



AIDS 22ND INTERNATIONAL AIDS CONFERENCE
2018 AMSTERDAM, NETHERLANDS
23-27 JULY 2018

BREAKING BARRIERS • BUILDING BRIDGES

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Should I Take PrEP?

A Mental Models Assessment of Young African Women's
Motivations for and Barriers to PrEP Initiation and Adherence

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USAID
FROM THE AMERICAN PEOPLE



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Background

- Despite decreases in new infections the past two years, young women in sub-Saharan African still have one of the highest HIV incidence rates globally (UNAIDS, 2013; 2014; 2018)
- Stigma, social & economic context as factors limiting prevention options.
 - Difficulties discussing HIV, negotiating partner HIV testing or condom use (Kacadnek et al, 2013; Jewkes et al, 2010; Montgomery et al, 2012; Maticka-Tyndale et al, 2010, Stadler et al, 2008)
 - Need for an HIV prevention tool that does not require partner cooperation, like PrEP
 - However, in several large trials, low use of such biomedical HIV prevention tools (van Damme et al, 2012; Murrain et al, 2015; Baeten et al, 2016)
- PEPFAR: Need to better understand and meet demand
 - Identify user preferences for delivery of PrEP and microbicides, followed by demonstration projects to test and optimise uptake, adherence and delivery

Background II

- Formative research for the USAID-funded **POWER initiative**, an open label demonstration project (PIs: Connie Celum & Jared Baeten)
 - Desire to address the *context* of PrEP in peoples lives (Celum et al, 2015)
- Purpose:
 - Understand **motivators** and **obstacles for women's initiation** of and **adherence to PrEP**, taking life context into account
 - *How do women construe their HIV risk versus other risks in their lives?*
 - *What is the value proposition of PrEP (for young women)?*

We drew on **decision science**, the study of...

How people should make decisions

(normative analysis)

How people do make decisions

(descriptive research)

How to help people make better decisions

(prescriptive interventions)

REASONS WHY “SHOULD” AND “DO” ARE DIFFERENT, CONT.

- Perspective taking failures:
 - not realizing situational factors in the decision
- Communication failures
 - Experts assume their knowledge is intuitive to others, and thus are wrong about what to communicate, or how to communicate it (avian flu)
 - Over-informing (full-disclosure)...
 - Under-informing (numeracy)...
 - Applying a behavioral principle incorrectly (incorrect setting, or without attention to its interaction with other principles, e.g., loss frames & affect)
- Biases & Heuristics

SOME BIASES AND HEURISTICS

Judgment

People are good at tracking what they see, but not detecting sample bias.

People have limited ability to evaluate the extent of their own knowledge.

Affect: People have difficulty imagining themselves in other visceral states.

People have difficulty projecting non-linear trends.

People confuse ignorance and stupidity.

People are present-biased.

Choice

People consider the return on investment in making decisions.

People dislike uncertainty, but can live with it.

People are insensitive to opportunity costs.

People are prisoners to sunk costs, hate to recognize losses.

People may not know what they want, especially with novel questions.

Fischhoff, 2013.

WHAT IS MENTAL MODELS RESEARCH?

How people interpret (risk) information and the subsequent choices they make are informed by their own intricate web of beliefs and theories - their “mental models.”

Behavioral interventions

- Bridge knowledge gaps
- Draw on values
- Use natural language

HOW DOES MENTAL MODELS DIFFER FROM OTHER QUALITATIVE APPROACHES?

1. Goes in-depth on **risk perceptions**, starting with general questions in the P's on language and becoming detailed down to quantitative assessment.
2. In-depth interview data are coded against **directional links** in **expert model**
 - Codes in link and thematic format
 - Illustrate directional beliefs, values, and (mis)conceptions not identified by expert model
3. Always followed by **survey** to assess prevalence of beliefs, values, etc.
 - To allow for statistical inference
 - Tie specific gaps to demographics or interactions
 - Pre-test pilot communications, etc.

Field Research Conducted at 3 Sites

- **Desmond Tutu HIV Foundation**
 - CAPE TOWN, SOUTH AFRICA
- **Wits Reproductive Health Institute**
 - JOHANNESBURG, SOUTH AFRICA
- **The Kenya Medical Research Health Institute**
 - KISUMU, KENYA



Methods

- **Expert Model** (March 2016)
 - Literature review, 6 phone interviews and 5 semi-structured surveys with HIV prevention experts
- **Lay Model** (In-Depth Lay Interviews, May - August 2016)
 - n = 48 African women (age 16-25) and 45 African men (age 18-60)
 - 2, 1-hr interviews per participant
 - Goal: In-depth probe into local motivators and barriers to PrEP
 - Coded against the expert framework (new codes added), kappa >.80.
- **Follow-up Lay Survey** (February - June 2017)
 - n = 444 (f 243; 87 at DTHF, 74 at Wits RHI, and 82 at KEMRI)
 - Goal: to establish prevalence of beliefs and attitudes identified in the interviews and identify demographic relationships to those beliefs and attitudes.

Results: Sample Demographics

- **Age** = 20 years (median)
 - 16-17 Yrs (24%), **18-22 (46%)**, 23-25 (30%)
- **Education:**
 - Primary (16%), **Secondary (64%)**, University (17%), and Graduate (3%)
- **Marriage & Children:**
 - **Single (84%)**, Single living together (6%), Married (6%), Separated (4%)
 - **68% = 0 children**
- **Heard of PrEP?** 44% yes
- **Know anyone using/has used PrEP?** 5% Yes

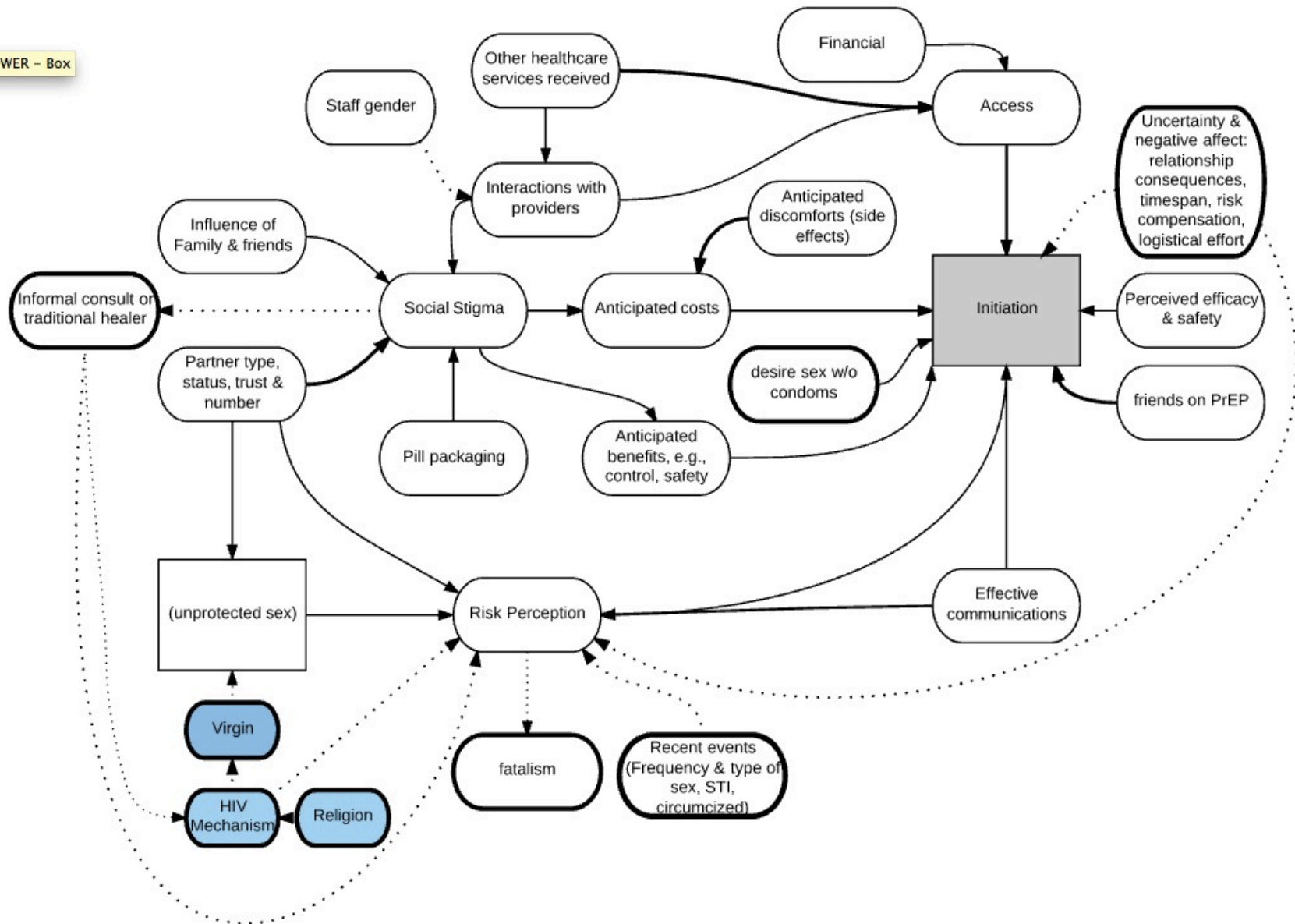
Results II:

Women's perceptions of relationships & sex

- **Sexual experience.**
 - Avg first sexual experience age 16.5.
 - Avg sexual frequency = between once a week and once a month.
- **Condoms.**
 - Women use condoms with main partners between “*sometimes*” and “*usually*” (3.33 out of 5, 1.35 SD).
 - Slightly more likely to use condoms with side partners, 3.88/5 (1.20 SD).
- **Side partner?**
 - Most women reported not having a side (.24, .43 SD), but they thought most women have 2.54 (1.12 SD) partners at one time.
 - 59% of men reported having a side (.49 SD). On avg, men thought that other men had 3.2 partners at a time (1.22 SD).
- **Norms.** Of 10 couples in the community, how many monogamous? Women said 5.02 (2.59 SD); men said 5.01 (2.50 SD).

Results III: Integrated PrEP Initiation Model

POWER - Box



Results IV: Gap Analysis - HIV Risk

- **Ps cared deeply about HIV risk**
 - 84% said HIV would be worse than getting pregnant. (Reason: social exclusion)
 - Ps see risk of pregnancy as 71.3%, LESS THAN 79.1% risk of contracting HIV. (unprotected sex 1x)

- **Ps overestimated their HIV risk**
 - Single exposure estimates greatly overestimated: Objective risk is ~.38% for women (.3 for men), but they perceive 79% & 65%, respectively.
 - Risk of infection accumulates over repeated exposures, but people estimate accumulation poorly. Ps overestimated in 10 and 100 encounters, too (96% F and 91% M, for both exposure levels).

- **Ps understood some aspect of HIV/PrEP mechanism, but not deeply**
 - *Understanding HIV*: circumcision, rough vs. not rough sex, STIs, etc.
 - *Not understanding PrEP*: interaction with immune system (efficacy concerns if one's sick, empty stomach, other meds), missed doses, interpreting side effects

- **For a subsample, perceptions of high risk + shallow understanding lead to problematic “immunity,” “divinity” or mistrust stories to explain why they haven’t gotten HIV**
 - For this subsample, HIV risk loses salience.

Results V: Gap Analysis

Uncertainty & Negative Affect/ Present-Bias

- Ps displayed a massive amount of effort trying to anticipate risks to their self-image and relationships
 - relationship turbulence (introducing trust issues into their relationship, family)
 - work through moral reflections about risk compensation (what kind of person am I?),
 - forecast—often uncomfortably—how long their period of risk would be, and what adherence costs would entail (empty stomach, other meds, how to interpret side effects since this is your immune system)

Results VI: Benefits

- **Positive Affect / Present Bias:** PrEP is...Control, Safety, Strength, & Conscientiousness
 - “I would not know when I would get raped or have unprotected sex so I would rather be on the safe side.” (Cape Town 1109.2)
 - “PrEP would affect my life in a lot of good ways because it would give me an opportunity to remind myself that there’s HIV out there, and now I am protecting myself from it. Why am I doing this? Because I don’t want to use condoms. But then its going to teach me on a daily basis that, okay, you are on PrPE, but change your life. Change your life. On a daily basis, [PrEP’s] gonna remind me of HIV, and that HIV is a thing that is out there. It’s something that can be a part of my life if I don’t take care of myself properly.” (Joburg 2103.2)

Conclusion:

A YAW-Centered Value Proposition

- Aspects of the initiation/adherence model were consistent with the expert model:
 - finance, stigma, access, interactions with providers
- Aspects were not:
 - HIV Risks
 - Non-HIV Risks: Relationships, self-image, forecasting the future, efficacy
 - Both of these inform present-bias. Both entail an affective, implicit valuation that can influence (sometimes, steer) cost-benefit judgment.
- Value Proposition
 - Benefits included belief in PrEP's effectiveness and positive emotions such as control and safety.
 - But, as one P said, "it's like 'gym-ing,' you can't see it."

Interest in PrEP

- 2 Questions:
 - After learning about PrEP's efficacy, they were asked, 'Now that you have learned a little about PrEP, how interested are you in learning more?' 4.3/5 (between "very" and "totally")
 - After being given information about the need for daily administration of PrEP, regular follow-up visits, and the need to continue with condoms, they were asked how interested they would be in trying it
 - 3.83/5 (between "somewhat" and "very")
 - Only 15 women reported "not at all," and their follow-up explanations entailed "lack of risk" (9) or "aversion to medicine/pills" (7)
- Ordered logistic regression to predict 172 women's interest in trying PrEP, LR $\chi^2(13) = 109.04$, $\text{Prob} > \chi^2 = 0.00$, $R^2 = .25$.
 - Living in Cape Town increased interest by 1.36 ($z=2.62$, $p=.01$)
 - Previous knowledge of PrEP increased interest by .89 ($z=2.44$, $p=.02$)
 - Believing one's self would use condoms less increased interest by .83 ($z=2.25$, $p=.024$)
 - Perceiving one can take PrEP daily increased interest by 1.84 ($z=4.14$, $p=.000$)
 - Each unit increase in self-assessed 1-Yr HIV risk increased PrEP interest by 1.84 ($z=4.14$, $p=0.00$)
 - Importantly: The following were not associated with interest: frequency of sex or condom usage, having side partners or suspecting that one's main partner has side partners.
- We asked about factors that would influence choice to take PrEP, such as: having to pay, side effects, travel far to get it/clinic visits, privacy, daily pill, partner not supportive, costs...
 - Few inputs are hard stops (except money/travel).
 - Ps who cite side effects as a game changer recant when informed they are short-term.

Implications

- **Communications**

- Marketing/Branding: To counter uncertainty/negative affect in forecasting relationship/identity consequences...positive affective images/branding, e.g. empowerment, bravery, norms
- Marketing/Counseling Content:
 - Risk Framing – communicate cumulative or lifetime risk rather than single-exposure risk.
 - Emphasize that neither beauty nor character are useful indicators of HIV infection.
 - Clinical counseling: Find a way to incorporate HIV and PrEP mechanism into counseling.

- **Create/use a decision tool:**

- Uncertainty and negative affect seemed to pause the PrEP decision calculus for some Ps. A decision tool can guide/direct P's attention to whether PrEP is right for her without activating relationship/identity/morality concerns.

- **Delivery**

- Overcome financial/logistical “hard-stops” by finding a way to bring PrEP (and services) to the people.
- Create PrEP-friendly health services.
 - Train health care providers in perspective taking. Increase empathy, decrease judgment
 - Hire peer educators, youth community healthcare workers or PrEP ambassadors who mitigate the need for this training

Thank you...

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Questions & Discussion

Demographics

Participant Attributes	Caucasian/MSM (f= m)		Black LGBTQ (f= m=)		IDU (f=75 m=76)		Total (f=244 m=200)	
Age (median):	20 (16-26)	22 (17-30)	20 (16-25)	26 (18-51)	20 (16-25)	22 (18-25)	20 (16-26)	22 (17-51)
Highest level of education:								
Primary School	2	1	15	5	12	6	29	12
Secondary School	66	40	50	32	53	59	169	131
University Degree	14	6	10	23	7	7	31	36
Graduate Degree	2	4	4	11	3	4	9	19
Marital Status:								
Single	75	46	60	37	69	69	204	152
Single but living together	5	2	5	3	5	7	15	12
Married	2	1	13	32	0	0	15	33
Separated	2	2	4	0	1	0	7	2
Know anyone using/has used PrEP:								
No	81	47	75	70	72	74	228	191
Yes	5	3	6	2	3	2	14	7