

# QUALITATIVE METHODS FOR STUDYING STIGMA

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# Rationale for using qualitative methods

- Stigma is something not easy to define and yet experienced very intensely by individuals and groups
- Quantitative measures may simplify and not be able to really get at the experience(s) of stigma
- Qualitative methods allow us to dig deeper, explore nuances, and delve into seeming contradictions
- Qualitative methods help us to understand why and how stigma operates

# Qualitative Approach and Methodological options

## □ Qualitative approaches / traditions:

- Grounded theory
- Phenomenology
- Narratives
- Case Studies
- Ethnography
- Etc.

## □ Classic qualitative data collection methods:

- In-depth interviews
- Cognitive interviews
- Focus groups
- Observation (part or non-part)
- Content analysis of documents, websites, video, art, etc.
- Etc.

# Less-Used, Innovative Methods

- Photo-Voice
- Mystery Shopper approaches
- Longitudinal (repeated) qualitative interviews
- Dyadic qualitative studies
- Analyses of social media posts
- Virtual focus group methods
  - ▣ e.g., asynchronous online focus groups with female-to-male trans masculine (TM) transgender individuals (Reisner et al., 2018)

# Challenges

- Can be a sensitive and emotional topic for people to talk about (but that's one reason why qualitative methods are good!)
- Interviewers may initially be uncomfortable asking people about stigma
- Sometimes people have a hard time articulating how stigma affects them
- Academic language regarding stigma is rarely the same as the way people talk about it
- It can be difficult for people to disentangle different types and dimensions of stigma that they experience (intersectionality)
- Sometime people say they experience NO STIGMA, but often it is because they hide their stigmatized identity

# General Tips

- Stigma is a sensitive topic, but if it is handled sensitively by interviewers, people usually appreciate the chance to talk about it
- Eliciting personal stories and/or getting people to react to vignettes can be useful tools
- Active listening and probing are particularly important to discover experiences of anticipated and internalized stigma.
- People who may be perpetuating stigma (e.g., healthcare workers) may be reluctant to recognize or admit that they are doing something that might stigmatize others; can ask them to talk about what they have seen others do

# Sampling

- Use purposive/theoretical sampling to make sure you are including appropriate variation in your study population
- Make sure you are including important minority groups and voices
- Make sure you include sufficient numbers according to variables that are theoretically important in stigma research
  - ▣ Age, sex
  - ▣ Time since diagnosis
  - ▣ Other stigmatized identities
- You may want to sample according to levels of stigma in a survey and/or achievement / non-achievement of a health outcome (e.g., viral suppression) in the context of a mixed methods design

# Example sampling plan for stigma focus groups

	<b>MSM living with HIV</b>	<b>Transgender women living with HIV</b>
Virally suppressed	3 groups	3 groups
Not virally suppressed	3 groups	3 groups

A total of 12 focus groups (N~72-96 participants)



# The Interview / Focus Group Guides

- Come up with good non-judgmental open-ended questions that elicit stories of how people have experienced (or avoided) stigma and discrimination
- Those stories will allow researchers to get an insider's view of how people experience and react to stigma
- Start out with less sensitive topics to break the ice, placing the critical questions around stigma in the middle of the interview guide, and winding down at the end with less emotional topics for good closure

# Coding and Analysis

- Pay attention to:
  - ▣ Types of stigma (e.g., HIV, TB, poverty, cancer, sex work, etc...)
  - ▣ Sources of stigma (family, community, health workers, intimate partner, etc...)
  - ▣ Dimensions of stigma (anticipated, internalized, perceived community, enacted, etc..)
  - ▣ Multiple levels of stigma (individual, interpersonal, community, structural)
  - ▣ Mechanisms for the effects of stigma (mental health, stress, etc...)
  - ▣ Resiliencies that may counteract stigma (social support, coping, empowerment, etc.)
- Rapid analysis techniques can be useful to get quick data for stigma-reduction intervention development / adaption

# Pros and cons of remote qualitative data collection?

## □ Pros:

- ▣ May be easier for people to participate from various locations around the country/world
- ▣ Can be perceived as more confidential (video off)
- ▣ Protects from exposure to COVID-19

## □ Cons:

- ▣ Not as easy to detect body language and other non-verbal clues
- ▣ Some people not able to access or are not comfortable with the technology
- ▣ May make it more difficult for interviewers/moderators to really connect with participants

# Example Study: Women's Adherence and Visit Engagement Study (WAVE) (R01MH104114, 2015-2019)

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Neilands

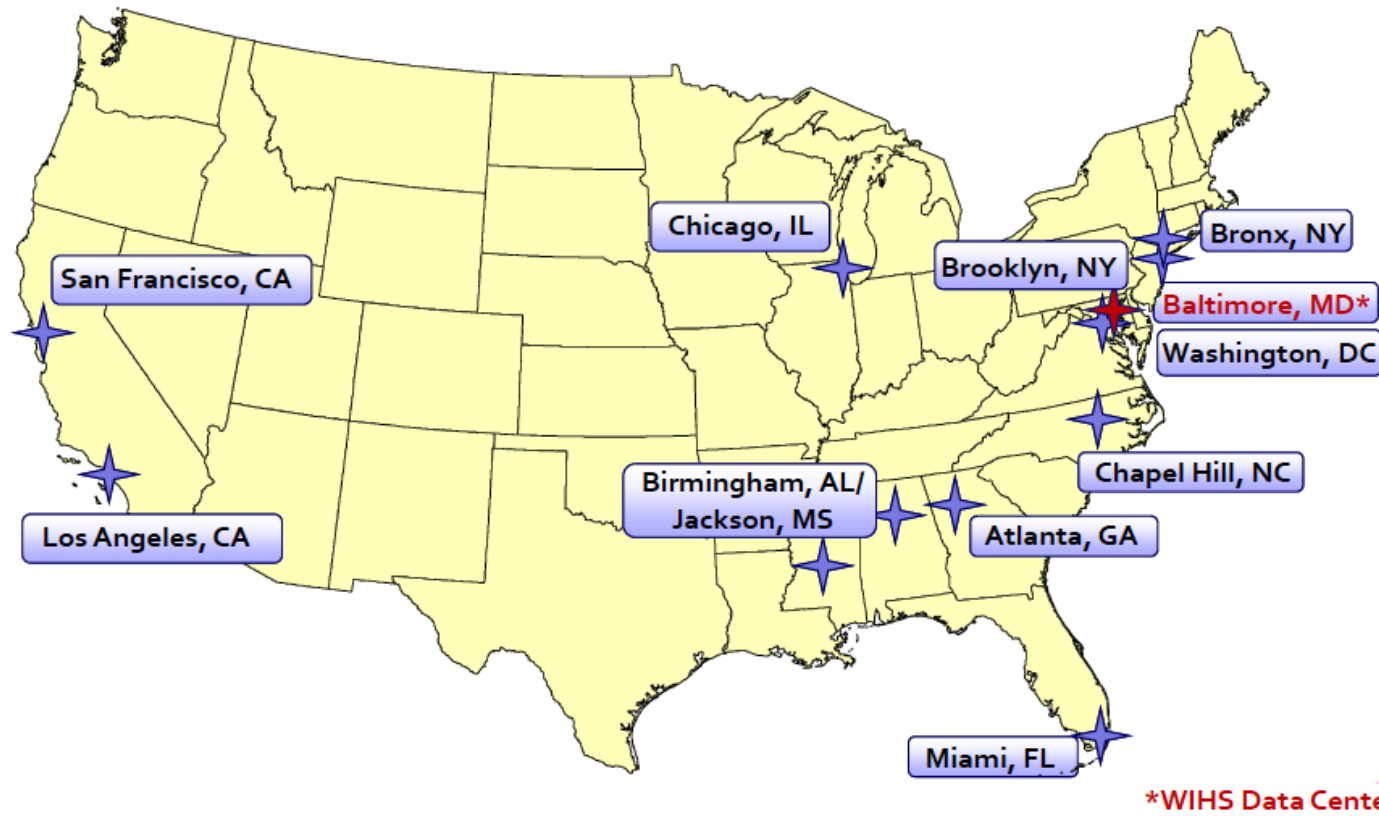
Studying Mechanisms and Longitudinal  
Effects of Stigma on Women's Adherence  
and Outcomes in the national Women's  
Interagency HIV Study (WIHS)



Funded by the U.S. National Institute of Mental Health (NIMH)

# The Women's Interagency HIV Study (1994-present)

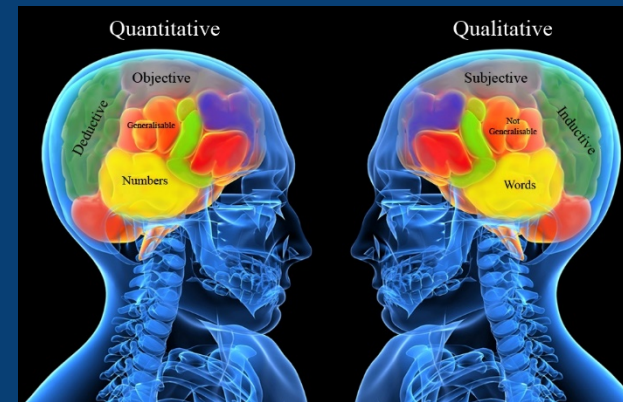
## *Women's Interagency HIV Study (WIHS) Sites*



# Aim 3

To examine the link between **intersectional stigma**—including stigma related to HIV, race/ethnicity, poverty, and gender—and adherence to HIV treatment recommendations using mixed methods research.

- Qualitative in-depth interviews with women living with HIV
- Questionnaires including validated measures of:
  - HIV-related stigma
  - Racism
  - Sexism
  - Poverty stigma





# Characteristics of Qualitative Interview

## Participants (N=76)

- WIHS Site:
  - ▣ 13 in Birmingham AL
  - ▣ 13 in Jackson MS
  - ▣ 25 in San Francisco CA
  - ▣ 25 in Atlanta GA
- Race: 46 African American, 20 Caucasian, 6 multi-racial, 1 Native American, 3 Not reported
- Ethnicity: 5 Hispanic or Latina
- Income: 63 low income; 13 mid-upper income
- Sexuality: 6 bisexual, 5 lesbian
- Age: 34 aged 50 years or older



# The Interview Guide: The beginning

## **AIM 3 QUALITATIVE INTERVIEW GUIDE RELATED TO INTERSECTIONAL STIGMA**

### **Theme**

### **INTERVIEW QUESTIONS**

#### **Ice-breaker/intro**

- ***Can you tell me a little about the neighborhood/area where you live? What do you like about it? What do you not like about it?***
- ***What comes to mind when I ask you about “your community”? Do you think about the place where you live? Another place or group of people? Who do you consider a part of your community?***

#### **Transition**

***Thanks so much for sharing that. Now that we have gotten to know each other a little better, I'd like to move into some of the main topics that we want to cover in this interview.***

# The interview guide: Eliciting barriers and facilitators to adherence to HIV treatment

- ***First, can you share with me the story of how you were first diagnosed with HIV? Can you tell me about how and when you first got into HIV care after being diagnosed?***
- ***Can you tell me about your visits to a doctor for regular HIV care? (By regular HIV care, I mean a visit to a clinic or doctor's office to have a check-up on how you're doing with your HIV. This does not include sick visits, emergency services, or hospital admissions for HIV; it does not include visits that are only for lab or blood work or X-rays, and it does not include your WIHS study or other research visits.)***
- ***Have you been going for regular HIV care visits, and if so, how is that going for you?***

# The interview guide: stigma questions

## Transition

Some of the barriers you have already mentioned (or that many people talk about) are **stigma (the negative ways that that people are viewed or feel because of their differences) and discrimination (being treated badly by others because of these differences)**. I would like to talk more about these topics now. I understand that these are sensitive topics, and some of these questions may bring to mind painful experiences. You are welcome to share only what you feel comfortable with, and can stop or take breaks at any time.

## Types of stigma and discrimination

What kinds of opinions or attitudes do you think people have about women living with HIV? What stereotypes do you hear about women living with HIV? (Or what assumptions do people make about women living with HIV?)

### Probes:

- What do people say about them as women?
- What do people say about them as mothers?
- What about their lifestyle? (substance use, sex life, etc.)
- In your opinion, what is going through the minds of people who discriminate against women living with HIV?

**Can you describe a time when you felt stigmatized or discriminated against?**

# Coding and Analytic Process

- Transcripts were coded and analyzed according to Braun & Clarke's steps of qualitative thematic analysis.
- A team of researchers developed an initial list of codes after data collection began. A priori codes were informed by intersectionality theory, literature review, the interview guide, and an initial review of the data.
- Four researchers coded all transcripts using Dedoose
- Twelve transcripts were double-coded in order to establish agreement on coding definitions and procedure.
- After coding, we ran queries to enable thematic comparisons between data tagged with different codes, or combinations of codes.
- Documents summarizing emerging ideas and concepts and patterns across transcripts were shared among the research team and discussed in group meetings.

# Findings: Intersecting stigmas experienced by diverse women living with HIV in the US

- Most commonly:
  - Gender
  - Race
  - Poverty
- But also:
  - Incarceration
  - Age
  - Weight

*“All my life I’ve always wondered what people discriminated against me for. Is it because I was Black? Is it because I was biracial? I never knew if people were discriminating against me because I was HIV-positive, because I was a woman. Honestly, I don’t know what. I can’t like really pinpoint. I just know that something. I guess it is like a gut feeling. Something just didn’t feel right. Like somebody insulted me and like later I’m like what was that for?”*

## Sexism, Sex Work Stigma, and HIV



“The men can do what they do and the women shut their mouths and take it. Women can’t do anything about it. That’s the whole culture...They downgrade a lot of us women who are prostitutes. ‘They are street girls, so HIV is what they get.’”

## Racism, Sexism, and HIV

“Yes, stigma affects me personally...Because, I’m a woman that’s living with HIV and I’m a black woman, too. So, I’m just kind of, I’m calling out these things a woman, and then a black woman, because these are things that’s been stigmatized the worst.”

## Poverty Stigma and HIV

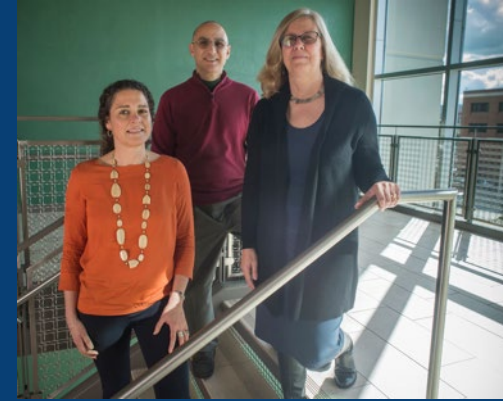
“...people just talk down on the poor women, and to the rich ones, people are just sorry that it happened, and then people are off to another subject. The poor ones, people are just constantly beating them up. Poor women already feel bad about their HIV status, but they constantly just are being reminded of it...It is a battle.”



# Conclusions

- Intersectional approaches have the potential to uncover the complexity of social processes of marginalization, barriers to accessing health and social services, and strategies employed to navigate stigma.
- HIV serostatus, race, gender, economic status, and sexuality are interdependent and profoundly shape life experiences, opportunities, and healthcare access and uptake.
- The rich complexity of women's lives in this study highlight the need for public health strategies to consider community, interpersonal and structural dimensions across intersecting, interdependent identities to promote the wellbeing, and reduce social and health disparities among women living with HIV.

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# MANIFESTATIONS OF STIGMA IN THE CONTEXT OF A NATIONAL ORAL PRE-EXPOSURE PROPHYLAXIS SCALE-UP PROGRAM IN KENYA

Investigators

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# Introduction

- Kenya included PrEP in national guidelines in July 2016
- In May 2017, Kenya launched a national PrEP scale up program
- Uptake has been progressive, but slow among some sub populations, and overall continuation rates consistently low
- Stigma was documented as a substantial barrier during PrEP clinical trials and demonstration projects

# The Jilinde Project

- Four year project that seeks to demonstrate effective PrEP integration and delivery at scale, in low resource settings
- Implemented in 10 out of 47 counties in Kenya
- PrEP provided through 93 sites to:



Men who have sex with men (MSM)



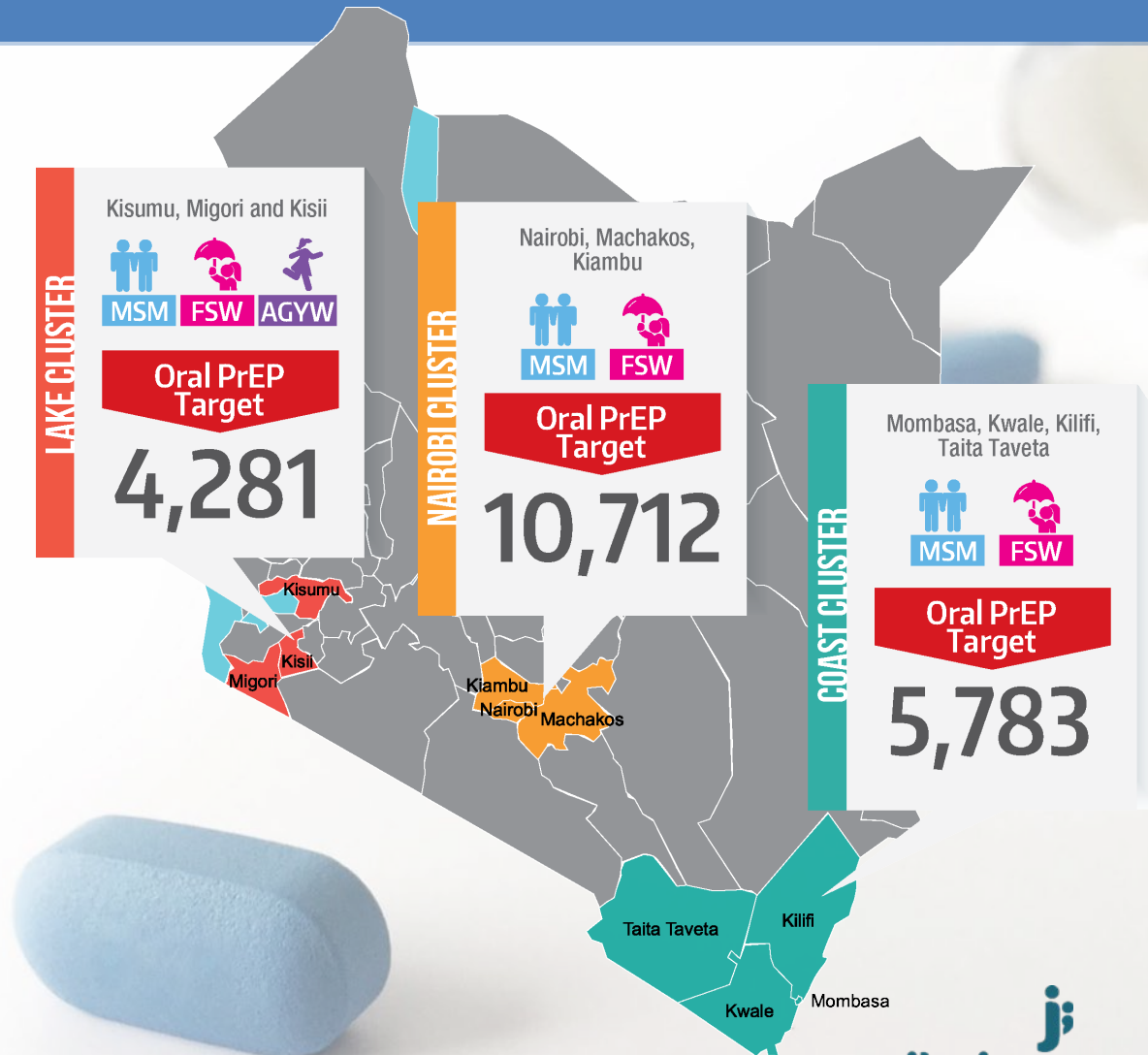
Adolescent girls & young women (AGYW)

Sero discordant couples (SDC)



General population (GP)

Female sex workers (FSW)



# Methods

- A qualitative study associated with Jilinde programmatic scale-up was conducted between October 2017 - November 2018
  - ▣ 22 focus group discussions (FGD) and 30 in-depth interviews (IDIs)
- Aim: to understand how stigma towards PrEP use is experienced in routine service delivery, in order to improve PrEP outcomes
- Ethical approvals were obtained from Kenya Medical Research Institute (KEMRI) and Johns Hopkins Bloomberg School of Public Health (JHSPH), and each participant provided informed written consent
- Purposively sampled former, current and potential PrEP users (FSW, MSM, AGYW), parents and sexual partners of AGYW, peer educators, and PrEP health care providers
- Conducted thematic data analysis



# Socio-demographic Characteristics

<b>Population Type</b>	<b>Participants (n=227)</b>	<b>Mean age (Years)</b>	<b>Sex</b>
MSM	36 (16%)	26	All male
FSW	28 (12%)	31	All female
AGYW	86 (38%)	21	All female
Parents of AGYW	12 (5%)	44	50% were male
Male partners of AGYW	10 (4%)	22	All male
Health care providers	29 (13%)	32	40% were male
Peer educators (FSW & AGYW)	26 (12%)	27	All female

# Summary of Key Findings

## STIGMA

### Types



Product



Behavior



Identity

### Sources

- Community
- Sexual partners
- Health care providers
- Peers
- Family

### Expressions

- Labelling
- Stereotypes
- Prejudice
- Discrimination

### Client outcomes of stigma

- Shame
- Loss of 'business'
- Fear of rejection
- Reputational damage
- Intimate partner violence
- Discrimination by providers



### Programmatic Impact

- Low PrEP uptake and continuation



# Types of Stigma

1

## Product stigma

“I have kept it a secret because the bottle is similar to that of ARVs. Someone who doesn't know about PrEP could think you have HIV...”

*(20 year old, AGYW PrEP user)*

# Types of Stigma

## 2 Identity stigma

“For male sex workers and MSM, you feel you are serving people you despise. Who wants to deal with these people?”

*(33 year old, female clinician)*

“MSM is seen as something bad, they take it as a curse. So when you are near them they reject you. They will be like eeh... you are a male prostitute...”

*(20 year old, MSM PrEP user)*

# Types of Stigma

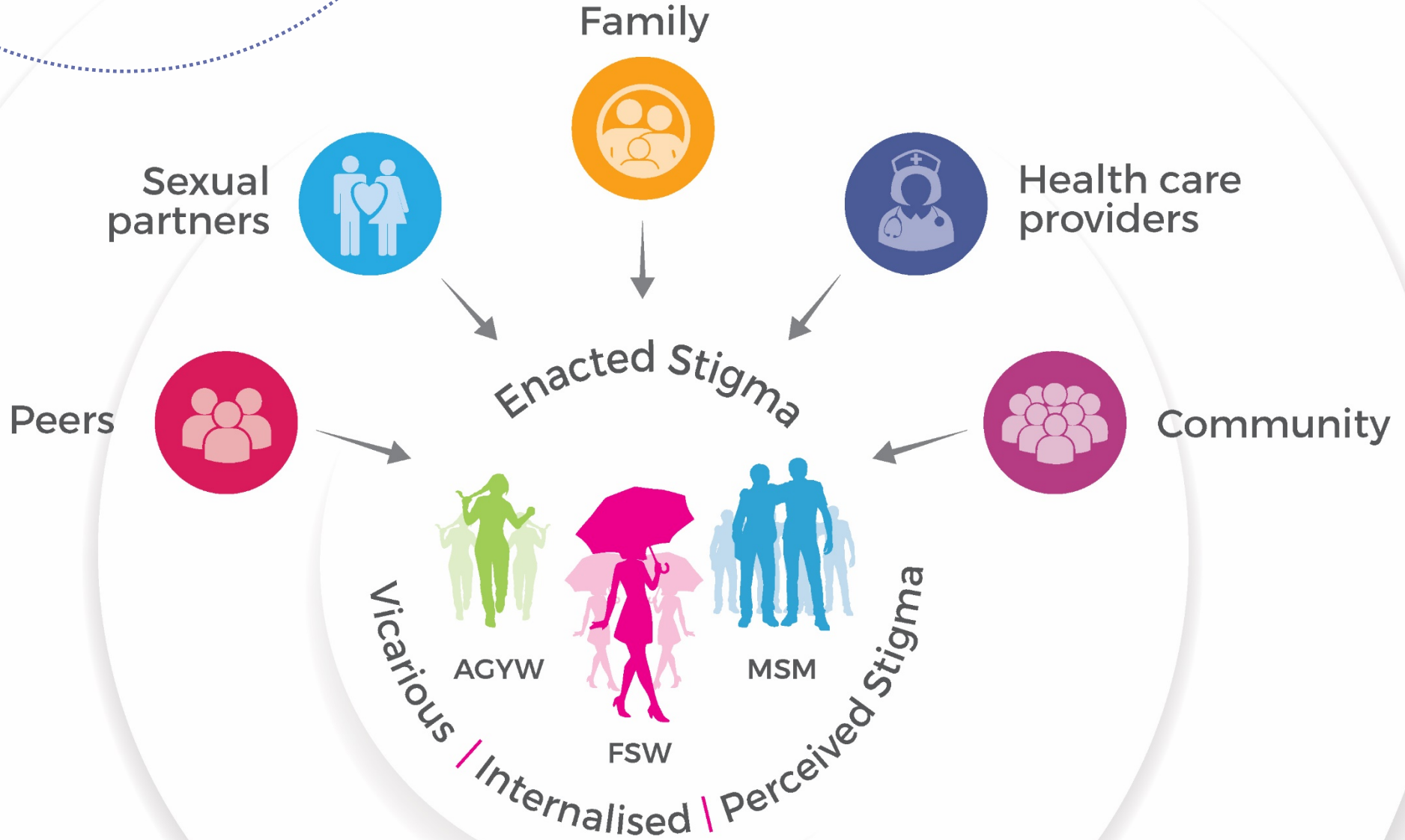
3

## Behavior Stigma

“My mother told me I have taken those drugs because I want to be a prostitute, so that even if I sleep with men, I don’t get the disease...”

*(22 year old, AGYW PrEP user)*

# Sources of Stigma



# Expressions of Stigma

## 1 Prejudice

“The reality is when the female sex workers come, if she is coming with an STI, you treat but with this attitude of, okay, it serves you right...”

*(41 year old, male clinician)*

## 2 Discrimination

“If you go for a refill, you will wait for so long because some of the clinicians don’t want to see PrEP clients. When they hear that this is a PrEP client, they say, ‘Tell them to wait first’...”

*(24 year old, AGYW Peer Educator)*

# Expressions of Stigma

3

## Stereotypes

“I’m really worried of this drug, PrEP, the children will become promiscuous. She will just be having sex with different men to get money...”

*(58 year old, parent of AGYW)*

4

## Labelling

“When you go to the hospital to collect the drug and you meet someone you know, they say... “So you take the HIV drugs, so you have AIDS..”

*(22 year old, AGYW, discontinued PrEP)*

# Client Outcomes of Stigma

- 1 Intimate partner violence
- 2 Fear of rejection
- 3 Provider discrimination
- 4 Loss of business
- 5 Shame & reputational damage

“I feared how I would tell  
the old man I was using  
PrEP because he would  
beat me.”

*(23 yr old, AGYW PrEP  
user)*

# Programmatic Impact of Stigma

1

## Low PrEP uptake & continuation

“What made me to stop taking PrEP was my two friends who said that I was HIV positive...”

*(22 year old, FSW, discontinued PrEP)*

“I stopped when we quarreled with my boyfriend. I had to stop in order to be at peace with him...”

*(22 year old, AGYW, discontinued PrEP)*



# Conclusions

- Stigma was a major contributor to peoples' choices around initiation and continuation of PrEP;
  - ▣ Stigma around the product,
  - ▣ Stigma around clients' behavior and identity
- While stigma was manifested differently for diverse populations, it was described as a major barrier to both uptake and continuation
- PrEP delivery programs should:
  - ▣ Prioritize interventions to address HIV related stigma at all levels, including sensitivity training for providers
  - ▣ Intensify awareness creation efforts to norm PrEP

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- 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



Questions???