

# **PrEP Learning Network:**

Identifying PrEP continuation challenges and approaches to support success

**September 12, 2019** 







## **OPENING**

# **APPLYING A BEHAVIORAL ECONOMICS (BE) APPROACH TO PREP CONTINUATION**

# **PREP CONTINUATION WITH AGYW**

# **DEFINING & MEASURING EFFECTIVE PREP USE ("CONTINUATION") AND IMPACT**

WRAP-UP AND NEXT STEPS



# This is our second session of the learning network

- Two primary goals of the learning network:
  - Create a forum to facilitate and accelerate sharing of PrEP scale-up experience, as well as implementation tools and resources across low- and middle-income countries (LMICs) within sub-Saharan Africa
  - Support epidemic control by helping countries achieve PrEP targets, such that AGYW and other target populations who need PrEP are able to effectively use PrEP and prevent HIV infection
- Our first session on August 22<sup>nd</sup> featured three implementing partners discussing their PrEP scale-up journeys

Several questions on continuation came up during our first session

What are the main reasons for **PrEP** discontinuation? What is the average length of stay on **PrEP** by population? How do you ensure that **PrEP** clients stay on PrEP? How do you integrate changing levels of risk into continuation and effective use?



# Today's discussion: PrEP continuation

# Today's speakers

Jessica Rodrigues Prevention Market Manager/ AVAC

**Gwen Chapwanya** SHAZ!HUB/Pangaea Zimbabwe AIDS Trust (PZAT) Zimbabwe

#### **Daniel Were**

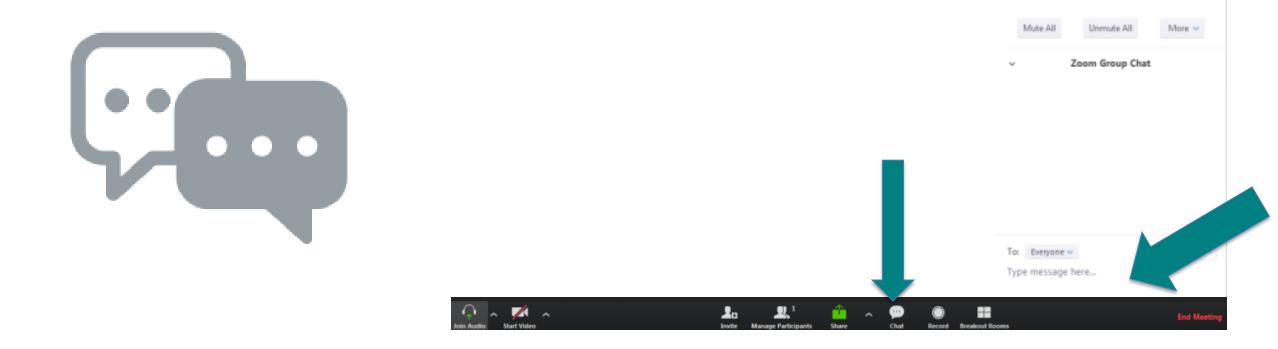
Jhpiego/Jilinde Kenya

Jason Reed Jhpiego Today we will explore PrEP Continuation through the lens of:

- Learning from two implementing partners about PrEP continuation challenges, effective strategies, and lessons learned
- Sharing recent findings from Think Tank on defining and measuring PrEP success and effective use
- Facilitating peer learning on PrEP continuation successes, challenges, and measurement questions

# Use the "Chat" feature to ask questions!

There is dedicated Q&A at the end of each presentation—please feel free to ask questions during this time or type your questions into the chat box at any point during the presentations

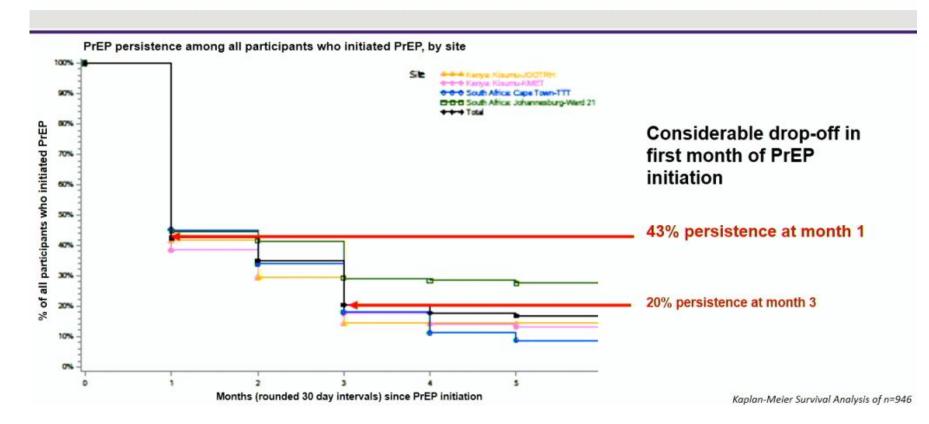


Participants (1)

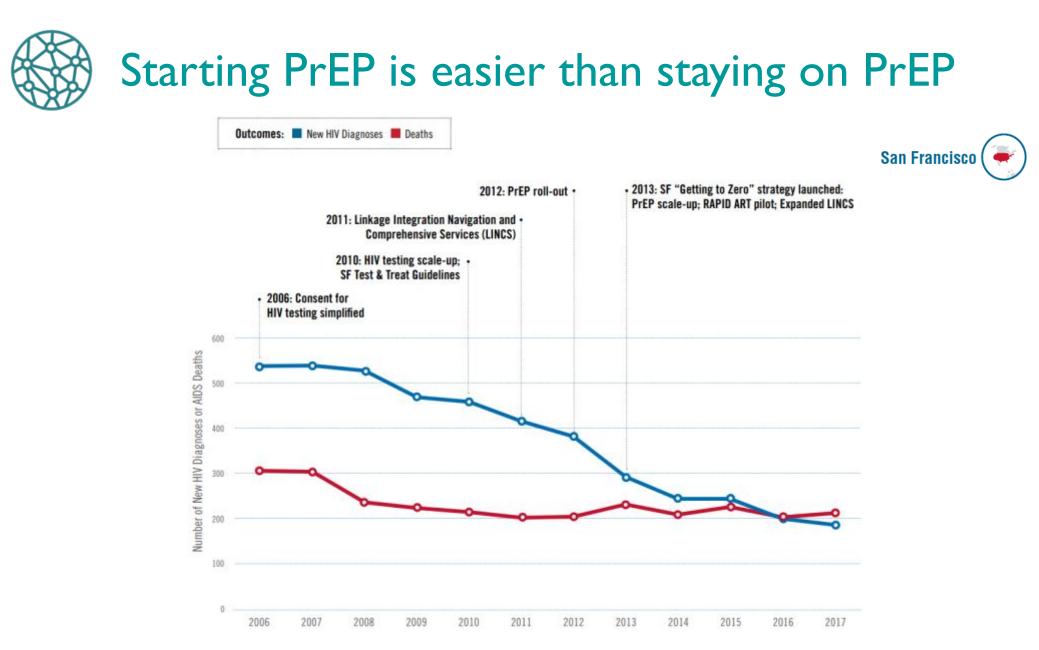
Saman... (Host, me, participant ID: 48)



#### PrEP persistence among all participants who initiated PrEP



Source: POWER Project, 2018



Source: amfAR, AVAC, FRIENDS of the Global Fight, Translation Progress into Success to End the AIDS Epidemic, 2019



- Use does not have to be so long as to extend to periods of no/low risk, nor so short as to leave periods of high risk unprotected
- 3 patterns of PrEP use
  - Continuous = start followed by use for X contiguous days (X = 30? 90? 180?);
     akin to ART "retention"
  - Episodic = start followed by use duration sufficient to cover risk, stop and restart based upon "short-term" risk cycles
  - Event-driven (2+1+1) = 1 loading dose start followed by 2 days' use

# All are effective!

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**WRAP-UP AND NEXT STEPS** 

# Applying a Behavioral Economics Approach to PrEP Continuation

Jilinde Project Experiences

Daniel Were, Project Director













Johns Hopkins University Affiliate

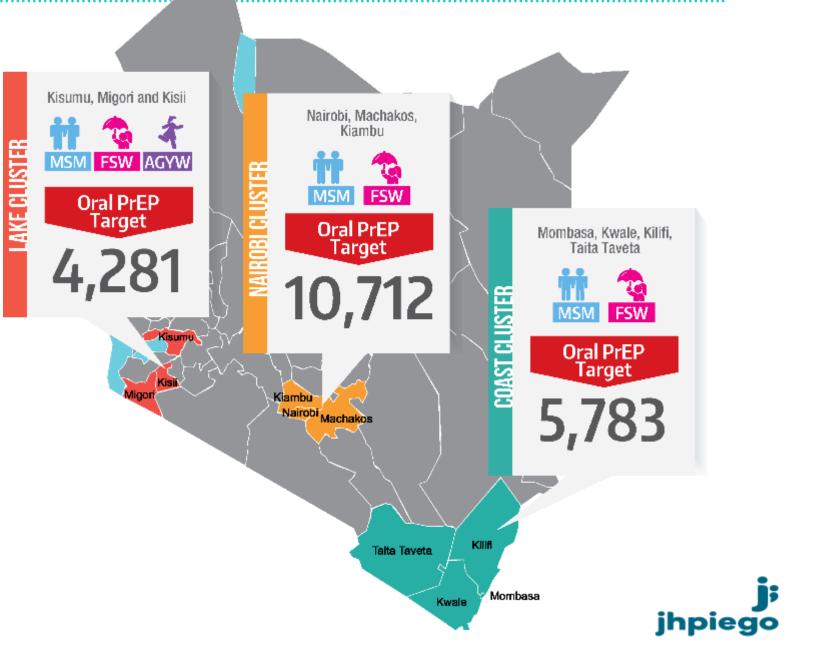
# **Jilinde Project Goal**

To demonstrate and document an effective model for scaling up oral preexposure prophylaxis (PrEP) as an HIVprevention intervention in low-resource settings



# Geographic & population targets

- Female sex workers (FSW)
- Men who have sex with men (MSM)
- Adolescent girls and young women (AGYW)
- Sero-discordant couples
- General population

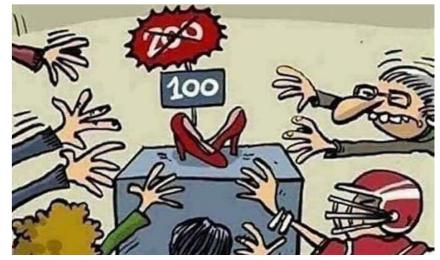


# What is Behavioral Economics?



A data-driven approach to understanding the psychology behind human behaviors and attitudes

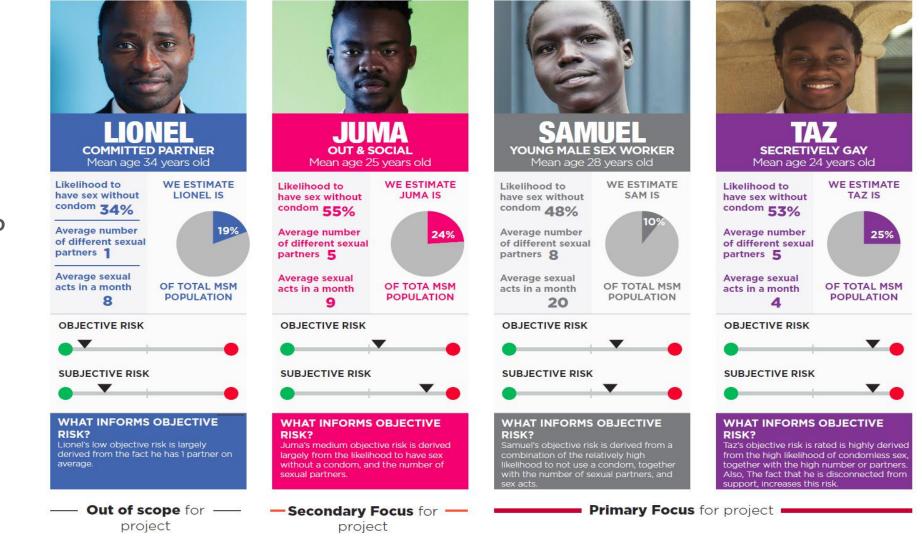
While human choices often seem non rational, this can be predicted...



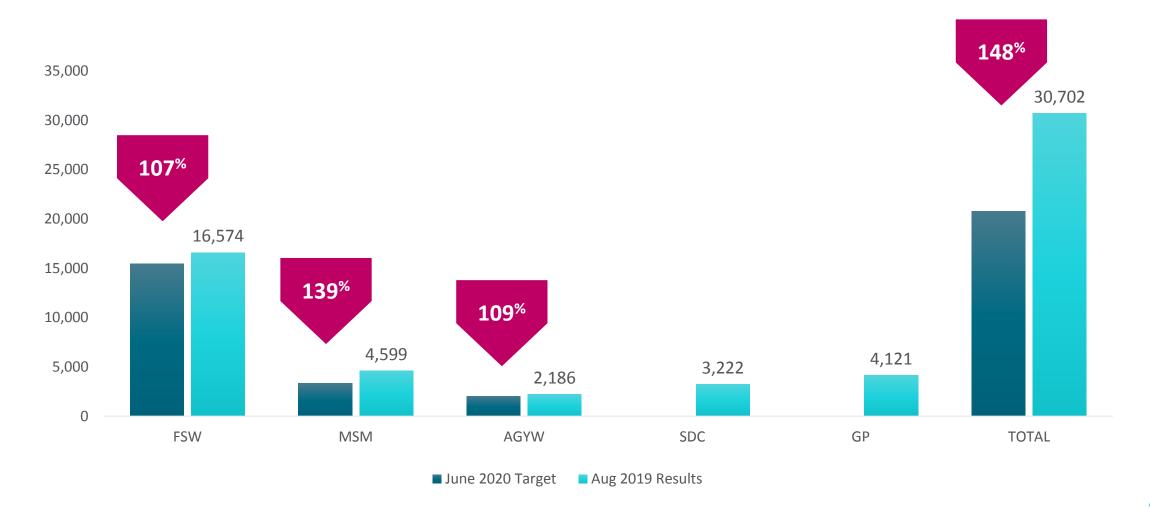


# **Behavioral Economics Segmentation for PrEP Uptake**

In year 1 & 2
 Jilinde used
 Behavioral
 Economics
 research for
 segmentation
 to support PrEP
 uptake



## 4 - Year Program Targets Surpassed in Year 3



Behavioral Economics segmentation contributed to accelerated PrEP uptake

ihpiego

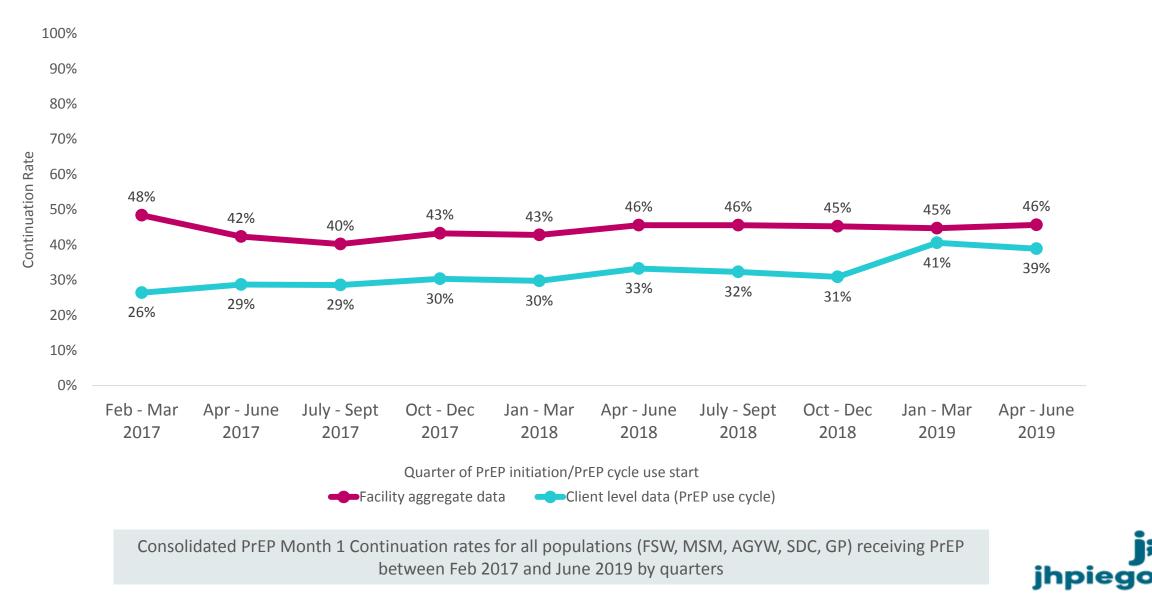
# **Context of PrEP Continuation**

- Continuation estimation depends upon data source and analysis method
- Throughout year-1, only site-level aggregate data available; access to client-level data for longitudinal analyses began in year-2
- Longitudinal analysis provides comparator for aggregate data-based continuation estimate
  - Client-level, longitudinal analysis provides best estimate of continuation, though more prone to missing data

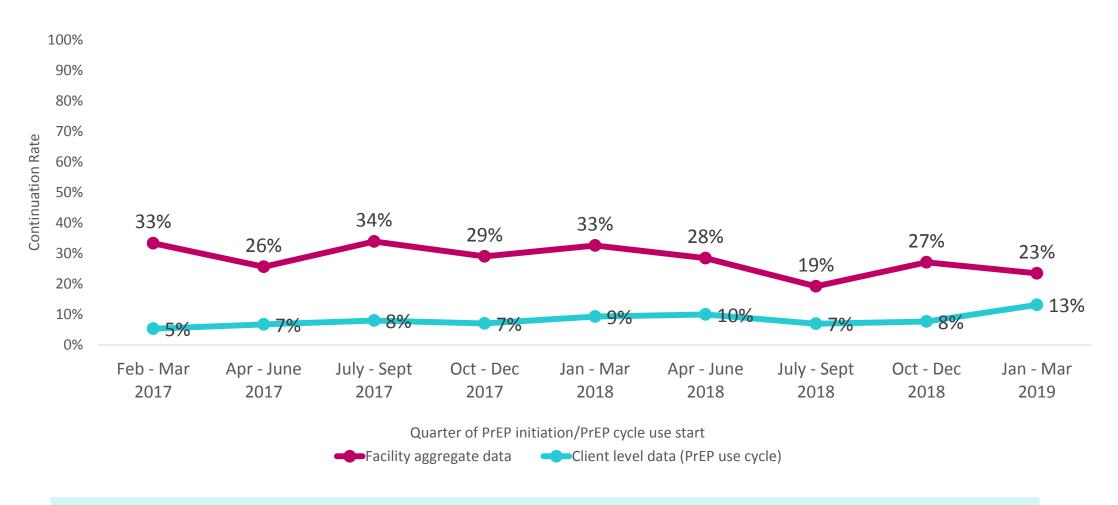
Longitudinal estimates generated by data-based algorithm using client-level data. Use "episode" defined as period of consistent refill(s), each within 37 days of prior prescription; otherwise (38+ days) triggers restart/new use episode



#### **Trends in Month 1 Continuation Rate: Facility Aggregate vs Client Level Data**



#### **Trends in Month 3 Continuation Rate: Facility Aggregate vs Client Level Data**



Consolidated PrEP Month 3 Continuation rates for all populations (FSW, MSM, AGYW, SDC, GP) receiving PrEP between Feb 2017 and June 2019 by quarters



# **Continuation Varies by Site and Population: Outlier Sites**



Continuation estimation for Kilifi and Mtwapa Drop in Centers in Mombasa County - client level data

jhpiego

# **Motivations and Barriers to Timely PrEP Refills**

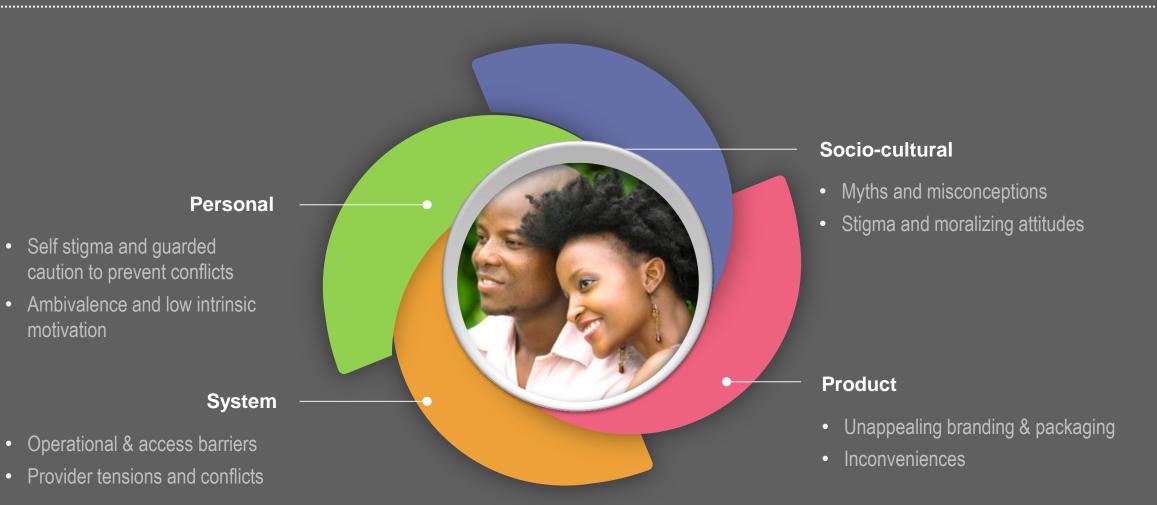
## **Continued Use**

- Need for protection (84.6%)
- Deriving confidence from PrEP (28.4%)
- Receiving adequate information (23.1%)
- Peer Educator support (14.8%)

#### Discontinuation

- Changed risk/ preferred prevention method (31.6%)
- Side effects (31.1%)
- Pill burden (19.7%)
- Negative clinic experience (18.9%)

# **Continuation Challenges**



Data from 9 FGDs with MSM, AGYW & FSW in 2019

# **Programmatic Course Corrections to Improve Continuation Rates**



# Facility-level interventions

- User support groups
- Phone call & SMS reminder
- Empathetic adherence counselling
- Community refills



Community-level interventions

- Client literacy
- PrEP buddies
- Physical tracing by peer educators
- PrEP champions/ satisfied users

# **Insights from Human Centered Design: Continuation Design Sprint**

#### #motivationisPower

Successful PrEP users connect daily pill taking with a larger sense of purpose. Taking pills becomes a daily reminder of this purpose and a positive ritual of self-affirmation.

"PrEP is my life! It gives me control to do what I want" **FSW** 

> "PrEP helps me achieve my dreams" **FSW**

#### **#givemechoices**

"Give choices. Take it or not but I don't really care." **FSW** 

MSM and FSW have a rebellious streak, and do not respond well to being told what to do. Current counselling models are directive, creating tension.

#makemefeelspecial

MSM and FSW crave affirmation for achieving the challenging task of adherence.

"PrEP is about me, connect with me and understand me" MSM

> "Make it like church" **MSM**

### **Design Questions: How might we.....**

Support clients to unlock their powerful PrEP Motivation?

Make clients feel more in control of the counselling interaction?

Make taking PrEP enjoyable and affirming?

# **Behavioral Economics for PrEP Continuation**

- Given low continuation rates, Jilinde is using BE to explore non rational behavioral barriers and levers to PrEP use
- Routine program data are insufficient to draw objective conclusions on actual barriers to continuation
- Human centered design has provided insights on the behavioral barriers



#### **Quantitative segmentation and validation**

- Predictors of persistence and dropout
- Discrete choice experiment relative value of key PrEP attributes to participants



#### **Qualitative Research**

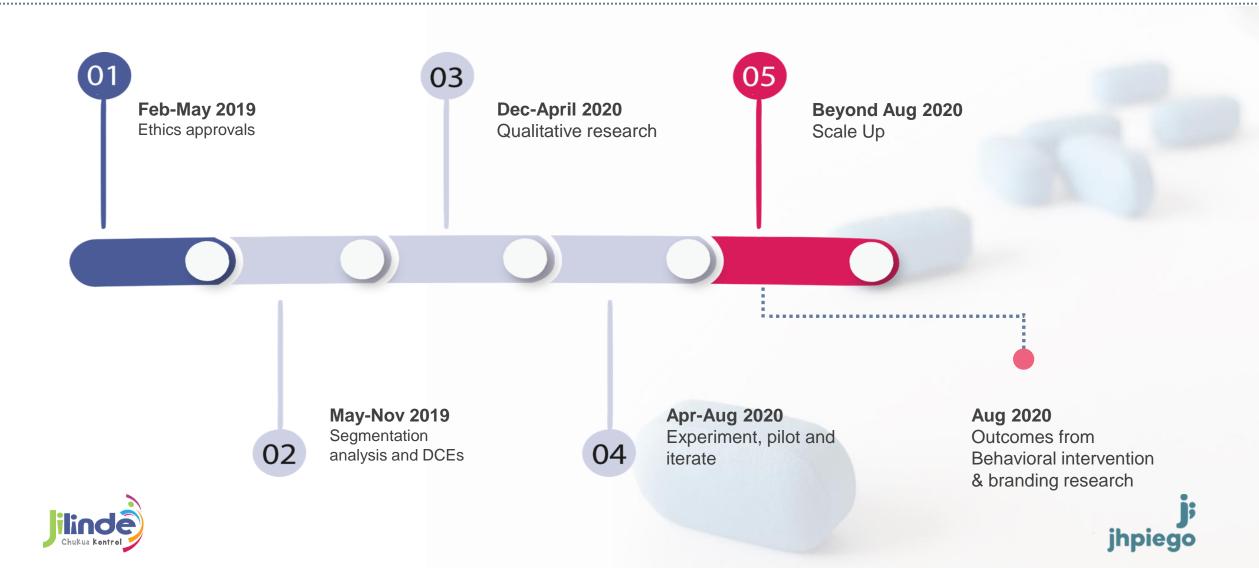
Segment specific barriers to continuation



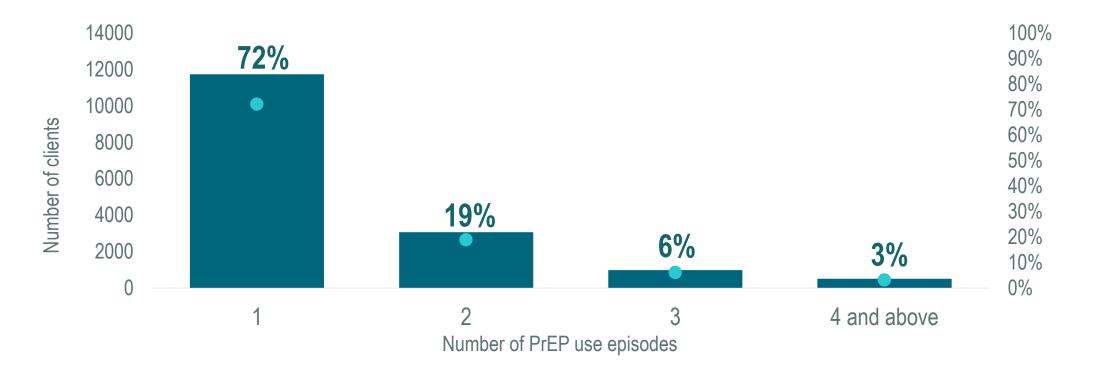




## **Timeline for Behavioral Economics Continuation Research**



## **Emerging Questions: Episodic Use of PrEP is Common**



28% of clients initiated on PrEP through Jilinde have more than one PrEP use episode

Conducting a prospective cohort study to understand in depth the explanations for different patterns of use across the population groups

ihpie

## Acknowledgements

- Bill & Melinda Gates Foundation
- Jilinde Partners (Jhpiego, NASCOP, Avenir Health, PSK, ICRH-K)
- National PrEP and Key Populations Technical Working Groups
- Gilead Health Sciences
- US President's Emergency Plan for AIDS Relief (PEPFAR)
- LINKAGES, GEMS and OPTIONS projects
- Prevention Market Manager (AVAC & CHAI)
- Partners Scale-up project
- Ministry of Health and County governments in Kenya
- Local Implementing Civil Society Organizations









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**WRAP-UP AND NEXT STEPS** 



# Uptake and Continuation of Oral PrEP among Adolescent Girls and Young Women: Lessons learned from the SHAZ! HUB in Zimbabwe

Gwendoline Chapwanya Project Coordinator Pangaea Zimbabwe AIDS Trust (PZAT)



# THE SHAPING THE HEALTH OF ADOLESCENTS IN ZIMBABWE (SHAZ!) HUB

- The HUB is a youth drop in centre in Chitungwiza, located within a private hospital supported by Ministry of Health and Child Care
- Began as a research site in 2003 conducting HIV prevention and treatment studies among AGYW
- In 2014, using lessons learned from research, it evolved into a youth drop in centre, under Pangaea Zimbabwe AIDS Trust (PZAT), that provides comprehensive sexual health and HIV services to approximately 1 400 young people aged 16-24 every year

# THE SHAZ! HUB: SERVICES PROVIDED

#### Health services

- STI screening and treatment
- HIV testing positives linked to care, negative linked to comprehensive prevention services including PrEP
- Peer support for HIV positives (CATS model)
- Pregnancy testing
- Contraception

#### Non-Clinical services

- Life skills training
- Sexuality education
- Vocational skills training (floor wax, toilet cleaner, cordials, candle making)
- Financial literacy
- Wifi and internet

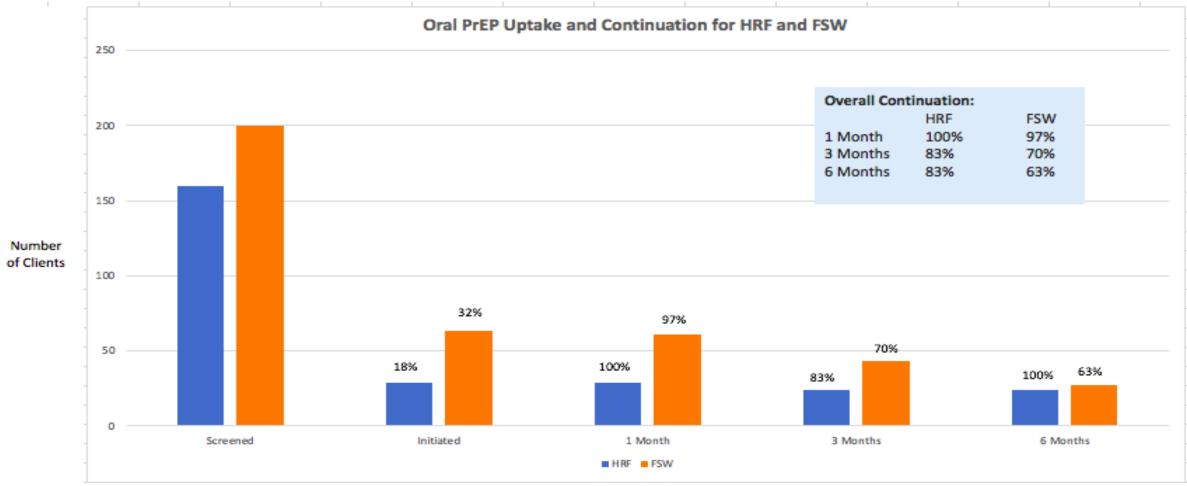


# THE SHAZ! HUB: PREP DELIVERY

- Started delivering oral PrEP in January 2018, initially in collaboration with PSI providing Truvada.
- With support from Gilead from May 2018, we hired more staff (nurse and two peer educators) and expanded our coverage
- Target population 16 24 year olds (AGYW, FSWs, MSM, transgender populations)
- Tools and reporting mechanism through MOHCC



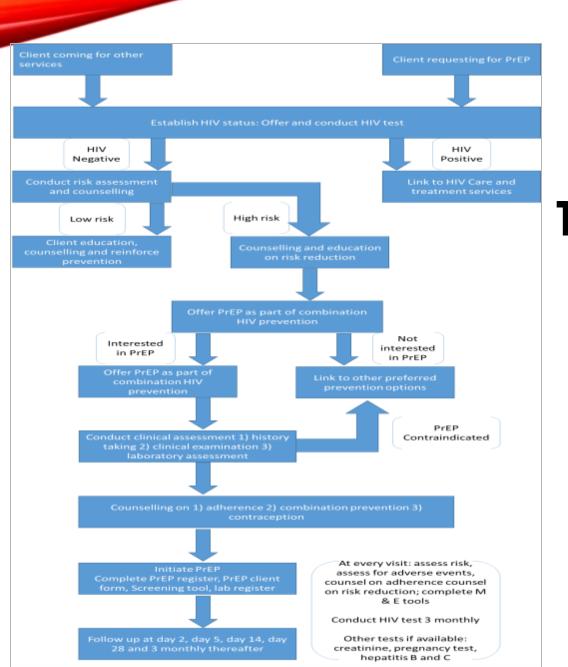
# THE SHAZ! HUB: AGYW CONTINUING RATES



AGYW Clients - High Risk Females (HRF) and Female Sex Workers (FSW)

1

# THE SHAZ! HUB: INTENSIVE AND STRATEGICALLY TIMED FOLLOW UP



### **ENABLING ENVIRONMENT**

- Using the readiness assessment tool to identify and select youth who are not only at risk, but interested in and ready to take PrEP
- Regular follow ups and interactions with peer mobilizers by text, call and home visits
- Youth friendly staff
- Youth friendly and confidential environment when accessing other services
- Supportive environments which enable the clients, staff and parents/ guardians to work together to support continuation

### **CASE STORY**

- Nikki is a young woman, aged 21, in a relationship with a taxi driver who is 38 years old.
- Nikki was aware of her HIV risk because she and her partner had been treated for STIs twice at an area clinic; however, Nikki wasn't able to even discuss the possibility of using condoms.
- One afternoon, Nikki met the SHAZ! HUB outreach team in her neighborhood. After receiving information on PrEP, she was enthusiastic to try it.
- Based also on a pre-screening that indicated her high-risk status, she was invited to come to HUB and was ultimately initiated on PrEP.
- At home, she hid her pills because she was afraid to disclose to her partner that she was on PrEP.

### **CASE STORY**

- One day about two months later, her partner came across the pill bottle. He asked her what the pills were for and she gave him a flier from the HUB about PrEP. The partner angrily tossed aside the flier and started beating her up. He accused her of being "promiscuous" and said, "These people are now encouraging you to be a prostitute."
- She then called the HUB peer educator. The peer educator intervened, told the partner about the benefits of taking PrEP, and encouraged him to come to the HUB to find out more about it.
- The following day Nikki and her partner came to the HUB together. They were counselled by the nurse, who encouraged the partner to get tested. He agreed, and his result was negative.
- From that time, Nikki says that her partner is now supportive of her PrEP use, even reminding her to take her pills on a daily basis. Nikki concluded that "She (the peer educator) helped me a lot. If it wasn't for her, my partner would have killed me."

### CHALLENGES IN INCREASING CONTINUATION

- Mobility
- Challenges with adherence because of the size of the pill
- Intimate partner violence
- Parent/ Guardian disapproving / being unsupportive
- Negative cultural perceptions around sex and youths from family, church and community

Authors:

Megan S. Dunbar

Gwen Chapwanya

- Joseph Murungu
- Imelda Mahaka
- Definate Nhamo
- Kayla Stankevitz

Theresa Hoke

SHAZ! HUB Staff and participants

# **THANK YOU**













#### **OPENING**

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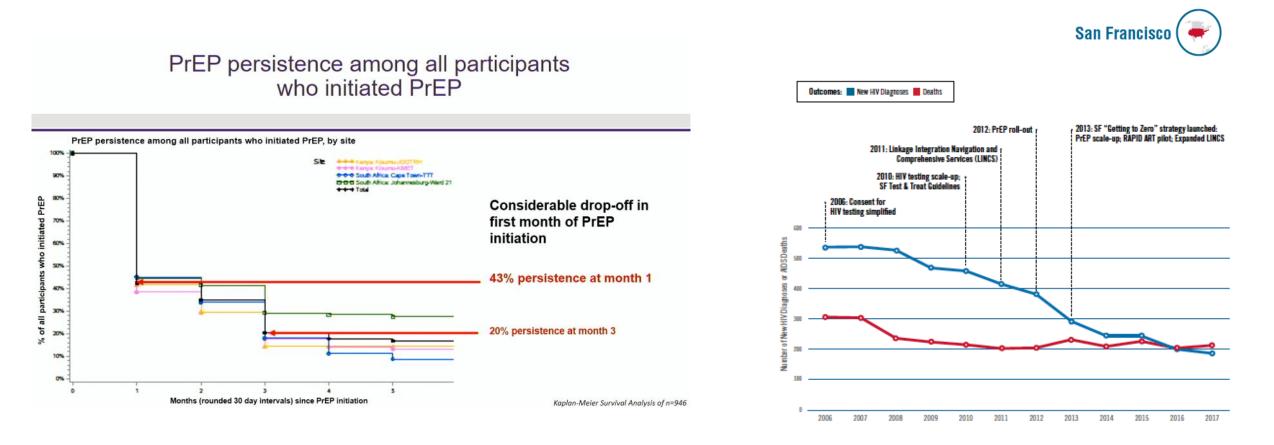
#### **DEFINING & MEASURING EFFECTIVE PREP USE ("CONTINUATION") AND IMPACT**

**WRAP-UP AND NEXT STEPS** 

## Defining and Measuring Effective Use of PrEP

Jason Reed, Senior Technical Advisor, Jhpiego Jessica Rodrigues, Director of Product Introduction and Access, AVAC





Source: POWER Project, 2018

Source: amfAR, AVAC, FRIENDS of the Global Fight, *Translation Progress into Success to End the AIDS Epidemic*, 2019



- Use does not have to be so long as to extend to periods of no/low risk, nor so short as to leave periods of high risk unprotected
- 3 patterns of PrEP use
  - Continuous = start followed by use for X contiguous days (X = 30? 90? 180?); akin to ART "retention"
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### All are effective!

Effective Use: No Single Definition = No Single Measure

## Measures: Cross-sectional & Longitudinal

Cross Sectional Measures – relatively easier	Comment				
<ul> <li>No. clients taking PrEP in reporting period/FY</li> <li>Started in reporting period/FY</li> <li>Started in prior reporting period/FY</li> </ul>	<ul><li>Analogous to PREP_NEW</li><li>Analogous to PREP_CURR</li></ul>				
No. clients that took PrEP in prior reporting period(s)					
<ul><li>Volume PrEP distributed</li><li>In reporting period</li><li>Cumulatively</li></ul>	When combined with # clients (above) can derive "coverage", if denominator known				
No. visits by visit type	Can derive <b>aggregate</b> % discontinuing, continuing, restarting				
Longitudinal Measures – relatively more difficult	Comment				
Client-level monitoring of Rx dates and volume dispensed at each Rx	Can differentiate continuous and episodic use, characterize use/non-use duration(s), identify client- level predictors of different use patterns; helpful for intervention				

## What does impact have to do with it?

- Modeling impact
  - Possible to model based upon person-time use across scenarios of person-time at risk
  - May be able to infer based solely upon "coverage", a product of volume distributed, number of clients served, and number in need
    - Data from US: declining incidence correlated with increasing PrEP coverage
    - Contraception: Couple-year protection (CYP) estimated solely upon product distribution (without assumptions about actual use)

## Proposing

- Continue cross-sectional measurements, including existing indicators
  - Sub-set of programs or sites collect longitudinal measures
    - Complement/validate cross-sectional measures
    - Identify predictors of sub-optimal use for intervention
- Add indicator of PrEP volume dispensed; when factored by number of clients, possible to estimate coverage (and perhaps impact)
- Proposed approaches inadequate for ED-dosing; I bottle/30 pills could cover up to 7 exposures with variable spacing between exposures
- Research/intensified monitoring to map use/risk to identify patterns and overlap in patterns, and to better understand the reasons why people stop taking PrEP if still at risk
- Cautious interpretation: low % continuation at X-months doesn't automatically reflect ineffective use

Target-setting

Capacity assessment

Tracking the PrEP cascade

Cost forecasting

Drug forecasting

Estimating impact

### PrEP-it Cascade Module

- Tracks monthly initiations and related metrics
- Requires entering continuation rates at 1, 3, 6, and 12 months after initiation. Continuation rates can come from:
  - Entering rates from existing M&E systems
  - Using continuation rates from other programs with provided rates of published studies from Kenya, South Africa, and Uganda
  - Entering a sample of client-level data into the Continuation Calculator

#### Continuation Calculator

- Assistance with calculating continuation rates requested during initial country visits
- Designed to calculate continuation rates with minimum data inputs
- Also calculates the percent that discontinue and reinitiate
- Optional feature can track reasons for discontinuation

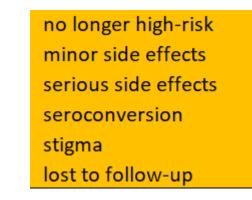
#### **STEP I: Specify reinitiation gap**

(# days after a missed appointment that would be considered discontinuation)

Reinitiation gap, in days

15

## **STEP 2: Edit reasons for discontinuation** (Optional)



#### **STEP 3: Enter client-level data**

(up to 10 return visits, 1000 observations)

					Return 1		Return 2	
ame/ID	Priority population	Discontinuation reason	Date initiated	# Days drug supply	Date returned	# Days drug supply	Date returned	# Days drug supply
100001	FSW	lost to follow-up	2-Jun-18	30	26-Jun-18	100	23-Sep-18	80
100002	MSM	minor side effects	3-Jun-18	30	14-Jul-18	90	14-Nov-18	90
100003	AGYW 15-19	lost to follow-up	3-Jun-18	7	10-Jul-18	30	6-Aug-18	60

lighter orange indicates dropdown menus based on prior steps

#### **STEP 4: Review results**

(Also linked to the **Continuation** tab in PrEP-it)

	TOTAL	SDC	FSW	MSM	AGYW 15-19	AGYW 20-24
Number initiating	100	20	26	28	14	12
% Continuation among initiating						
continued to month 1	45%	90%	46%	29%	21%	33%
continued to month 3	35%	75%	23%	29%	21%	25%
continued to month 6	15%	40%	4%	11%	21%	0%
continued to month 12	2%	5%	0%	4%	0%	0%
% Among discontinuing						
no longer high-risk	9%	25%	4%	4%	7%	8%
minor side effects	13%	5%	15%	14%	14%	17%
serious side effects	6%	5%	8%	7%	7%	0%
seroconversion	0%	0%	0%	0%	0%	0%
stigma	4%	5%	4%	0%	14%	0%
lost to follow-up	62%	55%	65%	68%	50%	67%
re-initiated PrEP	10%	10%	8%	11%	7%	17%











• What types of measures do you currently use to monitor continued/effective use of PrEP?

• And what has been your experience/lessons learned in implementing them?

• What considerations need to be taken into account when deciding what type of measure to use?



• What is the feasibility of measuring impact based on distribution of PrEP?

• What is needed at the global level and national levels to better understand use patterns and continuation trends?

• What additional research is needed to assess continued/effective use?

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## Upcoming sessions: Save the date!



Up next: Demand Creation: Developing an Insight-Driven Strategy

Speakers:

- Brian Pedersen, FHI 360
- Aigelgel Kirumburu, Jhpiego/Jilinde
- Michael Ngigi, ThinkPlace
- Elmari Briedenhann, Wits RHI

Coming soon:

#### From IPC to Mass Media: Developing a Media Mix for Your PrEP Communications

- Technical experts will discuss considerations in determining media mix for PrEP communications
- Implementing partners will share examples of tactics to promote PrEP, including social media and peer navigation programs.

#### Upcoming Sessions

- October 24<sup>th</sup>: PrEP Integration with STI/FP/MCH services
- November 21<sup>st</sup>:Target Setting and Costing
- January 23<sup>rd</sup>: Provider training
- **February 27**<sup>th</sup>: Continuation and Effective Use Interventions
- March 26<sup>th</sup>: PrEP for Pregnant and Breastfeeding Women
- April 23<sup>rd</sup>:Topics to be determined
- May 28<sup>th</sup>: Topics to be determined



- Scaling Up PrEP: 2019 PrEP Learning Network Regional Workshop
- Hosted by: OPTIONS, EpiC, and RISE
- November 11–13, 2019
- Blantyre, Malawi (Venue TBD)
- Meeting registration is free; participants are responsible for all of their own travel costs and travel arrangements

#### **Preliminary agenda**

#### Day I (November II) [OPTIONAL]

**PrEP introductory sessions** for participants in earlier stages of PrEP introduction

#### Day 2 (November 12)

Full convening launch and sessions on PrEP populations featuring sessions on AGYW, men who have sex with men (MSM), female sex workers (FSWs), and other key populations (KPs)

#### Day 3 (November 13)

Interactive problem-solving sessions on common challenges for PrEP scale-up including: building community awareness of PrEP, supporting effective use and continuation on PrEP, establishing PrEP M&E systems, and integrating PrEP into other health services

# Go to PrEPWatch for additional resources

- Webinars will be recorded and loaded onto PrEPWatch for you to access at a later date
- Additional resources that are complementary will also be included on PrEPWatch—including related research articles, tools and more to dive deeper into specific topics
- Registration for **upcoming webinars** can also be found on PrEPWatch

#### Virtual Learning Network

The PrEP Learning Network, hosted by OPTIONS, EpiC and RISE, provides national and sub-national ministries, implementing partners, community-based organizations (CBOs), and others working with PrEP around the world with the tools and resources, best practices, and opportunities to learn from others to help to advance PrEP scale-up.

Its monthly webinar series features presentations from experts in specific content areas, lessons learned and insights shared from implementing partners and government ministries, and new tools or research on specific topics related to PrEP scale-up, ranging from demand creation to continuation.

The following pages include links to register for upcoming PrEP Learning Network webinars, watch previously recorded webinars and access complementary resources, research and tools on webinar topics.

#### Webinars

PrEP Learning Network Launch Session

Thursday, August 22

During this first webinar session, implementing partners from three countries (Lesotho, Zimbabwe, and South Africa) will share their experiences with PrEP scale-up including current status of scale-up, successes, challenges encountered, and key insights learned. Recording / Slides / OPTIONS Tools and Resources / Resource Sheet

# **Poll:** What did you think of today's session?

~



# Thank you!



