

# Challenges with Oral Pre-Exposure Prophylaxis (PrEP) Disclosure among Adolescent Girls and Young Women (AGYW) in Kenya and South Africa

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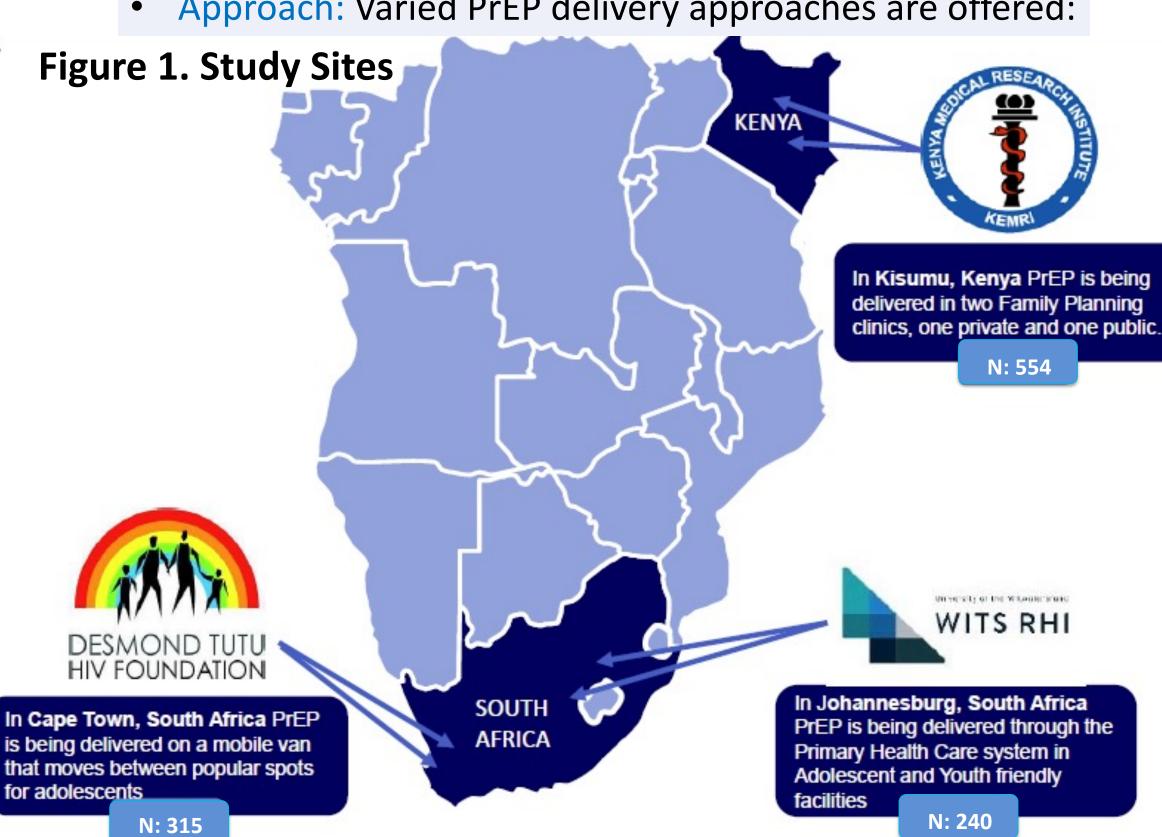
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# BACKGROUND

- Adolescent girls and young women (AGYW) have high HIV incidence and are a key population for PrEP implementation in Sub-Saharan Africa.
- PrEP use may be challenging to AGYW, given their need for social support and challenges with disclosure.
- We explored oral PrEP disclosure and its potential influence on PrEP persistence within POWER (Prevention Options for Women Evaluation Research), an ongoing study of PrEP delivery to AGYW in South Africa and Kenya.

#### **POWER STUDY**

- Design: Prospective, observational, open-label cohort study to evaluate delivery approaches, uptake, and adherence to oral PrEP among AGYW at 3 sites (Figure 1). Follow up is for up to 36 months at each location.
- Population: ≤3000 HIV-uninfected women ages 16-25
- Approach: Varied PrEP delivery approaches are offered:





# METHODS

- We are conducting in-depth interviews (IDI) with a purposive sample of POWER participants, N=68 to date.
- Interview guides covered participants' background knowledge of oral PrEP, decision about PrEP, experience with clinic, experience using PrEP, relationships, stigma or discrimination, and their advice to other PrEP users.
- We conducted a rapid analysis of transcripts and IDI summaries to explore non-study social support and opposition to oral PrEP over the first 6 months of use.

# **AUTHOR AFFILIATIONS**

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# RESULTS

#### **STARTING PREP**

- Most AGYW lived with parents, other family members, or their sexual partner (Table 1), making discreet use of PrEP foreseeably difficult.
- AGYW were concerned about household member discovery of the PrEP pills and had to consider whether to disclose PrEP use willingly, or risk accidental discovery.
- AGYW discussed how deciding on study participation, PrEP use, and disclosure could put their relationships in jeopardy.

"This is my life and if I wanna include someone else about my health [who doesn't show they care], I might as well lose them, so I just made my decision by my own that okay, I wanna come here and I'm gonna [ sic ] join the study and get the PrEP, ja. " (Johannesburg, 24 years)

**TABLE 1. Qualitative participant Demographics (n=68)** 

		Johann-		
	Cape Town	esburg	Kenya	Overall
	(n=22)	(n=22)	(n=24)	(n=68)
	20	21	22.5	21
Age (median, IQR)	(19-21)	(20-22)	(20-24)	(19-23)
Highest level of education				
Primary school (any)	0 (0)	0 (0)	5 (21.7)	5 (7.5)
Secondary school (any)	12 (54.5)	17 (77.3)	14 (60.9)	43 (64.2)
College or university (any)	10 (45.5)	5 (22.7)	5 (21.7)	20 (29.9)
Relationship status				
Single	22 (100)	22 (100)	13 (56.5)	57 (85.1)
Married	0 (0)	0 (0)	10 (43.5)	10 (14.9)
Household members				
Parent(s)	17 (77.3)	8 (36.4)	7 (30.4)	32 (47.8)
Other family	5 (22.7)	9 (40.9)	6 (26.1)	20 (29.9)
Husband/sexual partner	0 (0)	2 (9.1)	11 (47.8)	13 (19.4)
Number of current sex				
partners (median, IQR)	1 (1-1)	1 (1-1)	1 (1-2)	1 (1-1)
Earns an income	3 (13.6)	11 (50)	9 (39.1)	23 (34.3)

# **DISCLOSURE REACTIONS**

- Most participants disclosed PrEP use to select people in their lives, e.g. family members, partners, or friends; few told no one.
- Disclosure often resulted in misconstrued accusations of being HIV-infected and taking the PrEP pills for HIV treatment.
- Fear of this reaction and associated stigma was a common reason for non-disclosure.

"They won't understand me. Most of them will think that this drug is an ARV for those who are HIV positive. They won't understand that it is to prevent HIV infection...They are women whom I cannot even approach." (On why she hasn't told other young women about PrEP; Kisumu, 23 years)



#### HANDLING REACTIONS OF OTHERS

AGYW attributed accusative reactions like these to the lack of knowledge about PrEP in their communities.

> "You see, so a lot of people end up dying because they lack knowledge, they die without knowing that there's something like PrEP. You know, so if I tell my friend and my friend tells someone else and that person also tells someone, can you see that we can beat HIV?" (Johannesburg, 24)

- Participants sometimes addressed misconceptions through explanation, but often had to confront disbelief from partners and family until they provided explanation via sources such as pamphlets or the internet.
- If misconceptions were cleared, friends & family often became key sources of support or expressed interest in using PrEP themselves.

"[My mother] supported me and told me that I shouldn't be ashamed wherever I am, in my time of taking pills I should take it. Irrespective of what other people say, I should think of the reasons why I am using PrEP." (Cape Town, 19 years)

When they were believed, AGYW felt proud about educating their loved ones.

# SUGGESTIONS FOR ADDRESSING STIGMA

AGYW indicated that disclosure would be easier if there was more community education on PrEP, so they don't carry the onus of being others' first source of information about PrEP or face criticism from others.

> "Workshops will do, maybe going to schools, talking about PrEP there you know, and then you know every child is there, even when someone is taking it, they won't be judged because the clinic came to them and spoke about it." (Johannesburg, 20 years)

# Tutu Mobile Truck, Cape Town, South Africa



# CONCLUSIONS

- Although AGYW are accessing PrEP through studies and demonstration projects, most community members are still unaware of PrEP's existence
- The burden of education currently falls on AGYW's shoulders (the users themselves).
- Increased community education could facilitate disclosure of PrEP use by AGYW and foster better social support for adherence.















