# GPC KEY POPULATION COMMUNITY OF PRACTICE

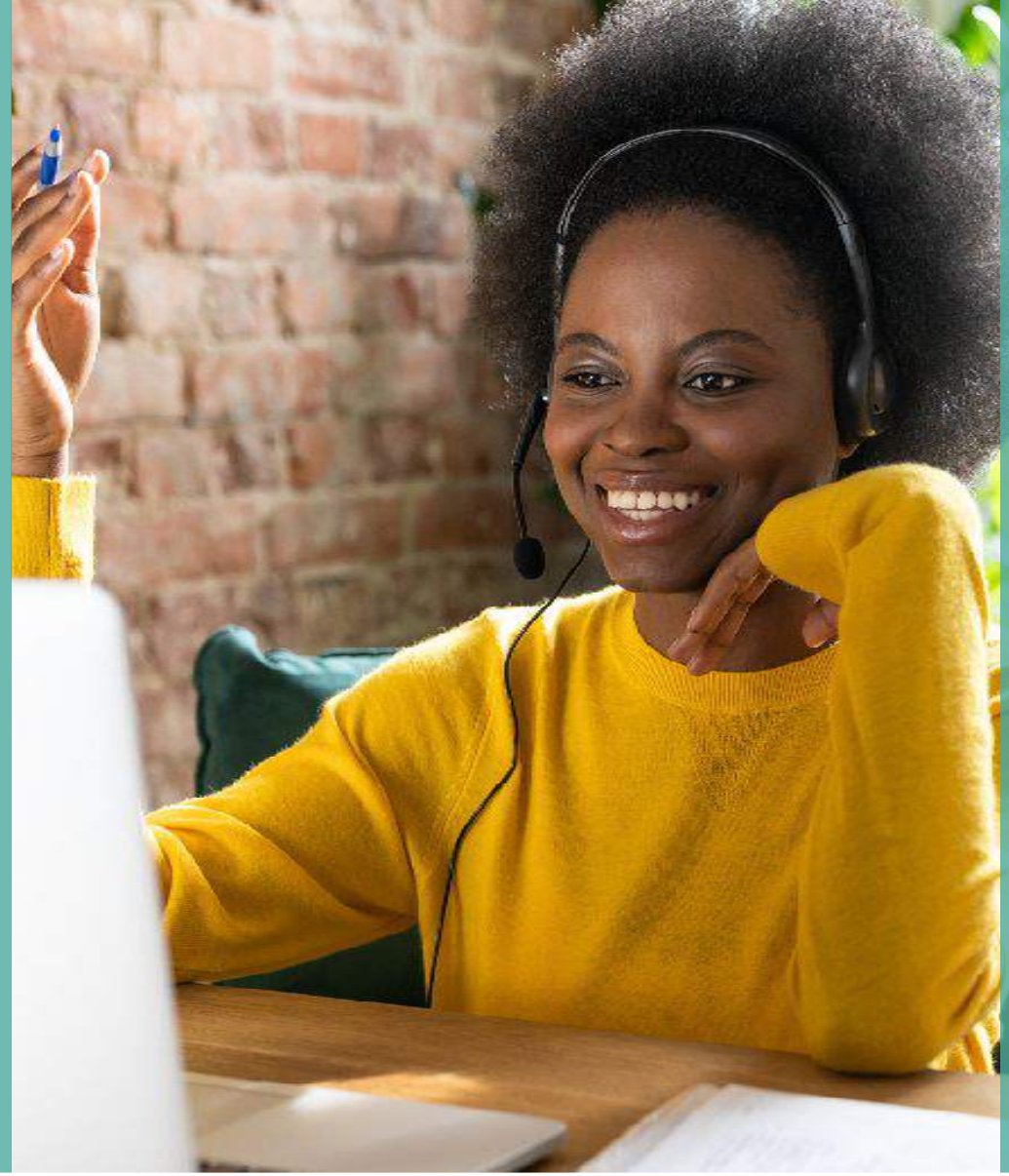
## WEBINAR | 4 April 2023

Measuring & monitoring the Key Population programme outputs & outcomes at national and global level

# POPULATIONS CLÉS DU GPC COMMUNAUTÉ DE PRATIQUE

## WEBINAR | 4 Avril 2023

Mesurer et suivre les réalisations et les résultats du programme
pour les populations clés aux niveaux national et mondial



GPC Global HIV Prevention Coalition

SOUTH TO SOUTH LEARNING NETWORK
The HIV Prevention Interchange

## HOUSEKEEPING

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# SESSION DETAILS

**AGENDA: Measuring and monitoring the Key Population Programme outputs and outcomes at National and Global Level** | Date – 4th April 2023

| Meeting chair: Tim Sladden and Clemens Benedikt | | 11:00 – 12:30 (CEST) | 16:00 – 17:30 (CEST) |
|---|---|---|---|
| Time | Session | Facilitators / Speakers | Facilitators / Speakers |
| 5 min | **Opening remarks**<br>Welcome<br>Objectives of the meeting | Tim Sladden | Clemens Benedikt |
| 25 min | **Global Overview:**<br>This will include sharing of the 2025 global targets in relation to key population programme and reflections around approaches to measure outputs and outcomes for Key Population programmes<br><br>Investment in robust monitoring and evaluation systems including available evidence to plan and improve programmes including funding requests<br><br>Need for programme data triangulation to improve programming and overview of the new monitoring and evaluation toolkit developed by UNAIDS | Keith Sabin, UNAIDS<br>Amrita Rao, JHU<br>Kate Rucinski, JHU | Keith Sabin, UNAIDS<br>Amrita Rao, JHU<br>Kate Rucinski, JHU |
| 2.5 min | **Priority (interactive)**<br>Why would you prioritize monitoring and evaluating Key Population programmes in your country? | Mentimeter | Mentimeter |
| 25 min | **Practical approaches to implementing a monitoring and evaluation system to monitor progress of KP programme**<br>Country presenters will share how the specific country has developed practical strategies led by the government to measure and monitor KP programmes. | Keshab Deuba and Neeti Sedhain, Nepal<br><br>Dr. Peter Mudioppe, Uganda | Dr. Jebet Boit, Kenya<br><br>Dr. Ketevan Stvilia, Georgia |
| 25 min | **Programmatic Key Population Community Led Monitoring (CLM) approach and practices**<br>Presenter(s) from KP-led organisations and networks will share their successful efforts and practices in leading community led monitoring processes | Shahnaz, Tais Plus<br>Viet Trinh, Light House | Aniedi Akpan, DHRAN<br>Sean Regg, Transbantu |
| 2.5 min | **Reflections (interactive)**<br>*What is the most important action you will take to strengthen the monitoring and evaluation of key population programme in your country?* | Mentimeter | Mentimeter |
| 5 min | **Closure**<br>Summary of actions and next steps | Tim Sladden | Clemens Benedikt |

# OPENING REMARKS

Tim Sladden

## OBJECTIVES

- To understand why monitoring and evaluation of Key Population program is critical
- To learn how countries are implementing monitoring and evaluation systems in relation to key population program
- To reinforce the need for community feedback and leadership in monitoring key population program

# GLOBAL OVERVIEW

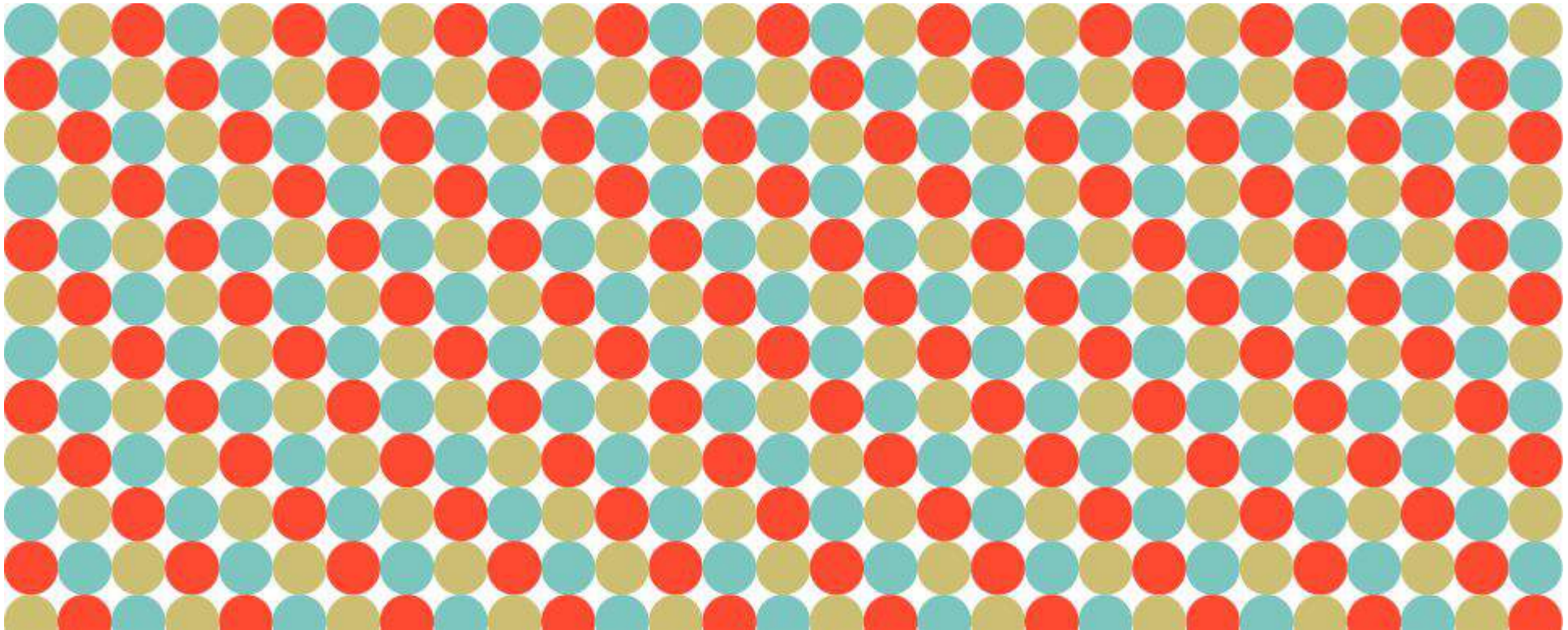
Keith Sabin, UNAIDS
Amrita Rao, JHU
Kate Rucinski, JHU

# ENDING AIDS BY 2030

KEITH SABIN

# Ending AIDS by 2030: it cannot happen unless we prioritize key populations

**Keith Sabin, UNAIDS Data for Impact practice**



# Global Ambitions

Human Rights

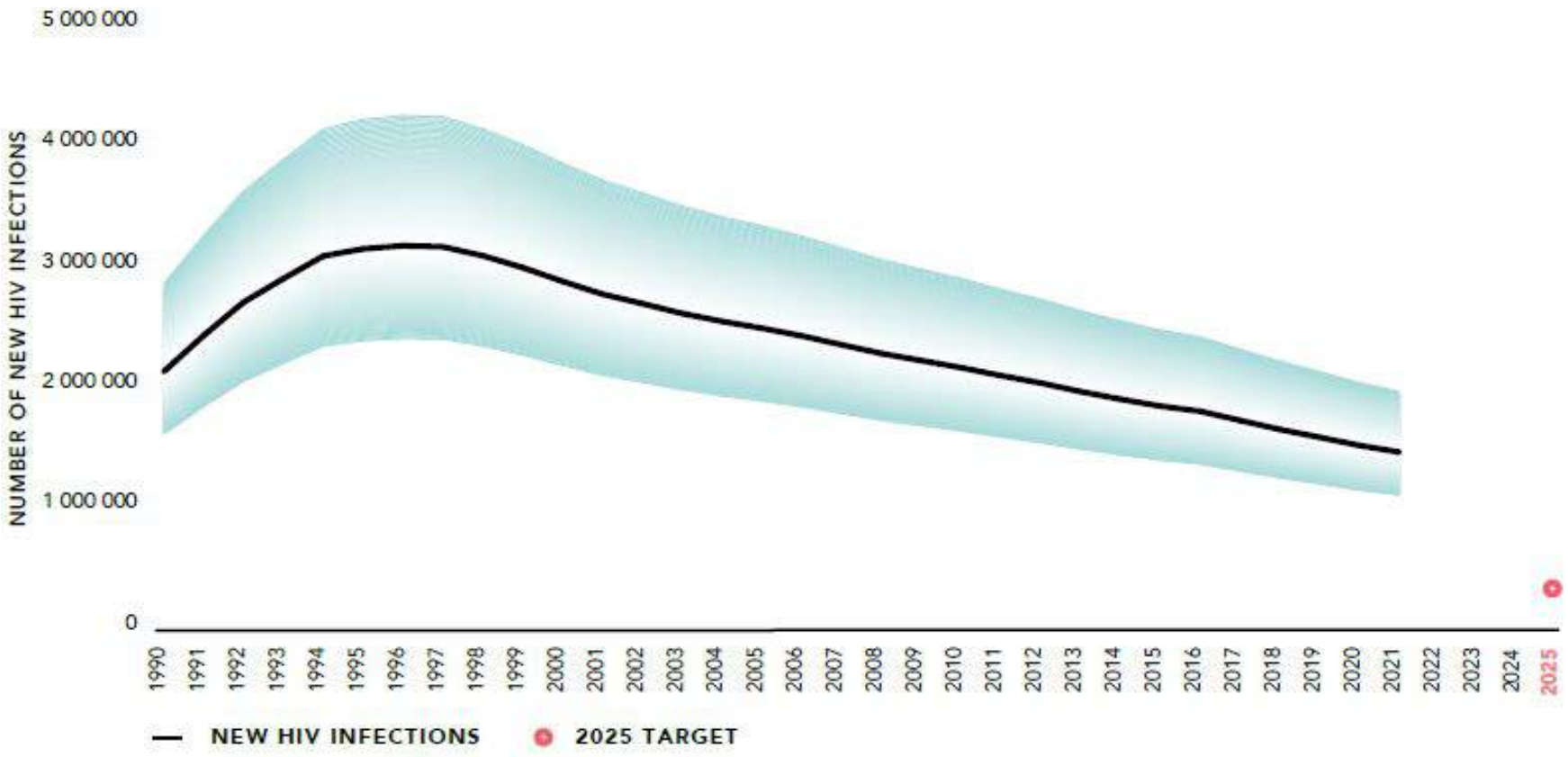
Ethics & Morality

Equality

**Public Health approach**
**Targets:** ***can we achieve without some groups?***
***=> utilitarian approach***

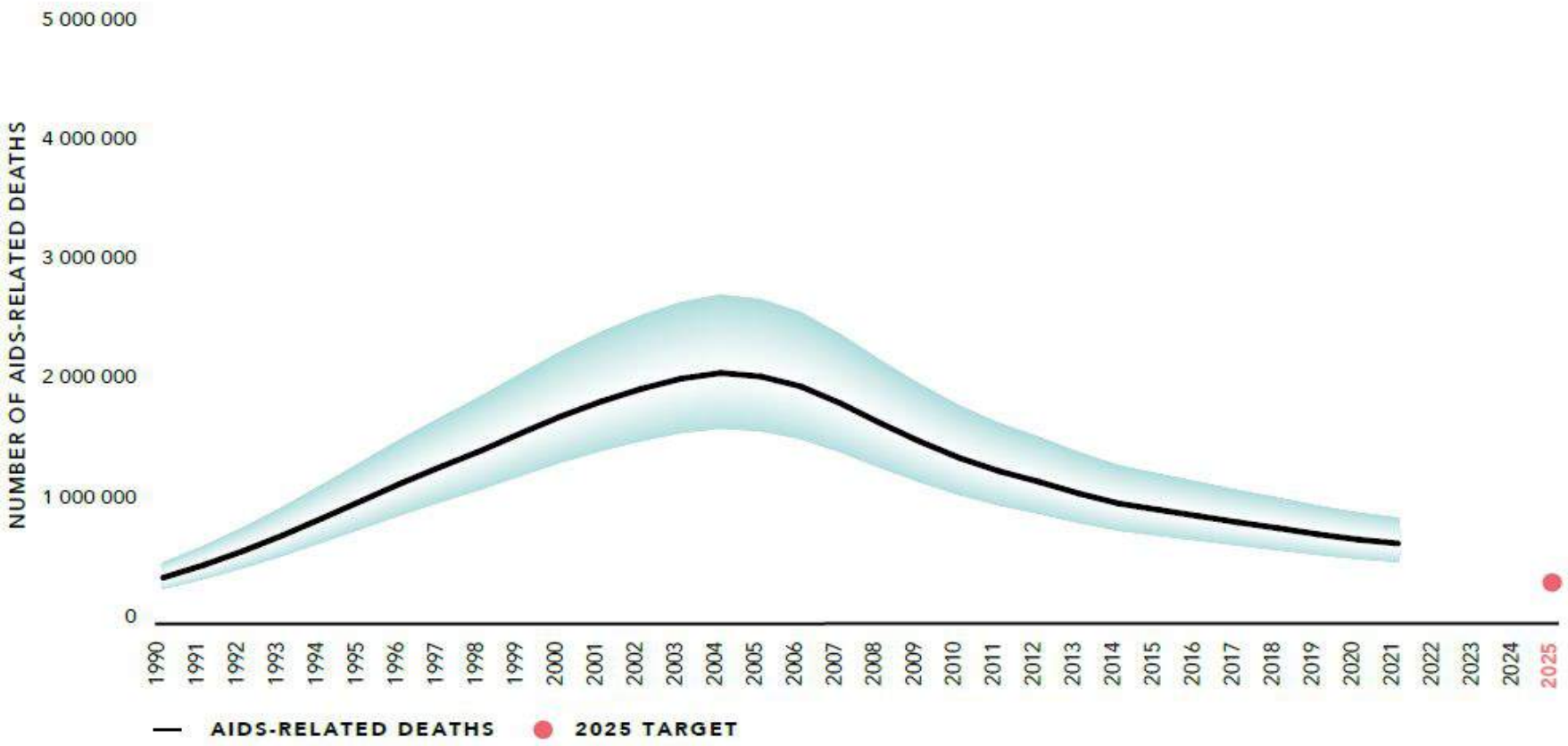
**Rights approach**
**Targets:** ***Apply to all possible groups?***
***=> Equity approach***

# Number of new HIV infections, global, 1990–2021, and 2025 target



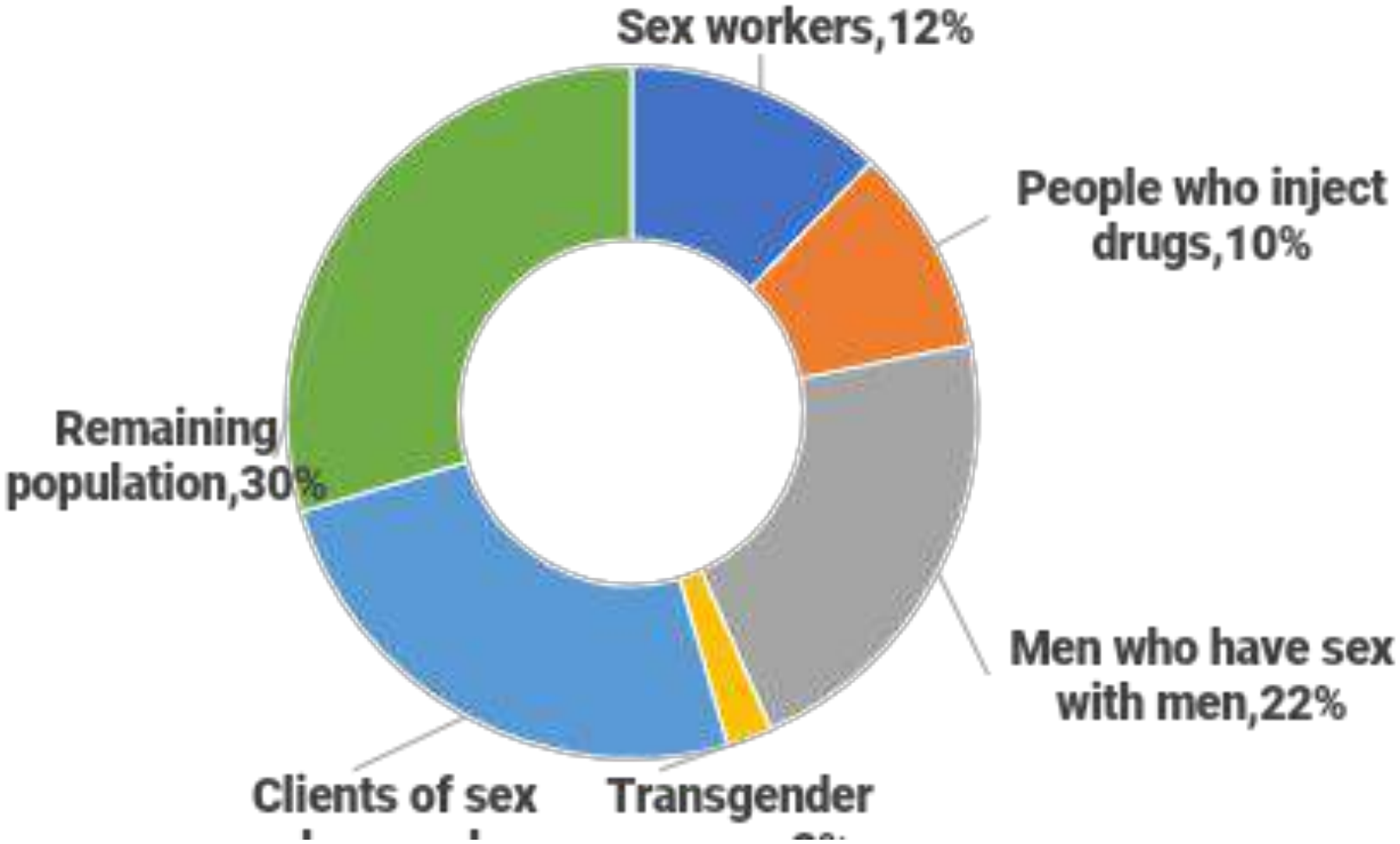

Source: UNAIDS epidemiological estimates, 2022 (https://aidsinfo.unaids.org/).

# Number of AIDS-related deaths, global, 1990–2021, and 2025 target




Source: UNAIDS epidemiological estimates, 2022 (https://aidsinfo.unaids.org/).

# Distribution of acquisition of HIV infection by population, global, 2021

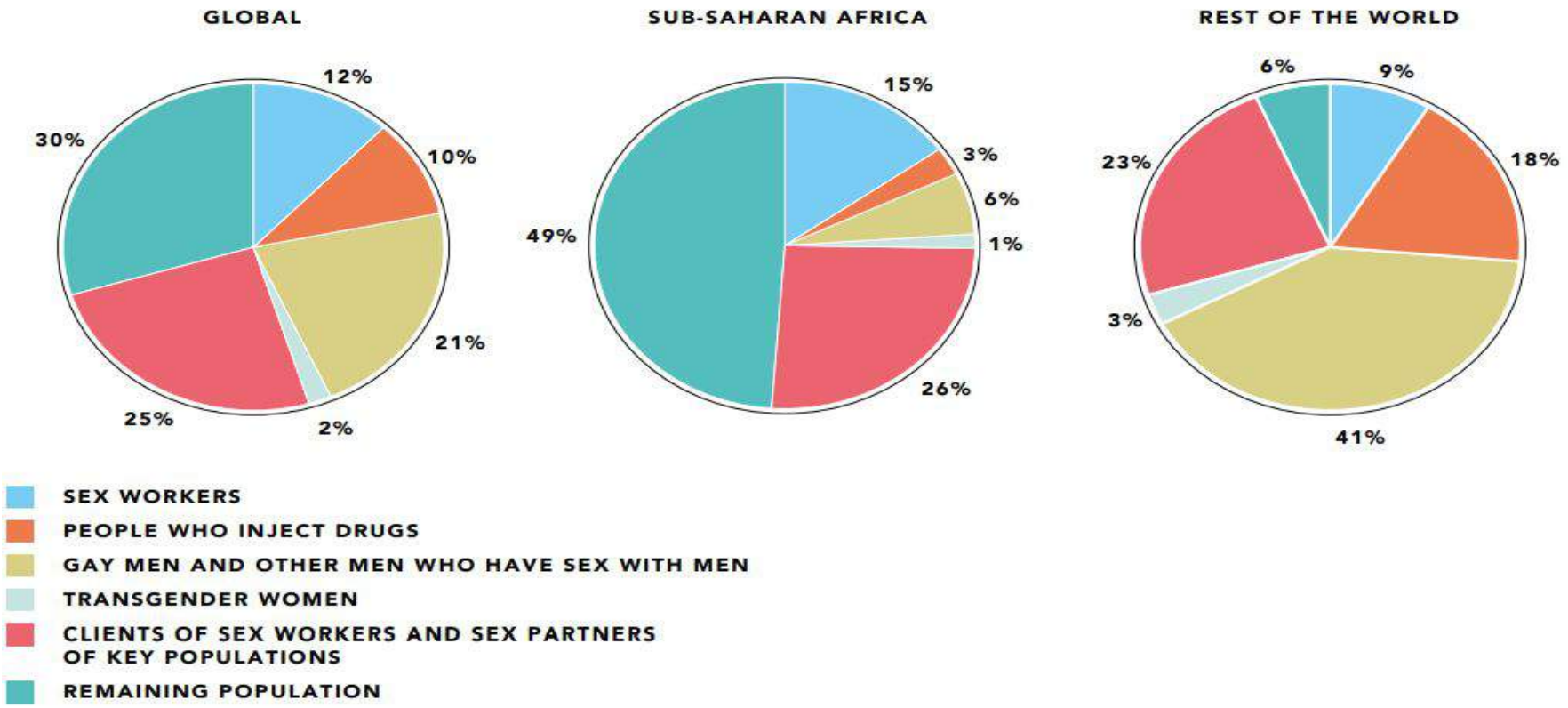



UNAIDS special analysis, 2022

# Sustainable Development Goal Indicator 3.3.1

**Number of new HIV infections. The number of new HIV infections per 1,000 uninfected population, by sex, age and *key populations* as defined as the number of new HIV infections per 1000 person-years among the uninfected population.**

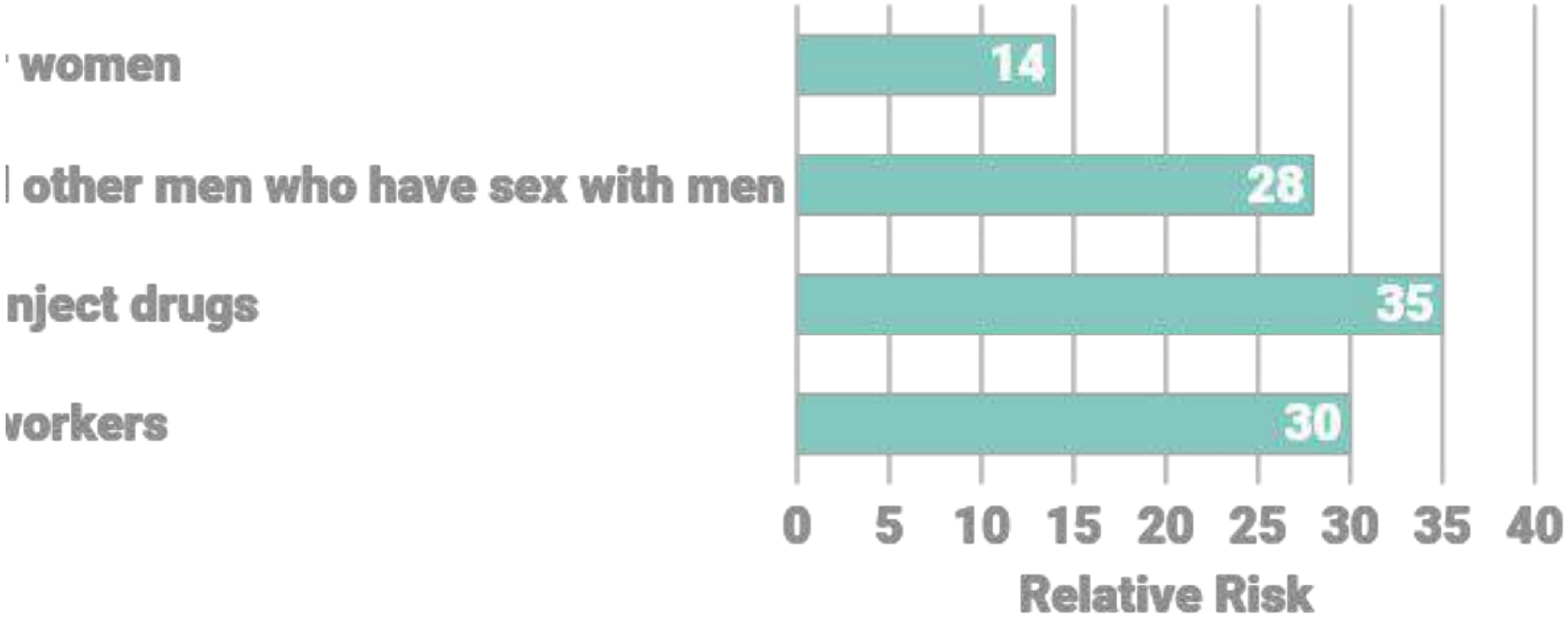
# Distribution of acquisition of new HIV infections by population, global, sub-Saharan Africa and rest of the world, 2021




Source: UNAIDS special analysis, 2022 (see Annex on Methods).

Note: Due to variations in the availability of data from one year to the next, we do not provide trends in this distribution. See Annex on Methods for a description of the calculation.

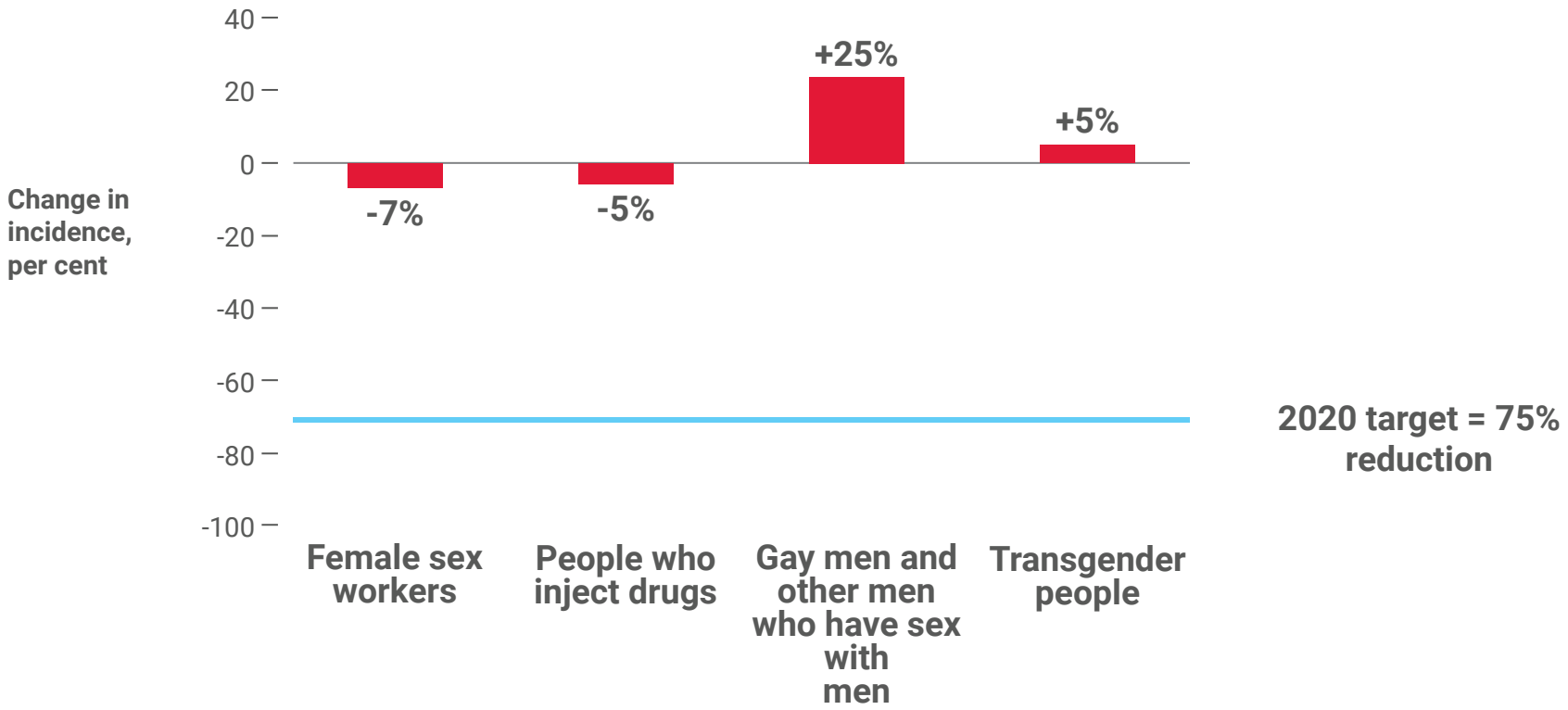
# Relative risk of acquisition of HIV infection by population, global, 2021




Risk compared to remaining population of same gender identity

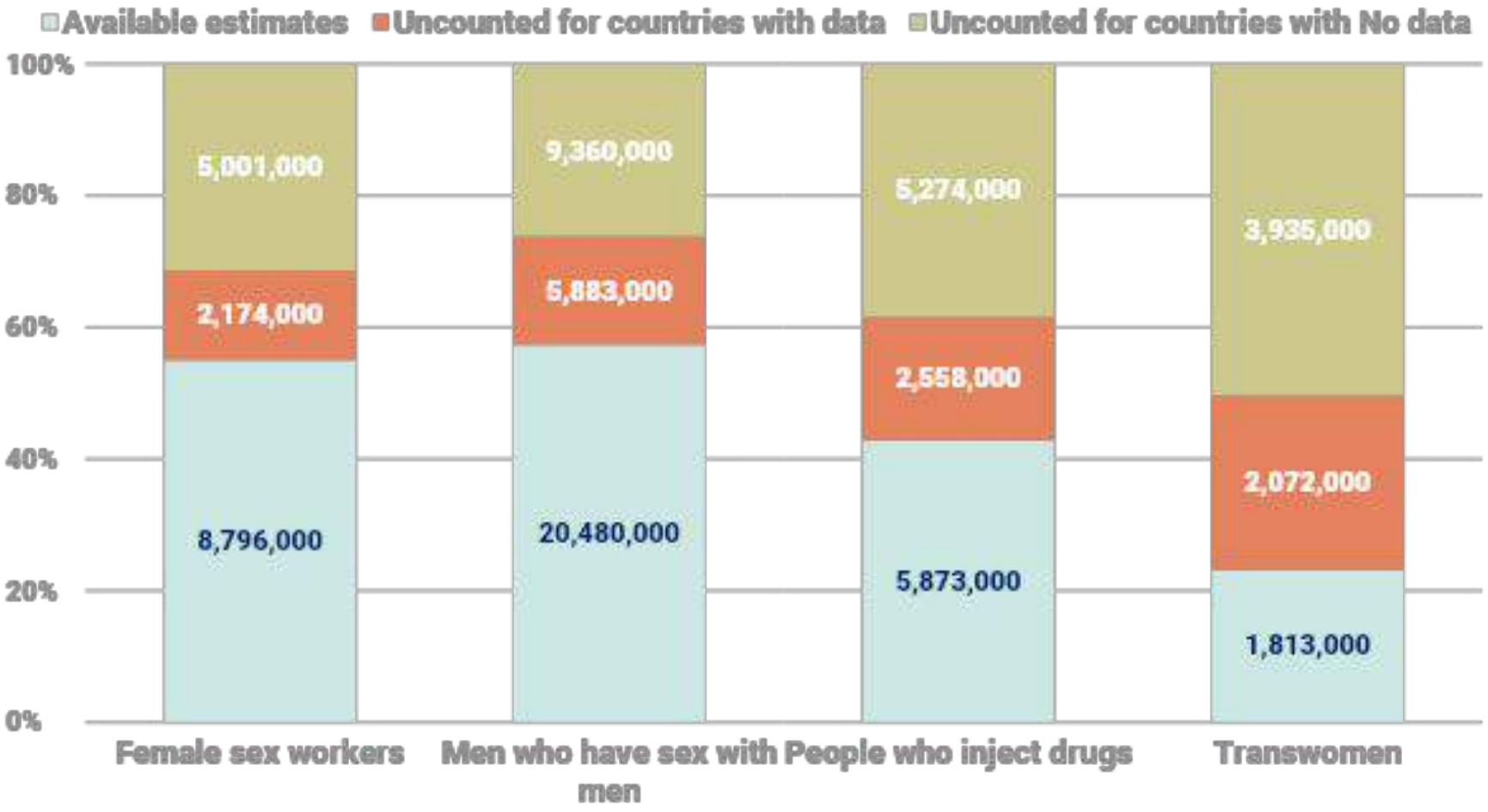
UNAIDS special analysis, 2022

# Percentage change in HIV incidence among key populations, global, 2010–2019




**Source:** UNAIDS special analysis of available key population data, 2020.

# Gap between country-reported key population size estimates and extrapolated sizes, global, 2020



# Targets thresholds for 2025

| | Criterion | Very high | High | Moderate and low |
|---|---|---|---|---|
| **Sex workers** | National adult (15–49 years) HIV prevalence | >3% | >0.3% | <0.3% |
| **Prisoners** | National adult (15–49 years) HIV prevalence | >10% | >1% | <1% |
| **Gay men and other men who have sex with men** | UNAIDS analysis by country/region | Proportion of populations estimated to have incidence >3% | Proportion of populations estimated to have incidence 0.3–3% | Proportion of populations estimated to have incidence <0.3% |
| **Transgender people** | Mirrors gay men and other men who have sex with men in absence of data | Proportion of populations estimated to have incidence >3% | Proportion of populations estimated to have incidence 0.3–3% | Proportion of populations estimated to have incidence <0.3% |
| **People who inject drugs** | UNAIDS analysis by country/region | Low needle–syringe programme and opioid substitution therapy coverage | Some needle–syringe programme; some opioid substitution therapy | High needle–syringe programme coverage with adequate needles and syringes per person who injects drugs; opioid substitution therapy available |

# Targets for 2025

| KEY POPULATIONS | Sex workers | Gay men and other men who have sex with men | People who inject drugs | Transgender people | Prisoners and others in closed settings |
|---|---|---|---|---|---|
| Condoms/lubricant use at last sex by those not taking PrEP with a non-regular partner whose HIV viral load status is not known to be undetectable (includes those who are known to be HIV-negative) | -- | 95% | 95% | 95% | -- |
| Condom/lubricant use at last sex with a client or non-regular partner | 90% | -- | -- | -- | 90% |
| PrEP use (by risk category)<br>▪ Very high<br>▪ High<br>▪ Moderate and low | <br>80%<br>15%<br>0% | <br>50%<br>15%<br>0% | <br>15%<br>5%<br>0% | <br>50%<br>15%<br>0% | <br>15%<br>5%<br>0% |

# Estimates of HIV-free key populations for ≈160 countries

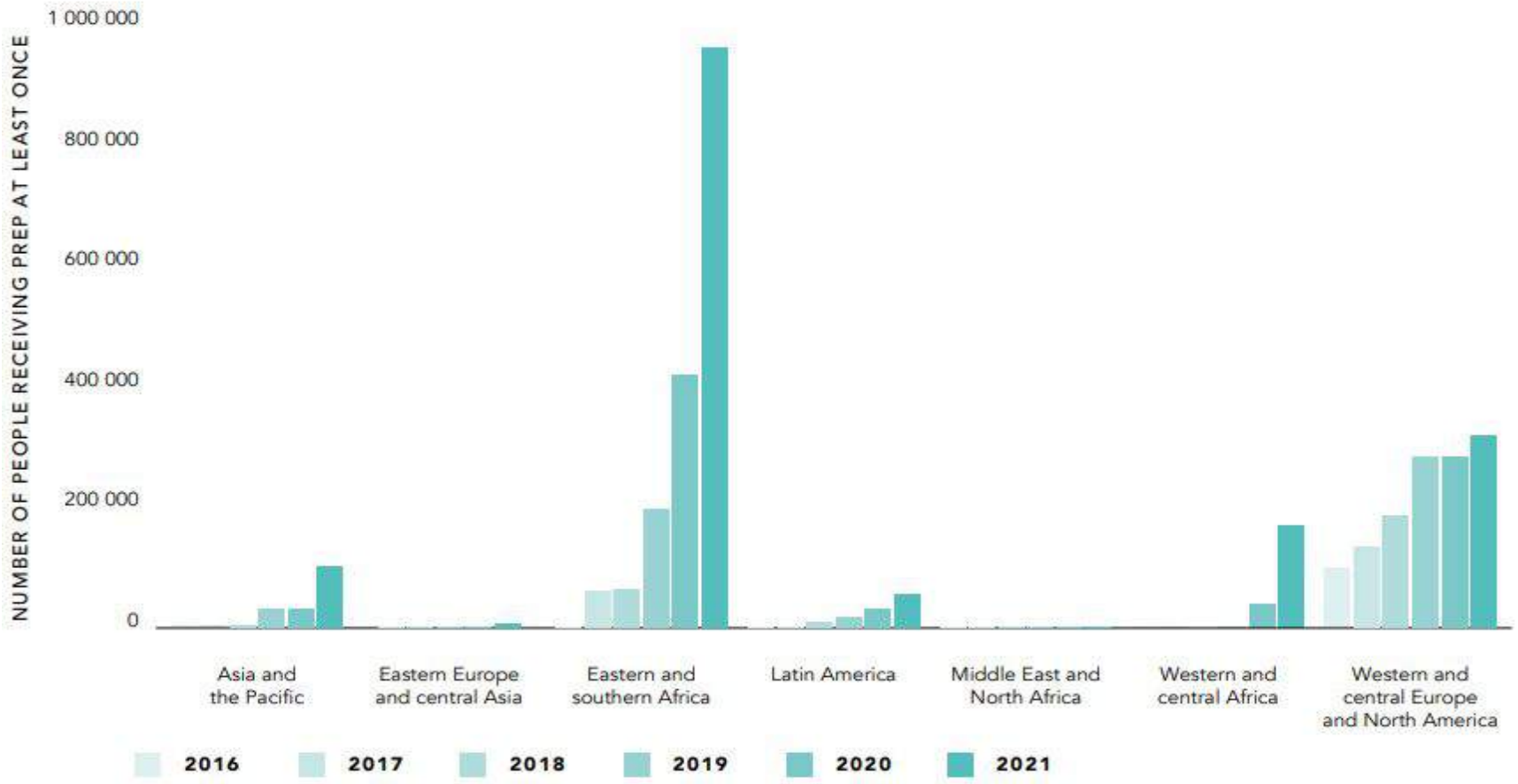
| Country | WB_Class | Max Estimated Med Risk | Est Med risk as % of PSE | Est High risk | Min Estimated High risk | Max Estimated High risk | Est high risk as % of PSE |
|---|---|---|---|---|---|---|---|
| Ghana | Lower middle income | 28592 | 21% | 71559 | 59761 | 82506 | 61% |
| Guinea | Low income | 1162 | 57% | 479 | 393 | 609 | 28% |
| Guinea-Bissau | Low income | 5211 | 55% | 3263 | 2627 | 3938 | 41% |
| Haiti | Low income | 45171 | 58% | 17111 | 14094 | 22075 | 25% |

# Translating Coverage Targets to Numbers: 2025

| Population | Population Size (Millions) | Coverage Target | Target (Millions) |
|---|---|---|---|
| FSW | 11.9 | 9.4% | 1.1 |
| MSM | 30.0 | 14.0% | 4.2 |
| Transgender | 5.3 | 15.8% | 0.8 |
| PWID | 12.3 | 5.3% | 0.6 |
| Prisoners | 10.4 | 1.4% | 0.1 |
| AGYW | 532 | 0.1% | 0.4 |
| ABYM | 571 | 0.02% | 0.1 |
| Adults 25+ with multiple partners | 163 | 0.3% | 0.5 |
| Total | 1336 | 0.6% | 8.0 |

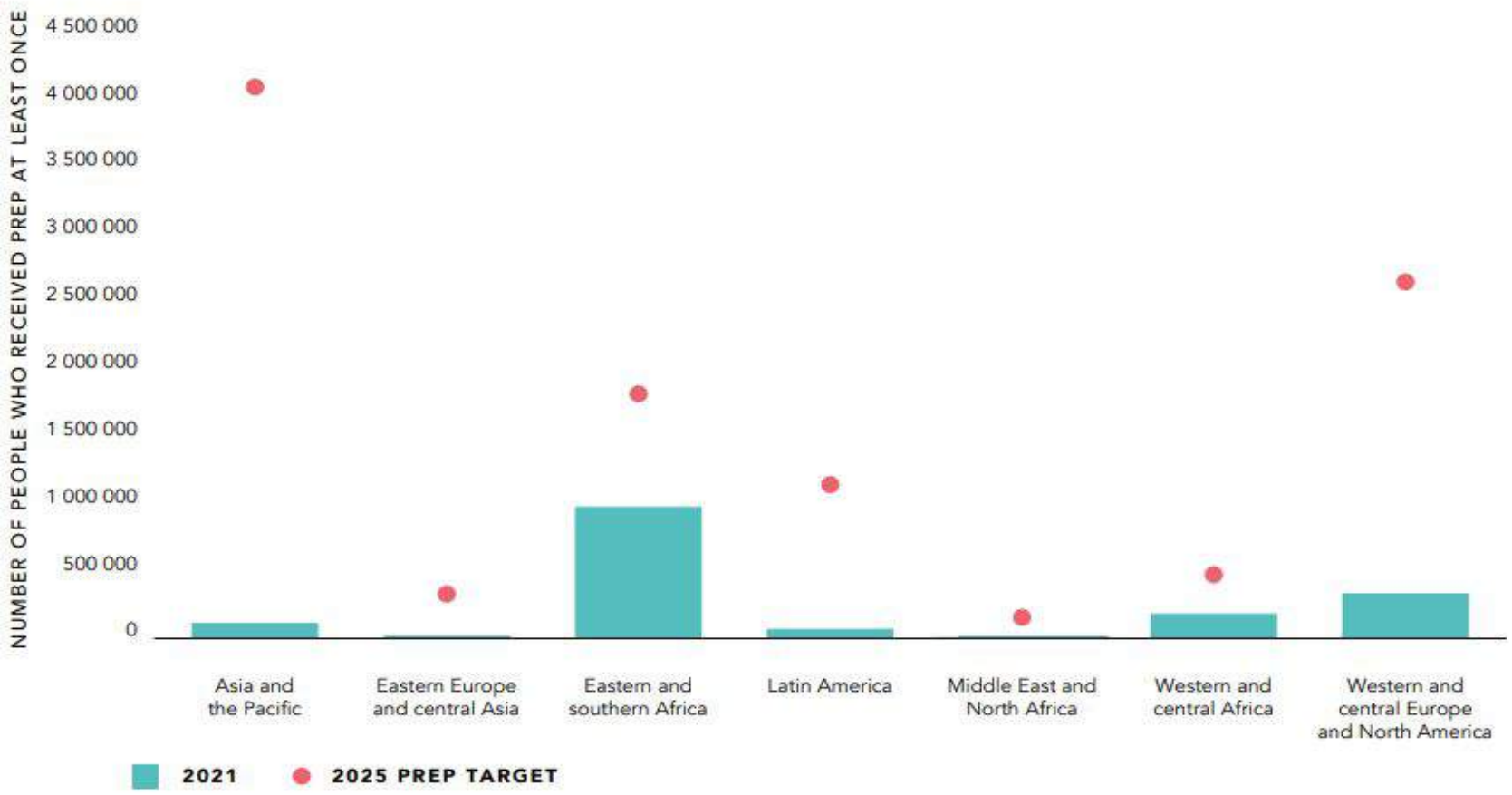
*Coverage target is weighted average across all countries and population risk groups.

# Number of people who received pre-exposure prophylaxis (PrEP) at least once during the reporting period, by region, 2017–2021



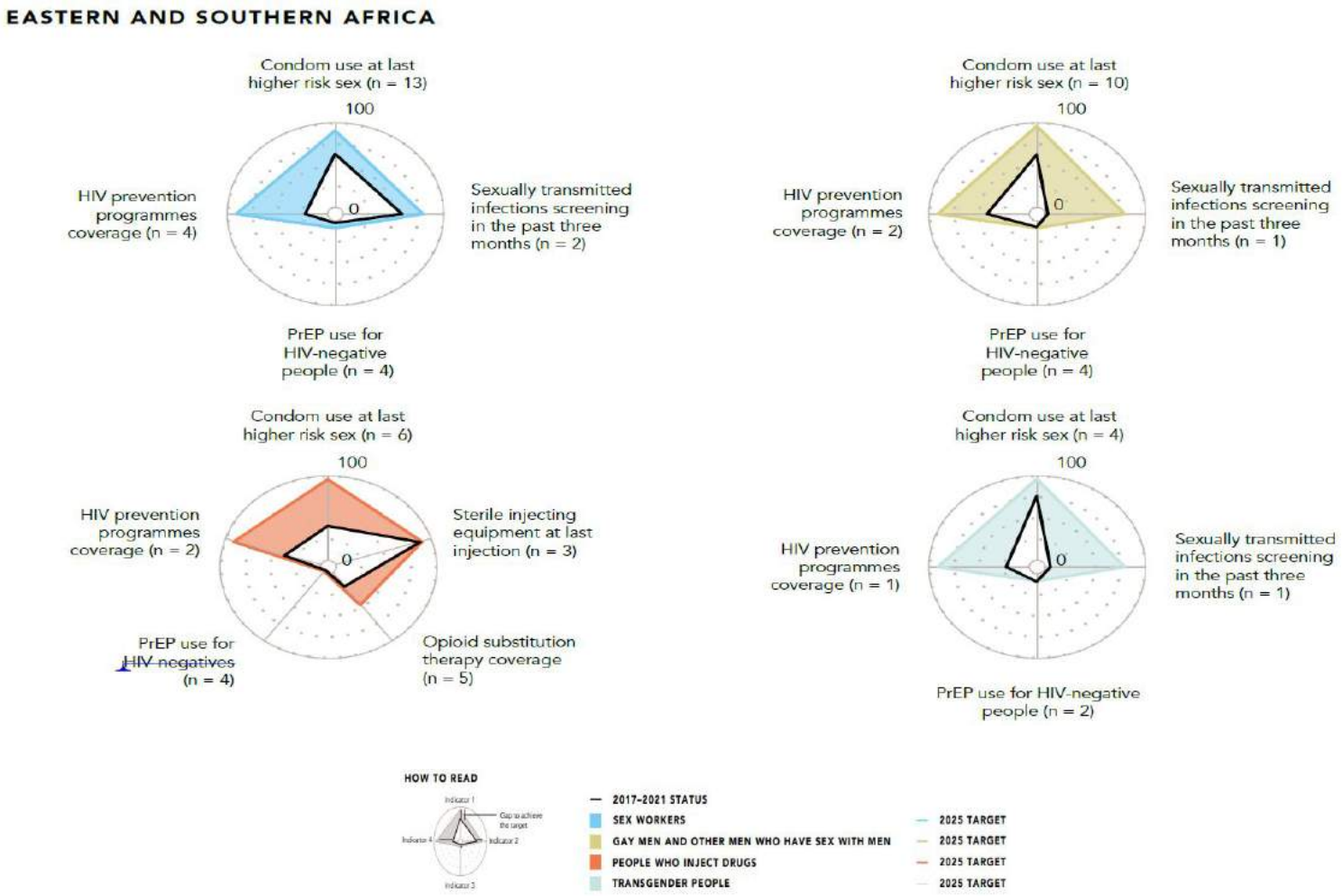

Source: UNAIDS Global AIDS Monitoring, 2022 (https://aidsinfo.unaids.org/).

# Number of people who received pre-exposure prophylaxis (PrEP) at least once during the reporting period, by region, 2021, and 2025 target




Source: UNAIDS Global AIDS Monitoring, 2022 (https://aidsinfounaids.org/).

# Gap to achieve the combination prevention targets among key populations, by intervention and region, 2017–2021




Source: UNAIDS Global AIDS Monitoring, 2022 (https://aidsinfo.unaids.org/); UNAIDS special analysis, 2022.

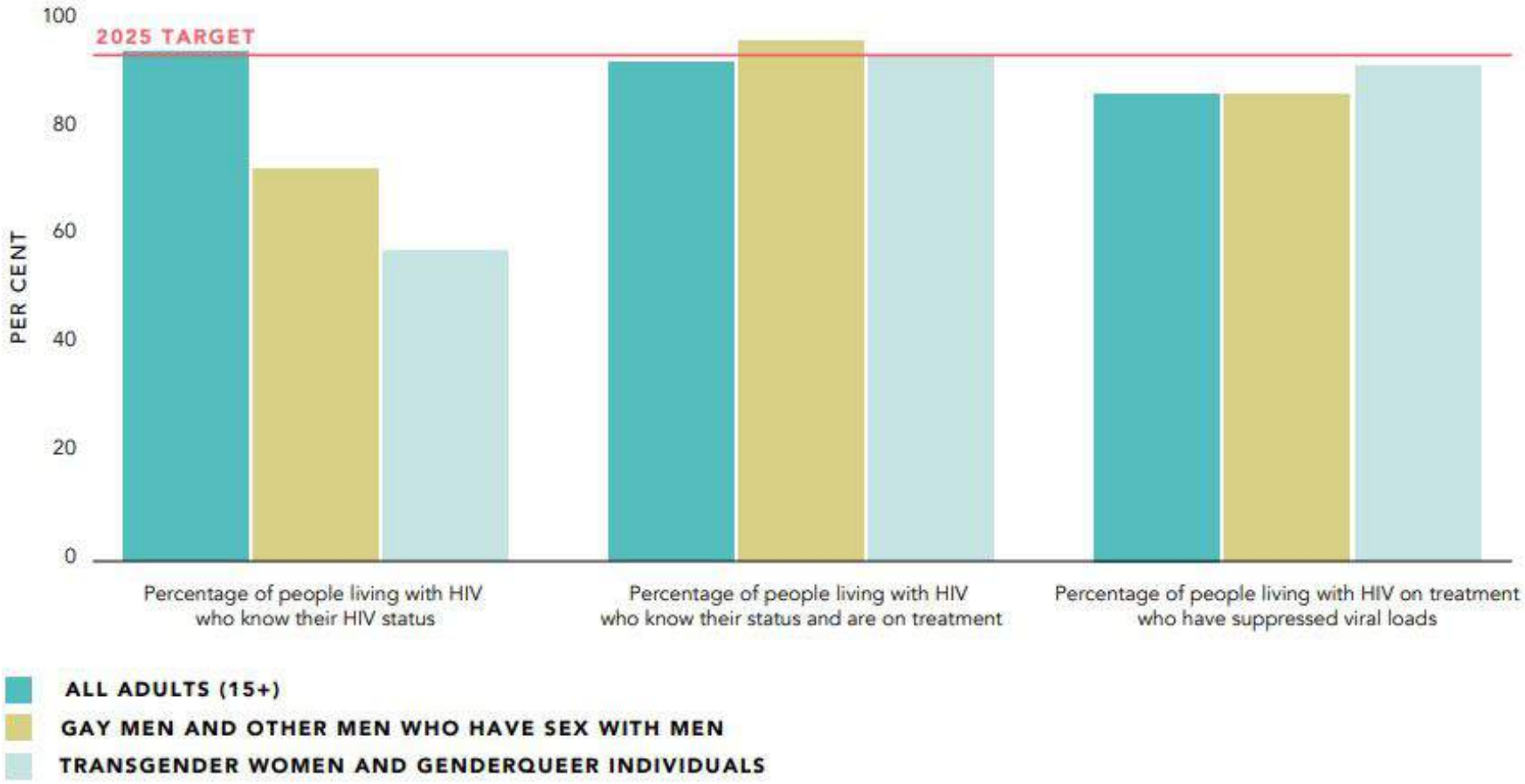
Note: "HIV prevention programmes coverage" refers to the key populations that reported receiving at least two prevention services in the past three months. Possible prevention services received included: condoms and lubricant and counselling on condom use and safer sex (all key populations); testing for sexually transmitted infections (sex workers, transgender people and gay men and other men who have sex with men); and sterile injecting equipment (people who inject drugs).

# HIV testing and status awareness among key populations, global, 2017–2021


Source: UNAIDS Global AIDS Monitoring, 2022 (https://aidsinfo.unaids.org/).

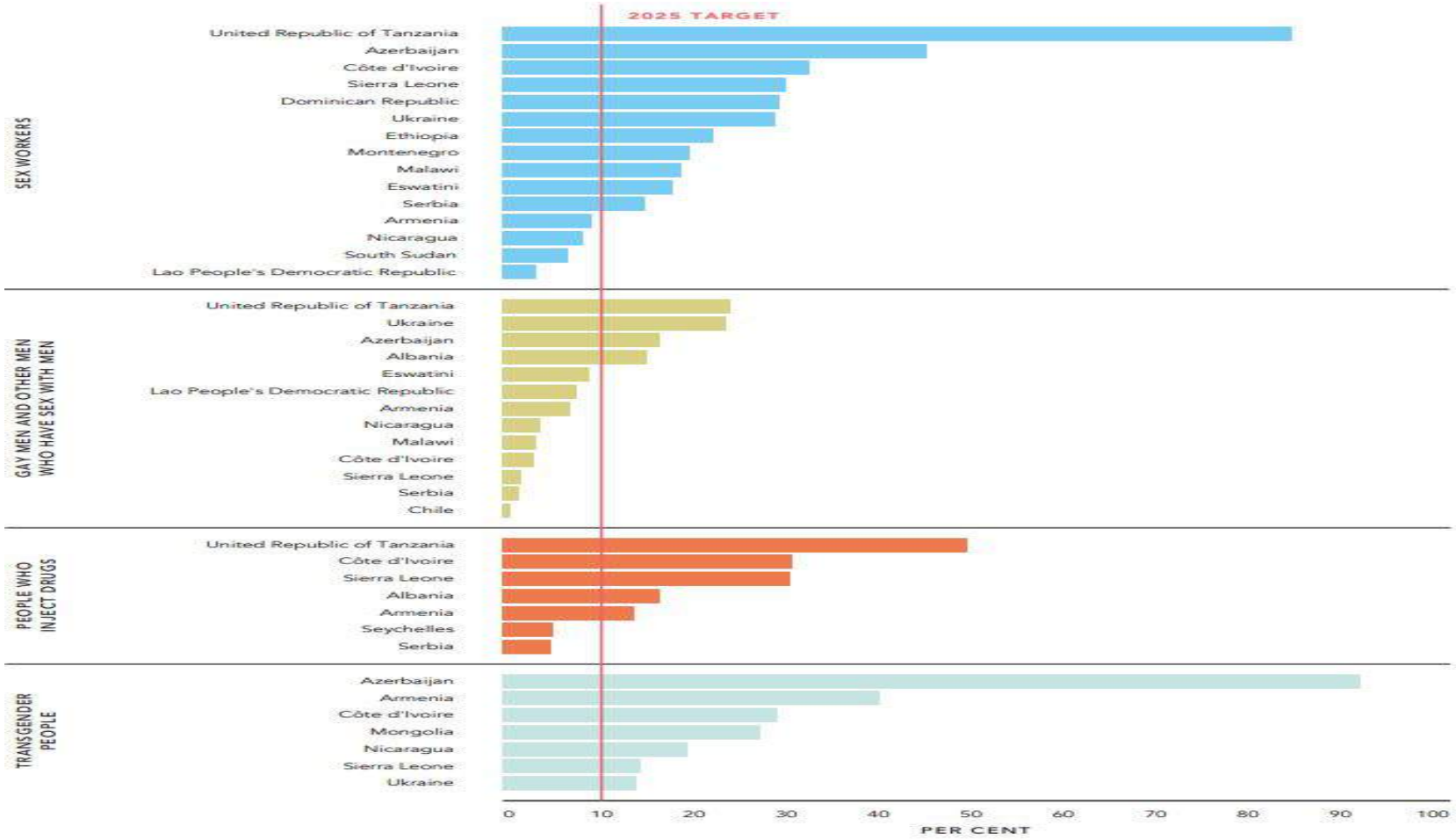
Note: Data include members of key populations who have been tested in the past 12 months and know that their results are negative, and ever-tested members of key populations who know that they are living with HIV.

# Inequalities in progress towards the 95–95–95 targets, by population, Zimbabwe, 2019




Source: UNAIDS epidemiological estimates, 2022 (https://aidsinfo.unaids.org/); Harris TG, Wu Y, Parmley LE, Musuka G, Mapingure MP, Chingombe I et al. HIV care cascade and associated factors among men who have sex with men, transgender women, and genderqueer individuals in Zimbabwe: findings from a biobehavioural survey using respondent-driven sampling. Lancet HIV. 2022;9(3):e182-e201.

# Key populations reporting having experienced physical and/or sexual violence in the last 12 months,

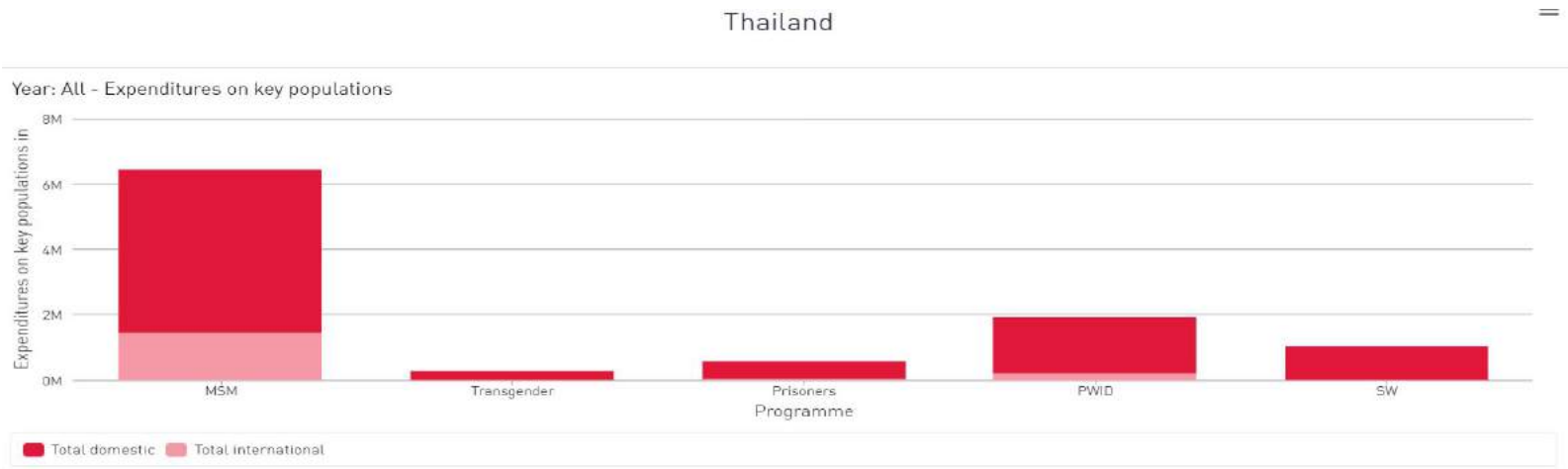


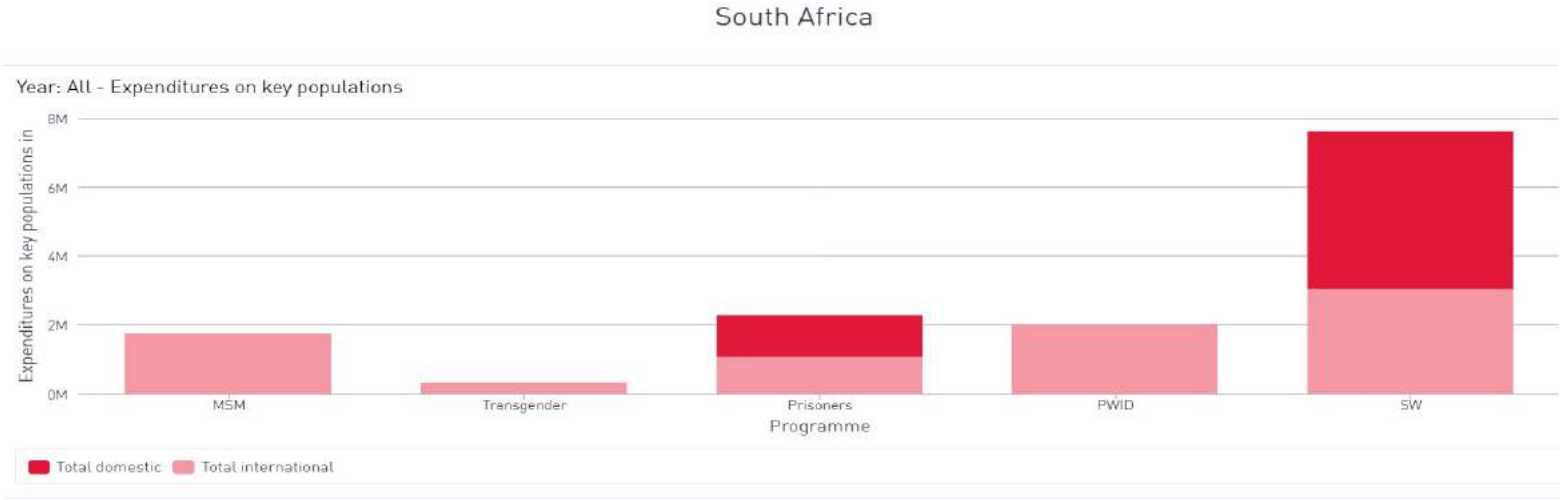

Source: UNAIDS Global AIDS Monitoring, 2022 (https://aidsinfo.unaids.org/).

# Countries with discriminatory and punitive laws,


Sources: UNAIDS National Commitments and Policy Instrument 2017–2022 (see http://lawsandpolicies.unaids.org/), supplemented by additional sources (see references in 'Laws and policies scorecard' figures in applicable regional profiles).

# Expenditures by countries on key populations programming, 2021



# Will we control AIDS by 2030?

**Yes, but only if we:**

- Expand prevention services for key populations (among others) in every country
- Expand HIV testing and treatment opportunities AND uptake for key populations

**The above only happens if:**

- Laws and policies are protective and supportive of key population communities
- Stigma and violence toward the different communities are reduced to nil

**The above only happens if:**

- Countries make serious commitments to address key populations which include budgetary commitments
- Countries admit the populations exist and show that they count by counting them

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# Data resources

AIDSInfo.unaids.org

Global AIDS Update 2022

World AIDS Day Report 2021

# USE OF ROUTINE DATA TO ANSWER PROGRAM-RELEVANT QUESTIONS

KATE RUCINSKI & AMRITA RAO

## OUTLINE

**Routinely collected program data**

- What is routinely collected data?
- Challenges and opportunities
- Developing questions of impact

**Example analyses using program data**

1. Patterns of PrEP use among FSW and AGYW in South Africa
2. Impact of implementation strategies on PrEP persistence among FSW and AGYW in South Africa
3. Extrapolation of population size estimates for FSW and MSM in Namibia

# ROUTINELY COLLECTED DATA

# Routinely collected data (Nicholls et al. 2018)

- Data collected for purposes other than research or without specific research questions developed prior to collection

- These data can support **1) clinical management** of patients or service users, and/or **2) monitoring and evaluation** of program activities

## Examples

- Clinical information from health records
- Health administrative data (e.g. claims or receipts of payment)
- Program registers
- Epidemiologic Surveillance Systems

# Process of data collection and capture

Clinical encounter between professional nurse/nurse counselor and the client (initiation or follow-up visit)

Nurse records information on paper **PrEP clinical form**

Form is stored in a folder with other client forms, and this folder is stored in a secure file cabinet

Folders are reviewed once a week by data capturers, and new data are entered in a single electronic **PrEP register**, one per site

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Possibility of data entry and linkage errors

# Using program data: challenges and opportunities

## Challenges

- Often incomplete or messy
- Challenging to access and obtain individual-level data
- Difficulty linking individuals over time (switching to different clinics, moved out of the area)
- Competing priorities to data collection

## Opportunities

- Data from real-world setting
- Already being collected, so does not involve additional person power or data collection costs
- Can help in studying much larger groups of people
- Answer questions that would otherwise be unethical or too expensive to study

# Development of questions of impact: a partnership

- Create research-practice partnerships or develop research capacity in-house

- Questions developed should be responsive to program needs and gaps in knowledge
    - Demand for services
    - Available resources
    - Implementation
    - Identification of hotspots (geographic, by population group, etc.)

- Continuous feedback from on the ground service providers about findings and adaptation

# Opportunity for impact

- Add rigor in evaluation of existing systems
- Answer program-relevant questions, while improving and strengthening systems
    - How data are **captured**
    - How data are **managed**
    - How data are **used**

# CASE STUDY EXAMPLES USING PROGRAM DATA

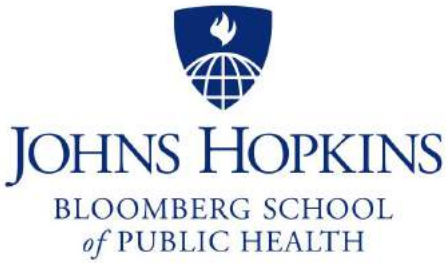
# 01

Examine patterns of PrEP initiation, discontinuation, re-initiation, and cycling among FSW and AGYW who initiated PrEP in South Africa

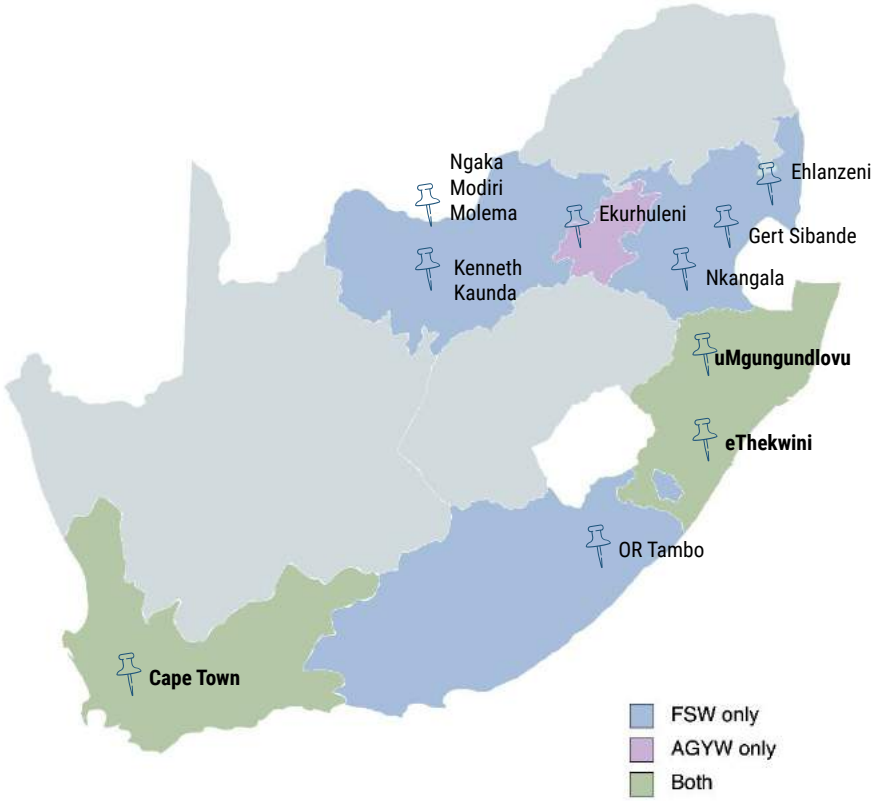
# Research – practice partnership


## TB HIV Care and Johns Hopkins University

- Longstanding research-practice partnership between TB HIV Care and JHU
- Data were reviewed together and questions were developed to be responsive to program needs and gaps in knowledge
- Adding methodologic rigor to the evaluation and understanding of existing systems



# Study population




Female sex workers and adolescent girls and young women receiving prevention services through TB HIV Care

Women would have been eligible if they were accessing other prevention services (testing for pregnancy or STIs; family planning) and were HIV negative

Multiple TB HIV Care Sites across 6 provinces

FSW: June 2016 - August 2021

AGYW: May 2018 - September 2020

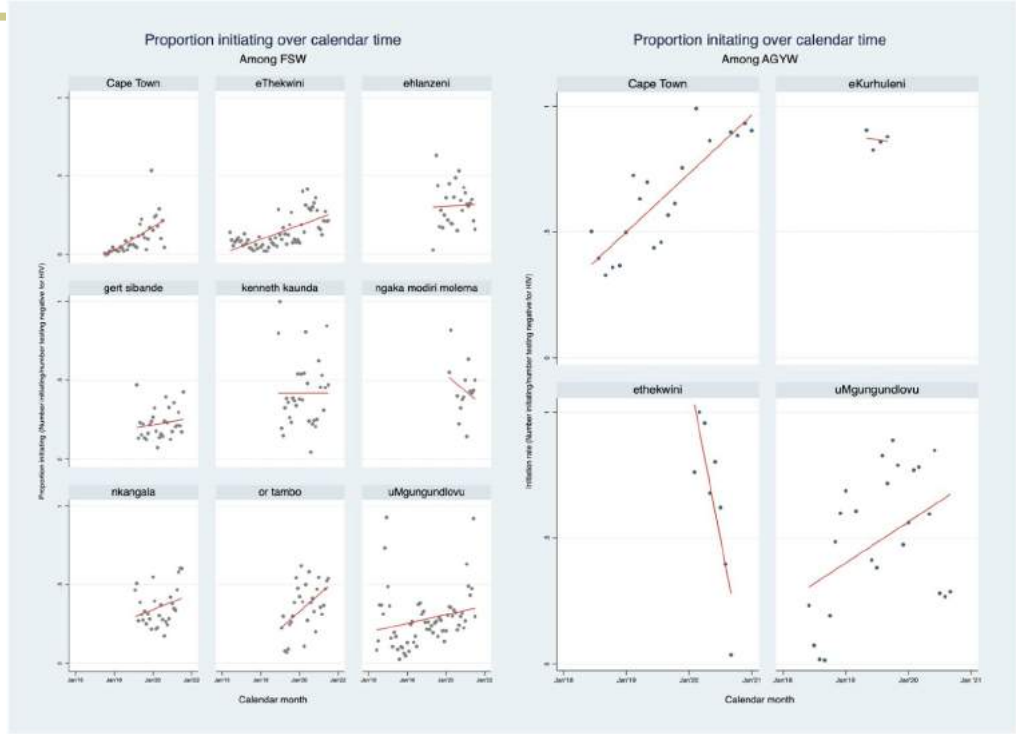
# 01) Examine patterns of PrEP initiation, discontinuation, re-initiation, and cycling among FSW and AGYW who initiated PrEP

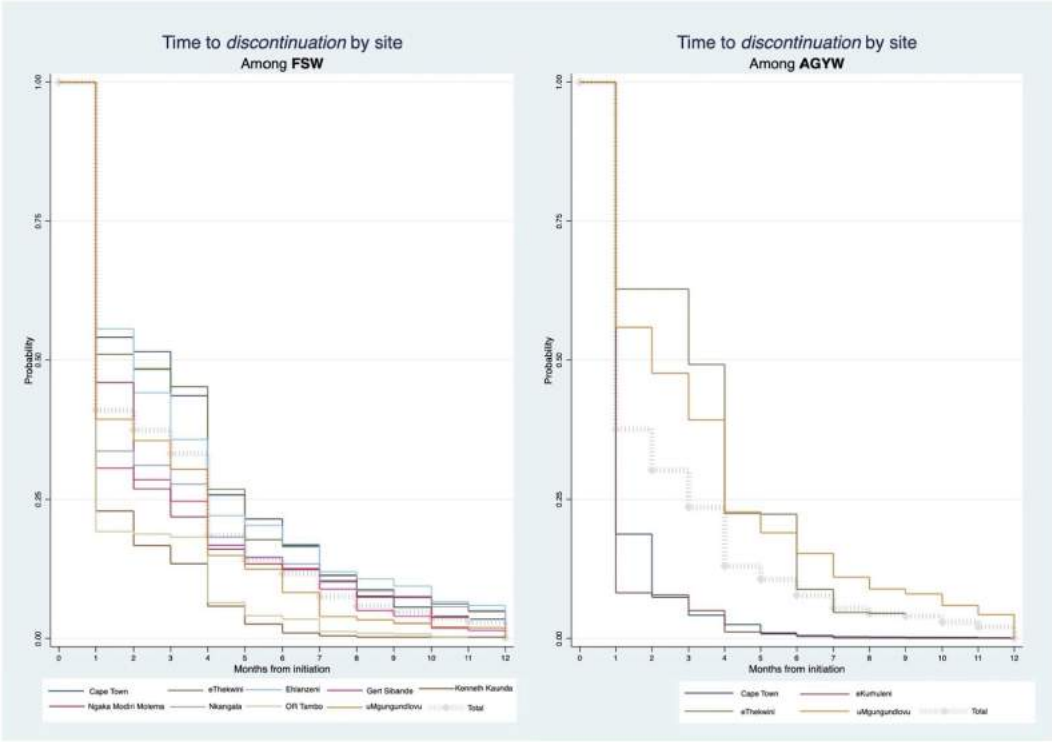
ANALYSIS

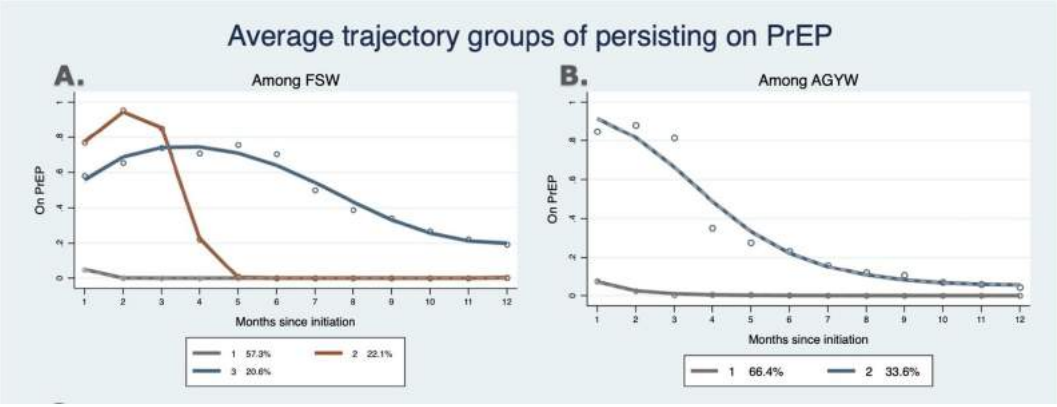
| | |
|---|---|
| Plotted the monthly proportion of eligible HIV negative encounters who initiated PrEP over **calendar time** | Initiation (monthly) |
| Estimated time to PrEP discontinuation and plotted Kaplan-Meier survival curves | Discontinuation |
| Estimated time to re-initiation and plotted cumulative incidence using complement of KM curves | Re-initiation |
| Group-based trajectory modeling | Cycling |

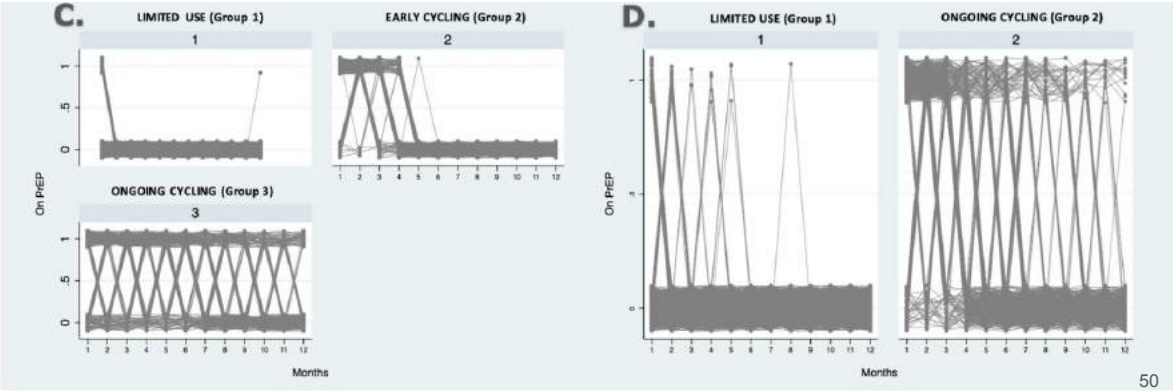
# 01) Examine patterns of PrEP initiation, discontinuation, re-initiation, and cycling among FSW and AGYW who initiated PrEP

RESULTS



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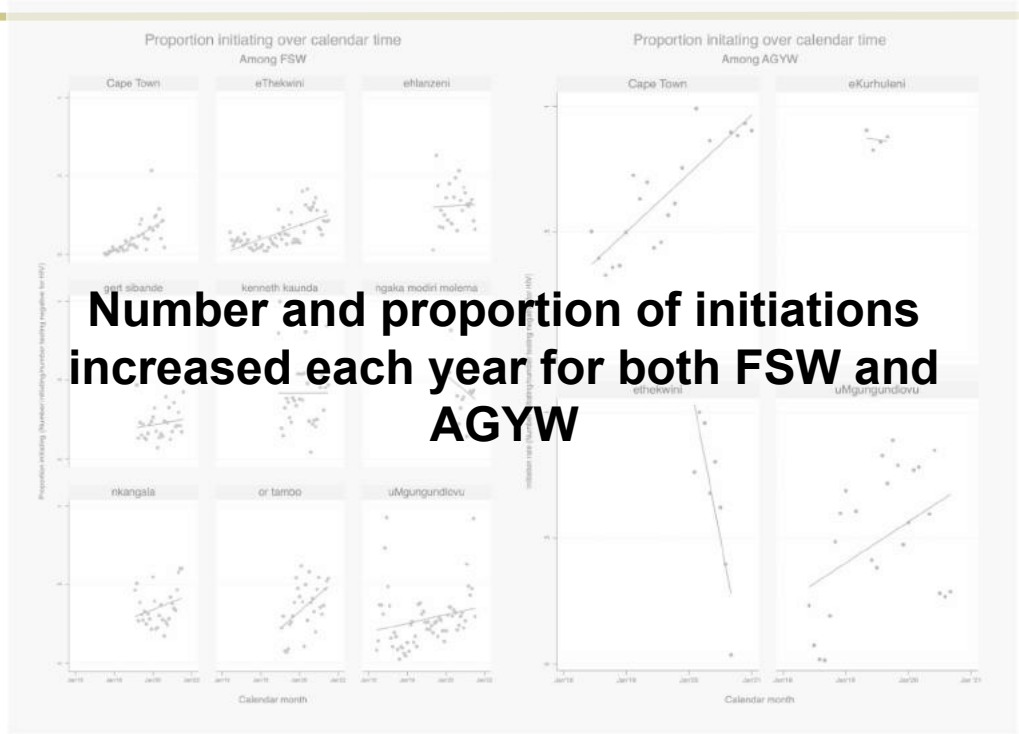
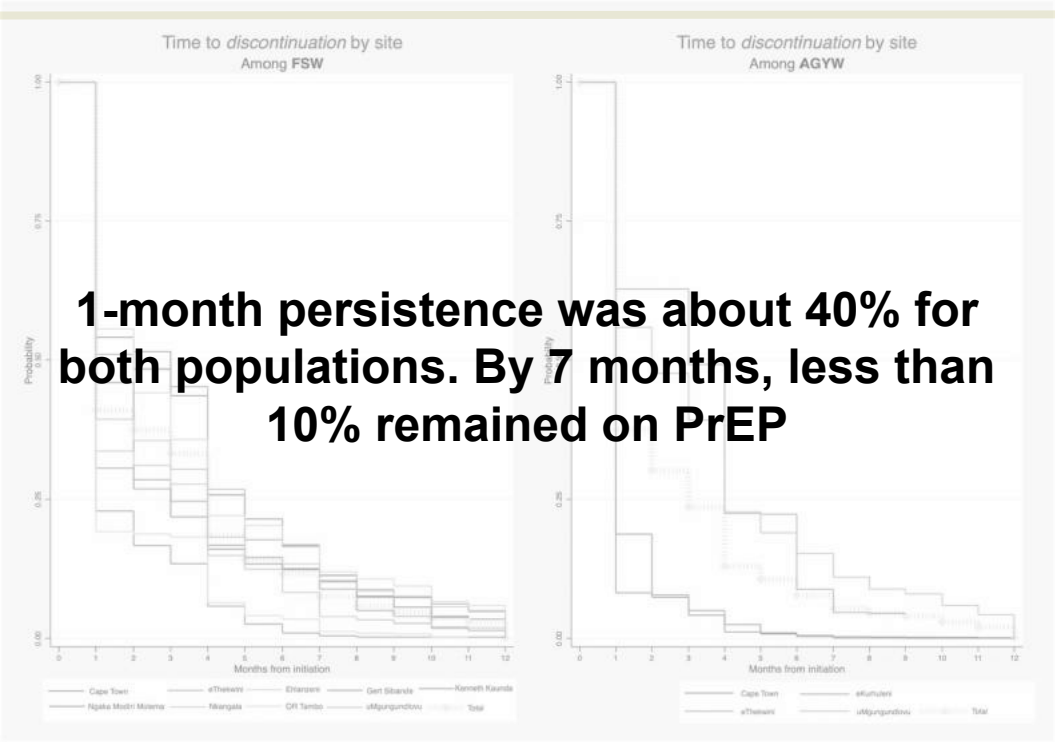
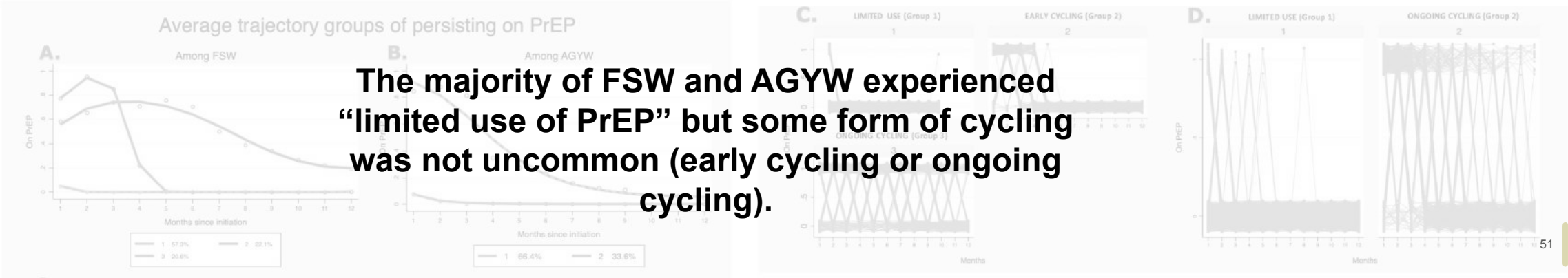
RESULTS




**Number and proportion of initiations increased each year for both FSW and AGYW**




**1-month persistence was about 40% for both populations. By 7 months, less than 10% remained on PrEP**




**The majority of FSW and AGYW experienced "limited use of PrEP" but some form of cycling was not uncommon (early cycling or ongoing cycling).**

# 02

Evaluate the impact of implementation strategies on PrEP persistence among FSW and AGYW served by TB HIV Care

# 02) Evaluate the impact of implementation strategies on PrEP persistence among FSW and AGYW served by TB HIV Care

OUTCOME

**PrEP persistence at one month**

Whether or not a client returned to pick up her PrEP refill at one-month following initiation

Data at the individual level were **aggregated to produce monthly site-specific counts** of the number of women who picked up their 1-month PrEP refills and counts of the number of women who initiated PrEP in the prior month (who would be expected to pick up a PrEP refill)

# 02) Evaluate the impact of implementation strategies on PrEP persistence among FSW and AGYW served by TB HIV Care

STRATEGIES

- **WhatsApp support groups**: groups of PrEP users where members can discuss successes and challenges in using PrEP

- **Clinical mentoring for providers**: weekly meetings conducted with PrEP providers, led by a nurse clinician or clinical trainer to review best practices for PrEP provision
- **Mobile van PrEP provision**: decentralized delivery of PrEP in the community using a TB HIV Care mobile van

- **SMS PrEP refill reminder**: text messages sent one week before and one day before scheduled refill
- **Generic SMS support**: text messages of support sent once a week designed to empower and promote self efficacy
- **Loyalty rewards program:** incentives in the form of airtime (credit used to make calls, send texts, or access the internet) for initiating and returning for PrEP visits
- **Case management approach**: Nurse clinicians and assigned case managers provide dedicated follow-up of PrEP users to support and guide with HIV prevention care

# 02) Among FSW

RESULTS

We evaluated the independent impact of…

1) clinical mentoring for providers

2) SMS refill reminders and support texts

3) case management approach, and

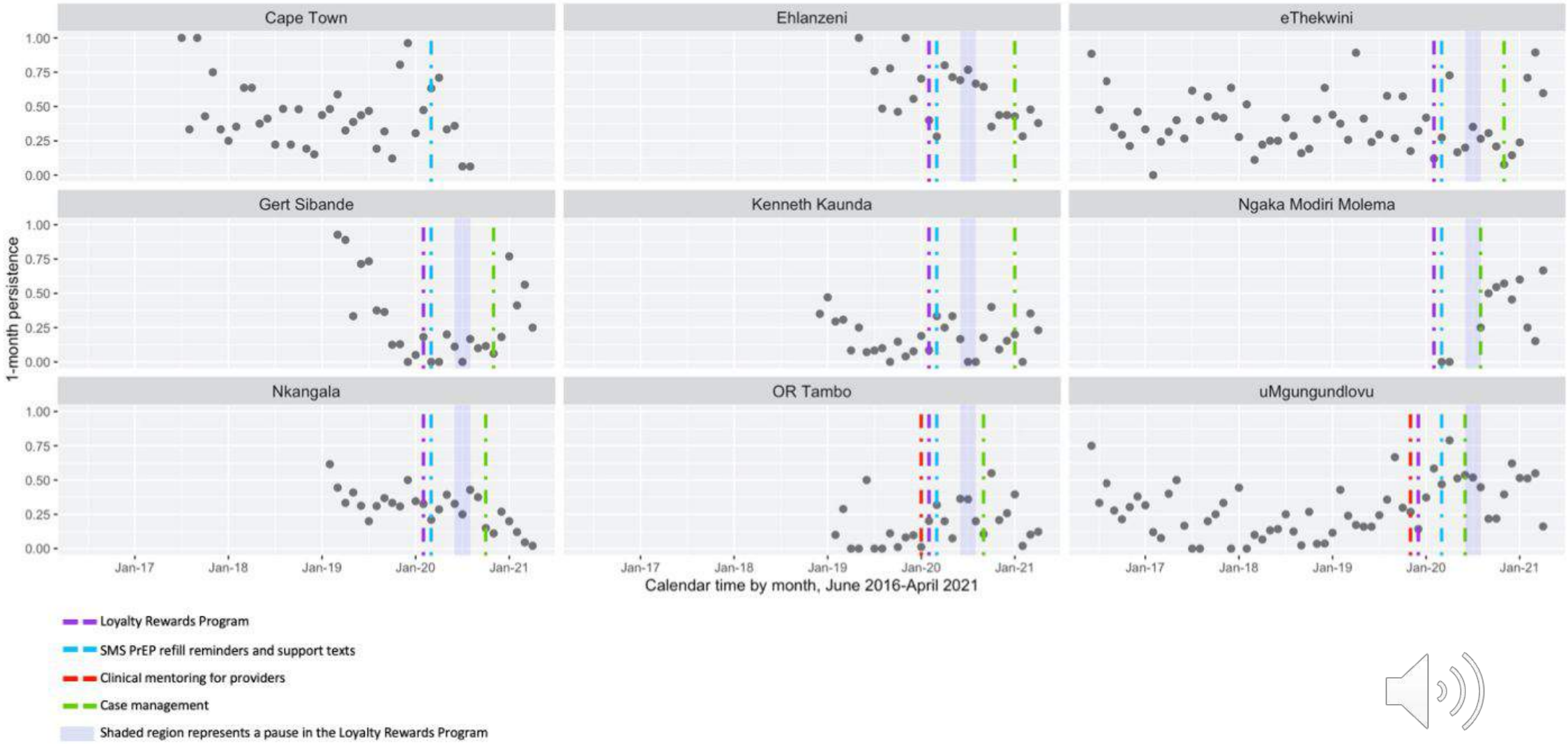
4) loyalty rewards program

$$Y_t = \beta_0 + \beta_1 T + \beta_2 X_1 + \beta_3 X_2 + \beta_4 X_3 + \beta_5 X_4 + \beta_6 (COVID) + offset(person\ time)$$

Where X1 represents clinical mentoring for providers, X2 represents SMS PrEP refill reminders and support texts, X3 represents the case management approach, and X4 represents the loyalty rewards program

# 02) Among FSW

RESULTS



# 02) Among FSW

RESULTS

Introduction of **clinical mentoring for providers** was associated with a **12%** increase in 1-month persistence (95% CI: 1.03, 1.23).

Introduction of **SMS support and refill reminders** was associated with a **33%** increase in 1-month persistence (95% CI: 1.18, 1.50).

Introduction of **the case management approach** was not associated with any increase in 1-month persistence (95% CI: 0.92, 1.13).

Introduction of **the loyalty rewards program** was associated with a **26%** decrease in 1-month persistence (95% CI: 0.67, 0.82).

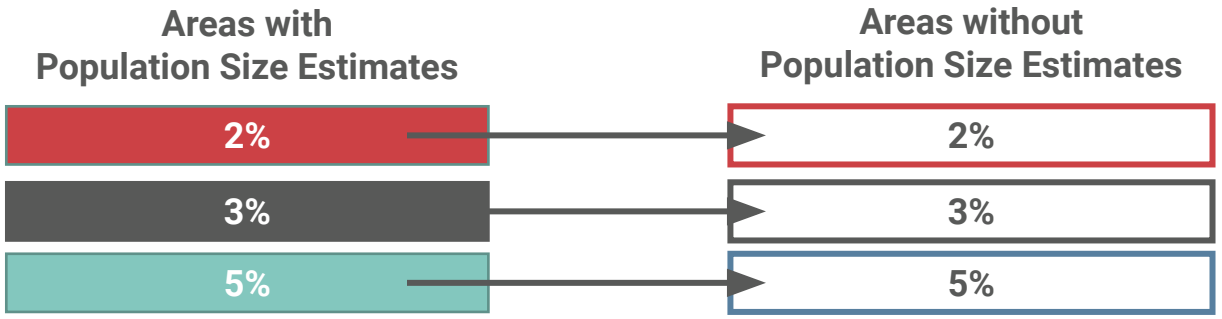
# 03

# Extrapolation of population size estimates for FSW and MSM in Namibia

# 03) A lack of reliable population size estimates (PSE) for key populations contributes to gaps in knowledge across the HIV cascade

- Size estimates are among most volatile, unreliable estimates in HIV public health
- Nonexistent in rural, remote areas and/or settings with most unmet needs
- Small area estimation can help fill in gaps

**Program data are typically excluded from small area estimation approaches**



# 03) In Namibia, differences in PSEs exist within and across regions for FSW and MSM

Table 1. Direct Estimates (2012-2014, 2019), n (95% CI), by Key Population and Region*

| KP | Region | Direct Estimation Method | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Mapping | Key Informant Interview | Unique Object Multiplier | Wisdom of the Crowds | Literature Review | Stakeholder Consensus | SS-PSE |
| FSW | Zambezi | 284 (142-426) | 300 (50-4300) | 5299 (3500-8575) | 300 (100-1000) | 84 (47-251) | 800 (380-2000) | 674 (318-2426) |
| | Ohangwena | 158 (79-237) | 100 (30-800) | 1494 (1249-1822) | 500 (300-1000) | 85 (47-254) | 900 (775-2750) | 900 (775-2750) |
| | Erongo | 322 (161-483) | 330 (200-1000) | 2352 (1597-4557) | 700 (200-2000) | 241 (134-723) | 900 (825-1500) | 1057 (576-3369) |
| | Khomas | 528 (264-792) | 100 (50-1700) | 5240 (3373-11706) | 600 (200-1500) | 1582 (1055-2110) | 3000 (1800-3400) | 2196 (1651-2382) |
| MSM | Karas | 282 (141-423) | 1132 (200-2948) | 1714 (1292-2359) | 100 (40-400) | 84 (24-138) | 500 (300-650) | - |
| | Oshana | 78 (39-117) | 2000 (250-5184) | 3538 (2379-5632) | 150 (50-500) | 157 (45-259) | 500 (350-800) | - |
| | Erongo | 488 (244-732) | 100 (70-300) | 2982 (2013-5808) | 70 (40-250) | 427 (122-701) | 610 (475-658) | 670 (410-1610) |
| | Khomas | 460 (230-690) | 300 (100-1600) | 2229 (1699-3240) | 400 (no bounds available) | 1207 (345-1983) | 2416 (850-4000) | 2210 (382-10410) |

*Data collected between 2012-2014 and 2019[18,19]

Source: Loeb et al. (in prep)

# 03) Program data may be used to “ground truth” for key populations

- Quarterly data provided by community-based HIV service providers can approximate the number of individuals engaging with HIV programs
- While imperfect, can cumulatively function as a lower bound for PSEs in districts or regions where services are being provided

**How can we systemize the integration of program data in small area estimation approaches?**

# 03) Triangulating multiple PSEs using prior beliefs via a consensus-estimation approach

- Triangulator (formerly Consensus Estimator) developed by Dr. Ian Fellows et al. (https://epiapps.com/shiny/app_direct/shinyproxy_combine_estimates/)

- Leverages known information about the distribution of each population to inform a singular estimate for each region

- Weights each direct estimate based on user-defined confidence (e.g., multiplier methods may be more rigorous than wisdom of the crowd methods)

# 03) Weighting PSEs based on quality of study implementation and prior beliefs

- PSE methods ranked by level of confidence (0-100)
- Internal "tests" explored varying levels of confidence to calculate triangulated PSEs for each region
- Prior beliefs for the distribution of the derived size estimates were defined based on quarterly program data

Supplemental Table 1. Example Determination of Confidence Values, FSW in Zambezi

| | **Design Confidence** | | |
|---|---|---|---|
| **Method** | **Test 1** | **Test 2** | **Test 3** |
| Mapping | 75 | 75 | 85 |
| Key Informant Interview | 55 | 60 | 65 |
| Unique Object Multiplier | 85 | 85 | 95 |
| Wisdom of the Crowd | 40 | 40 | 50 |
| Literature Review | 60 | 60 | 70 |
| Stakeholder Consensus | 65 | 60 | 75 |
| SS-PSE | 90 | 90 | 99.9 |
| | **Results from Consensus Estimator Tool** | | |
| | **Test 1** | **Test 2** | **Test 3** |
| **Median (SD)** | 429.29 (90.91) | 425.34 (92.66) | 367.62 (66.58) |

Source: Loeb et al. (in prep)

# 03) Changes in extrapolated PSE proportions after including program data

FSW

Table 2. Absolute and Proportion Estimate Differences in FSW Extrapolated Estimates Before and After the Integration of Programmatic Data

| | **Simple Imputation** | | **Stratified Imputation, HIV Prevalence** | | **Stratified Imputation, Population Density** | |
|---|---|---|---|---|---|---|
| Stratified Imputation | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion |
| Greater than Median | 0.019 | 0.028 | 0.026 | 0.040 | 0.011 | 0.034 |
| Less than/Equal to Median | | | 0.014 | 0.012 | 0.028 | 0.010 |

MSM

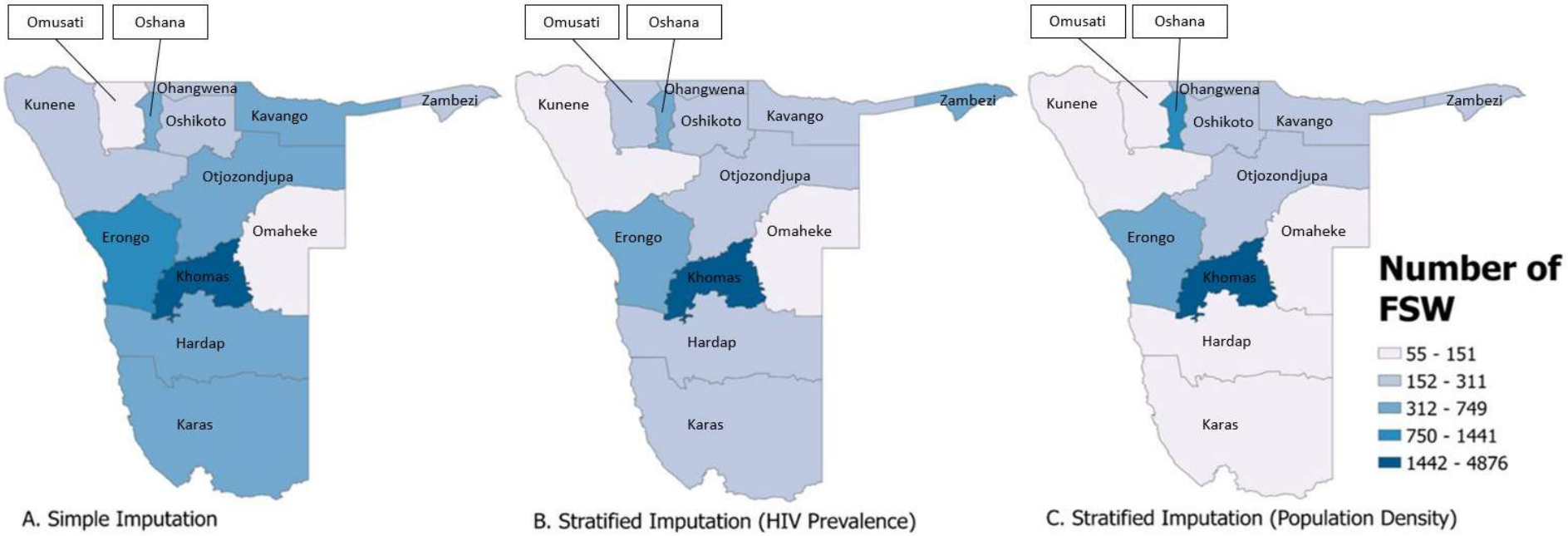
Table 3. Absolute and Proportion Estimate Differences in MSM Extrapolated Estimates Before and After the Integration of Programmatic Data

| | **Simple Imputation** | | **Stratified Imputation, HIV Prevalence** | | **Stratified Imputation, Population Density** | |
|---|---|---|---|---|---|---|
| If Stratified Imputation | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion | Pre-Programmatic Data Proportion | Post-Programmatic Data Proportion |
| Greater than Median | 0.015 | 0.0075 | 0.021 | 0.008 | 0.014 | 0.0045 |
| Less than/Equal to Median | | | 0.013 | 0.007 | 0.015 | 0.010 |

Source: Loeb et al. (in prep)

# 03) Among FSW

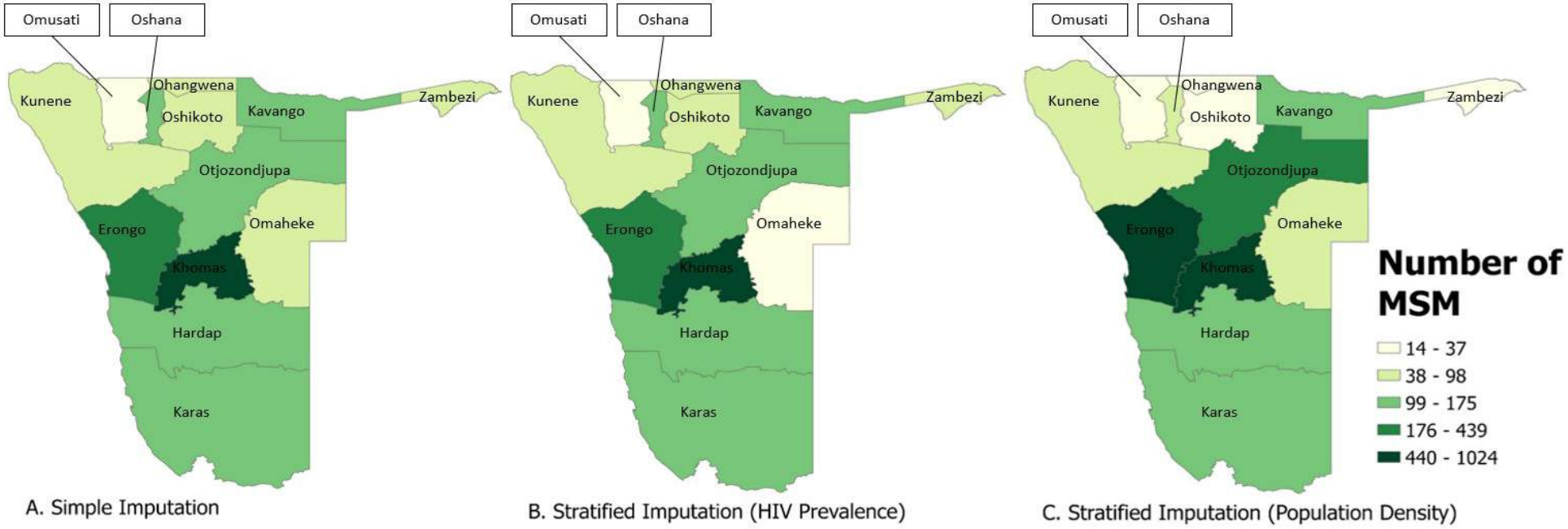
**Extrapolated national estimates** ranged from 4777 to 13148, comprising **1.5% to 3.6%** of **women ages 15-49**




Source: Loeb et al. (in prep)

# 03) Among FSW

**Extrapolated national estimates** ranged from 4611 to 10171, comprising **0.7%-1.5% of men ages 15-49**




Source: Loeb et al. (in prep)

# 03) Summary of implications

- Using SAE approaches, we combined epidemiologic and program data to generate subnational size estimates for key populations in Namibia

- The inclusion of program data increased the proportion of FSW in high-density/high HIV prevalence regions and decreased the proportion of MSM in all regions

- Future work is needed to determine how best to include program data in KP size estimation studies, ultimately bridging research with practice to support a more comprehensive HIV response.

# DISCUSSION

# Program data present an opportunity for:

- Collaboration
- Repurposing existing data and analyses and infusing additional methodologic rigor
- Shedding light on program-relevant questions

## WITH THANKS

**Questions?**

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Data.FI
Data for Implementation

JOHNS HOPKINS
BLOOMBERG SCHOOL of PUBLIC HEALTH

PEPFAR

TBHIVCARE

USAID
FROM THE AMERICAN PEOPLE

# PRIORITY

Mentimeter

# PRACTICAL APPROACHES TO IMPLEMENTING A MONITORING & EVALUATION SYSTE TO MONITOR PROGRESS OF KP PROGRAMME

Keshab Deuba and Neeti Sedhain, Nepal
Peter Mudioppe, Uganda

# PRACTICAL APPROACHES TO IMPLEMENTING A M&E SYSTEM TO MONITOR PROGRESS OF KP PROGRAM: THE CASE OF NEPAL

KESHAB DEUBA AND NEETI SEDHAIN

## OUTLINE

- Background on DHIS2 tracker-based information system to strengthen M&E of HIV program. What issues we wanted to solve?
- Features and benefits of the developed DHI2 Tracker information system to monitor and evaluate KP program
- Conclusions

# Background: Information system challenges to monitor progress

- Once individual infected with HIV, she or he has to enroll in treatment for whole life. Recoding of treatment details and analyzing/reporting its outcomes using paper-based registers is not feasible.

- Existing system unable to track duplication of cases across the sites due to lack of unique identifier system. Reported aggregated data. (overestimation of ART Coverage, double reporting of same patient/client to system etc.)

- We don’t know in real time ‘what intervention/program working or what’s not’ due to no individual-level information of PLHIV who enrolled in HIV care?  Ex. Not possible to know characteristics/reasons of poor performance of clients in HIV care (adherence, retention, treatment failure etc.)

# Background: Information system challenges to monitor progress

- Time consuming to prepare report manually and submit aggregated monthly data to system. Difficult to generate real time or at least latest data of clients in HIV care (On ART, LTFU, Death etc.)

- Lack of coordination and cooperation among healthcare workers in the R&R of HIV data is caused by the vertical donor-specific information system, resulting in a lack of synergy in their efforts.

# What issues we wanted to solve?

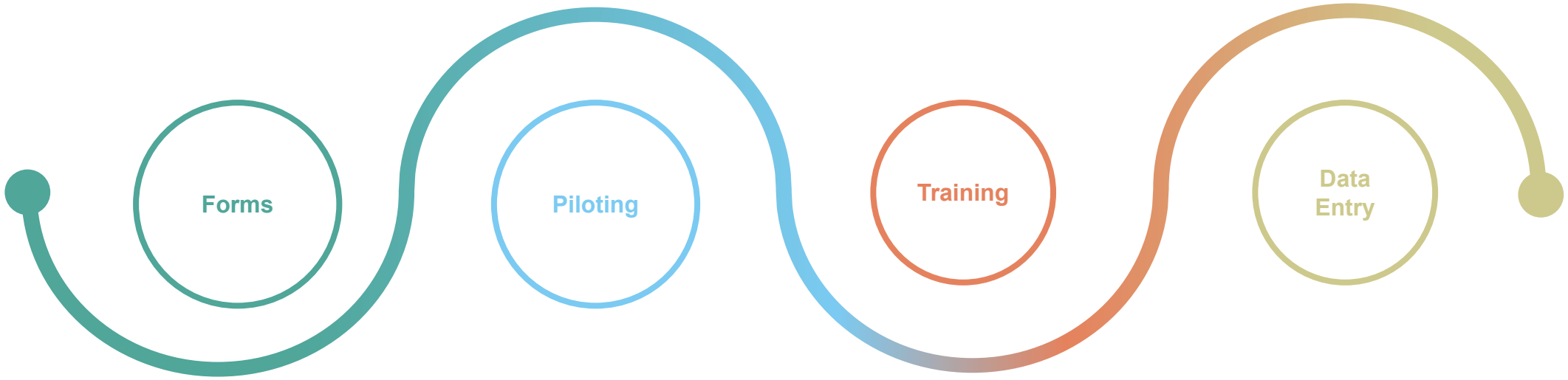
**A patient-centered concept that would:**

- prevent duplication of patient records,
- provide easy access to individual-level data at all levels
- generate data for the entire HIV continuum, ensuring a unified source for recording and reporting HIV-related data to the national HMIS.
- to facilitate monitoring outcome and impact indicators or program planning and help health workers offer custom care services to KPs and PLHIV based on their specific needs at any given time.

**Solution involved using DHIS2 Tracker:**

- to collect individual-level data for whole HIV continuum;
- integrating DHIS2 with a biometric system for client/ patient enrollment and verification;
- and interconnecting an existing mHealth system used to generate SMS notifications to PLHIV for improved retention in care.

# With Leadership of Government And Financial/Technical Support From FHI360/PEPFAR, Save The Children/ Global Fund Programs and Others developed Information System




## Forms developed

All the partners required variables identified considering NHSP, GAM and donor reporting requirement

## Piloting

Developed forms piloted and feedback received and shared with developer

## Users Trained

User Manual Developed

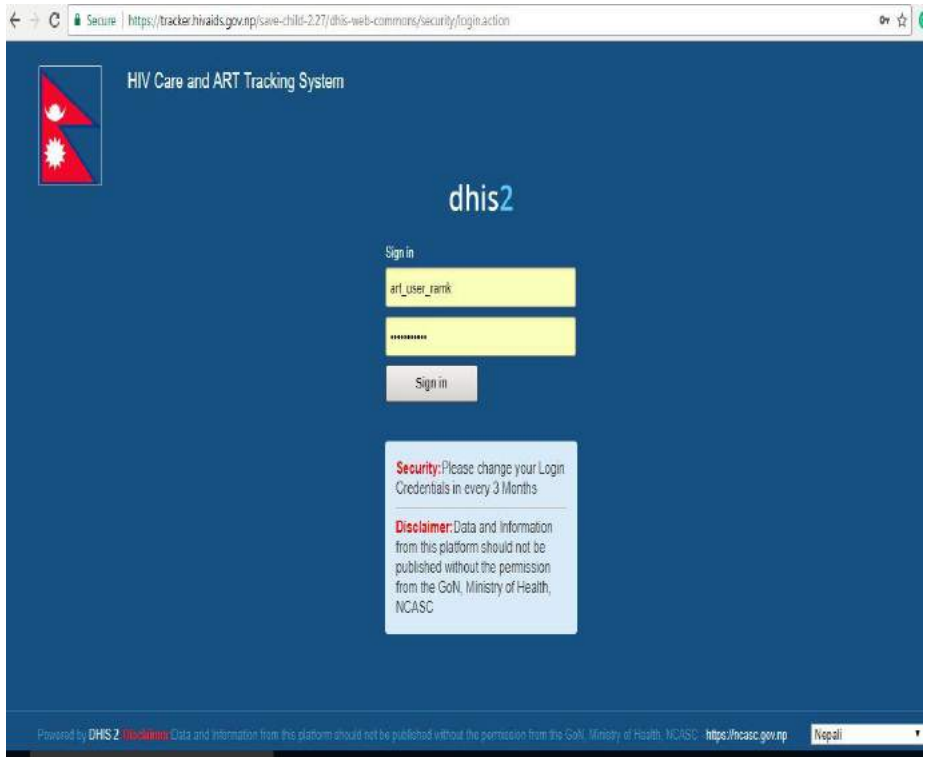
HWs trained in all seven provinces of Nepal

## Data Entry

Resource (RAM, Hard disk, NAS) upgraded, and data entered after addressing minor feedbacks and user details

Program indicators /Dashboard developed

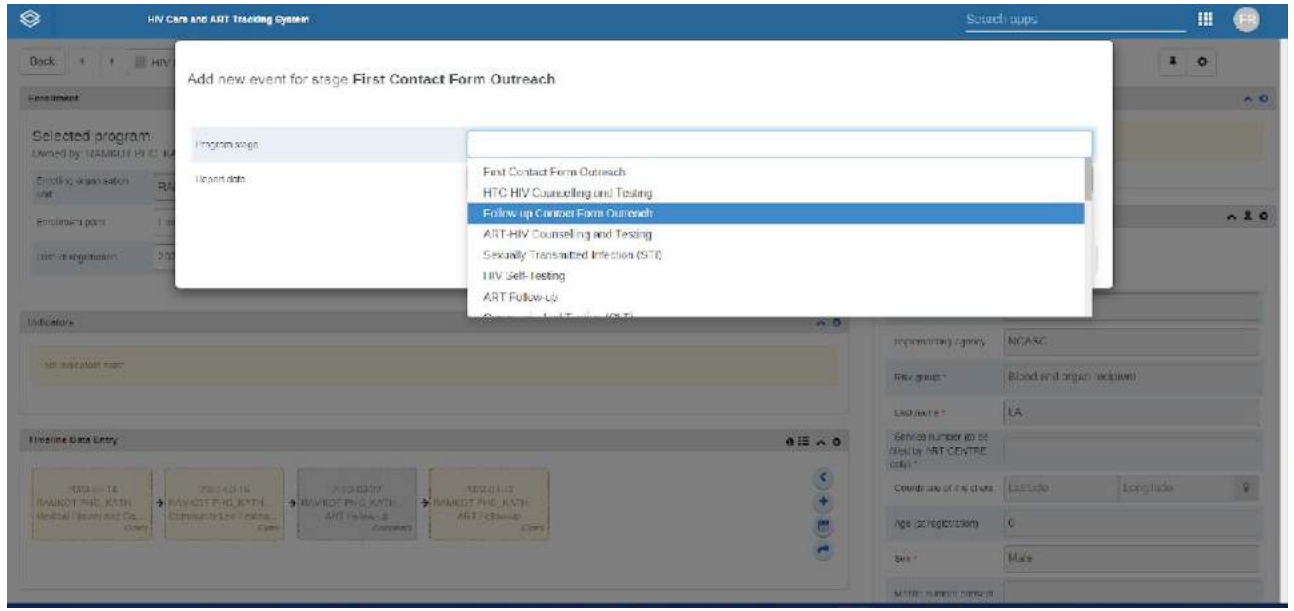
# HIV care and ART tracking system features



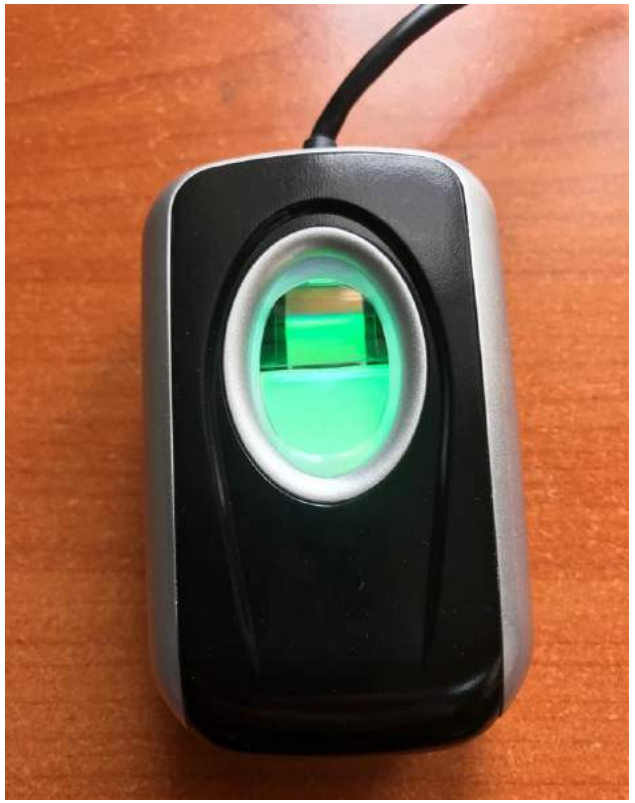

# DHIS2 Tracker capture app allows the following functionalities:

- **Registration and enrolment of the client** in the HIV program

- **Referring client** from HIV prevention, to testing and if found HIV positive then to ART, and ART to ART for follow-up visits or Care and Support services.



# Biometric system



- Help us to **identify existing patient** using Biometric Device and link to access the **patient dashboard in DHIS2 Tracker**

- **Add new patient into system**. Link to add patient details in the ‘DHIS2 Tracker Capture’ app.

- Updating fingerprints of a patient referred from **HTC with the Client Code and Referral Slip**

# Linking DHIS2 Tracker and mHealth

- **Third party SMS gateway has been linked with DHIS2 for sending SMSs** to the enrolled PLHIV who have given consent for being part of the mHealth program.

- Custom scripts based on a scheduler are used to filter the patients, the **type of message and periodicity of the SMSs** being sent.

# Linking DHIS2 Tracker and Biometric System

- Two apps have been developed for the Biometric integration, one on server side bundled with the DHIS2 war file, and a client-side app installed on the end user PC.

- A PC has been exclusively set-up as the fingerprint server, the DHIS2 server interacts with the fingerprint server for patient identification via a configuration file.

- Fingerprint reader captures the client's fingerprint through the client-side app and generates a Fingerprint ID which is sent to the fingerprint server, and DHIS2 server to get stored as one of the patient's attributes.

- Please follow the link for biometric code: https://github.com/hispindia/Biometrics-Nepal

# mHealth

- Event can be scheduled in Tracker so that text messages (SMS) reminders can be sent in mobile of patient for specific purpose specially **to improve retention in HIV treatment**

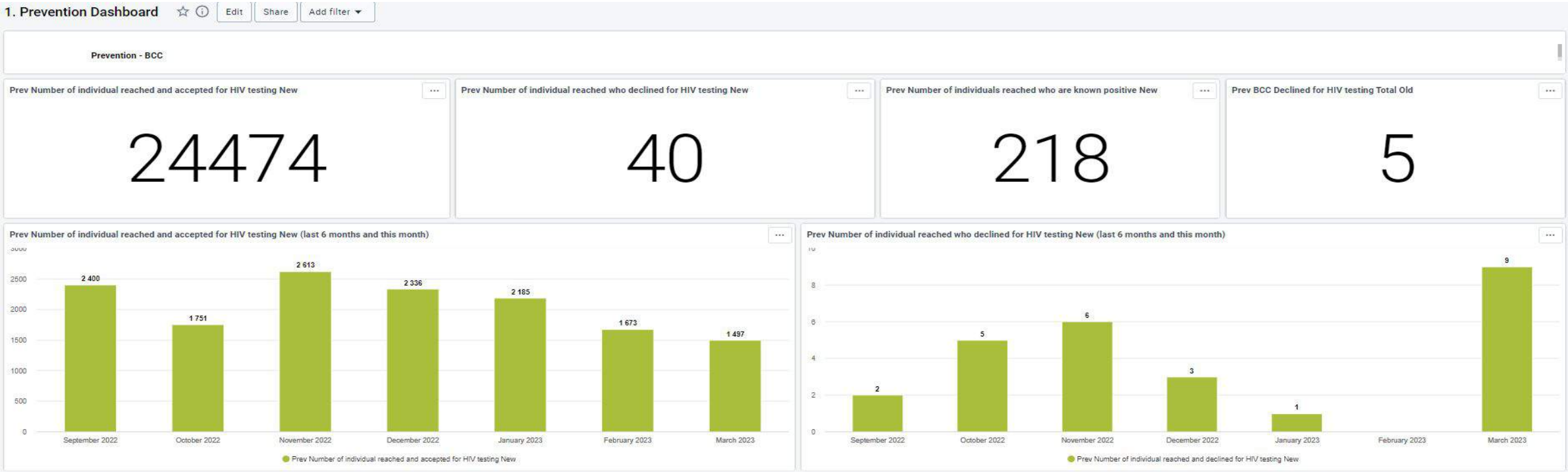
- System can push **two types of text messages** in mobile of patient :
  1. Appointment reminders for pill pick up, CD4 test, viral load test, EID test etc.
  2. General awareness messages for positive prevention, eVT, importance of regular health check-up etc..

- All text messages developed in Nepali.

# Total Program Indicators/ Indicators in HIV Care and ART Tracking System to Monitor Progress of KP Program

| | Prevention | Testing | STI | Treatment | Care and support | Total |
|---|---|---|---|---|---|---|
| Program indicators/indicators already developed | 100 | 54 | 2 | 749 | 17 | 922 |
| **Program indicators/indicators to be developed** | **952** | **4827** | **253** | **4017** | **258** | **10307** |
| Total program indicators or indicators in system | 1052 | 4881 | 255 | 4766 | 275 | 11229 |

# Developed dashboard



# Different strategies to motivate sites

- Sites can **generate monthly report with one click and upload it to national system** so that they don't have to prepare report in HMIS recommend format manually which save their time
- Site can monitor **both aggregated indicator and individual level data** of patient for response. Also developed site level dashboard.
- For example, **to show the list of clients who need attention based on the parameters** of retention in treatment, adapting to dispensing practices, virological suppression and on-time pill pickup
- Organized several **capacity development** activities
- Developed **YouTube videos** to learn more about information system: https://www.youtube.com/channel/UCO3Dq5vnPPSYxGb9qEhq2hA


# Example 1: Monitor progress at National/Provincial level dashboard – retention in care

Score Card

Home

Nepal x

This Year x Last Year x

Options

EWI Scorecard - Retention in Care

Target achieved / on track | Progress, but more effort required | Not on track | N/A | No data

Increase from last period | Decrease from last period

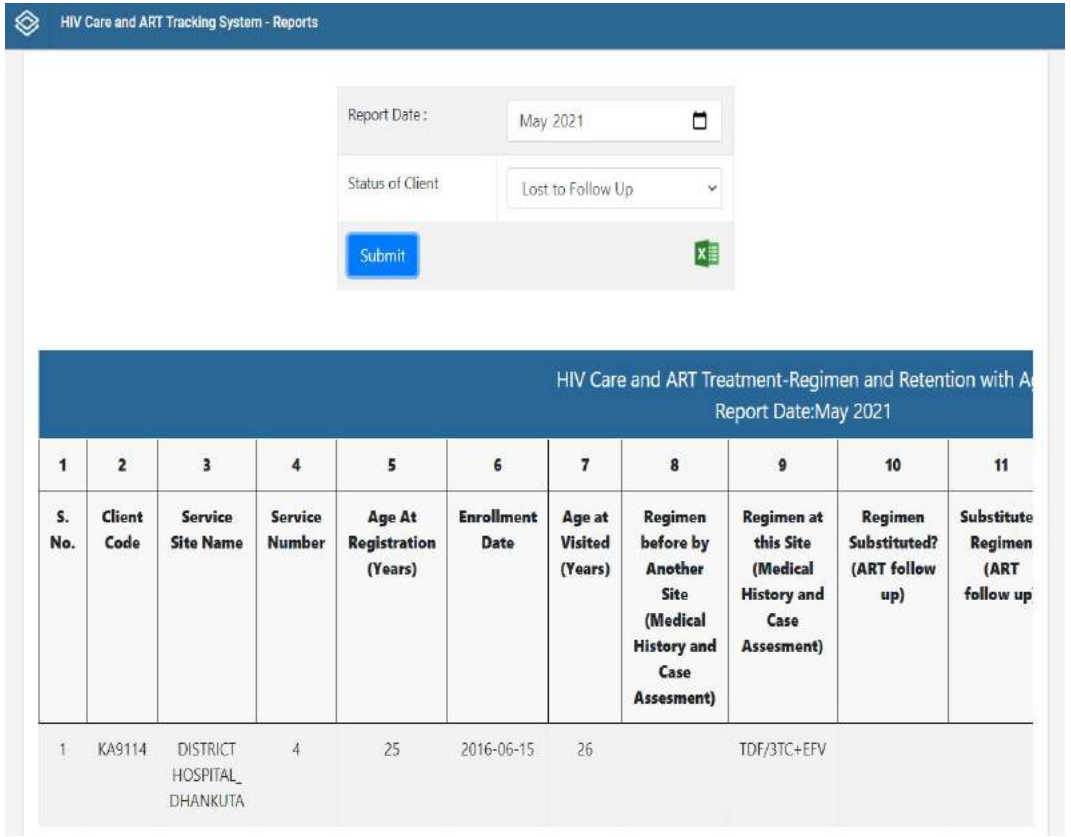
| Search for organ | Group A | | | | Group B | | | | Group C | | | | Group D | | | | Group E | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | EWI-% Retention in care Group A. PLHIV ART start period <12 months (< 15 Yrs) | | EWI-% Retention in care Group A. PLHIV ART start period <12 months (>= 15 Yrs) | | EWI-% Retention in care Group B. PLHIV ART start period from ?12 months to ?23 months (< 15 Yrs) | | EWI-% Retention in care Group B. PLHIV ART start period from ?12 months to ?23 months (>= 15 Yrs) | | EWI-% Retention in care Group C. PLHIV ART start period from ?24 months to ?35 months (< 15 Yrs) | | EWI-% Retention in care Group C. PLHIV ART start period from ?24 months to ?35 months (>= 15 Yrs) | | EWI-% Retention in care Group D. PLHIV ART start period from ?36 months to ?47 months (< 15 Yrs) | | EWI-% Retention in care Group D. PLHIV ART start period from ?36 months to ?47 months (>= 15 Yrs) | | EWI-% Retention in care Group E. PLHIV ART start period from ?48 months to ?59 months (< 15 Yrs) | | EWI-% Retention in care G PLHIV ART start period fro months to ?59 months (>= | |
| | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | 2020 | 2019 | |
| Nepal | 90 | 92.5 | 88.83 | 92.76 | 89.44 | 85.48 | 83.79 | 86.16 | 88.93 | 89.31 | 82.12 | 82.84 | 76.57 | 87.66 | 77.03 | 81.28 | 81.3 | 75.15 | 76.69 | 77 |
| 1 Province 1 | 95.24 | 100 | 93.53 | 95.04 | 100 | 90.91 | 83.41 | 89.53 | 86.36 | 100 | 70.89 | 82.01 | 90 | 88 | 72.18 | 71.38 | 100 | 83.33 | 78.95 | 7 |
| 2 Province 2 | 72.73 | 100 | 90.77 | 93.55 | 90.48 | 69.57 | 87.05 | 91.43 | 92.31 | 90.48 | 85.07 | 88.72 | 76.19 | 92.86 | 75.54 | 87.12 | 76.92 | 77.27 | 68.06 | 78 |
| 3 Province 3 | 93.33 | 87.5 | 84.04 | 90.2 | 82.14 | 86.96 | 83.56 | 79.41 | 87.93 | 76.92 | 85.54 | 80.24 | 62.26 | 85.19 | 76.24 | 82.74 | 83.87 | 63.64 | 79.02 | 7 |
| 4 Gandaki Province | 94.12 | 71.43 | 89.52 | 94.74 | 87.5 | 94.12 | 87.19 | 87.6 | 92.31 | 100 | 87.22 | 86.94 | 80 | 92.31 | 77.02 | 87.04 | 84.62 | 77.27 | 75.62 | 76 |
| 5 Province 5 | 95.45 | 100 | 89.26 | 91.49 | 95.24 | 89.66 | 82.91 | 89.18 | 90.57 | 95 | 81.18 | 82.81 | 90.91 | 88.46 | 79.25 | 79.77 | 80 | 90.63 | 74.31 | 79 |
| 6 Karnali Province | 66.67 | | 89.58 | 100 | 85.71 | 66.67 | 83.33 | 90.2 | 100 | 85.71 | 87.69 | 87.5 | 100 | 100 | 80.77 | 86.15 | 66.67 | 100 | 71.67 | 8 |
| 7 Sudurpaschim Province | 100 | 100 | 92.06 | 91.8 | 85.71 | 85.71 | 80.21 | 87.39 | 84 | 84.62 | 79.39 | 79.93 | 75 | 80.49 | 82.91 | 79.82 | 81.82 | 69.57 | 81.18 | 8 |

# Example 2: Monitor progress at health facility level

- Health facility can monitor **both aggregated EWI indicator and individual level data** of patient for response.

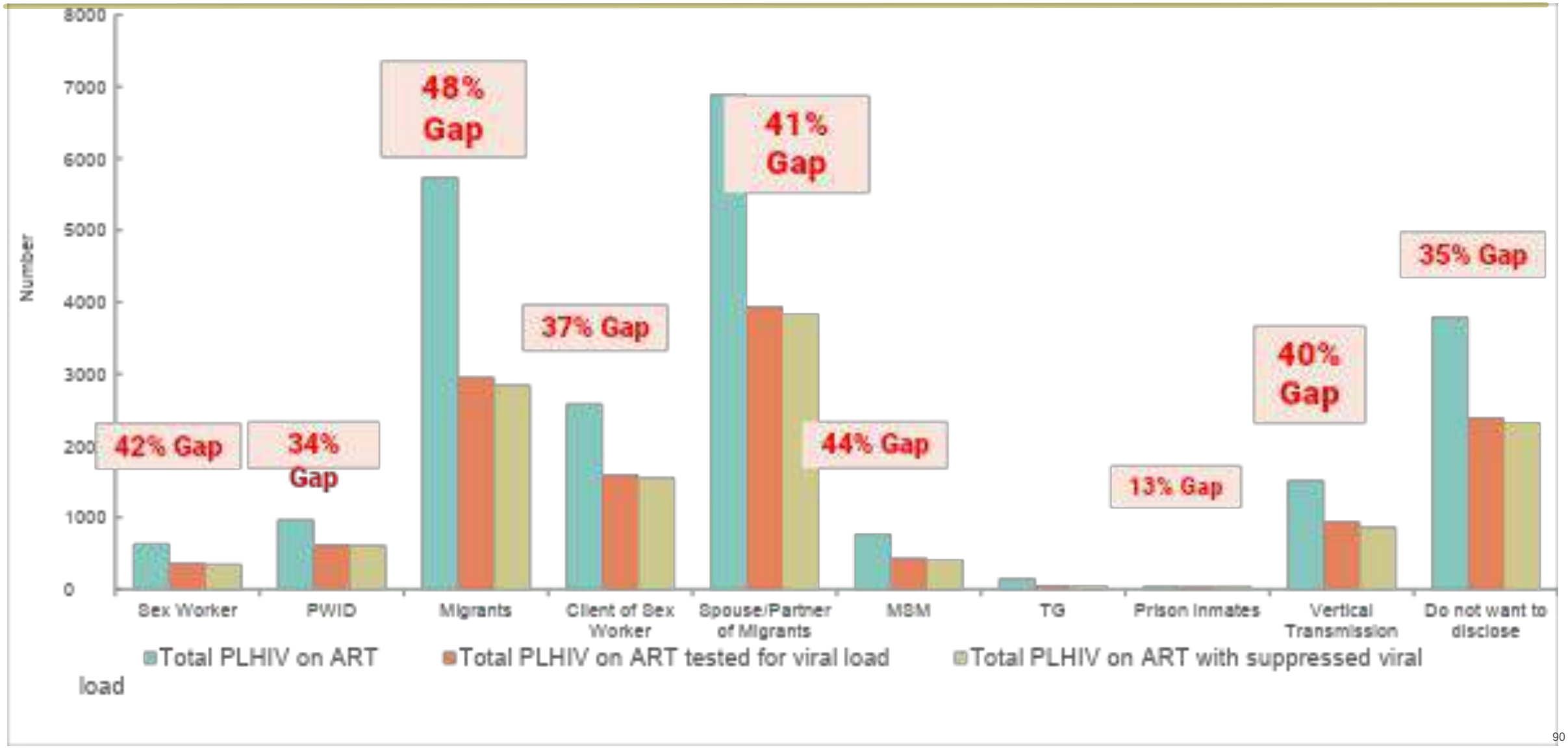
- **Show the list of clients/KPS who need attention based on the parameters** of adapting to dispensing practices, virological suppression and on-time pill pickup.

## Individual level




| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 |
|---|---|---|---|---|---|---|---|---|---|---|
| S. No. | Client Code | Service Site Name | Service Number | Age At Registration (Years) | Enrollment Date | Age at Visited (Years) | Regimen before by Another Site (Medical History and Case Assesment) | Regimen at this Site (Medical History and Case Assesment) | Regimen Substituted? (ART follow up) | Substitute Regimen (ART follow up |
| 1 | KA9114 | DISTRICT HOSPITAL_ DHANKUTA | 4 | 25 | 2016-06-15 | 26 | | TDF/3TC+EFV | | |

# Example 3: Monitor third 95 by KPs or geography



# Conclusion

- Our information system provide **real time data/evidence from heath facility levels to province and federal levels which in turn support in monitoring progress or effectiveness of programs/interventions.**

- Easily identified health facilities or program performance below desired targets support in **prompts investigation and implementation of programmatic and/or public health actions to improve quality of HIV services/programs.**

- **Dashboard alerts health facilities** about specific areas (poor retention, unsuppressed viral load etc.) which require attention and supports overall optimization of patient care.

## ACKNOWLEDGEMENTS

- Governments (NCASC, NPHL)
- **Donors**: Global Fund, PEPFAR
- Community organizations and other technical partners

# DEVELOPING A SIMPLIFIED SURVEY METHOD FOR HIV, VIRAL HEPATITIS AND STI SURVEILLANCE AMONG KEY POPULATIONS: BBS-LITE, UGANDA

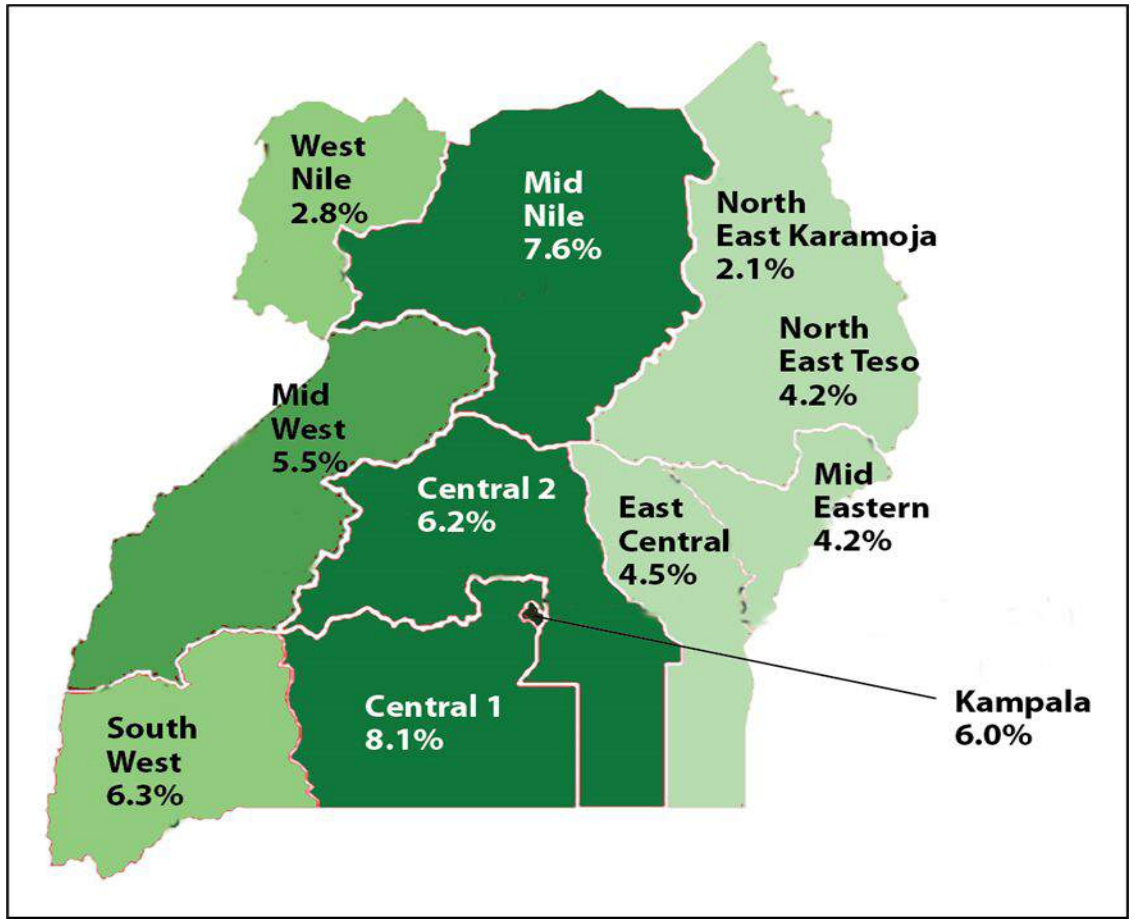
PETER MUDIOPPE

## OUTLINE

- Uganda Country HIV context
- Methodology for HIV viral hepatis surveillance in Uganda
- Overview of BBS-lite
- What was required to prepare the workforce to undertake the study?
- Training of data collectors
- How did the study impact service provision
- Challenges in the recruitment
- What other benefits came from the study?
- Results
- Lesson learnt

# Uganda country HIV context

| Uganda-spectrum 2022 | |
|---|---|
| Estimated PLHIV | 1,433,337 |
| • Male | 535,752 (37%) |
| • Female | 897,585 (63%) |
| Prevalence (15-49) | 5.07 |
| Number of new HIV infections | 51,516 |
| • Male | 18,506 (36%) |
| • Female | 33,010 (64%) |
| Incidence per 1000 | 1.21 |
| • Male | 0.88 |
| • Female | 1.55 |



# Methodology for HIV, viral hepatitis surveillance in Uganda

## Two approaches have been employed for HIV, Viral hepatitis surveillance in Uganda

**Integrated Biological and Behavioural Surveillance (IBBS)**

- Community-based systematic survey designed to assess risk behaviors and the prevalence of HIV and other sexually transmitted diseases among the most-at-risk populations, in order to improve tracking of the HIV epidemic and program planning done by CDC

**BBS-lite**

- A survey methodology developed by WHO and UNAIDS  as a lite version of bio-behavioral survey hence BBS-lite- survey. Cheaper, less intense, less costly and can be done locally by services providers

# Overview of BBS-lite in Uganda

**Populations: PWID and SW**

- PWID and SW have higher estimated HIV prevalence
- Accessible through HIV services
- Data required for planning of future services (OAMT for PWID)

**Location: Eastern Region**

- 3 districts (Busia, Mbale, Tororo)
- 9 health facilities
- Selected to avoid survey being in the field the same time and location as IBBS

**Recruitment:**

- May-June 2022

# Study cycle

Protocol development with community consultations (districts, health facilities, CSOs, and CBOs)

Training of health workers and peers as data collectors and piloting of data collection tools

Developing and uploading of data collection tools to the online ODK

Districts entry meetings

Data collections

Data analysis

# What was required to prepare the workforce to undertake the study?

**A pre-visit was made to all the districts and facilities were the study was to be conducted with the following objectives**

- To introduce the pilot to the district authorities, implementing Partners and the facility leadership
- To select the data collectors (one coordinator, one data collector of the SWs and one for the PWIDs)
- To identify a central data training site
- To identify a site for piloting of the tools during the training

# Pre-visit meeting with the IPs and District about the survey


# Meeting with the facility team to discuss the survey

# Training of data collectors

**General objective for the training**

- To train research assistants/data collectors who will get information from the study participants

**Specific Objectives of the training**

- To clearly understand the BBS-lite tools to be able to collect high quality data
- To pilot the data collection tool
- To enable participants clarify on any unclear questions from trainers
- To guide participants on BBS lite survey methodology and timelines
- To clearly understand the study SOPs

# 27 Data collectors were trained(3 per Facility-coordinator, data collector for SWs and one for PWIDS

# Piloting of the data collection tools during the training

# Support supervision during data collection

# Support supervision during data collection to the facility

# Joint support supervision (MoH &UNAIDS)

# How did the study impact service provision?

- Data collectors noted that the data collection exercise did not add significantly to the work workload because this was done alongside their routine activities( outreach and at the facility) which was well planned
- Data collection was done during outreaches and at facilities which was seen as a tool that would help them provide services to the real target groups(PWIPs and SWs) therefore, this was not seen as work overload
- Some of the data collectors noted that through the screening and interviewing of the PWIDS and SWS they were able to come closer to these sub-population because of the increased time of interaction hence their needs were better understood and health workers were able to provide better services or refer them for the services not available
- The additional funds provided to the facility like the facilitation for the SDA, Transport , payment for mobilization etc. this just improved services delivery to the target group because facilities were able to have more outreaches in a month than before

# How did the clients of the services react to the survey?

- Majority, of the data collectors reported not to have any challenges during the recruitment of participants because these were already peers to them

- The health workers who collected the data were already known because they were providing services like HTS, Condom, PrEP , ART etc.

- The use of coupons helped to give more information about the services available and gave contact information of the health workers

# Challenges in recruitment of participants

- Some data collectors noted having challenges in the recruitment especially those who tried to recruit participants when they did not have money for reimbursement, these were forced to stopped the data collection exercise until they got the money for the reimbursement

- Some research assistants noted that they had challenges sending away the ineligible participants after they had been mobilized to come through the coupons.
    - The peers had told them of some facilitation or they read on the coupon given to them that they would get transport refund if eligible.
    - Those whom we sent away saw the health service providers as being discriminative

# What other benefits came from the study?

**Increase on the number of clients seen because of the mobilization done by peers. The quotes below attest some challenges brought by data collection**

- The coupons given brought on board more new clients whom we had never reached and more new unknown hot spots were identified through the coups and the peers. This increased on the number of clients seen every day
- The data collection exercise also increased on the new positive identified which lead to increased counselling, follow up and referral to the preferred point of care by the client
- The negative clients identified were also provided with other preventive services like PrEP which in turn increased on the work load
- Through the interviews more time was spent and more needs were identified for the clients hence creating a lot of time with the client or making referrals

# Recruitment

| | Sex workers | People who inject drugs |
|---|---|---|
| **Individuals screened** | 1,093 | 772 |
| **Eligible** | 897 | 444 |
| **Consented and recruited** | **859**<br>• Outreach: 74%<br>• Facility walk in: 16.4%<br>• Snowball coupon: 9.5% | **417**<br>• Outreach: 70.7%<br>• Facility walk in: 13.2%<br>• Snowball coupon: 16.1% |
| **Existing clients**<br>(Already in prevention, care and treatment program) | 637 (74.2%) | 302 (72.4%) |
| **Non-clients**<br>(Not in prevention, care and treatment program at any facility) | 222 (25.8%)<br>• Outreach: 70%<br>• Facility walk in: 18.2%<br>• Snowball coupon: 11.8% | 115 (27.6%)<br>• Outreach: 68%<br>• Facility walk in: 12.5 %<br>• Snowball coupon: 19.5% |

## Results: Sex workers

| | | |
|---|---|---|
| | Female | 99.2% |
| | Male | 0.2% |
| | Transgender | 0.6% |
| | Median age (IQR) | 27 years (23, 30) |
| **Condom use last 3 sex encounters with clients** | Did not use at all | 17.1% |
| | One time | 18.5% |
| | Two times | 24.2% |
| | **Three times** | **40.2%** |
| **Received condoms/lubricant from program:** | In last 1 month | 43.3% |
| | In last 3 months | 18.0% |
| | In last 6 months | 10.4% |
| | > Last 6 months | 6.5% |
| | **Never** | **21.8%** |
| **Use of PrEP:** | In last 1 week | 13.8% |
| | In last 6 months | 15.5% |
| | > Last 6 months | 10.6% |
| | **Never** | **60.1%** |
| **Tested for STIs:** | In last 1 month | 27.4% |
| | In last 3 months | 15.5% |
| | In last 6 months | 7.6% |
| | > Last 6 months | 7.0% |
| | **Never** | **42.6%** |
| | **HIV positive** | **19.3%** |
| | **HIV positive who knew status** | **73.5%** |
| | **HIV positive on ART** | **72.9%** |

## Results: People who inject drugs

| | | |
|---|---|---|
| | Female | 5.0% |
| | Male | 94.5% |
| | Transgender | 0.5% |
| | Median age (IQR) | 25 years (23, 29) |
| **Frequency of injection:** | Daily or almost daily | 21.8% |
| | Weekly | 28.8% |
| | Monthly | 36.0% |
| | Les than monthly | 13.4% |
| **Primary drug of choice** | Heroin | 43.9% |
| | Cocaine | 42.7% |
| | Pharmaceutical opioids | 3.6% |
| | Methamphetamine | 6.0% |
| | Other | 3.8% |
| **Use of PrEP:** | In last 1 week | 9.5% |
| | In last 6 months | 22.0% |
| | > Last 6 months | 7.6% |
| | **Never** | **60.9%** |
| **Received needles and syringes from program:** | In last 1 month | 8.2% |
| | In last 3 months | 11.5% |
| | In last 6 months | 4.6% |
| | > Last 6 months | 1.7% |
| | **Never** | **74.1%** |
| | **HIV positive** | **3.6%** |
| | **HIV positive who knew status** | **52.8%** |
| | **HIV positive on ART** | **53.3%** |

# How data generated has been used

- New peers have been identified and new hotspots –New links through chain referral
- Planning for focused outreaches at facility level (mobile outreaches)
- Setting up community Drop in Centre(DIC)
- Micro planning at facility level –New hotspots were identified
- The data has been used in the Global fund and PEPFAR COP 23 application

# Lesson learnt

- BBS-lite provides a simple methodology to understand the extent of HIV prevalence among KP and levels of health service access, while using minimal resources
- BBS-lite empowers local health managers to conduct studies
- Local communities can take the lead in refining data collection tools, data collection and validation of results
- BBS-lite study takes a short time to conduct and provides results able to inform decision making and implementation in ‘real time’
- Recruiting from outreach and through chain-referral is able to reach KP who have not previously accessed services and who may be engaged in services and benefit from them
- Utilizing local health and peer workers as data collectors is possible and does not add disrupt service provision or become too great a burden on workload
- Data can be collected for different study populations at the same locations and during the same time

# Dissemination of BBS-lite study

# THANK YOU

# KEY POPULATION COMMUNITY-LED MONITORING APPROACH AND PRACTICES

Shahnaz, Tias Plus
Viet Trinh, Light House

# COMMUNITY-LED MONITORING

SHAHNAZ

# Tais Plus (Kyrgyzstan)

- **Tais Plus** is a community-led organization created by sex workers with sex workers' funding.
- Our mission is to strengthen the sex workers' community to achieve better living and working conditions for sex workers.
- 1997 -- initiative group
- March 3, 2000 - officially registered
- March 3 later became International Sex Workers' Rights Day which has been celebrated since 2001 ☺️ since the Sex Workers' Festival in India.

# Community-led monitoring (CLM)

- **Time frame:** 2016-2022, continues in 2023

- **Geographical coverage:** all regions of the country where they have HIV prevention programs with sex workers

- **Support:**
  - UNDP; Global Fund Project: Community Systems' Strengthening and Overcoming Legal Barriers (2016-2022).
  - SWAN, Robert Carr Fund project (the project ended in 2021)
  - NSWP, Project funded by the Global Fund's Community, Rights and Gender Strategic Initiative (2020, 2021-2023)

SWAN sex workers' rights advocacy network

UNDP

nswp Global Network of Sex Work Projects
Promoting Health and Human Rights

# CLM summary

- **Approach:** Community-led monitoring is built on SWIT – Sex Workers Implementation Tool

- **Audience:** Since the majority of activities with sex workers are implemented in the NGOs, community-led monitoring was primarily organized with the NGOs who work with sex workers. We included HIV-services and medical institutions which provide STI services into the community-led monitoring in 2020.

# What is CLM ?

- Community-led monitoring is a process whereby communities gather information:
  - about service provision
  - about conditions which influence the quality and accessibility of services
  - about legal barriers, etc.

- and later use this information to
  - Improve the quality of services
  - achieve positive legal change
  - Influence project implementation, etc.

**Data collected during community-led monitoring should become the integral part of the national monitoring and evaluation system.**

# SWIT is the CLM basis for programmes with sex workers

- Community-led monitoring should run on some model or ideal version.
- In other words, we need to aspire to achieve something better comparing what we **have today** with what we want to see **tomorrow**.
- SWIT serves as this ideal model for programs with sex workers.
- SWIT is the lens we are looking through


# CLM arrangement and tools

- Yearly monitoring plan
- TORs for the team together with plans for each visit
- Team training prior the CLM visit
- Questionnaires for the NGOs staff, friendly physicians, lawyers, and state institutions
- The topics for the questionnaires can vary depending on the goal and can include: counselling and testing, STI services, legal support, community engagement in the NGO's work
- Meetings with sex workers
- For the period 2016-2020 Tais Plus has developed the set of questionnaires for focus group discussions, interviews as well as discussion plans for meetings with sex workers

## Forms of CLM

- Visits to the organizations (NGOs, state institutions, and private clinics) which provide services to sex workers
- Meetings with sex workers during the CLM visits
- Questionnaires that sex workers fill in (experience from Bishkek)
- Collecting data about issues that sex workers faced, and solving those issues.

**We are now facing the task of turning CLM into a regular procedure with broader community participation.**

# CLM team composition

- Ideally, the team should consist of community members.
- There should be 2-3 people on the team.
- If the topic of the visit concerns specialized issues (such as STI services or legal assistance), one of the participants should know this issue well. In such cases, the team should include an ally, for example, a lawyer or a doctor.
- Role of other communities in the CLM team - we get the possibility to build solidarity and mutual understanding between communities

## Partnership approach of CLM

Our monitoring is special because we do not come to control our partner NGOs work, we **come as partners**:

- we recognize the value of the NGO's work;
- we try to understand the context of working in a different town;
- we understand that change takes time;
- Together we look for opportunities to improve the quality of services and the situation in general, especially in the field of human rights
- We share examples of our own work, for example, our practices of community empowerment
- We share results of joint work: we send and present our partners our reports and results of drafting the country's funding applications.
- Together we develop practical skills in the format of mini-trainings or in the field (sessions, meetings with sex workers)

# CLM reporting

- After the CLM visit we prepare a visit report with recommendations and agree it with the NGO we have visited.

- Then we send result of the CLM to the main **donors** who are funding programs in the country, present during the **CCM meetings**, and send to the state **institutions**.

- The CLM results are also presented during relevant meetings and seminars, for example during the meetings with sub recipients of GF grants, thematic meetings devoted to certain topics.

- CLM data are used while developing national documents - the national HIV programs, country funding requests to the GF

## Which benefit CLM, brought to the sex workers' community

- HIV-services NGOs have changed their approaches to working with sex workers (counselling and testing take place not 5 minutes but more, and the relationships with sex workers are becoming more those of partners than those of the organization and its beneficiary/client)
- We learned from one another and adopted the experiences of other organizations in the area of receiving state funding, diagnostics, and affordable STI treatment.
- Based on CLM we could clearly see our priority and then include them in the country GF funding applications
- We developed new tools for routine CLM which are now being implemented all over the country. Sex workers who are staff members of HIV service organizations grew into community experts who are now organizing interviews. They have acquired basic research and monitoring skills throughout those years.
- Over the years, HIV-services NGOs have gradually changed their approaches and their vision, thanks to this, our joint advocacy efforts bring more results.

## CLM issues and needs

- CLM training and acquiring practical skills is a lengthy process and requires resources. Over the years, about 40 people from the community have been trained, but there is a turnover in NGOs, new employees come in who need to be trained, and maintaining skills requires practice and updating knowledge. Now the current CLM team includes 5-7 people.
- Sex workers who are CLM experts, they are at the same time employees of NGOs, sometimes this affects their position: people will not say things that can harm them at their main place of work
- Since 2023, Tais Plus has refused to work with GF grants due to the position of the Principal Recipient and the FPM on achieving the indicators. GF funding for CLM has also ceased.
- Additional resources are required to expand CLM and implement routine CLM
- Advocacy for Change: Community-led Organizations stay alone when it comes to critical issues
- Need to make sex worker emergency response systems part of the CLM, but there is no resource for this yet

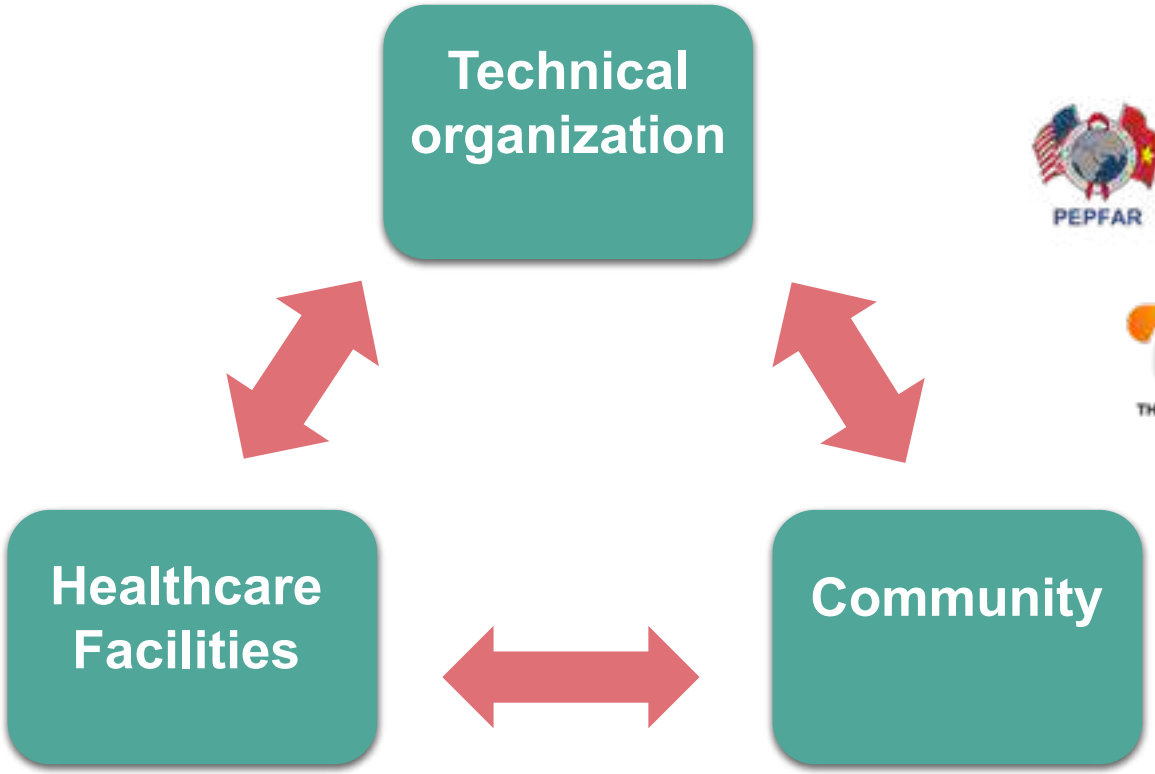
# THANK YOU

# OVERVIEW: COMMUNITY-LED MONITORING INITIATIVES IN VIETNAM

VIET TRINH

# Our amazing journey

# KP-friendly model




KP Friendly
Cơ sở Y tế thân thiện

**The collaboration between community and health facility is key to create long-term changes towards friendlier health facilities for KP.**

# Activities


Pre & post assessment

Consensus meeting

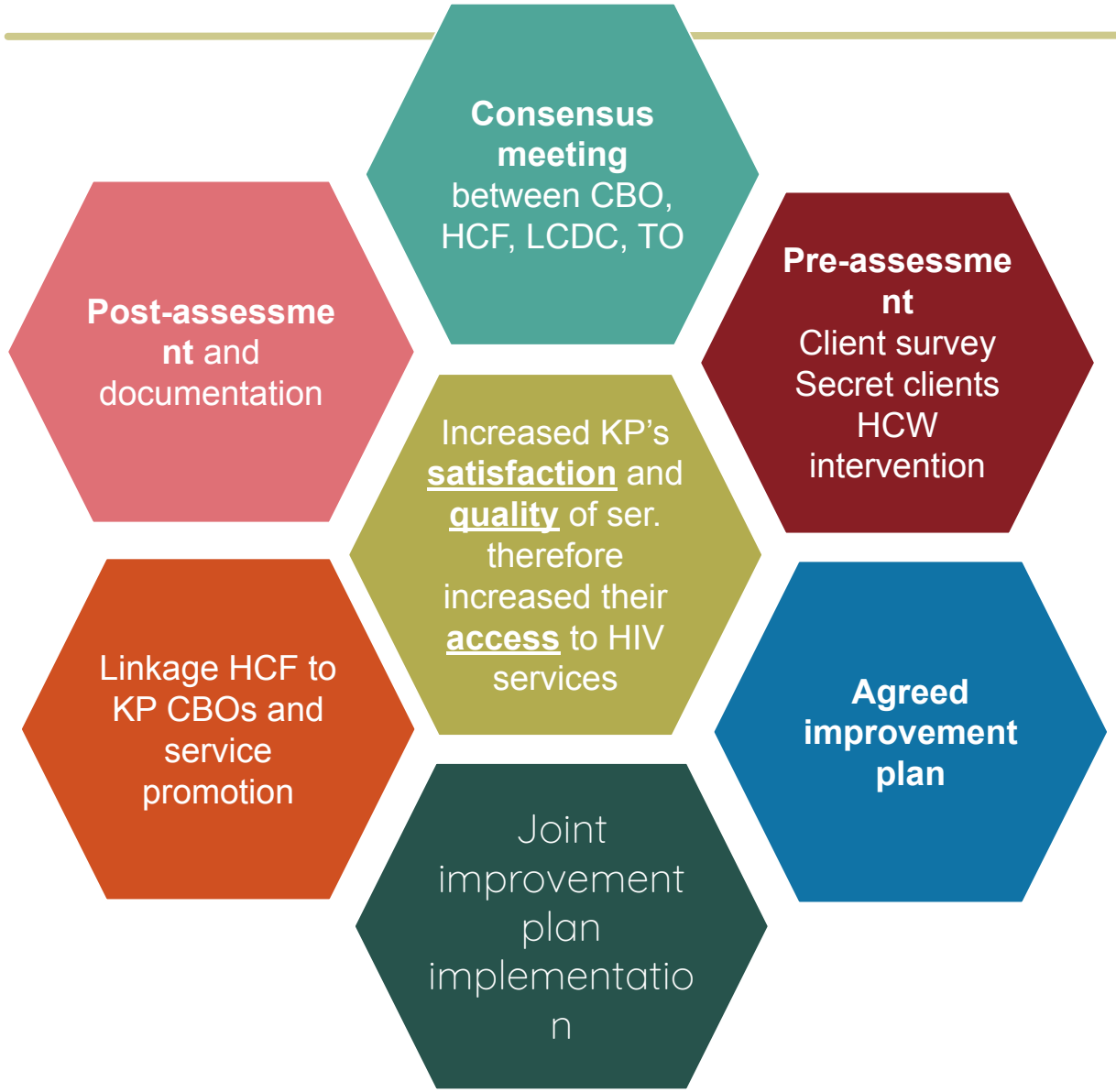
Re-decoration

Training for HCP

Assist and skill building


Community meets HCP

# Design and achievement




1. 18 HIV service facilities in 3 provinces
2. > 360 healthcare workers and non-medical staffs were sensitized and trained
3. 6 CBOs were capacitated and involved
4. Significant increase of client satisfaction and number of clients
5. Strong partnership CBO, HCF, LCDC.
6. Potential scaling-up by Global Fund
7. National KP friendly standard

# Community empowerment

Advocacy training 2017

TEACH Reginal Training 2018


SRHR Forum for Youth 2019

Community engagement in GF 2020

Organizational development

Digital communication training

# Using Data for Community Monitoring and Health Collaboration

Consumer Advisory Boards, Community Score-Cards, KP-Friendly Model innovations utilize client feedback to monitor and improve service quality.

- Consumer Advisory Boards* are a **bridge between health staff & clients**. Established under the authority of the Department of Health.
  - **Engage** in discussions about quality of care
  - **Inform and educate** about available services
  - **Elicit** client feedback on service quality
  - **Participate** in QI initiatives
  - **Facilitate** Community Score-Card between clients & health providers



- CAB model Adapted from New York State HIV Quality of Care Program

# Data is the Foundation for Dialogue and Change

LIGHTHOUSE

**FEEDBACK FORM**

**Introduction:** we are working on improving our quality of care delivering to you and try to create a friendly environment for you in our health settings. We would like to hear your feedback on this visit and your feedback/comments will be very valuable to us. It will take less than 5 minutes to finish the form.

There are 5 scales at each question, please choose the most appropriate answer for you by tick (ð) to that answer. We thank you very much for your information.

Date: __ __/ __ __/ __ __ __ __ (dd/mm/yyyy)

| # | Services | Very poor | Poor | Fair | Good | Very good | NA |
|---|---|---|---|---|---|---|---|
| 1 | Registration and health insurance procedure | | | | | | |
| 2 | Doctor services | | | | | | |
| 3 | Nurse services | | | | | | |
| 4 | Pharmacy services | | | | | | |
| 5 | Lab services | | | | | | |
| 6 | Waiting time for examination | | | | | | |
| 7 | Waiting time for medication pick-up | | | | | | |

- The CAB utilizes multiple feedback mechanisms and data points to focus and tailor interventions:
  - Client feedback forms
  - Comment boxes and hotline
  - Facility S&D assessments & QI projects
  - Site-level reports on Same-Day ART, Multi-month dispensing, viral load
  - Community score-card scores
- These data are considered validated for health providers and provincial health agencies to act upon.

# Initial Results Show Sustainable Improvements in Service Quality

## After 1 year of CAB Activity

# CAB & Community Score-Cards Promote Joint Monitoring and Redress


- A two-way, participatory, community-led QI tool used for **assessment, planning, monitoring and evaluation** of health services.
- CAB facilitated the **selection of indicators** by service users and health providers that will be scored
- Two provinces initiated scoring for 4 sites
- 2 rounds of scoring in 2 facilities so far

*Adapted from Community Scorecard Toolkit by Advancing Partners & Communities project

# #UPROOT SCORECARD

UNAIDS | GLOBAL NETWORK OF YOUNG PEOPLE LIVING WITH HIV

## #UPROOT Youth-led scorecard on the HIV response for adolescents and youth

YEAR: 2022 | COUNTRY: Vietnam

TOTAL SCORE: 5.6 /10

| | | |
|---|---|---|
| 1: LAWS & POLICIES | Score: | 6.27 |
| 2: PARTICIPATION | Score: | 4.25 |
| 3: PARTNERSHIPS | Score: | 5.83 |
| 4: BENEFICIARIES | Score: | 5.83 |
| 5: LEADERS | Score: | 5.83 |

SCORING KEY:

| | |
|---|---|
| Green (8-10) | The country is on track in addressing the unique needs of A&Y in the HIV response |
| Amber (6-7.9) | The country needs to accelerate their A&Y interventions to meet the unique needs of A&Y in the HIV response |
| Red (0-5.9) | The country is at risk of leaving A&Y behind in the HIV response |

- Youth-led index
- Feasible youth-friendly implementation
- To measure the meaningful participation and leadership of A&Y in national HIV strategy
- Data collected and verified via:
  - Desk review
  - Community consultation
  - Consultation with stakeholders and government representatives

# REFLECTIONS

Mentimeter

# CLOSURE

Tim Sladden