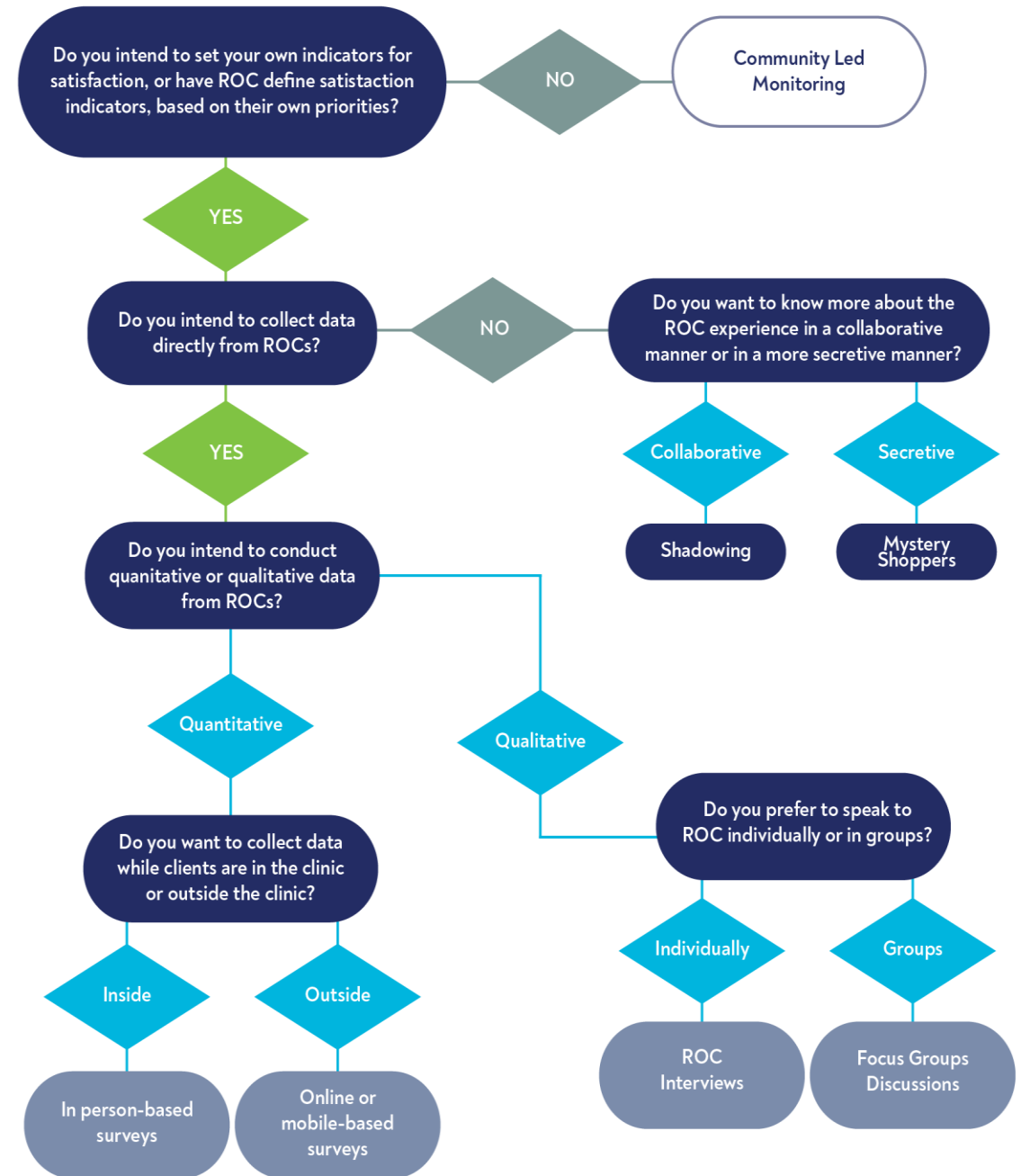
<b>Provider attitude</b>	Recipients of care were more satisfied when HCW were courteous, friendly, kind, and approachable, and when they delivered education and health information while demonstrating respect for their participation in the decision-making process.
<b>Technical competence</b>	Recipients of care tend to be more satisfied if they believe their care provider possesses technical competence and adheres to high standards of technical skill.
<b>Accessibility</b>	Facility cleanliness, comfort, and infrastructure correlated directly to recipient of care satisfaction. Apart from physical factors, process related issues such as waiting times for services was of critical importance.
<b>Efficiency</b>	Recipient of care satisfaction was more likely when they considered their treatment to be effective and their health improved.

## Considerations in selecting satisfaction dimensions:

- Need for both objective and subjective indicators
  - Objective: How long did you wait at the health facility today?
  - Subjective: Were you treated with respect by health facility staff?
- Usefulness of both quantitative and qualitative data
- Importance of matching the assessment strategy to the context
  - In some settings, only limited data collection is feasible
  - In others, more robust triangulation can be conducted

# Key Decisions for RCS Strategic Planning

<b>The Who?</b>	Are you interested in assessing satisfaction from recipients of care themselves – directly, or from alternative methods that include observation from inside the service delivery side?
<b>The What?</b>	Does the study team aim to develop their own indicators for assessment or engaging with recipients of care themselves to develop indicators?  What type of data does the team seek to have- qualitative (richer and more complex) data or quantitative (quicker and more simplistic) data?
<b>The When?</b>	<i>When would the team seek to elicit data from recipients of care? (i.e. Immediate post visit)</i>
<b>The Where?</b>	Where would the team seek to elicit data from recipients of care? (ie paper survey form, electronically)



# Various approaches to data collection for assessment



## Quantitative approaches:

- Feedback boxes
- Paper-based surveys
- Electronic/online surveys
- Phone/SMS-based surveys



## Qualitative approaches:

- Exit interviews
- In depth interviews (in-person or telephone based)
- Focus group discussions



## Approaches that can be either quantitative or qualitative (mixed methods):

- Community led monitoring
- Direct observation through recipient of care shadowing
- Direct observations using “secret shoppers”

## Recommendations for ensuring that results are linked to action and improvement

- As health planners design, implement and evaluate HIV program improvement interventions, using the RCS lens can lead to a more inclusive and comprehensive approach.
- Meaningful engagement with established networks of recipients of care is vital at all stages of the process
- Use of human centered design approaches in planning services is showing promise in creating systems and services that are more acceptable
- Evidence points to the importance of embedding RCS assessment into national quality management and M&E policies and platforms.
- Quality improvement methods and tools can drive implementation of locally appropriate solutions at health facility levels.



# Using Client Feedback to Improve NCD Integration in Zambia

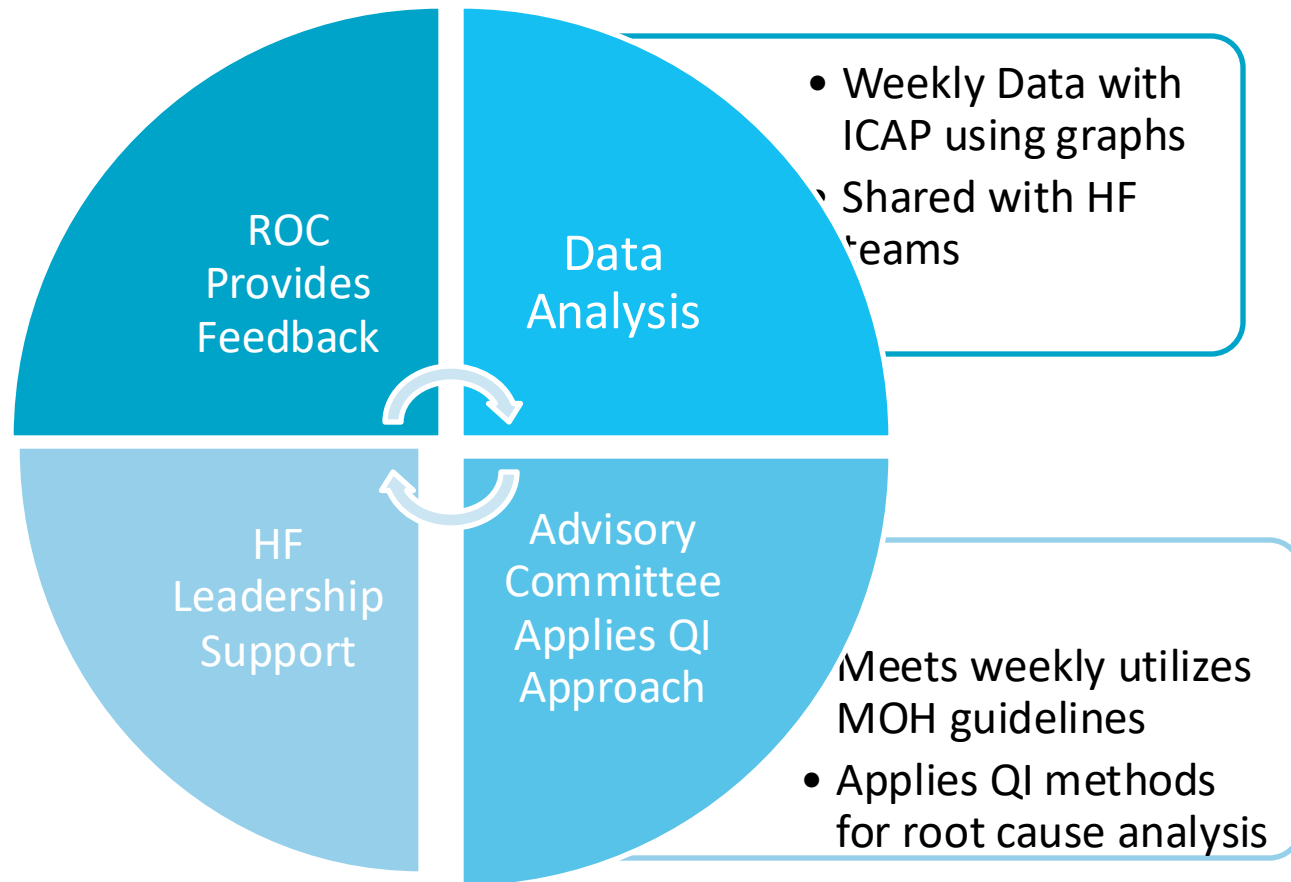
Anthony Mutiti, M.D.  
ICAP Zambia



# Recipient of Care Satisfaction and Feedback Programs Background in Zambia

- The Ministry of Health(MoH) in Zambia strives to ensure continuous improvement in health services.
- Client feedback is one of the tools used to improve performance and minimize treatment interruption among ROC.
- Multiple client feedback tools in Zambia have included self-assessments, suggestion boxes, grievance desks, and recently, in 2023, a structured client satisfaction tool.
- To augment existing tools and improve feedback utilization, ICAP in Zambia introduced a customer feedback kiosks program using electronic tablets for ROC receiving HIV services at three health facilities: **Kaoma District Hospital, Mulambwa Clinic, and Senanga General Hospital**
- At the end of an appointment for integrated NCD and HIV services, each ROC is encouraged to give feedback about their service by responding to a set of questions on the self-service tablet at the kiosk.

# Client Feedback Program Approach



- Improvement in service delivery at facility benefits the ROC as they receive quality service, ensuring client satisfaction.
- Facility able to lobby for resources from the Ministry and IPs using data driven feedback from ROC.
- The feedback program will be reviewed continuously to ensure continuous quality improvement in service delivery.

# Client Feedback Methods

- Questions are available in both English and local languages (Lozi and Tonga).
- Questions were developed using an ICAP baseline assessment with facility staff and ROC stakeholders.
- No identifiers are required and only the ROC is allowed at the Kiosk.
- 4-6 questions with multiple choice response options, there are no free text options.
- Feedback is confidential, anonymous, and immediately uploaded on a web-based database.
- Only designated ICAP staff access the back-end to retrieve and analyse feedback to produce monthly aggregated results shared with the facility teams.

## Examples of Questions

- How was the service you received today? *Good, Fair & Poor* ,
- Was your BP checked today? Y/N
- What did the health care worker say about your BP?
- Did the health care worker counsel you about your BP? Y/N
- What would you like the facility to improve on? (*waiting time, IEC materials, health messages*)

# Customer Feedback and Quality Improvement

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Every Friday, health facility staff, led by the ART in-charge, review client feedback data and discuss action to be taken.

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The health facility staff and QI teams have started integrating feedback from ROC into overall hospital quality management programs.

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ROCs indicated the need for more medical supplies in the facility.

The HF management applied QI methods in collaboration of the MoH and IPs to the strengthen of the commodity supply unit.

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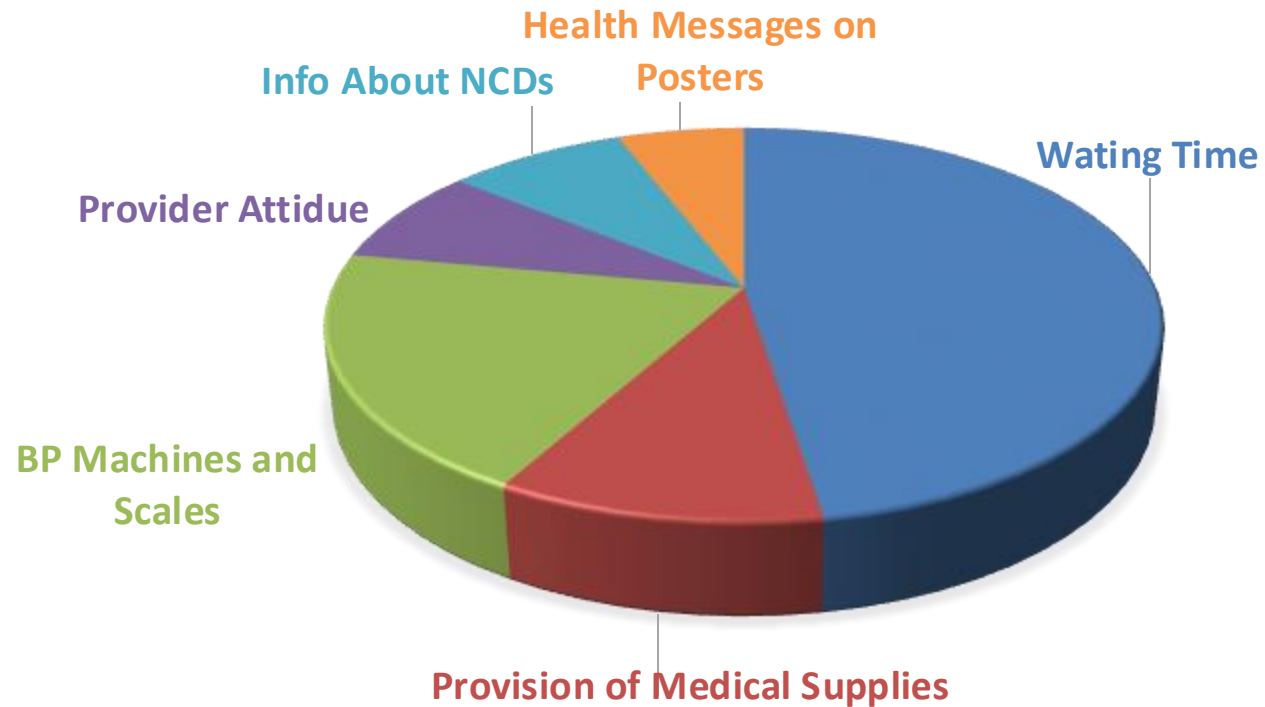
ROCs feedback included a demand for more IEC materials regarding NCDs.

The MoH and ICAP Zambia has developed and provided NCD IEC materials and have distributed at a number of health facilities



# Example of Customer Feedback at Kaoma District Hospital February to June 2024 Responses (n=440)

## What can the health facility improve?





## Taking action on Feedback Data at Koama District Hospital

- Results from the feedback indicated a need for more health education on NCDs, and BP machines, scales, and charts and reduction in waiting time.
- Subsequently the facility
  - Increased the content of NCD information in the daily health talks.
  - Sourced and placed additional IEC posters NCD.
  - Acquired additional BP machines, weighing machines, and BMI charts.
  - Consolidated enrolment of ROCs in DSD models as a way of reducing waiting time.

# Summary of Data at 3 Health Facilities January to June 2024

## **Total Feedback Entries:**

Approximately 1,200 respondents for each facility and 2,707 total for all three facilities

**Service Feedback:** 95% rated the service as "Good."

**Gender Distribution:** 68% of respondents are female.

**Age Range Distribution:** 91.5% of respondents are "25 and above."

## **Blood Pressure (BP) Check:**

- 97% reported that their BP was checked.
- 89.6% received a "Normal" BP result.
- 92.3% were counseled about their BP.

## **Weight Check:**

- 98.2% had their weight checked.
- 48.1% received "Normal" feedback regarding their weight.

## **NCD Counseling:**

- 92% received counseling related to NCDs.

# Way Forward

- The MoH, Provincial Health teams, and HF staff will continue to monitor feedback data monthly and apply QI as needed.
- Data will help support design and planning for integration of HIV services.
- Planning for wider scale up and spread to additional facilities.



HIV Learning Network

The CQUIN Project for Differentiated Service Delivery

Thank you.



Thank you!





# Nigeria

**Adebola Adekogbe**

**Senior Manager for SI & Quality  
Improvement**

**Center for Integrated Health Programs  
Nigeria**



# Case Study Presentation Outline

## Background and Context

## Methodology

## Survey Criteria/Timeline

## Findings

- *Sociodemographic Profile*
- *Access to care*
- *Healthcare provider communication*
- *Perception about quality of care*
- *Overall satisfaction with quality of care*

## Challenges

## Best practices

## Recommendation

# Background and Context

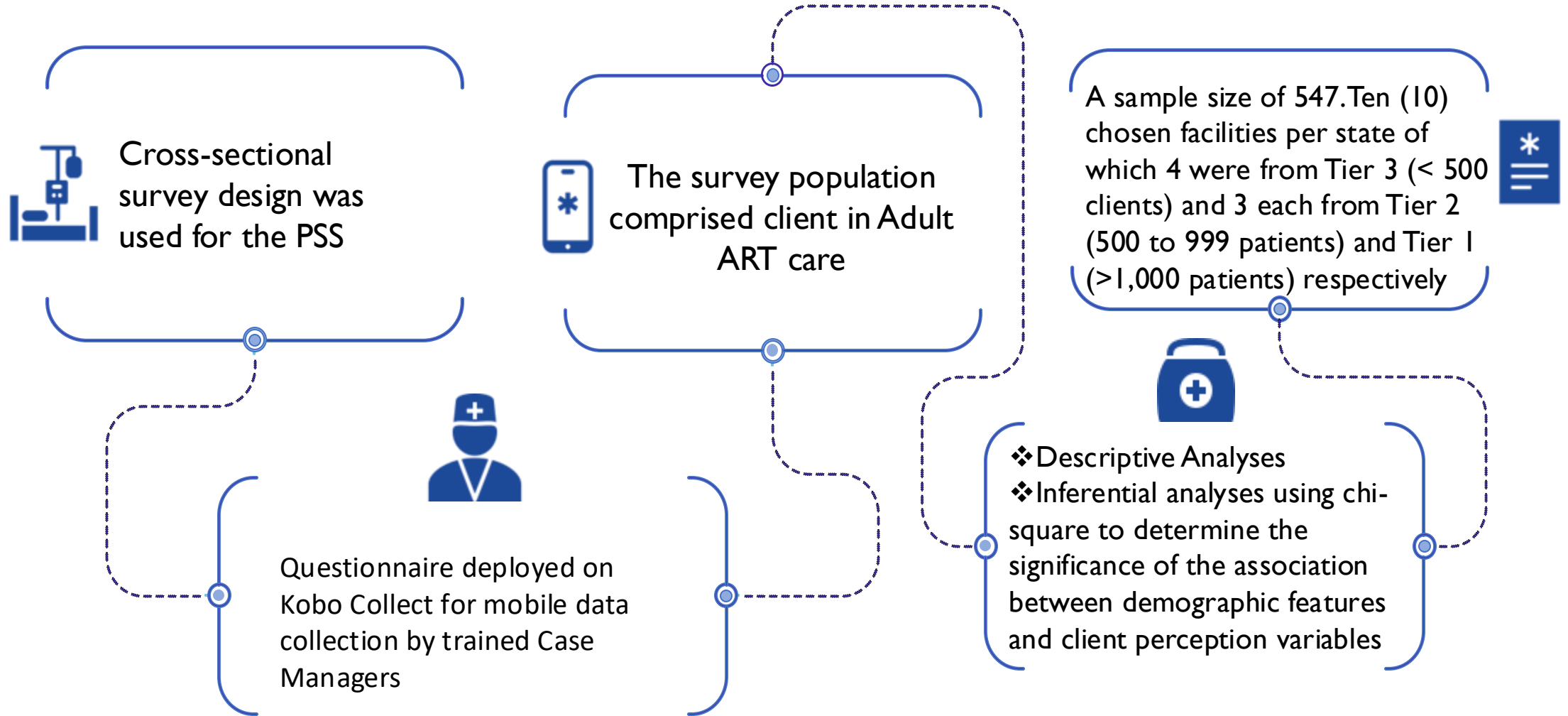
- ✓ Nigeria's progress towards 95-95-95 by the end of 2023 is **87-97-96**
- ✓ Centre for Integrated Health Programs (CIHP) is a leading Indigenous non-governmental organization, promoting better health outcomes for all Nigerians
- ✓ With funding from PEPFAR, CDC, CIHP implements the Innovate, Recalibrate, Integrate and Surge to Build Resilient Systems for Sustained HIV Epidemic Control (IRIS) Project in four states in Nigeria: Gombe, Kaduna, Kogi & Lagos
- ✓ A total of 167,195 PLHIV were on ART persons under the IRIS project across Lagos, Gombe, Kaduna, and Kogi states at the end of December 2023.
- ✓ Majority 84% (140,387) were at least 20 years old

- ✓ The patient satisfaction survey (PSS) was conducted to gather feedback on clients' experiences, such as access to care, providers' communication and quality.
- ✓ Understanding these elements will allow service provision to be tailored to the needs of clients more effectively

## **The objectives of the PSS were:**

- ✓ To assess satisfaction with Adult ART services.
- ✓ To identify areas of concern to improve the quality of services provided to clients at the facility
- ✓ To use the findings from the survey to improve overall program implementation

# Methodology



# Methodology

The following were excluded from the survey:

All clients who were less than 20 years of age.

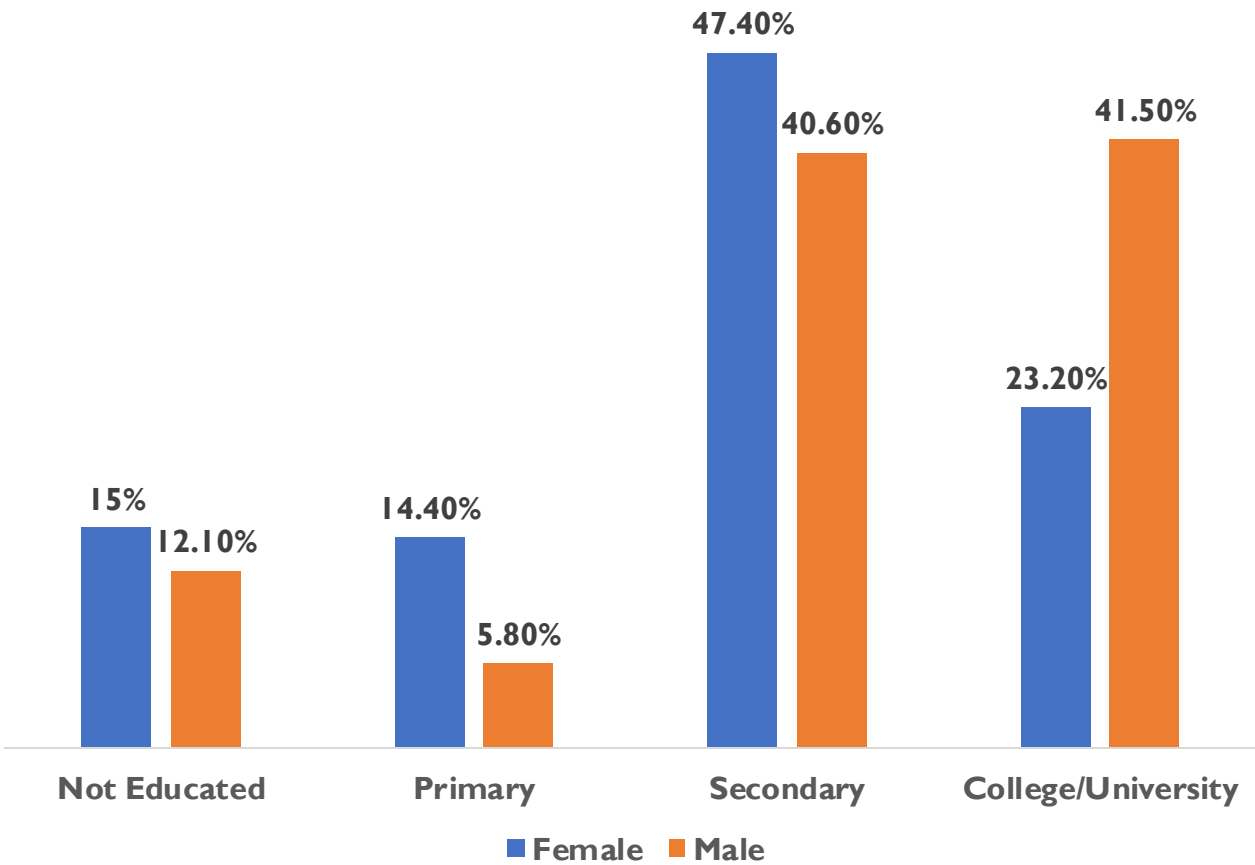
All clients 20 years and above who started treatment after December 31, 2023

- PSS data was collected for 2 weeks from May 7-22, 2024  
- ART clients attending HFs for services were targeted

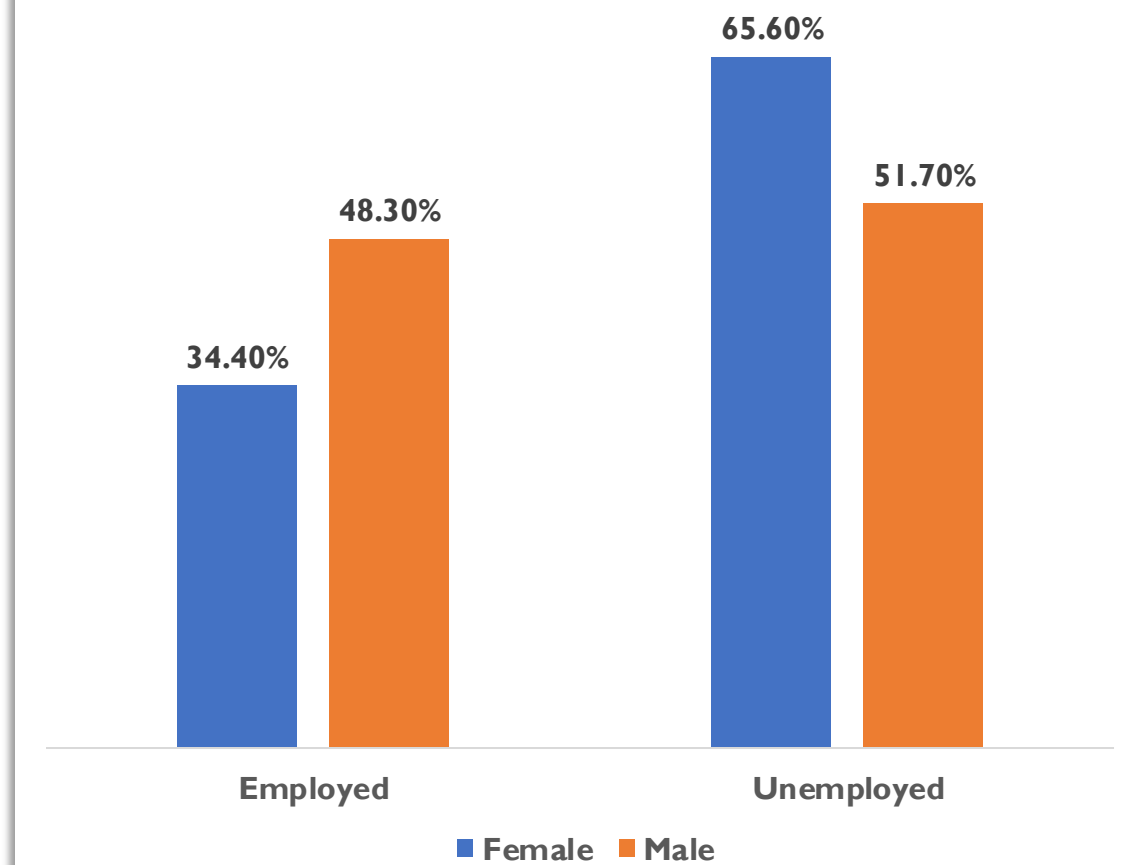


# Socio-Demographic Profile of Survey Participants

### Educational Status and Sex

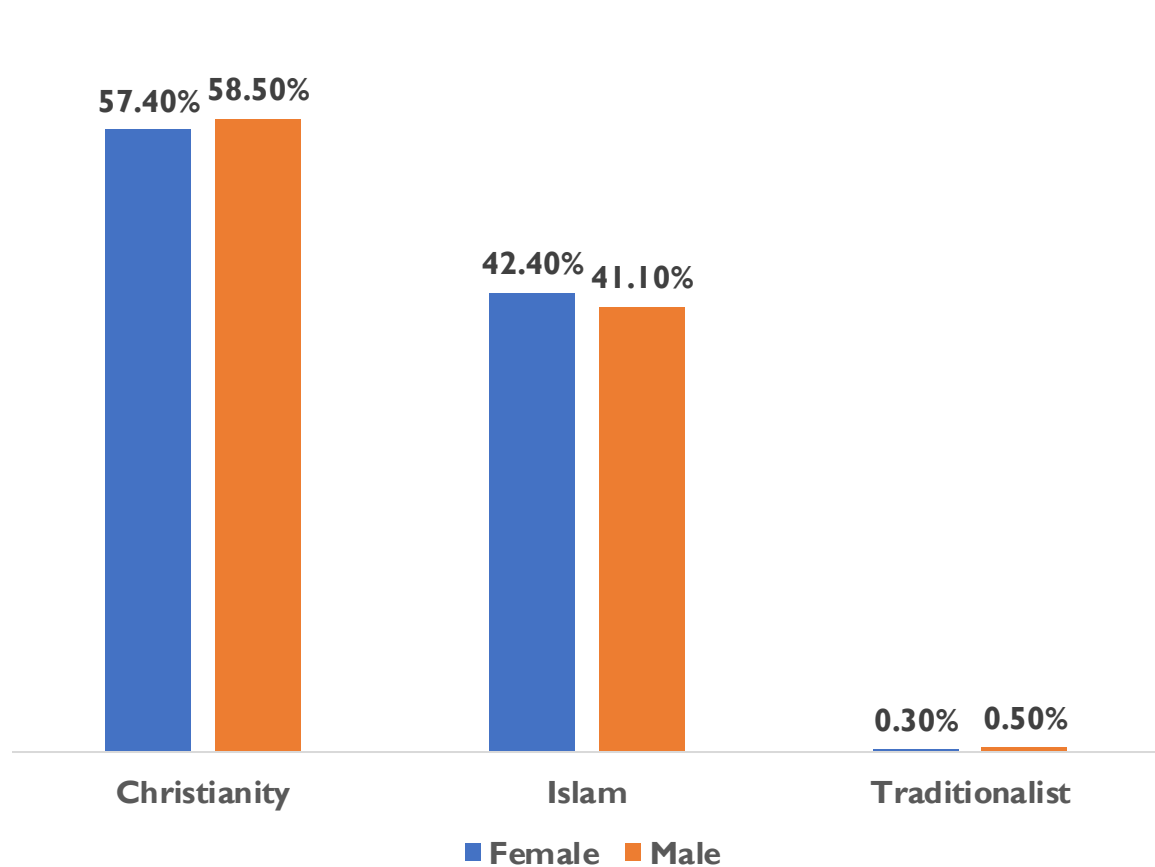


### Employment Status by Sex

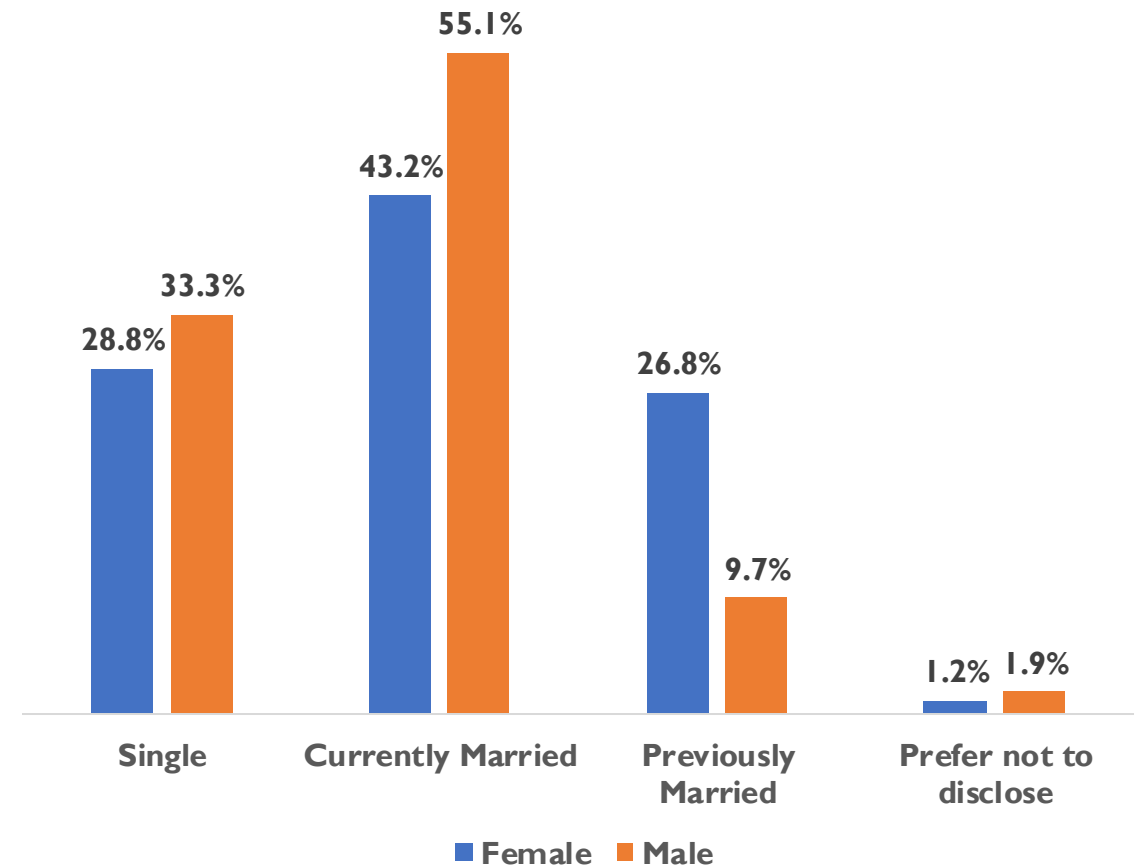


# Socio-Demographic Profile of Survey Participants

Religion by Sex Distribution



Marital Status by Sex



# Access to care: Ease of transportation for clinic visit

Socio-demographic profile by ease of transportation for clinic visit

Socio Demographic Variables	Ease of transportation n=547		X <sup>2</sup> - value
	Most times	Never	
<b>Sex</b>			
Female	156(46.7%)	178(53.3%)	1.540
Male	104(52.3%)	95(47.7%)	0.215
<b>Age Group</b>			
20-24	24(68.6%)	11(31.4%)	16.831 0.010
25-29	43(63.2%)	25(36.8%)	
30-34	34(49.3%)	35(50.7%)	
35-39	49(45.0%)	60(55.0%)	
40-44	41(50.6%)	40(49.4%)	
45-49	26(39.4%)	40(60.6%)	
50+	43(41.0%)	62(59.0%)	
<b>Educational Level</b>			
College/ University	64(40.3%)	95(59.7%)	9.392 0.025***
Not Educated	40(54.1%)	34(45.9%)	
Primary school	26(42.6%)	35(57.4%)	
Secondary school	130(54.4%)	109(45.6%)	
<b>Employment Status</b>			
Employed	82(39.6%)	125(60.4%)	11.383 0.001***
Unemployed	178(54.6%)	148(45.4%)	
<b>Are you a Student</b>			
No	211(45.4%)	254(54.6%)	16.905 0.000***
Yes	49(72.1%)	19(27.9%)	
<b>Religion</b>			
Christianity	156(51.1%)	149(48.9%)	0.204 0.903
Islam	104(46.0%)	122(54.0%)	
Traditional religion	0(0.0%)	2(100.0%)	
<b>Marital Status</b>			
Currently Married	103(40.7%)	150(59.3%)	18.143 0.000***
Single	100(61.7%)	62(38.3%)	
Previously Married	49(44.5%)	61(55.5%)	

# Findings: Ease of transportation for clinic visit

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**Clients aged 20-29 years** often face significant challenges in accessing care in health facilities compared to the older age group (45 and above). Potentially due to differences in income, financial stability, or access to transportation options.

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**Education level** highlights disparities- those with higher education faced lesser transportation challenges most time for clinic visits compared to those with lower or no education.

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**Employment status** significantly affects clients' access to care, with employed individuals less likely to face transportation challenges most of the time compared to their unemployed counterparts.

- These findings suggest that transportation assistance or financial support programs might be especially beneficial for unemployed individuals to improve their access to necessary services
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**Non married individuals** appeared to face significant transportation challenges most of the time for clinic visits followed by previously married individuals while those currently married were least affected.

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# Findings: Access to care and payment issues

## Socio-demographic profile by payment barriers

The analysis reveals that demographic factors—including gender, age, educational qualification, employment status, student status, religion, and marital status—do not significantly influence whether individuals encounter payment issues that hinder access to services during clinic visits.

This could be attributed to the fact that most HIV-related services like viral load tests are free of costs.

# Findings: Healthcare providers' communication

Socio-demographic profile by communication in language client understands

Socio Demographic Variables	Communication in the language client understand n=547			X <sup>2</sup> - value
	Most times	Sometimes	Never	
<b>Sex</b>				
Female	325(95.6%)	9(2.6%)	6(1.8%)	1.033
Male	197(95.2%)	6(2.9%)	4(1.9%)	0.597
<b>Age Group</b>				
20-24	33(91.7%)	1(2.8%)	2(5.6%)	21.627 0.042
25-29	63(90%)	3(4.3%)	4(5.7%)	
30-34	70(100%)	0(0%)	0(0%)	
35-39	109(97.3%)	1(0.9%)	2(1.8%)	
40-44	80(98.8%)	1(1.2%)	0(0%)	
45-49	66(95.7%)	0(0%)	3(4.3%)	
50+	101(92.7%)	6(5.5%)	2(1.8%)	
<b>Educational Qualification</b>				
College/ University	156(94.2%)	2(1.2%)	7(4.5%)	12.380 0.054
Not Educated	71(93.4%)	5(6.6%)	0(0.0%)	
Primary school	59(96.7%)	1(1.6%)	1(1.6%)	
Secondary school	236(96.3%)	4(1.6%)	5(2.0%)	
<b>Employment Status</b>				
Employed	13(6.1%)	9(4.2%)	190(89.6%)	2.878
Unemployed	10(3.1%)	13(4.0%)	299(92.9%)	0.237
<b>Are you a Student</b>				
No	456(95.8%)	10(2.1%)	10(2.1%)	1.370
Yes	66(93.0%)	2(2.8%)	3(4.2%)	0.504
<b>Religion</b>				
Christianity	303(95.9%)	5(1.6%)	8(2.5%)	1.497
Islam	217(94.8%)	7(3.1%)	5(2.2%)	
Traditional religion	2(100%)	0(0.0%)	0(0.0%)	0.827
<b>Marital Status</b>				
Currently Married	252(96.6%)	3(1.1%)	6(2.3%)	18.258
Single	125(94.7%)	2(1.5%)	5(3.8%)	0.019
Previously Married	107(96.4%)	3(2.7%)	1(0.9%)	

# Summary of communication in language client understands

Employment status, student status, religion and sex did not show statistically significant association with the frequency of communication in a language the client understands and is consistent across these groups

Marginal significant association between educational qualification and communication effectiveness in respect of language understood by clients. Higher education levels (College/University) might be associated with slightly more challenges in communication, whereas those with less education report better communication experiences

**Marital status** was found to have a statistically significant association with communication effectiveness, indicating that married individuals tend to experience better communication (most times) compared to those who are single, who report slightly more difficulties in communication.

There is a statistically significant link between **age and the frequency of communication** in a language the client understands. Younger age groups, particularly those between 20-29, are more likely to report communication difficulties (sometimes or never), while middle-aged groups (30-44) experience better communication. However, individuals aged 50 and above show a slight increase in communication challenges



# Findings: Healthcare provider's communication

Socio-demographic profile by providers' response to client questions

- ❑ The data indicates that **level of education** is the only socio-demographic factor significantly associated with difficulty in understanding healthcare providers' explanations regarding HIV care. Individuals with secondary education, report more challenges in comprehension.
- ❑ Other factors, such as gender, age, employment status, student status, religion, and marital status, do not show statistically significant associations, suggesting that understanding is generally consistent across these groups.
- ❑ *To address this disparity, tailored educational materials in simplified language, and additional support could help bridge the comprehension gap and ensure that all patients receive and understand critical information about their HIV care*

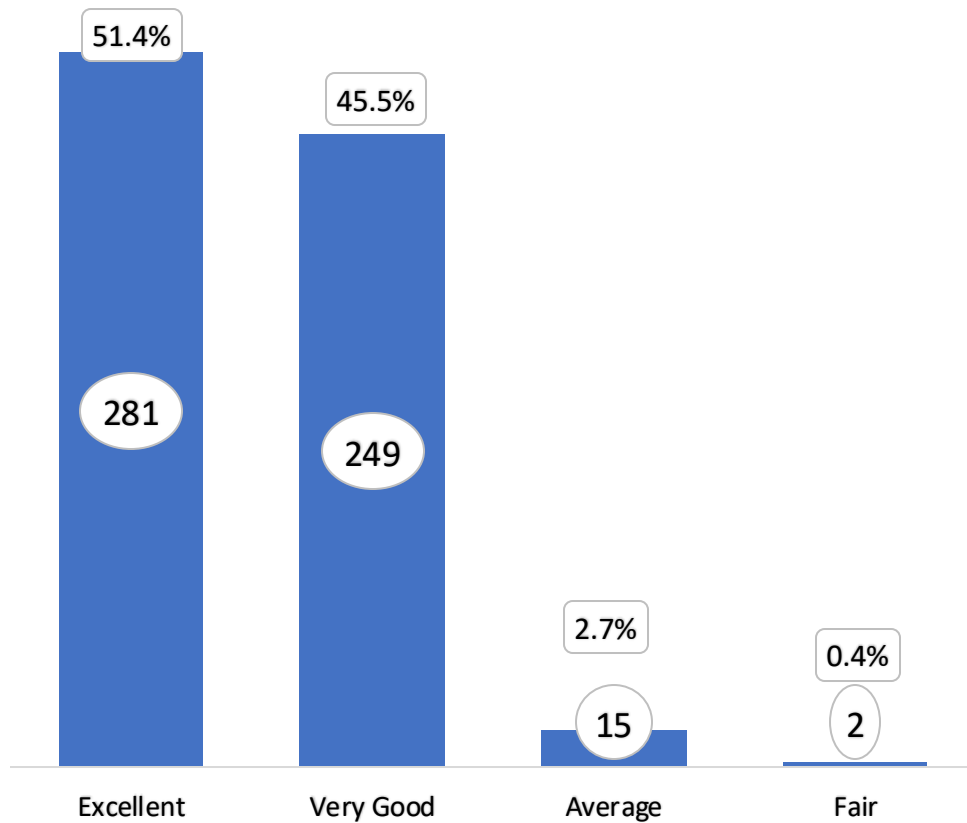
# Findings: Perception of quality of service

Socio-demographic profile by Perception of unfriendliness of providers

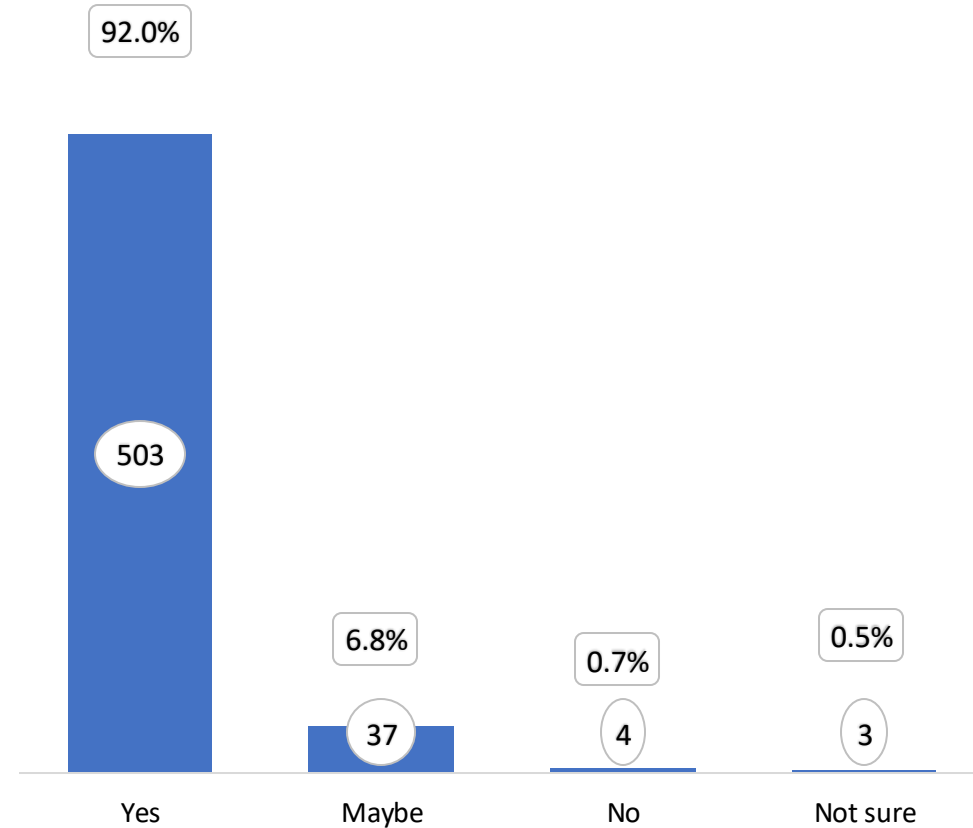
Socio-Demographic Variables	While waiting, the providers were unfriendly (n=547)			X <sup>2</sup> -value/p-value
	Most times	Sometimes	Never	
<b>Sex</b>				
Female	24(7.2%)	18(5.4%)	292(87.4%)	1.250
Male	10(5.0%)	13(6.4%)	179(88.6%)	0.535
<b>Age Group</b>				
20-24	4(11.1%)	3(8.3%)	29(80.6%)	11.090 0.521
25-29	5(7.4%)	1(1.5%)	62(91.2%)	
30-34	3(4.4%)	6(8.8%)	59(86.8%)	
35-39	4(3.7%)	6(5.5%)	99(90.8%)	
40-44	8(9.9%)	5(6.2%)	68(84.0%)	
45-49	2(2.9%)	3(4.3%)	64(92.8%)	
50+	8(7.6%)	7(6.7%)	90(85.7%)	
<b>Educational Qualification</b>				
College/ University	16(9.9%)	11(6.8%)	135(83.3%)	7.047 0.317
Not Educated	4(5.3%)	6(8.0%)	65(86.7%)	
Primary school	3(5.1%)	2(3.4%)	54(91.5%)	
Secondary school	11(4.6%)	12(5.0%)	217(90.4%)	
<b>Employment Status</b>				
Employed	16(7.5%)	18(8.5%)	179(84.0%)	5.700
Unemployed	18(5.6%)	13(4.0%)	292(90.4%)	0.058
<b>Are you a Student</b>				
No	29(6.2%)	26(5.6%)	413(88.2%)	0.516
Yes	5(7.4%)	5(7.4%)	58(85.3%)	0.773
<b>Religion</b>				
Christianity	17(5.4%)	18(5.8%)	277(88.8%)	1.354 0.852
Islam	17(7.7%)	13(5.9%)	192(86.5%)	
Traditional religion	0(0.0%)	0(0.0%)	2(100.0%)	
<b>Marital Status</b>				
Currently Married	19(7.4%)	15(5.9%)	222(86.7%)	2.560 0.634
Single	10(6.1%)	11(6.7%)	142(87.1%)	
Previously Married	4(3.6%)	5(4.5%)	101(91.8%)	

# Findings: Overall satisfaction with quality of HIV care

Overall quality of service received



Willingness to recommend health facility to others for HIV care



# Summary of perception about quality of service

## **Summary of perception of unfriendliness from healthcare workers**

- No statistically significant associations were found across gender, age, educational qualification, employment status, student status, religion, and marital status with the perception of healthcare providers being unfriendly.
- Most of the clients reported that they “Never” experienced unfriendliness.
- This indicates that healthcare providers are consistently maintaining a high standard of care and there should be continuous efforts to ensure that this level of consistency is upheld and improved.

## **Summary of perception on adequate attention of providers**

- The analysis shows that most socio-demographic factors are not significantly associated with the perception of receiving sufficient attention from healthcare providers, except for educational qualification. Individuals with higher levels of education reported slightly better experiences of receiving adequate attention.
- Communication strategies should be tailored to meet the needs of clients with lower levels of education.

## **Summary of perception of confidentiality**

- The analysis shows that most socio-demographic factors are not significantly associated with the perception of confidentiality during clinic visits.
- Educational qualifications and marital status show a significant association with comfort levels regarding confidentiality. The overall similarity in perceived confidentiality across different demographics is a positive finding.

# Best Practices, Challenges and Limitation

## Best Practices



Provision of dedicated encrypted mobile device to maintain the confidentiality of clients' information during survey data collection



The use of mobile applications such as kobo-collect for in-person data collection and transmission to a secured server done to promote data security, quality, and ease of analysis



Selection and training of Case Managers, who have prior knowledge of the HIV program, for survey data collection



The alignment of data collection exercise with client's clinic appointment visit to promote participation

## Challenges and Limitation



Internet connectivity issues in distant facilities prevented prompt upload of survey data to the staging server.



Additional technical support was required to assist with uploading data from Kobocollect to the server



Few data entry fields from the survey tool were skipped leading to incomplete responses

# Key Recommendations and Take Aways



Prioritize clients with lower levels of education, the unemployed, and unmarried individuals for intervention to address logistical and transportation issues and improve clinic visits and overall care.



The current level of communication between healthcare workers and clients regarding medication should be sustained with an increase focus on younger clients to optimize the provision of tailored age-appropriate information on medication adherence



Provide education on available DSD models to all eligible clients, especially those with higher levels of education, the employed, and the married

Thank you!





# ITPC

Jelena Bozinovski, International  
Treatment Preparedness Coalition



# CLM for improved Recipient of Care Satisfaction

*CLM :- “A science-based accountability innovation that puts communities first.”*

Jelena Bozinovski

Community Data & Advocacy Manager

September 3<sup>rd</sup>, 2024



# Community-Led Monitoring Defined

- CLM is a process where communities take the lead to routinely monitor *issues that matter to them*.
- Communities then work alongside policymakers to co-create solutions to the problems they have identified.



When problems uncovered through CLM aren't resolved, communities escalate with evidence-based advocacy and campaigning until they achieve implementation of corrective actions by duty bearers.



# Key CLM Definitions

## 1. UNAIDS

*HIV community-led monitoring (CLM) is an accountability mechanism for HIV responses at different levels, led and implemented by local community-led organizations of people living with HIV, networks of key populations, other affected groups or other community entities.* ([https://www.unaids.org/sites/default/files/media\\_asset/establishing-community-led-monitoring-hiv-services\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf))

## 2. PEPFAR

*Community-led monitoring (CLM) is a technique initiated and implemented by local community-based organizations and other civil society groups, networks of key populations (KP), people living with HIV (PLHIV), and other affected groups or other community entities that gathers quantitative and qualitative data about HIV services.* (<https://www.state.gov/community-led-monitoring/>)

## 3. Global Fund

*Mechanisms that service users or local communities use to gather, analyze and use information on an ongoing basis to improve access, quality and the impact of services, and to hold service providers and decision makers to account.* ([https://www.theglobalfund.org/media/9622/core\\_css\\_overview\\_en.pdf](https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf))

## 4. French 5%

*Community Treatment observatories are based on community, local and citizen involvement and are located within the health system and provide a complementary alternative to institutional information systems and aim to improve health systems, from local practices to public policies, by highlighting the accountability of each actor. They aim to highlight problems and to collect information on the state of access and the quality of health services.*

([https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-10/Community-health-observatories-capitalization\\_0.pdf](https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-10/Community-health-observatories-capitalization_0.pdf))





# CLM Principles

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Despite slightly different CLM definitions by UNAIDS, Global Fund and PEPFAR and FRENCH 5%, the **key three principles** of CLM:

- a) Community-LED (community ownership)
- b) Community organization for effective monitoring, and
- c) Community focus on enacting change and ensuring accountability

...are consistently present in all definitions.



# What Is Community-Led Monitoring?

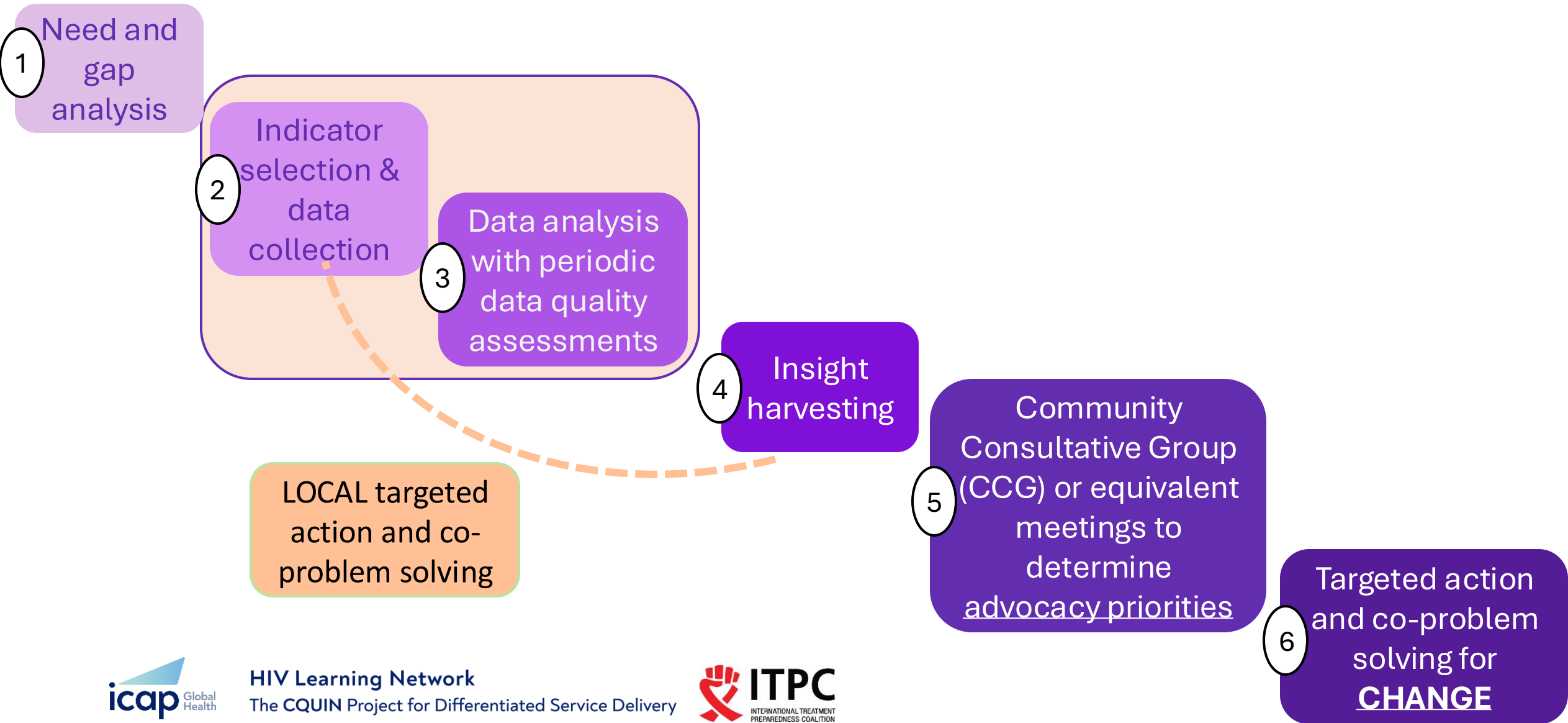
CLM Is NOT...	CLM IS
X Community-BASED	✓ Community- <b>LED</b>
X Indicators are set by outside entities (governments, donors); data collected corresponds to established M&E systems and frameworks	✓ Indicators are determined by communities and correspond to their own priorities; provide a valuable piece of the <b>whole data story</b>
X One-time evaluation (a “snapshot”)	✓ Routine, <b>recurring data collection</b> over time (usually monthly or quarterly)
X Data is owned by entities outside of the community (governments, healthcare facilities)	✓ Data is owned by communities
X Fault-finding	✓ Fact-finding
X The end goal of the data is to understand the trends and issues	✓ The end goal is to <b>improve a particular issue</b> that has been identified as important by communities

# ITPC's Community-led Monitoring (CLM) Model





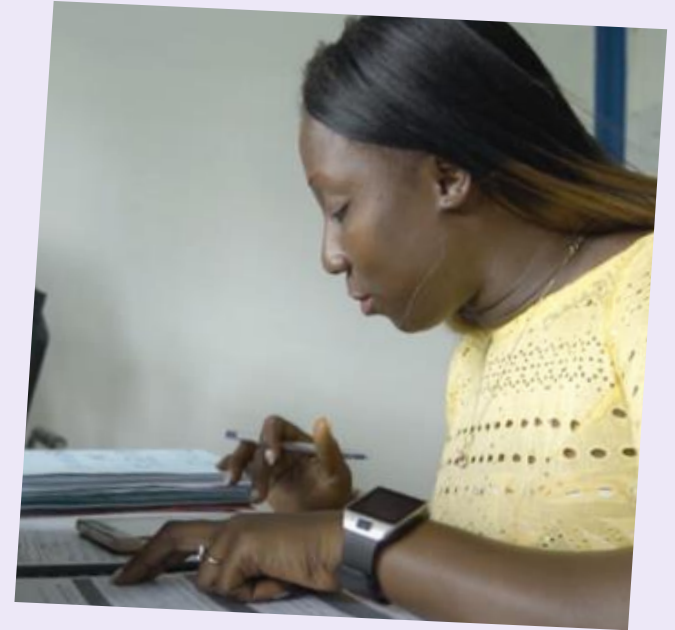
# CLM in 6 Steps



# The Citizen Science Project

**PURPOSE: Monitor impact of COVID-19 on HIV and TB Services, particular attention to prevention**

- **2 countries:** Malawi and South Africa
- **33 health facilities:**
  - 14 in Malawi (eight in Kasungu and six in Dedza)
  - 19 in South Africa (all on the West Rand)
  - **INCLUDING: 6 non-governmental service providers** (two in Malawi and four in South Africa)
- **58 data collectors**
- **989,848 beneficiaries** in this catchment area
- **3+ years** of continuous monitoring (October 2020-December 2023)
- **Monitoring:** 30+ indicators in Malawi and 20+ indicators in South Africa.
  - Qualitative and quantitative
- **39 Life Maps participants:** citizen journalists documenting the more personal aspects of how HIV, TB, and COVID-19 affect their daily lives, using photography, narrative, and textual tools.



**ITPC data collector, conducting a survey of clinic records as part of community-led monitoring.**



# The Triple I Report - 2023 CLM Data Report

## Available now!!

*Insight, Influence & Impact: 10 Big Change Stories  
from the Citizen Science Community-Led  
Monitoring Project in 2023 in 4 languages.*



# Top-line CLM Outcomes in 2023 – MALAWI



People accessing ART at sites with a CLM-informed DSD strengthening intervention were six times more likely to be in a DSD model (6.79 OR 95% CI 6.04-7.63) and **twice as likely to be virally suppressed** (2.34 OR 95% CI 2.16-2.54) as sites without DSD strengthening.



The number of **HIV tests among young sex workers doubled** (from 217 in 2022 to 434 in 2023), as did HIV positivity (from 1.7% to 2.4%), following CLM engagements with district hospitals to designate key population focal points and KP clinic spaces.



CLM data was used to engage District Condom Coordinators and train condom distributors, which led to a 23.4% increase in condom distribution in 2023. This contributed to **fewer new infections** in the two districts, which fell from 868 in 2022 to 632 in 2023.



CLM advocacy secured a commitment from the Global Fund to procure 50 new GeneXpert machines. As a result, 39% of TB tests at our CLM sites in 2023 were Xpert tests, up from 18% in 2022. **People diagnosed with TB and enrolled onto treatment nearly tripled**, from 320 in 2022 to 907 in 2023.



Following CLM advocacy to expand static VMMC sites, the proportion of **circumcisions among men aged 15 years and older increased** from 77% in 2022 to 82% in 2023. According to the Naomi model, there were 205 new HIV infections among men in this age group in the two districts in 2023, down from 284 in 2022.



# Top-line CLM Outcomes in 2023 – SOUTH AFRICA



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).



# Framework for the Application of CLM: AAAAA

Availability	Accessibility	Acceptability	Affordability	Appropriateness
				
<ul style="list-style-type: none"> <li>Do the required health services, medicines, commodities and supplies exist?</li> <li>If so, do they exist when they are needed and in adequate supply?</li> </ul>	<ul style="list-style-type: none"> <li>Are there long travel distances or wait times?</li> <li>Are hours of operation convenient?</li> <li>Are referral processes along the care cascade smooth?</li> </ul>	<ul style="list-style-type: none"> <li>Is there a high quality of care?</li> <li>Are services provided free of stigma and discrimination?</li> <li>Are the human rights of patients promoted and protected?</li> </ul>	<ul style="list-style-type: none"> <li>Do services require out-of-pocket spending on behalf of the client?</li> <li>Is the service delivery model(s) efficient?</li> <li>What is the sustainability of the response?</li> </ul>	<ul style="list-style-type: none"> <li>Are services tailored to the specific needs of key and vulnerable populations?</li> <li>Are age and gender considered in service packages?</li> </ul>



# When Communities Lead

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- **Ownership of the Process** – communities have a vested interest in the outcomes; data collected does not “vanish” as it often does with other traditional researchers. Community systems are also strengthened in the process – staff develop skills in data management, M&E and advocacy, orgs. build program track record etc. (CSS).
- **Appropriate & Responsive Interventions** – solutions are closer to the issues; community-led interventions can generate more valuable (honest) insights to address their pressing needs.
- **Action- & Accountability-focused Results** – data collection & analysis is for a purpose; it is directly linked to advocacy or other targeted action to improve quality and service delivery and hold duty-bearers to account. **Success is measured here.**





**Learn More:**  
[CLMHub.org](http://CLMHub.org)  
[library.clmhub.org](http://library.clmhub.org)



Thank you!



# Panel Discussion

**Moderator: Lawrence Khonyongwa**  
**Executive Director, Malawi Network of**  
**People Living with HIV (MANET+)**





**Patrick Akpan,  
NEPWHAN, Nigeria**



**Eric Akoji,  
MOH, Nigeria**



**Anthony Mutiti,  
ICAP, Zambia**



**Adebola Adekogbe,  
CIHP, Nigeria**



**Jelena Bozinovski,  
ITPC**



