



PREVENTION OPTIONS FOR
WOMEN EVALUATION
RESEARCH (POWER)
FORMATIVE WORK REPORT



Submitted to the United States Agency for International Development (USAID) on Behalf of the POWER
Study Team

Program Title: Prevention Options for Women Evaluation Research (POWER) Study, Drs. Connie Celum and Jared Baeten, Co-Directors
Cooperative Agreement Number: AID-OAA-A-15-00034
Submitted on August 10, 2017



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ACKNOWLEDGEMENTS

The POWER team thanks Drs. Nichole Argo, Tamar Krishnamurti and Baruch Fischhoff from Carnegie Mellon University (CMU) and Dr. Ariane van der Straten, Danielle Wagner, Dr. Alexandra Lutnick, and Dr. Sarah Roberts from RTI for their leadership in the study design, data collection and writing of this report.

We would also like to thank Drs. Elizabeth Bukusi, Linda-Gail Bekker and Sinead Delany-Moretlwe, the principal investigators at each site, and the coordinators who implemented this work: Josephine Odoyo, Laura Myers, John Imrie and Nomhle Khoza. We thank the staff at Kenya Medical Research Institute (KEMRI) in Kisumu, Kenya, Desmond Tutu HIV Foundation (DTHF) in Cape Town and Wits RHI in Johannesburg for their rigorous efforts in collecting these data. Importantly, we also thank all respondents who shared insights into their thoughts and experiences.

The RTI team would like to thank Shannon O'Rourke for her efforts throughout this project and contributions to this report.

The CMU team is grateful to Daniel Kusbit, who expertly helped to manage this project throughout its life, and to each of POWER's mental models research assistants and interns, listed below by time period and product.

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Report Creation (CMU):

Jenn Kuflewski, Ariana Zahedi, Xiaonan Shao and Regina Brecker. Special thanks to Jenn Kuflewski, who created the survey tables in the Appendix.

We are grateful to Rachel Johnson and Jennifer Morton at the University of Washington for their skillful guidance and support, and to Jared Baeten and Connie Celum for supporting the mental models research vision.

LIST OF ABBREVIATIONS

ARV	Antiretroviral drugs
CHW	Community health workers
CMU	Carnegie Mellon University
DTHF	Desmond Tutu HIV Foundation
HTS	HIV Testing Services
IUD	Intrauterine device
KEMRI	Kenya Medical Research Institute
KI	Key informant
KIIs	Key informant interviews
MM	Mental models
POWER	Prevention Options for Women Evaluation Research
PrEP	Pre-exposure prophylaxis
RTI	RTI, International
STI	Sexually transmitted infection
WRHI	Wits RHI

EXECUTIVE SUMMARY

In the context of biomedical technologies and approaches for HIV prevention, oral pre-exposure prophylaxis (PrEP) has provided a new and highly effective strategy to prevent HIV for individuals at substantial risk. Young women in sub-Saharan Africa have among the highest HIV incidence rates globally. However, in the context of placebo-controlled trials of oral and topical PrEP, young women have had lower PrEP uptake and adherence than others, making this population of particular importance. More data are needed to demonstrate how to effectively scale-up PrEP with a focus on program delivery – the gap that Prevention Options for Women Evaluation Research (POWER) Study seeks to address. The POWER Study aims to characterize choice, uptake, early adherence and, through open cohorts in a demonstration projects, seeks to identify cost-effective and scalable delivery models to this key population. POWER is focusing on populations at three sites in Johannesburg and Cape Town, South Africa and Kisumu, Kenya.

Before the cohorts are established, however, it is essential to conduct formative research among African women, men and healthcare providers, focusing on motivators and obstacles for initiation of and adherence to oral PrEP in order to inform: 1) communication messages, 2) decision tools and 3) feasible and acceptable delivery strategies. The formative research in POWER was spearheaded by Carnegie Mellon University (CMU) and RTI International (RTI). CMU focused on mental models about PrEP through in-depth interviews and follow-up surveys with PrEP experts, young women and men. RTI oversaw in-depth interviews with key informants, focusing on provider perspectives about PrEP delivery to young women.

CMU adopted a mental models approach to understanding young African women's motivations for and barriers to using PrEP. In-depth mental models interviews were conducted with 48 young African women (age 16-25) and 45 men (age 18 and up) from Cape Town and Johannesburg in South Africa, and Kisumu, Kenya. Interviews sought to better understand local motivators for and barriers to PrEP initiation and adherence amongst young women. A follow-up survey (N=444; 243 females, 201 males) was then performed at each site to establish the prevalence of the beliefs and attitudes identified in the interviews, and to identify demographic relationships to those beliefs and attitudes.

RTI conducted formative research with key informants at the three sites from June 2016 through September 2016. A total of 47 key informants (KIs) were interviewed across the three sites (Cape Town = 17; Johannesburg = 15; Kisumu = 15). People interviewed were primarily women, had completed college and were involved in community support or clinical work (e.g., community leaders, counselors, social workers, community health workers and clinicians).

Key Findings

Mental Models findings about participants' relationships and interest in PrEP

- While most young women did not report multiple partners, perhaps due to discomfort or social desirability bias, they reported that multiple partners are the norm in their communities.
- Our formative work demonstrated that HIV risk is more salient to these women and men than local healthcare providers tend to think: in the interviews and a follow-up survey, young women and men report thinking that contracting HIV would be worse than having an unwanted pregnancy.
- Lastly, women across age groups report a strong interest in trying PrEP. Factors predictive of interest in trying PrEP include: living in Cape Town, previous knowledge of PrEP, a woman's personal assessment of her one-year HIV risk, the belief that one would be good at taking PrEP almost daily and her expectation that she will use condoms less if she takes PrEP. The vast majority of our qualitative and quantitative sample described PrEP as a tool for much-needed empowerment and control over their HIV risk, and in the survey, the average woman rated the benefits of taking PrEP (in terms of feelings of safety and individual and community empowerment) as more influential on their decision to try it than the costs (in terms of side effects, clinic visits and daily effort).

Mental Models findings about PrEP initiation

- Many aspects of the young women's initiation model were consistent with the expert model. For instance, "Finance," "Stigma," "Access to health services" and "Interactions with Providers" were frequently cited nodes in our sample, and each bears a critical connection to decisions about PrEP initiation.
- In other ways, divergences in the lay and expert models provide key insights that can inform PrEP messaging and delivery. The first major difference concerns the "value proposition" of PrEP, from the perspective of young women. In contrast to the public health perspective, which is focused on health, for young women the value proposition is influenced heavily by *present bias*, which is the common tendency to value the costs and benefits of now over those of the future. For instance, upon first learning about PrEP, young women (and men) were excited at the prospect of being able to have condomless sex without worry; this was cited as a primary motivator for some, followed by disappointment upon realizing that PrEP will not protect them against STIs. However, the present bias is not simply about sex. Young women desire safety because of the well-being and empowerment it can make them feel as well. And perhaps above all, as seen in the creation of the node "Uncertainty and negative affect," young women want to feel good about themselves and their relationships. Thus, for some, the potential challenges that PrEP poses to young women's relationships with their partners and families, and to their own sense of character and identity, can greatly impact their decision calculus. Human relations may be impossible to predict, but the mere prospect of loss seems to anchor decision-making for a great deal of prospective PrEP users.
- Young women exhibited vast overestimates of risk per single exposure to HIV (and, to a lesser extent, cumulative exposures). While *optimism bias* (perceiving one's own risk to be less than others') has been found elsewhere it was not demonstrated in the mental models interview or survey samples.

- Young women exhibited a broad, but limited, understanding of the mechanism of HIV, meaning that accurate calculations of personal risk may not be happening. Instead, young women appear to follow a heuristic whereby having multiple partners, and certainly multiple types of partners, signifies a need for PrEP.

Mental Models findings about PrEP adherence

- PrEP is a new concept, thus young women harbor many questions and incorrect beliefs about how it works and how they should use it. Issues that came up in this sample include: whether PrEP can be taken concurrently with other medications, whether it can be taken on an empty stomach, and whether one should continue taking it when they become sick or experience side effects, since it is seen as a medication that impacts the immune system.
- Interviewees and survey respondents read a description of PrEP and how to take it. However, that description offered a very short communication about PrEP's mechanism. Many young women did not understand how PrEP would accumulate over time in the bloodstream, and therefore assumed there was a 1 to 1 relationship between taking the pill each day and being protected for that day. This assumption could lead to poor adherence patterns, or tip the scales of a cost-benefit analysis against PrEP.
- Young women forecasted negative emotions related to taking the pill, especially emotions related to stigma and relationship and identity uncertainties.
- Young women were very concerned about side effects, often proclaiming that side effects were a deal breaker. However, once the short-term nature of side effects was emphasized, many felt they could persevere.

Key Informants Findings

- Nearly half of KIs thought that young women are very concerned about preventing pregnancy, but they highlighted some of the reasons that may prevent them from using contraception. These included limited education about family planning, concerns about side effects and impacts on fertility after long-term use and resistance from male partners. KIs primarily promote condoms, abstinence and "long-term" methods such as the injection, implant or intrauterine device (IUD) as contraceptive methods.
- KIs held a diversity of perspectives regarding young women's concerns about HIV. Some felt that young women are definitely concerned, while others felt the opposite. Even in situations where young women are concerned, difficulties negotiating condom use with male partners leave them unprotected. In addition to male-partner resistance, KIs described the ways in which poverty leads to HIV becoming a secondary concern to basic survival needs. Condoms, abstinence and regular HIV testing were the most promoted HIV prevention methods by the KIs.
- Few KIs, even among those working in HIV-related fields, were knowledgeable about PrEP. KIs underscored the need for training to address common concerns and misconceptions around PrEP and improve provider and stakeholder knowledge. Training should address identified concerns around: adherence, end user acceptability, potential effects on young women's risk behavior, PrEP stock maintenance and staffing/training for PrEP provision.

- KIs highlighted concerns around the accessibility and convenience of HIV testing and PrEP services for young women, especially due to staff biases against sexually active young women. To address accessibility needs, KIs encouraged private services be offered in close proximity to where young women live and spend time, with well-advertised, consistent schedules. KIs recommended ensuring that service staff are approachable by having staff who can relate to young women and provide nonjudgmental health services.
- To relay PrEP promotion and educational messages effectively to young women, KIs proposed peer educators/counselors, community healthcare workers of matched age (when possible), support groups and PrEP ambassadors.
- Due to existing stigma around taking a daily pill because of associations with ARV use and promiscuity, KIs advocated for positive messaging around PrEP to garner community buy-in and prevent stigmatizing views of PrEP users. Because KIs believed peer, male partner and family buy-in would be important for young women's uptake of PrEP uptake and ability to adhere, they suggested targeted messaging to these groups as an important component of encouraging young women's uptake and adherence to PrEP.
- A comparison of data from the KIs and interviews with young women revealed that the two groups have similar perspectives and are in agreement about the potential barriers for PrEP uptake and implementation. The examination of these two data sets did not reveal any salient divergence of opinions.

Recommendations to optimize PrEP uptake and use among young women

1. It will be essential to create youth-friendly clinical and delivery spaces. Young women were especially enthusiastic about mobile clinics and HIV testing services (HTS).
2. In terms of messaging content:
 - a. Given overestimation of HIV risk and related rationalization, focus on cumulative risk messaging rather than single exposure frames when doing formal risk assessments;
 - b. Given general enthusiasm for using PrEP to escape condoms, emphasize that PrEP will not protect against STIs or pregnancy, so condoms and/or family planning methods are still needed; and
 - c. Given uncertainty about what happens when adherence is less than 100%, communicate that there is partial protection with occasionally missing a pill.
3. From the mental models research, for messaging it is important to feature the immediate emotional benefits of PrEP usage (e.g., control, empowerment, health, strength), as they will be most motivational. It is useful for campaigns to make PrEP a norm. We recommend avoiding prompting or trying to address the relational and identity uncertainties that PrEP introduces. One way to do this would be creation of a decision tool that provides personalized recommendations based on risk and preferences allowing young women to answer the question of whether PrEP is good for them before introducing questions of how it will work in their life.
4. According to the KIs, messaging around PrEP should be positively-oriented to garner community buy-in and prevent stigmatizing views of PrEP users. Because KIs believed peer, male partner

and family buy-in would be particularly important for PrEP uptake and adherence, these groups should also be targeted for messaging.

5. To ensure accessibility and convenience, discrete PrEP and HIV testing services should be offered in close proximity to where young women live and spend time, with well-advertised, consistent schedules.
6. Work needs to be done to address the deeply embedded biases and judgments providers hold about sexually active young women to ensure PrEP and HIV testing services are accessible to young women.
7. Programming should enable the use of young women PrEP ambassadors for outreach and education, as suggested by both young women and KIs. These ambassadors would include, but not be limited to, 1) peer ambassadors: young women who have successfully used PrEP and could offer support to others who want to start PrEP; as well as 2) young staff ambassadors: who could demonstrate and encourage youth-friendly services among staff. Involving young people, whether they are ambassadors, health providers or peer counselors, will make information about PrEP more accessible and engaging.
8. Provider and stakeholder training should address concerns around the following: PrEP adherence, end user acceptability, potential effects on young women's risk behavior, PrEP stock maintenance and staffing/training for PrEP provision.

INTRODUCTION

Young women in sub-Saharan Africa have one of the highest human immunodeficiency virus (HIV) incidence rates globally (1, 2). This is in spite of progress with antiretroviral treatment and other effective HIV prevention interventions such as HIV testing, medical male circumcision, promotion of condoms and behavioral risk reduction. Drivers of HIV risk among young African women include age, unprotected sex, sexually transmitted infections, older partners, multiple partners, low relationship power, intimate partner violence, sex work and alcohol use (2-11). Compounding these issues, young women are often unable to discuss HIV, negotiate partner testing or condom use due to concerns about preserving their partnership, gender-based violence and economic loss (9, 12-16). Given ongoing high HIV incidence among African women, particularly young women, a strong need exists for primary prevention strategies that do not require women to secure active male cooperation. As such, microbicides and oral pre-exposure prophylaxis (PrEP) hold great promise as gender-transformative prevention interventions for this key population.

The prevention field has had uncertainty about next steps for African women, for whom social context often limits prevention options and given several large trial results suggest low use of biomedical HIV prevention tools (17-19). The World Health Organization and the U.S. President's Emergency Plan for AIDS Relief have called for better understanding of user preferences for delivery of PrEP and microbicides, and demonstration projects to test and optimize uptake, adherence and delivery approaches, particularly for young women at risk. Importantly, the context of randomized clinical trials of microbicides and PrEP are very different from typical programmatic settings. In HIV prevention trials, participants may have a variety of motivations not present in non-trial conditions, including access to personalized, high-quality health services and monetary reimbursement for research visits. However, as these prevention tools move into open-label demonstration and programmatic use, motivation of young women may increase by using a product known to be effective (20-22).

Core challenges in moving from clinical trials to implementation of microbicides and oral PrEP include finding ways to communicate effectively, assisting target populations in assessing their risk and increasing their motivation to use these strategies, providing support for sustained use and identifying feasible, scalable delivery models. Opinions and reactions of healthcare providers and other key stakeholders will shape both availability and young women's beliefs about safety, efficacy and utility of new prevention technologies. Given the urgency for effective HIV prevention for young African women, it is important not to waste effort or resources on introduction of oral PrEP – or the next efficacious technology – without progress in understanding supply and demand-side issues (4, 10, 23).

This report presents formative research conducted by the Women's Global Health Imperative/RTI International and Carnegie Mellon University to understand the perspectives of young women, men and healthcare providers and other KIs in South Africa and Kenya on delivery of oral PrEP and other HIV prevention services for young women ages 16 to 25. Data gathered during this formative phase will be utilized in the POWER open label demonstration project to inform PrEP delivery methods and identify

provider training needs. We have also compared the formative findings from the KI interviews with those from interviews with young women to identify KIs' information gaps, areas of misunderstanding and bias regarding HIV prevention and oral PrEP delivery.

METHODS

All formative research was conducted in partnership with the following organizations in South Africa and Kenya:

- Desmond Tutu HIV Foundation (DTHF), located at the Institute of Infectious Disease and Molecular Medicine at the University of Cape Town. DTHF is under the leadership of Dr. Linda-Gail Bekker.
- Wits Reproductive Health Institute (Wits RHI) at the University of the Witwatersrand in Johannesburg. Dr. Sinead Delany-Moretlwe is the Director of Research at Wits RHI.
- The Kenya Medical Research Institute (KEMRI), located in Kisumu, Kenya. Dr. Elizabeth Bukusi is Chief Research Officer at KEMRI.

Mental Models Approach

The Mental Models (MM) research approach (Morgan et al., 2001) combines systems thinking with theories and methods drawn from across the social and behavioral sciences. The strength of the MM approach comes from its in-depth understanding of the target audience: it examines the beliefs and values undergirding their choices, decisions and actions, as well as their perceptions of the magnitude of the risks and benefits from various options, and the assumptions underlying these beliefs. The MM approach has been applied to health topics as diverse as adolescent sexual behavior (24), mammography (25), breast implants (26) and cancer (27).

The structural core of the MM approach is the contrast between an *expert model*, which summarizes scientific evidence and professional experience about a decision or health behavior, with lay *mental models*, which describe how non-technical experts (here, young African women and men) view those issues. This comparison is critical because experts often define a problem differently from their target audience, for instance, focusing too much on particular outcomes (e.g., health, risk) while neglecting other outcomes that drive decisions (e.g., preserving intimacy, sustaining relationships). The contrast between expert and lay models allows researchers to identify areas of discrepancy that are amenable to change through messaging or decision support tools (e.g., a user-administered interactive tool that helps women assess their HIV risk and motivations for PrEP). It does so by addressing critical misunderstandings, supporting correct beliefs and clarifying value uncertainties. It also allows researchers to design delivery of that content in a way that overcomes both logistical and personal barriers (e.g., providing missing material resources, bridging critical information gaps, tapping into appropriate motivations for behavioral change and supplying social support). For an overview of the mental models methodology, see Table 1, "Six steps to mental models research," in the Appendix C.

In-Depth Interviews with Key Informants

The DTHF, KEMRI and Wits RHI outreach teams have well-established community networks. At each site, and in consultation with the RTI team, community advisory boards and project staff were responsible for identifying the KIs to be interviewed. Target KIs included providers of HIV, family planning and traditional health services to young women; providers of other youth services; and community leaders. The target sample size per site was 15-17 KIs to achieve data saturation.

DATA COLLECTION

Mental Models: Creation of an Expert Model

To construct an integrated assessment of the decision factors influencing PrEP initiation and adherence, we surveyed the literature, conducted one-hour phone interviews with eight leading academic experts, and implemented an online qualitative survey designed to solicit expert feedback on the factors influencing young southern African women's decisions to engage in unprotected sex, take an HIV test and initiate and adhere to PrEP (see Appendix B, "Expert Survey," for the survey protocol). As per the mental models methodology, the survey included open-ended questions that then became specific to the extent of soliciting risk estimates. Each quantitative estimate was followed by an open-ended prompt to encourage the narrative or causal explanation behind the estimate. Seven experts from public policy and research participated in the online survey, including employees from the Ministries of Health in South Africa and Kenya, HIV epidemiologists and site investigators. Importantly, our expert elicitation was not meant to reflect the views of local providers—none of our experts were health providers from the sites in which our formative work took place.

Coding and Analysis. Textual data coding was our primary qualitative analytical approach to summarize, extract meaning and condense the data. We used an online software called the Coding Analysis Toolkit (CAT). A preliminary codebook was derived from concepts found in the literature and confirmed by the subject-area expert interviews. Transcripts of the expert phone interviews and data from the online surveys were coded against the preliminary codebook by two independent judges at CMU. Wherever possible, ideas were coded into one of the solid black links identified in Figures 1 and 3, for models of PrEP Initiation and Adherence, below. Ideas not addressing relationships were coded into a single node. When additional codes were identified in the online survey responses, our coding team discussed them and, if most agreed, the codebook was modified accordingly. To begin, each coder applied as many codes as seemed appropriate to each idea. Each coder then learned how many codes the other coder applied, and was offered the chance to revise their initial codes if they felt it warranted. This process continued until final codes reached a kappa, or inter-coder reliability, of 0.8. Links were drawn into a mental models diagram using LucidChart, an online diagramming software.

Mental Models: Creation of a Lay Model: Interviews with African Young Women and Men

The nodes identified in the expert model were used to create a lay interview protocol focused on young women's understanding and beliefs about how PrEP would fit in with their daily lives and worldview. The interview began with open-ended questions, so that respondents could invoke their own intuitive framing and language. Questions then became specific, such that detailed knowledge and attitudes could be assessed and analyzed for accuracy and concept frequency, forming a mental map.

Interview Procedure. Our formative research goal was to understand motivators for and barriers to PrEP initiation and adherence in young women. We thus threw a broad net, attempting to understand not only the range of beliefs and attitudes related to HIV prevention and PrEP, but also the broader life situations of young women, into which they would be integrating oral PrEP. Two in-depth interviews (IDIs) were conducted with each interviewee in order to facilitate the collection of this broad range of data without fatiguing the participant, and to build up to more sensitive sexual and reproductive health questions after a rapport had been built with an interviewer. The first IDI covered home life, daily schedule, goals and aspirations, social and cultural life, perceived risks in the context of relationships and sex and condom use (for the full protocol of Interview 1, see Appendix E). The second interview focused on interviewees' experiences with and attitudes towards clinics, their knowledge, attitudes and risk perceptions about sexual and reproductive health and HIV, including questions about HIV testing and preferred testing locations, as well as their knowledge about and interest in PrEP (for the full protocol of Interview 2, see Appendix E).

The interview protocols included structured questions that, at their most specific point, elicited quantitative ratings on topics such as the risk of contracting HIV, ratings of clinic experiences, level of trust in one's main and side partners, relationship norms and interest in PrEP. To address concerns about numeracy within the target population, all quantitative questions were asked in narrative format (e.g., 1=*not at all*, 5 = *completely*, or *extremely safe/trustworthy*, etc.) or by having participants provide spatial estimates of risk, e.g., to mark a line from left to right where the furthest left stood for "Impossible, or 0 percent chance" and the further right represented "Certainly/Definitely, or 100 percent chance."

Interviewers at each site were trained in the interview protocol and mental models technique by an expert researcher from CMU. All interviews took approximately one hour. They were conducted in the participant's preferred language with preferred gender of interviewer, wherever possible. Interview locations at each geographical site included local clinics, youth centers or discrete public settings (chosen at the discretion of the participant) that ensured privacy. All interviews were audio-recorded, transcribed verbatim and translated into English, then sent to CMU for quality control (QC) and coding. In addition to the interviews, a demographic survey form and summary report (a short review of interview highlights and quantitative responses that interviewers completed in English prior to beginning the next interview) were sent to CMU.

Recruitment. Young women aged 16-25 years were our target sample for the mental models interviews. Since these young women report engaging in intimate relationships with both young men as well as men who are much older, we also sampled men across a larger age range to capture the beliefs and values of those who are potential partners—and potential influencers—of our target group. Thus, participants were eligible for the study if they were:

- Women age 16-25 or men age 18-65;
- Sexually active;
- Without previous participation taking PrEP or in PrEP studies; and
- Fluent in one of the study languages, and able and willing to provide consent/assent.

Participants were recruited through community outreach at each site, through local HIV testing services and primary healthcare clinics and from community events, via word of mouth, community-based organizations, secondary schools and colleges. Site community representatives were asked to provide input on recruitment materials before they were submitted to the Institutional Review Boards/Ethics Committees (IRB/EC) for review. Recruitment materials were approved by the site IRB/ECs prior to use.

Mental Models Follow-Up Survey

While mental models interviews can establish a rich and broad overview of the beliefs and attitudes within a population, they are inherently limited because they reflect such a small number of participants. Thus, we chose to conduct a follow-up survey in order to establish the prevalence of beliefs and attitudes associated with PrEP in South African and Kenyan communities, and, if possible, to tie specific beliefs and attitudes to key demographics such as age and risk.

Many of the quantitative questions in the lay interview protocol were incorporated into the mental models survey, or adapted for it based on the framing and language used by interview respondents. Questions covered included: demographics, sex and condom use frequency, monogamy and condom use norms; HIV risk perceptions; knowledge about and interest in PrEP; and ratings of positive and negative factors associated with PrEP (e.g., stigma, cost, feeling safe, etc.), to get at the value proposition of PrEP. Concerns about numeracy were addressed by using narrative or spatial response formats, as in the interviews.

Survey Procedure. Surveyors at each site were trained in the survey protocol by an expert researcher from CMU. All surveys were self-administered, however, survey administrators were available at all times to answer questions and respondents were instructed to seek guidance from the administrators at two points in the survey. Surveys took approximately 30-40 minutes to complete. They were conducted in the participant's preferred language, wherever possible. Interview locations at each geographical site included local clinics, youth centers or discrete public settings that ensured privacy.

Recruitment. Survey eligibility was the same as that of the mental models interviews. Participants were recruited through community outreach at each site, via local HIV testing services, primary healthcare clinics, community events, word of mouth, community-based organizations, secondary schools and colleges. Recruitment materials were approved by the site IRB/ECs prior to use.

Key Informant Interviews

Data collection took place at the three sites from June 2016 through September 2016.

Interviews with KIs focused on the person's role in the community, their knowledge and perspectives about HIV prevention and their experience working with young women. Participants were asked about their perceptions of young women's sexual and reproductive health-seeking behaviors, attitudes around HIV and HIV testing and potential interest in PrEP. They were also asked about barriers and facilitators for young women around PrEP access and adherence, as well as appropriate educational and communication messages for PrEP. The key aim of these interviews was to gain local perspectives about these topics to help inform the implementation and delivery of PrEP in each location (Appendices A and B).

The protocol was approved by ethics committees at all three research sites and the University of Washington IRB as the prime institution. The RTI IRB reviewed the project and determined RTI to be non-engaged due to the use of de-identified data. All participants provided informed consent for the interview. Interviews were audio-recorded and conducted in English with the exception of one interview conducted by an interviewer in English, but with the facilitation of a fluent Xhosa translator. Demographic forms were completed before the interview was over. Within 24 hours of each interview, the interviewer (or note taker, if a note taker was available and present for the interview) completed a detailed summary report about the interview, including key quotes, in English. Sites transmitted audio recordings to RTI within three days of the interview, and summary reports and demographic forms were transmitted within one week of the interview. All audio files and reports were transmitted using a secure version of Google Drive.

Site coordinators were responsible for monitoring and ensuring interview quality. In addition, RTI reviewed the first audio recording of each interviewer at all three sites for quality control. If issues were flagged with an individual's interviewing skills, subsequent audio files would be reviewed, and the interviewer would be provided with written feedback and suggestions for improvement. RTI reviewed and queried demographic forms and summary reports within one week of submission, and sites were required to respond back to the queries within one week. Once all queries were resolved, the demographic forms and summary reports were finalized by RTI and resent to the site of origin, where a hard copy of the documents were stored in participants' files.

DATA ANALYSIS

Coding and Analysis of Expert Model

Coding and Analysis. Textual data coding was our primary qualitative analytical approach to summarize, extract meaning and condense the data. We used an online software called the Coding Analysis Toolkit (CAT). A preliminary codebook was derived from concepts found in the literature and confirmed by the subject-area expert interviews. Transcripts of the expert phone interviews and data from the online surveys were coded against the preliminary codebook by two independent judges at

CMU. Wherever possible, ideas were coded into one of the solid black links identified in Figures 1 and 3, for models of Initiation and Adherence, below. Ideas not addressing relationships were coded into a single node. When additional codes were identified in the online survey responses, our coding team discussed them and, if most agreed, the codebook was modified accordingly. To begin, each coder applied as many codes as seemed appropriate to each idea. Each coder then learned how many codes the other coder applied, and was offered the chance to revise their initial codes if they felt it warranted. This process continued until final codes reached a kappa, or inter-coder reliability, of 0.8. Links were drawn into a mental models diagram using LucidChart, an online diagramming software.

Coding and Analysis of Lay Model

Coding of Interviews. Prior to coding, each quality controlled transcript was formatted by *codeable idea*, uploaded to Dedoose, a cloud-based coding software, and then coded in a manner similar to what was described above.

Content Analyses. Once coding was completed, we collapsed each of the interviewee's identical codes so as not to overweight mere repetition. We then computed the percentage of codes that mention each model link. These percentages represent respondents' relative emphasis on each link overall, irrespective of their total number of comments. Links were drawn into a mental models diagram using LucidChart, an online diagramming software, and weighted according to percentage (see Figures 2 and 4, below).

Analysis of Mental Models Survey Data

At each site, hard copy survey responses were entered into a Google Form by two separate data enterers. The double entries were checked for discrepancies by CMU using an automated excel function; discrepancies were then double-checked against the original survey by a third individual from the survey site. This discrepancy-correction process was repeated until all data was without discrepancy. For the quantitative data, CMU performed the summary statistics, ANOVAs and regressions; open-ended responses were coded into categories.

Coding and Analysis of Key Informant Interviews

Once summary reports were finalized, they were analyzed by RTI. Key information from the reports was entered into a rapid analysis table by an RTI analyst, and was reviewed by other RTI team members. The rapid analysis table was divided into sections about participant roles in the community, information about health behaviors of the young women participants interact with and participant perspectives on the delivery and implementation of PrEP in their community.

This approach to data analysis allowed for a timely exploration of emerging themes. After data from all reports were entered into the table, RTI sent the rapid analysis table to the three sites for review to ensure that all key themes were represented and accurately portrayed. After receiving approval from all three sites, RTI team members conducted an analysis of the information recorded in the table and identified key themes and differences across sites. In this report *in vivo* terms, noted by the KIs

themselves and quoted by staff in detailed summary reports, are identified by quotation marks and italic font.

RESULTS

Mental Models: Respondent Characteristics

Forty-eight young women (15 at DTHF, 15 at Wits RHI and 18 at KEMRI) and 45 men (15 at each site) completed both interviews. Numeric estimates throughout this report are drawn from this full sample (a demographic table for the full sample can be found in Appendix F). The qualitative coding and analysis in this report, however, draws from a slightly smaller sample.¹ The qualitative mental models analysis thus comprises interviews with 40 females (13 from DTHF, 10 from Wits RHI and 17 from KEMRI) and 30 males (10 from DTHF, 9 from Wits RHI and 11 from KEMRI).

The median age of female and male respondents across the total sample was 20 and 24.5 years, respectively (the age breakdown for women was 15% 16-17 year olds, 63% 19-22 year olds and 17% 23-25 year olds; the age range for males was 19-51). The vast majority of respondents in both samples had completed high school but not college, and did not have children. A demographic table for the qualitatively coded sample can also be found in Appendix F.

While the focus of this report will focus on the rich revelations found in the qualitative mental models interviews, a follow-up survey was conducted to establish the prevalence of the beliefs and attitudes identified in the interviews, to connect them to key demographic variables such as age and risk profiles, and to alert the research team to instances where type of method might have influenced responses (for instance, a one-on-one interview could consistently further or lessen response bias when questions involve stigma). In the pages that follow, for brevity's sake, we only report survey findings when they *diverge* from interview findings, or when they add greater clarity regarding the views and attitudes of key subpopulations (however, descriptive statistics for each survey variable are included in Appendix H). To provide a sense of the survey's representativeness, however, we present participation statistics here.

The survey collected responses from two hundred and 43 young women (87 at DTHF, 74 at Wits RHI and 82 at KEMRI) and 201 men (52 at DTHF, 77 at Wits RHI and 72 at KEMRI). The mean age of female and male respondents was 20 and 22, respectively. The survey was able to increase representation of the youngest and oldest age brackets, as compared to the interview sample, with 24% age 16-17, 46% age 18-22 and 30% age 23-25. The age range for males was 17-51. Similar to the interview sample, the majority of women and men had completed high school but not college, and 70% of women and 65% of men did not have children.

¹ Due to logistical and IRB delays, data collection started and ended beyond schedule. Unfortunately, since we were unable to maintain our summer coding team past August, we were only able to code those interviews that arrived before August 15. Interviews that arrived after August 15, 2016 were reviewed by the coding team in an effort to find new codes. However, none were found: we had reached saturation with the previously coded interviews.

Relationships and sex. Perceptions and beliefs about sex and relationships are important inputs into sexual behavior and HIV prevention, thus we report these data from the IDI sample. Women and men reported their first sexual experience as being age 17 and 16.5, respectively, on average (see Appendix G for full table).² In interviews, respondents made distinctions between their “main” and “side” partners. Men described longer durations of their current main relationships than women (4.13 vs. 2.2 years, on average) because the male sample included older respondents, some of whom were married for years. Only one-third of women in the interview sample, and one-quarter of women in the survey, reported having a side partner (in the interviews, only women from Kisumu answered this affirmatively). Seventy-seven percent of men in the sample reported having side partners.³

Both men and women perceive the norm to be multiple partners. Across sites, women estimated that the average woman has 2.9 partners at a time, and men estimated that the average man has 4.8 partners at a time.⁴ When asked to consider couples in their neighborhood, both men and women thought that only four out of 10 would be monogamous.⁵

Despite recognizing that most people have more than one partner, however, both women and men in our sample reported having a lot of trust for their main partner (4 and 3.8 out of 5, on average, respectively, where 3 = *somewhat*, 4 = *a lot* and 5 = *totally*). Both men and women reported having less trust for side partners, however, women reported using condoms with main and side partners almost equally, at 3.3 vs. 3.5 out of 5, between *somewhat* and *a lot*.⁶

What risk is more salient: Pregnancy or HIV? Our expert interviews described a mainstream provider belief that young women are more worried about pregnancy than HIV. To better understand risk salience in young women’s lives, we therefore asked participants, “What would be worse, getting [a girl] pregnant when you did not want to or getting HIV?” Eighty-four percent of female respondents and 92 percent of male respondents said *contracting HIV would be worse*.⁷ Most said they felt this way because HIV brings social exclusion, as described by this woman from Cape Town (1101.2):

You can raise a child even though you were not expecting him or her. But HIV... it looks like it is difficult to live with...When a person has it, it is like the person is not a person among other people.

Follow up interview questions eliciting risk estimates for pregnancy and HIV were consistent with their reported fears: in the event of having unprotected sex a single time, young women rated their likelihood of getting pregnant as less than their likelihood of contracting HIV from an HIV positive person, although both estimates were high (71.3% vs. 79.1%, respectively). It is important to acknowledge the arguments

² Survey averages for first sexual experience were ~.5 years lower for women and men, at 16.53 and 16.16, respectively.

³ In the survey, 59 percent of men reported having side partners.

⁴ In the survey, men estimated that the average male has 3.21 partners at a time.

⁵ In the survey, both men and women estimated that 5 out of 10 would be monogamous.

⁶ In the survey, women reported using condoms with sides slightly more often (3.86, closer to “a lot”).

⁷ In the survey, eighty-one percent of women and seventy-eight percent of men said contracting HIV would be worse.

of those who felt pregnancy would be worse than HIV: they focused on the fact that HIV can be hidden while one continues to pursue their life goals, but a baby would end their education and put an end to their career goals.

Interest in PrEP. Most women in the sample had either not heard of PrEP, or mistakenly thought PrEP was PEP.⁸ Upon a brief explanation of PrEP, young women were very interested in trying it (4.6 out of 5, where 4 = *a lot* and 5 = *extremely*). Some, like this woman from Johannesburg (2103.2), acknowledged that her current lifestyle was risky and therefore she wanted to protect herself:

R: Extremely interested.

I: Okay, why do you say that?

R: Because I feel like I'm prone to... not I am prone, like I have a high chance of getting HIV right now in my life because, like I said, for my low self-esteem, my ideals on life and the way I see myself, and the way I treat people in my life. I feel like PrEP will make me safer, like I won't like have that much stress. That, okay, I am giving this person my body, and he's [sic] gonna infect me, okay, although if he infects me I know that I am fine because I am using the medication.

In the follow-up survey, we asked two separate questions about interest in PrEP. The first survey question, “*Now that you have learned about PrEP, how interested would you be in learning more?*”, occurred after respondents were given the same brief written explanation of PrEP that was used in the interview. In terms of *learning more about PrEP* women’s responses averaged between *very* and *extremely* interested, 4.3 out of 5. Only women selected “*Not at all interested;*” and each offered a handwritten explanation. Two cited their lack of risk or faithfulness to their partner, and one did not like to take pills.

Survey participants were then asked the following: “*After reading the information above [about PrEP], what questions do you have?*” Sixty-four percent responded to this question, sometimes with lengthy or personally detailed vignettes. Responses were coded into categories; categories that were referenced 20 times or more included: Side Effects (53), Effectiveness of/Trust in PrEP (37), Necessity of taking it daily (29), How to access PrEP (28), PrEP vs. PEP and other HIV prevention or treatment pills (24), Mechanism, or how PrEP works (21), and how long to take PrEP (20).

Next, respondents were provided details about the need for daily administration of PrEP, regular follow-up clinic visits and the need to continue wearing condoms when having sex, despite being on PrEP. Then they were asked about their interest in PrEP a second time: “*Having learned more about PrEP, how interested would you be in trying it?*” Here, women averaged a response of 3.83 out of 5 (between *somewhat* and *very*).⁹ Given that the follow-up information about PrEP focuses more on the

⁸ Similar to the interview results, fifty-five percent of women and sixty-one percent of men in the survey had not heard of PrEP.

⁹ The survey offered respondents a “don’t know” option, yet the values were mistakenly kept 1-5 (with “don’t know” measured as “5”). Thus, the scale for these questions was 1-4 (not at all, a little, very, extremely), taking away the middle ground of “somewhat” for respondents. For readability’s sake, the values have been standardized for the purposes of this POWER Formative Report

responsibilities that come with taking PrEP than the benefits it provides, this drop in interest seems logical. Importantly, average interest by young women is still strong. Only 15 women reported being “*not at all interested*,” and a majority of their follow-up explanations fell into two categories: “lack of risk” (9) or “aversion to medicine/pills” (7).

Several survey items showed a positive, significant relationship with women’s interest in trying PrEP, including: interest in learning more about PrEP ($r=.48, p=.00$), site ($r=.34, p=.00$), zero income ($r=.23, p=.00$), the expectation that the average woman has more than one partner ($r=.23, p=.00$), personal HIV risk assessment for the next year ($r=.26, p=.00$), the woman’s belief that she would use condoms less if she took PrEP even though it does not protect against STIs ($r=.13, p=.05$), perceived ability to take PrEP on a daily basis ($r=.48, p=.00$) and age group ($r=.15, p=.02$). It is noteworthy that certain HIV risk items were *not* correlated with Interest, such as: frequency of sex, frequency of condom usage (with main or side partners), having side partners or suspecting that one’s main partner has side partners.

Follow up contrast analyses found that young women in Cape Town profess significantly more interest in trying PrEP than do women in Johannesburg or Kisumu, with an average score of 3.41 out of 4. This is significantly higher than women in Johannesburg [mean 3.07, contrast=.34, $f(1)=6.25, p=.01$], and women in Kisumu [mean 2.66, contrast=.75, $f(1)=31.12, p=.00$].¹⁰ Women reporting zero income were significantly more likely to profess interest in PrEP than those reporting any income at all (3.46 out of 4, vs. 2.94, respectively [contrast = -.5, $F(1)=10.73, p=.00$].¹¹ Young women in the 18-22 age group were most interested in trying PrEP (mean 3.17 out of 4) and youths age 16-17 were least interested (mean 2.75), leading to a significant contrast [.42, $f(1)=8.07, p=.01$]. The 23-25 age group (mean 3.14) was also significantly more interested in PrEP than 16-17 year olds [contrast=.39, $f(1)=6.05, p=.02$].¹²

In a preliminary causal analysis, an ordered logistic regression was conducted to predict 172 women’s *interest in trying PrEP* using the correlates mentioned above; the model explained 25 percent of the variance.¹³ When controlling across variables, several correlates lost significance, including: age group, the expectation that most women have more than one partner, a binary variable capturing “zero income”, and first-exposure interest in PrEP. However, living in Cape Town increased interest in trying PrEP by 1.36 ($z=2.62, p=.01$), having previous knowledge of PrEP increased interest by .89 ($z=2.44, p=.02$), believing one’s self would use condoms less if they took PrEP increased interest by .83 ($z=2.25, p=.024$), the perception that one can successfully take PrEP daily increased interest by 1.84 ($z=4.14, p=.00$) and each unit increase in self-assessed HIV risk increased PrEP interest by .02 ($z=3.00, p=.00$). Follow up tests will be conducted and reported in a manuscript for publication this summer.

report, however it should be noted that survey respondents were given different response options than interview respondents and this might have slightly altered how they responded.

¹⁰ Anova model with $R^2 = .12, F(2,235)=15.57, p=.00$.

¹¹ Anova model with $R^2 = .05, F(1, 198)=10.73, p=.00$.

¹² Anova model with $R^2=.04, F(12,235)=4.46, p=.01$.

¹³ LR $\chi^2(13) = 109.04, Prob>\chi^2 = 0.00, R^2 = .25$.

The mental models interviews also asked how much control participants felt over their HIV risk—once in the context of their sex lives and once, after describing PrEP, as a forecast of how they would feel if they were taking PrEP. Although women professed to feeling “a lot” of control in their lives without PrEP (4.2/5, where 5 = *total control*), they said they would feel nearly *total control* with it (4.7/5). Although the difference between their ratings of felt control is not large, on average, responses to the follow-up prompts indicated that this small difference in perceived level of control was felt powerfully by the young women. Some, like this woman in Cape Town (1109.2), interpreted PrEP as a tool for warding off uncertainty: “I would not know when I would get raped or have unprotected sex so I would rather be on the safe side.” Others, like this young woman from Johannesburg (2103.2), implied that using PrEP would remind her of her risk level and empower her to be more responsible:

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 that HIV. Why am I doing this? Because I don't want to use condoms. But then it's going to teach me on a daily basis that okay, you are on PrEP, but change your life. Change your life. On a daily basis, something's [sic] 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.

In summary, our participants were drawn from high-risk communities in Cape Town and Johannesburg, South Africa and Kisumu, Kenya. While most young women did not report—and may not have felt comfortable reporting—multiple partners, they perceived multiple partners to be the norm for women and men in their communities. It appears that HIV risk is more salient to individuals in these communities than local healthcare providers tend to think: both young women and men reported thinking that contracting HIV would be worse than having an unwanted pregnancy. Lastly, women reported a strong interest in trying PrEP, even once they learned about the effort and potential costs involved with adherence. Factors predicting reported interest in trying PrEP include: living in Cape Town, having previous knowledge of PrEP, believing that one would use condoms less if they took PrEP, the perception that one can successfully take PrEP daily and self-assessed HIV risk increased. The vast majority of our interview sample explained that PrEP could provide them much-needed empowerment and control over their HIV risk, a claim that was supported by the survey data.

Mental Models: An Integrated Assessment of PrEP Initiation

The core of the PrEP initiation mental model comprises the variables that both experts and young women said would influence a young woman's decision to initiate PrEP (indicated by solid black lines).

This narrative will briefly describe those links before focusing on the links provided by young women alone (indicated by dotted black lines).

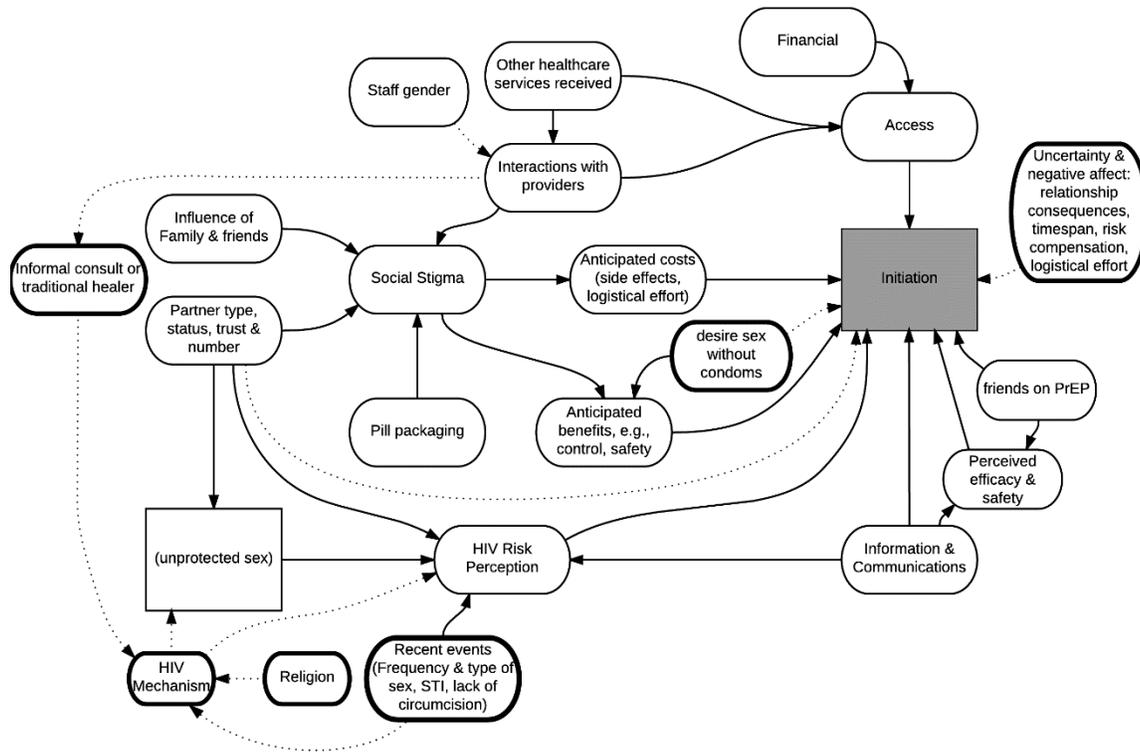


Figure 1. An integrated assessment of PrEP initiation (expert and lay, women and men). Boxes represent decision points, and ovals represent variables influencing those decisions. Solid black arrows indicate links between variables described by experts; dotted black arrows indicate unmediated links mentioned by respondents; links mentioned by experts but not interviewees are not shown. Demographics and variables expected to influence many nodes within the model (for instance, mental illness) are not placed within the model. The nodes that are emphasized in the gap analysis below are bolded.

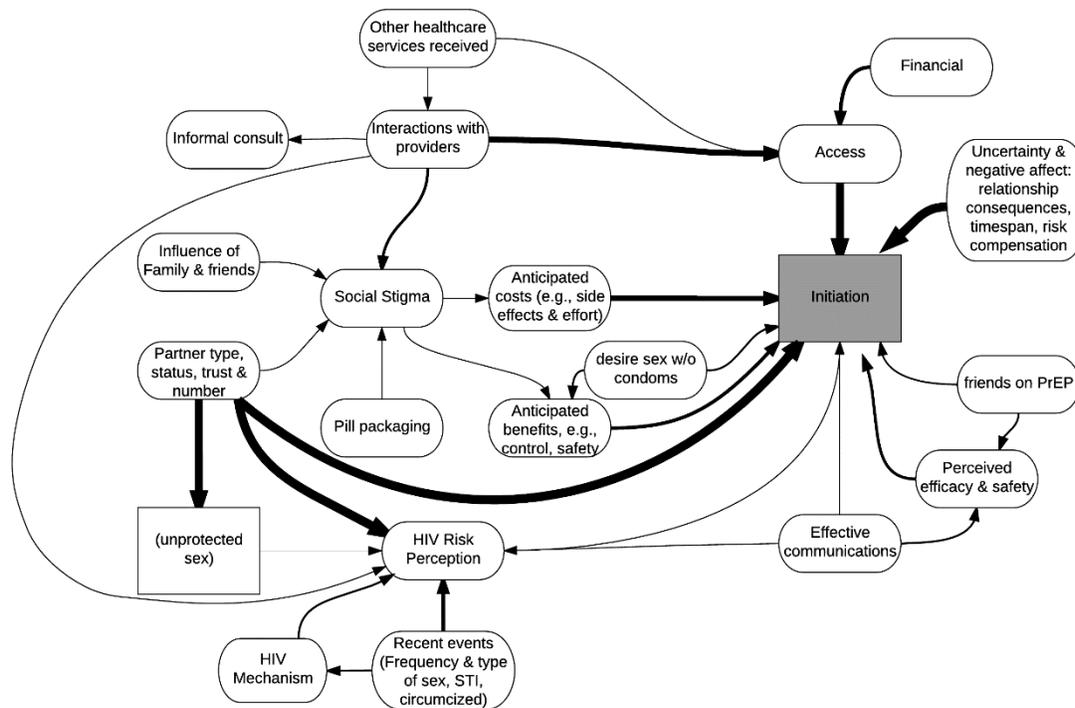


Figure 2. Model of PrEP initiation—Young African Women. The thickness of each arrow corresponds to how frequently that link was mentioned.

Stigma. Beginning at the center left of Figure 1, and as documented in the literature, young women’s thinking about HIV risk and prevention is influenced by social stigma—the felt or anticipated feeling of judgment and shame related to HIV (28-33). The extent to which one experiences or anticipates stigma is itself influenced by factors such as the “Support of friends and family,” the influence of one’s partner or partners (“Partner type, status, trust & number”) and the way one is treated or expects to be treated by healthcare providers when they seek care for HIV prevention (“Interactions with providers”). Moreover, the appearance of the PrEP pill and packaging (“Pill packaging”) is similar enough to the look of antiretrovirals that people associate it with HIV treatment (and being infected by the virus).

Anticipated Costs and Benefits. Moving rightward, the stigma that is experienced or anticipated in association with PrEP can feed into how one anticipates the costs and benefits of PrEP. For instance, one “Anticipated cost” that young women referenced frequently was the logistical time and effort that would be required to take PrEP daily, and to visit a clinic for refills and testing. As a woman in Cape Town (1108.2) noted:

R: I would not be interested [in PrEP] if there would be no place to hide the pill.

I: Ok the fact that you have to take it every day, how does that affect your interest, would you be interested not at all, a little bit, somewhat, a lot or extremely?

R: Somewhat.

I: Somewhat, why?

R: Because I would have to wake up and take pills and have to go to the clinic to get pills. No, sometimes I would be lazy and tell myself that I am not going today, I will go tomorrow.

I: Let's say you were given a packet of pills so they would be with you at home every day.

R: Yhoo, no, [it would still influence me] a little bit.

I: A little bit, why?

R: A little bit because sometimes I would leave my place rushing and forget it there.

Stigma could increase anticipated costs by increasing the effort needed to physically (and relationally) hide PrEP from family, friends or partners. Similarly, felt or anticipated stigma related to PrEP could distract from or decrease the salience of some of the benefits one may anticipate from PrEP, such as feeling greater control over one's risk.

Critically, both men and women saw PrEP as making them able to have sex without condoms, which, while true in the case of monogamous serodiscordant couples, may not hold for non-monogamous couples given that PrEP cannot protect against STI risks. Indeed, our sample's focus on the ability to have sex without condoms led us to create an unmediated link between it and PrEP Initiation ("Sex without condoms - Initiation"). For some individuals, more in the case of men than women, realizing that PrEP would not necessarily enable condomless sex seemed to dampen their interest in PrEP.

Access to care and services. Another major area of influence on PrEP initiation includes healthcare provision and access to health services and PrEP (here, "Access"). Both experts and young women noted that access is heavily influenced by financial constraints (the financial ability to take time from work, secure transport to and from the clinic and obtain services and/or medicine), exposure to other health services through which one can learn about PrEP (such as standard clinic visits, or voluntary counseling and testing centers) and past interactions with healthcare providers at these places. Because these inputs have been well explored in other publications, we do not address them at length here—with one exception. Several young men and women referred to provider gender as a large factor in the quality of patient-provider interactions, in particular focusing on negative and judgmental interactions they've experienced with female (but not male) providers. For instance, a male participant (1204.2) in Cape Town reported the follow:

I: When you suspect that you have an STI what do you do?

R: I go to men's clinic.

I: Why the men's clinic?

R: Men's clinic is easy because you know that all patients have the same problem. People don't go there for different problems. Everyone goes there for the same problem, no one will laugh at you. There the government made things easy for us because most men are afraid, they would rather go to the traditional healers when they have STIs... People go to them because they are avoiding going to the clinic because they don't want to be insulted by the nurses. So they choose to go to the traditional healers and get "bottles" [medication] from the traditional healers for cleansing. But men's clinics make things easy.

A woman from Cape Town (participant 1102.2) shared similar thoughts:

I: Let's talk about clinics now. We are going to rate it the same way we rated that clinic. Let's start with how friendly is their staff.

R: They are a 4. Friendly, very friendly.

I: Why do you say so?

R: Because it's mostly males.

I: Are males very nice?

R: Yes, males are nice.

As described by the male respondent above, feeling judged or uncomfortable with health providers can cause young women and men to seek other sources of care, including traditional healers who may not have the knowledge to inform or treat the patient correctly. Other respondents in our sample reported making purposive efforts to get “informal consults” with clinic staff outside of clinic hours, relying on informal connections and a less-stressful setting in order to obtain a more positive interaction. As seen in Figure 2, these interactions with providers have bearing on whether women feel willing to continue to access care through regular clinic channels. Lastly, while several experts noted the importance of a formal risk assessment in enabling a woman to accurately determine her risk, young women did not describe such a link. Even when they would rate the knowledge of nurses as high, some women concluded that the judgments and biases of the nurses made them unable to accurately assess their personal situation.

Uncertainty & Negative Affect. Moving down and to the right of access, we see a respondent-driven link titled, “Relational and identity uncertainty.” Interviews with young women and men revealed a great deal of uncertainty and conflict surrounding the anticipated but impossible-to-calculate relational, moral and identity consequences of PrEP. Anticipated relationship changes comprise the bulk of this node, and included references to difficult emotions or status changes that could occur in romantic, familial or friendship relations. Most respondents concerned about changes in romantic relationships referenced serious partnerships and worried about changing a dynamic of trust (even if they were not 100% sure that their partner was trustworthy). As a woman from Johannesburg (2102.2) reported:

[Taking PrEP] would affect my current relationship. Like I said, we are protecting ourselves and we both are HIV negative—or I assume that we are both HIV negative, right? (laughing)—so if I'm taking the PrEP, there would be questions about why. 'Why are you taking PrEP? Are you sleeping around? What is it?' Yes.

A woman with a serious partner in Kenya (3109.2) reflected on the potential for long-term changes to her and her partner's trust dynamic:

I: What if your partner would not be supportive of you taking PrEP. Would you say [that would influence you] not at all, a little, somewhat, quite a bit, extremely?

R: Extremely.

I: Why do you say that?

R: Because I'd feel maybe now the two of us, we will now start having trust issues. Maybe he'd

feel, 'You're doing something on the side, that's why you're doing this.'

Other women focused more on their own well-being, however, they remained wary of how PrEP could cost them a future relationship they might care about, once disclosed. This was the concern of a young woman in Kisumu, Kenya (3108.2) who shared the following:

For a single woman like me, I will keep quiet with it...I will figure out what to do with my life before telling the person whom I love. Sometimes you can tell the person whom you like only for him to run away from you. It can therefore be difficult to disclose to anyone.

Thus, the conditional question of whether one would disclose or not disclose PrEP appeared to loom large for those who felt themselves in committed relationships as well as those who didn't. The idea that their partner might take PrEP, and whether he would tell her about his use of PrEP, engendered similar consternation. A woman from Kisumu (3118.2) reacted to the idea that her partner would take PrEP without telling her:

I: If you found that your main partner was taking PrEP, how would you feel?

R: Ok . I will feel untrusted because it is like he is not trusting me, or rather he has other partners outside who may be positive and now he wanted to prevent himself from getting the disease. Maybe he thought I was HIV positive and never wanted to approach me and tell me so.

I: Would you want him to tell you?

R: Yes

I: Would you trust him more or less?

R: I will not trust him.

I: Will his taking PrEP make you want to take PrEP too?

R: No

In addition to anticipated relationship turbulence, disclosure raised questions about identity and morality, e.g., about how one should manage their integrity with close others. A woman from Johannesburg (2103.2) focuses on the challenge of having to consistently lie to her family in order not to suffer their judgment:

What would also be difficult is my family. Every day they see me taking medication, like, 'What's up with you, why are you taking medication?' I can lie, but to what point am I [sic] gonna keep on lying? Ja, I think those are [sic] gonna be the challenges.

Sometimes respondents' concerns were neither moral nor relational, but instead raised seemingly unanswerable questions about their future, or what levels of risk and insecurity their future would hold. While the man from Kenya (3212.2) below had not had a formal risk assessment and medically-informed discussion about using PrEP through periods of risk, his first assumption was that he was at risk and would always be at risk, thus he would be committing to PrEP for life:

I: So now soon PrEP will be made available at various places like clinics and maybe hospitals or Pharmacies. However, to be able to take PrEP, you will have to do a couple of things. The first would be to take an HIV test to make sure that you don't already have HIV. Then you will have to take it every day at approximately the same time every day in order for it to work. How does this sound to you?

R: It sounds so challenging.

I: What is it that is challenging?

R: You have to take the pill for the rest of your life.

Perceived efficacy and safety. As clinical trials with PrEP have demonstrated, if young women do not perceive PrEP to be safe and effective, they will not take it (safety and effectiveness themselves are influenced by the perceived intentions of the medical community) (30). Scholars have anticipated that participants would respond with more trust amidst demonstration projects, and that expectation bore out in our interviews. In response to the question, 'Do you believe that PrEP is effective and/or safe?' Eighty-five percent of interviewees said that PrEP is safe and effective due to the immense amount of research that has gone into it, or because it has international approval. As one woman from KEMRI stated, "...if [the] World Health Organization recommends it then that means that it is safe" (3112.2). However, the fact that PrEP is new leaves it open to doubt by a few, such as this young woman from Johannesburg (participant 2103.2):

R: Maybe you are on PrEP but you get HIV...

I: Oh, so are you saying that you have doubts that it might be effective?

R: Yes.

I: What informs those doubts, I mean like why do you...where do they come from?

R: Because it's something new and I have not come across it...obviously when something is new, and you have not heard about it, you obviously [sic] gonna have doubts. So, I feel like it's a fifty-fifty percent chance that it actually works.

Both experts and young women acknowledged that having friends on PrEP could influence initiation, either by serving as an example of PrEP's safety and effectiveness or by creating a norm. Similarly, exposure to information—especially effective communications about PrEP—was expected to influence initiation. In this model, the node for "Knowledge and communications" includes what individuals have learned from messaging campaigns (e.g., flyers, billboards, social media, radio and TV spots), educational outreach via schools and formal risk assessments with healthcare providers in a clinical setting.

Risk Perception. Moving left, the next cluster of nodes surround "HIV Risk Perception." Both experts and young women agreed that the extent to which a young woman perceives herself to be at risk for HIV will inform whether or not she will initiate PrEP. As mentioned above, several noted the importance of formal risk assessments in helping individual women to determine their risk. Most also acknowledged that young African women are familiar with the STI, pregnancy and HIV risks associated with unprotected sex ("Unprotected sex"), and would be able to self-identify some level of HIV risk according

to the role that unprotected sex plays in their lifestyle. Experts and young women agreed that young women's risk perception, as well as how often they have unprotected sex, would be influenced by the number of partners they had (most respondents declared a 1-1 association between multiple partners and risk), partner age (older partners were associated with likely pressure to not use condoms and greater likelihood of STIs), the relationship status of the partner (this could refer to a "main" versus a "side," or whether the sexual relationship was transactional or emotional) and how much trust the young woman feels for the partner ("Partner Type, Status, Trust & Number"). Indeed, as seen in Figure 2, these partner attributes factor prevalently into young women's risk perception, but they were also mentioned in high frequency as unmediated links to PrEP initiation in interviews with young women, who viewed multiple partners or transactional sex as almost heuristic indicators that one should take PrEP. This raises the question of whether and how often women consciously and explicitly consider their risk. On the one hand, experts referenced (and young women demonstrated some knowledge of) risk factors that typically double as triggers for HIV testing, here titled, "Recent Events." One example is getting an STI, or fearing one has the symptoms of one. Below, a woman from Johannesburg (2105.2) connects the experience of the STI to feeling much more unsafe about her HIV risk:

R: *(Laughs.) Ja, I had an STI.*

I: *Ja, okay.*

R: *Ja, I don't know what's it called. I really didn't ask, I just felt so bad. I felt dirty. I mean who has an STI? And then I felt like maybe my life is a little unsafe, if I can get an STI.*

Other references included in the "Recent events" node are: high frequency of sex, an increase in sexual frequency, an "on" period in intermittent sex, or engaging in new types of sex; engaging with a partner who is uncircumcised; or thinking that one might have had sex with an HIV positive person. Past behavioral research has found two types of decision-making biases to affect HIV related decision-making: *optimism bias*, the tendency to underestimate one's own level of risk and *under-accumulation bias*, the failure to appreciate how one's cumulative level of risk grows through repeated exposures (34). In this sample, similar to past research, participants highly overestimated the risk per single and repeated sexual exposures to HIV. While the actual risk of contracting HIV from a single sexual exposure is 1/1000 for heterosexuals, participants perceived the risk for a "wo/man like you" to be 79 percent and 65 percent, respectively¹⁴. Participants also estimated the risk that accumulates over repeated exposure to HIV poorly. When asked to predict the risk of "a wo/man like you" to contract HIV after having sex with an HIV+ person ten times, women and men estimated 96 and 91 percent, respectively and on average. Similarly, predictions of risk for a "wo/man like you" after having sex one hundred times with an HIV+ person were 96 and 92 percent, for women and men respectively. Personal risk assessments were also elicited for each of these scenarios (see Appendix E), but did not reveal an optimism or pessimism bias for men or women with respect to their own odds versus those of others. We initially thought this finding might be the result of a methodological limitation, since participants were asked about their own risk *after* being asked to assess on behalf of someone like them, providing them

¹⁴ In the survey, women reported mean risks for a "woman like you" with 1, 10, and 100 unprotected exposures to HIV at 67.37 (25.93), 83.82 (22.48), and 91.77 (15.19), respectively. Men provided slightly lower estimates of 58.08 (31.2), 82.5 (21.59), and 88.54 (19.23), respectively.

an anchor. However, follow-up surveys did not demonstrate a significant difference between risks assessed for “self” and “other,” nor for risks assessed for “self” versus characters in a narrative.

HIV Mechanism. The node for “HIV mechanism” was created in order to capture how and how much respondents understand about the HIV virus, and to see whether respondents linked these understandings to risk perception or behavior. As apparent in Figure 1, analysis revealed three lay linkages with potentially significant effects.

The first link, “Beauty-HIV mechanism,” represents a handful of statements made by men, whereby a woman’s beauty seemed to heuristically indicate to them that she lacked disease. One man from Cape Town (1201.2) explained:

R: There are guys who don't use a condom even when they are sleeping with someone for the first time. I have been there, too. You see a cute girl and conclude that they can't be HIV positive. That thing cannot enter into her.

I: It cannot enter into her?

R: That's what you tell yourself, that a very cute girl like this one...but you're lying to yourself.

The depictions in these interviews do not suggest that beauty influences a person’s perception of risk *salience* (as would desire) as much as they suggest that beauty serves as a heuristic for health, or a form of motivated reasoning. While this was a male-specific theme in the interviews, it is also possible that women were simply uncomfortable talking about these sorts of motivations for sexual behavior. To further test whether or not beauty may play a role in risk perception and behavior, we have included an experiment in the follow-up surveys.¹⁵

The second link of interest here pertains to alternative cultural and belief systems, and draws on the linkage between “HIV Mechanism” and religion, as well as that with traditional healers. In a section of the interview designed to elicit knowledge and beliefs about treatment for HIV, interviewers sometimes prompted respondents about traditional medicine. In response, one woman from Cape Town (1109.2) answered:

I: Do you sometimes hear about people using traditional medicine?

R: Yes, I do sometimes. People believe that there is HIV and then [the] HIV that people get as a result of witchcraft, so if they believe they are bewitched they use traditional medicine to try and cure it.

This passage assigns the origin of HIV to two different categories—a regular, mundane transfer of the virus as medically known, and one through bewitching—then prescribes a treatment according to origin. The respondent is describing a cognitive approach to HIV as if it is two different HIV viruses, two different mechanisms. Several other respondents noted that if you believe in a treatment—whatever treatment you are using—or, if God wills it, you can be cured. Lastly, in Cape Town, early on during a site visit for

¹⁵ While analysis is still in preliminary stages, we appear to see main effects for attractiveness on risk perception. Results will be written up in a manuscript this summer.

this project, the CMU team met and interviewed a counselor who explained to us that both traditional medicines and ARVs can cure HIV—his preference was to support patients in whatever treatment they most believed in. While these knowledge inaccuracies may not have to do with PrEP per se, they do have bearing on if and how one engages medical services; they might also diminish belief in medical models of PrEP mechanism and effectiveness.

Inadequate understandings about how HIV works might also lead young women to engage in riskier behaviors, or not see the need for PrEP. The “Recent events – HIV mechanism” link captures inaccuracies related to how HIV is transferred, which can influence an individual's risk perception. Some of these belief inaccuracies deal with overestimation of HIV risk, cumulatively and *per exposure*, as discussed above. Others, however, come from misapplying nuggets of truth surrounding risk factors, while inaccurately assuming the rest. For instance, both men and women exhibited broad knowledge that circumcision reduced HIV risk, as seen in this statement by a Kenyan female (3204.2):

There are those other measures like circumcision, which can reduce....the rate, the spread of the virus, but for someone who is not circumcised and then has also not used the condom, the -- I think you are actually likely to, to contract the virus, yeah.

But many employed inaccurate beliefs linking circumcision to HIV immunity. These words from a male Kenyan respondent (3209.2) represent a common theme from the interviews:

R: I went and got circumcised, so I trust that I cannot get HIV 100%.

I: So you mean it is impossible.

R: Yeah.

A similar logic was applied to the idea of rough versus gentle sex. Respondents were familiar with the fact that abrasions or specific sexual acts increase the risk of HIV transmission, and talked about how gentle (unprotected) sex or simply not engaging in those acts allowed them to control risk. On the one hand, this is a positive consequence of HIV education and messaging in southern Africa: young people know enough about risk factors to incorporate what they know into their decision-making. On the other hand, particularly because beliefs about transmission risk are so overestimated and because men and women know or assume they've been exposed to HIV and were not infected, knowledge about factors that can decrease risk were sometimes parlayed into rationalizing narratives to explain individual immunity.

Mental Models: An Integrated Assessment of PrEP Adherence

The model of PrEP adherence was drawn from a portion of the interview dealing with whether and what participants had heard about PrEP, as well as reactions to a short summary about PrEP and what taking PrEP would require (see Appendix E). Nodes that were included in the initiation model often came up again, and won't be discussed here. New nodes are described below.

Miss a Pill. In the interviews and the survey, a majority of women doubted their ability to take the pill every day. However, 81 percent of female survey respondents anticipated being able to take PrEP at

least 3-4 times per week. Both the young women and the experts shared similar understandings on factors that can cause young women to miss a pill, such as drug and alcohol use the night before, the effort involved in remembering and making an effort to take a daily pill, the difficulties of traveling with PrEP or taking it consistently when one may be sleeping at other’s houses and the challenges of storing PrEP when one lacks a private space. Young women brought up another node as well, titled “Sick.” This node refers to taking medication when you are in fact not sick, trying to take more than one medication at a time, and the aversive experience of taking pills on an empty stomach.

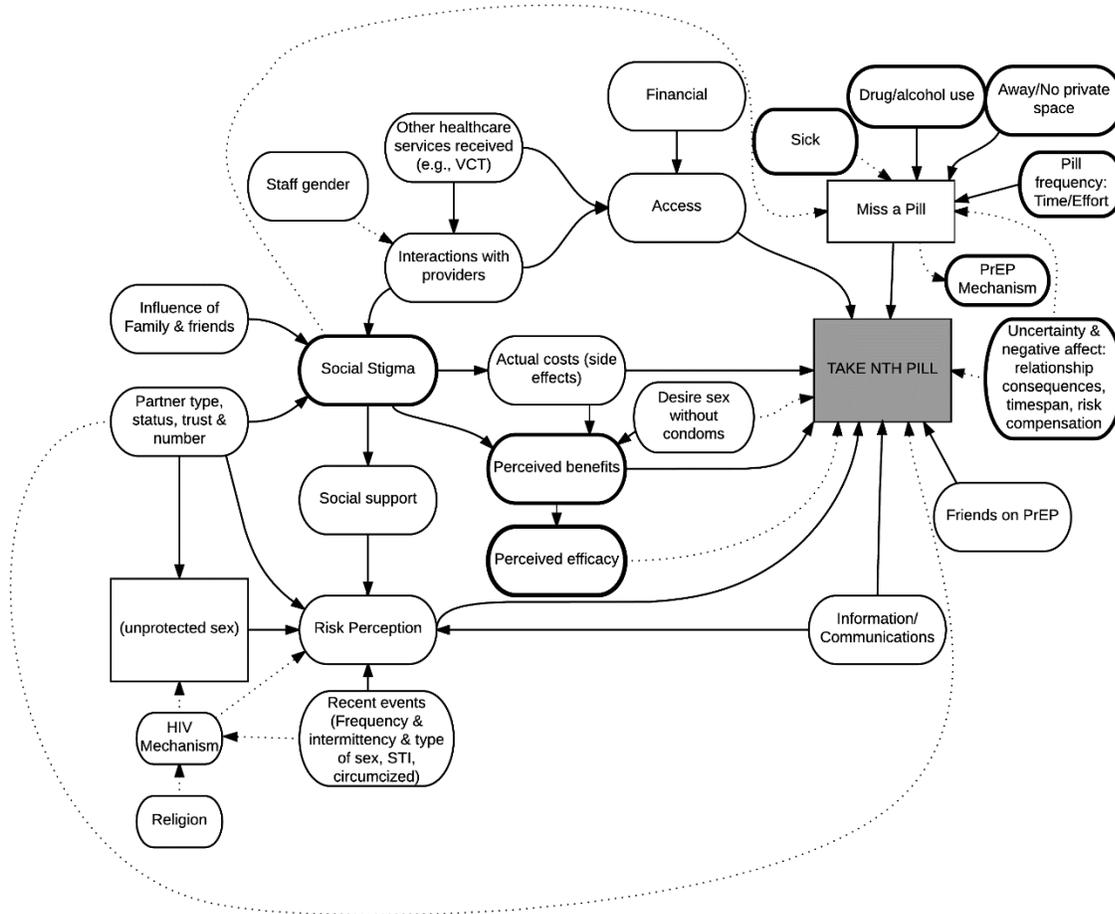


Figure 3. Integrated Diagram of PrEP Adherence Decisions.

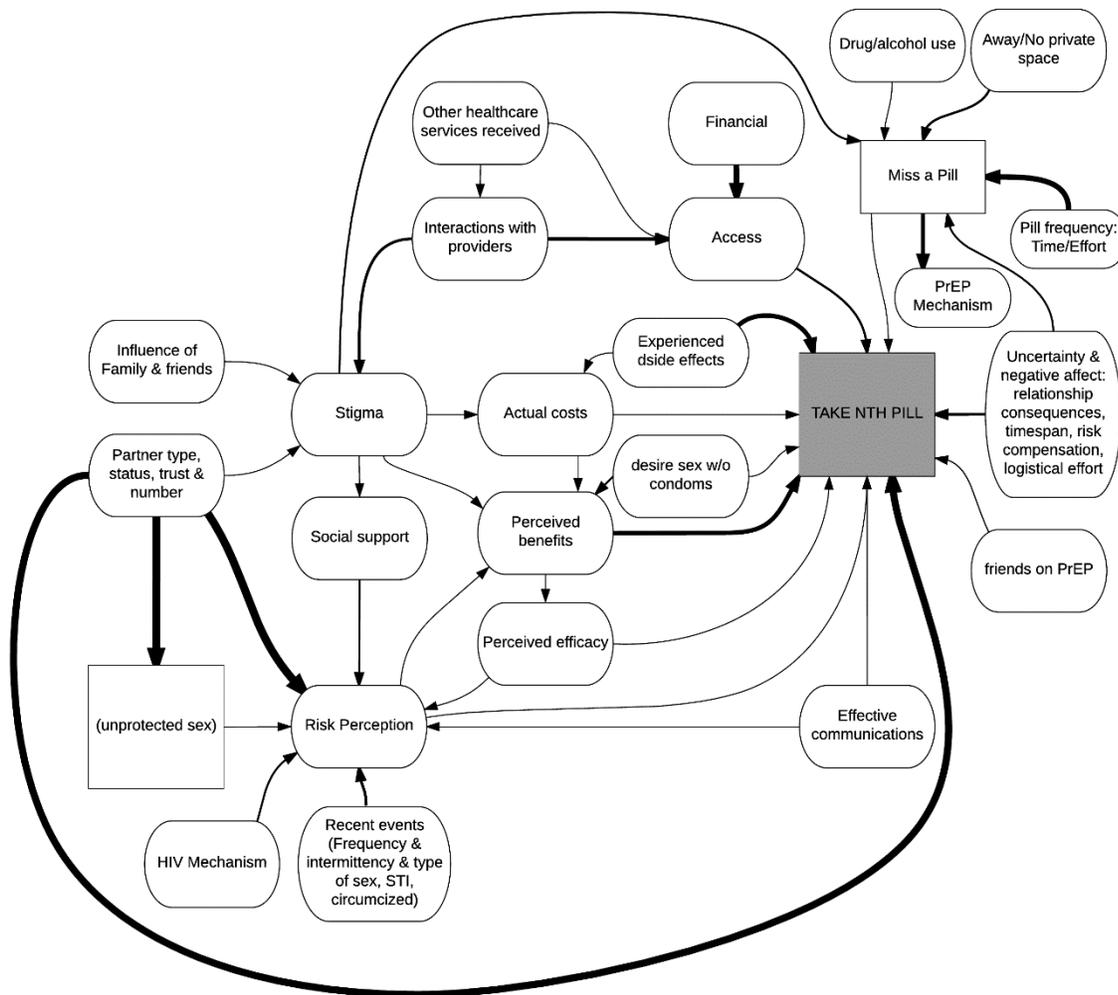


Figure 4. Lay Model of PrEP Adherence – Young Women

Here, a woman in Kisumu (3117.2) refers to how difficult it can be to remember medication when you don't have an obvious sickness reminding you to take it:

I: Do you think you would be able to take it every day around the same time?

R: No....People take drugs with reasons. If one has malaria, they will remember to take the drug because of fever. In this case, you are not sick, you are just okay. Everything is fine with you but then you start taking drugs. You will therefore forget to take the drugs easily. If you want to engage in sex, that is the time you will remember that you never took drugs.

Several other young women raised questions about whether they could take PrEP while on medications for another illness, or if one should stop taking PrEP if they became sick with a passing cold or flu and needed medications for that. Lastly, a woman from Johannesburg (2102.2) discusses her difficulty imagining taking PrEP amidst hunger:

I: What are some reasons that can make someone to miss taking the pill?

R: ...So, sometimes you may find that there is no food at home and then here are the pills. You have to take them but it's just that you just can't take medicine on an empty stomach. You know that yes you can, but you will collapse.

Another reason cited for missing a pill came directly from the “Stigma” node. Several young women suggested that, despite believing PrEP to be the right choice for her, the act of taking it might make a woman feel so ashamed that she misses a day or longer. Young women also reported uncertainty about PrEP’s relationship consequences (“Uncertainty and negative affect”) as a factor in whether or not one might miss a pill. As a woman from Kenya (3106.2) explained: “If I lack support of the partner at times...I may be taking it, yet he doesn’t like the issue of me taking the PrEP, so it will force me. Sometimes I take it sometimes I don’t take it.” Invoking the issue of identity, a man from Kenya (3206.2) described his frustration over the fact that the daily oral PrEP regimen is so similar to an ARV regimen:

...[Taking the pill every day will influence me] because there will be no difference between taking PrEP or the anti-virus...the antiretroviral. And so it will extremely affect me. So what is the difference between me the negative from the positive person?

Adherence (“Take Nth Pill”). Both experts and young women agreed that missing a pill is dangerous in that it can sometimes lead to quitting. This could simply be the result of habit formation (or lack of it, captured by the “Miss a pill – Take Nth pill” link), but some young women foreshadowed a cognitive pitfall about what could happen if they missed a pill and tried to restart. This logic is captured in Figure 3 as “Miss a Pill - PrEP Mechanism.” One version of this logic depicts a direct, immediate-term relationship between PrEP usage and protection such that each day’s dosage is seen to protect a person for about a day:

2110.2

I: So what do you think happens if you miss taking a pill or you forget to take one?

R: If you miss a pill and...you have unprotected sex with the person who is HIV positive, you will get HIV positive.

3117.2

I: What do you think happens if you miss a pill, or forget to take one?

R: If you miss taking the drug, you are lowering the immune and you are spoiling the dose in that you will have to restart the dose.

1104.2

R: I don't trust this pill.

I: Okay, why?

R: The reason I don't trust is because you must take it every day. So I don't take it this one day, I don't use a condom, I sleep with someone who has HIV, I am going to get it spread to me...

While none of the young women linked “PrEP mechanism” directly to “Take Nth Pill,” their misperceptions of how PrEP works could lead to mistrust or frustration with the pill, negatively influencing adherence. Simply addressing the mechanism of how and why PrEP can remain relatively effective after a missed dose might be useful.

The initiation model included a node for “Safe/Effective,” which is entitled, “Perceived efficacy” in Figure 3; it covers women’s perceptions of whether PrEP works, and how women will perceive it to be working for them. In general, respondents seemed to trust that the pill would protect them. However, one woman from Johannesburg (2104.2) noted the potential motivational difficulty that might come from not being able to see change, or results:

I: What do you think are some of the reasons that someone may have for missing the pills?

R: ...They might get tired of it, like when I gym and I don't see results, I end up letting it go. So, someone might see this as gyming.

That said, in terms of “Perceived benefits,” over half the respondents seemed to prioritize their anticipation of *feeling secure and in control* with PrEP (see Figure 4). Many young women even shared a giddiness about that security, like this one in Johannesburg (2105.2):

*I would have total control, oh ja, that would be a good feeling...Ja, 'cause I can't get [HIV]!
There is no way, it's protecting me as much as condom...Start and be shabby for no reason
(both laugh), all the time shabby, these pills will save my life. I am getting it, never mind.*

While male respondents mentioned “desire sex without a condom” frequently as a motivator for adherence, it barely came up with female respondents. “Experienced side effects” did, however. Many women expressed concern about how difficult the side effects might be, and some who expressed enthusiasm for PrEP said they would stop it if they suffered from headaches, nausea or diarrhea. Others, like this woman in Cape Town (1101.2) who had a poor understanding of PrEP’s mechanism, explained how the discomfort of side effects would likely inform her pattern of adherence—in a manner that would, unfortunately, increase her risk:

I: If you have side-effects, perhaps, a headache or you want to throw up, what would you do?

R: I would take it a little bit, only when I know that I am going to sleep with someone....Because it is giving me those problems or that pain.

Despite the very frequent and strong negative reactions to PrEP’s potential side effects, most participants professed being willing to work through it if they were only short-term.

Key Informants: Respondent Characteristics

A total of 47 KIs were interviewed across the three sites (see Table 1). Participants were in majority women, had completed college and were involved in community support or clinical work.

Table 1: KI characteristics.

	DTHF (N=17)	Wits RHI (N=15)	KEMRI (N=15)	All Sites (N=47)
Median age	41	39	36	40
Gender (% female)	76%	80%	69%	72%
Highest level of education:				
<i>Secondary school or less</i>	47%	20%	13%	28%
No schooling	0%	7%	0%	2%
Primary school	6%	0%	0%	2%
Secondary school	41%	13%	13%	23%
<i>Certificate and/or college</i>	53%	67%	53%	57%
Certificate	0%	0%	7%	2%
College	6%	0%	13%	6%
College diploma	47%	67%	33%	49%
University degree	0%	7%	27%	11%
Post-graduate degree	0%	7%	7%	4%
Occupational role:				
<i>Community support</i>	47%	40%	47%	45%
Community health worker	18%	0%	0%	6%
Counselor/social worker/advocate	6%	33%	27%	21%
Youth services provider	24%	0%	0%	9%
NGO/project management	0%	7%	20%	9%
<i>Clinical</i>	35%	47%	33%	38%
General nurse	0%	33%	0%	11%
Family planning nurse	12%	0%	7%	6%
HIV/AIDS nurse	12%	0%	0%	4%
Medical officer	0%	0%	13%	4%
Clinic management	12%	13%	13%	13%
<i>Other</i>	18%	13%	20%	17%
Religious leader	0%	0%	13%	4%
Traditional healer	12%	13%	7%	11%
Political leader	6%	0%	0%	2%

Note: AIDS=acquired immunodeficiency syndrome, DTHF= Desmond Tutu HIV Foundation, HIV= human immunodeficiency virus, KEMRI= Kenya Medical Research Institute, N=sample size, NGO=non-governmental organization, Wits RHI= Wits Reproductive Health and HIV Institute.

Levels of education varied between the sites and reflect the roles of KIs. In Cape Town (DTHF), a higher proportion of people with positions at the community healthcare worker (CHW) and direct youth services/care level were interviewed. This is reflected by the larger percentage of informants without a college degree or certificate at that site.

KI Perspectives: Family Planning

KIs' perspectives about young women's family planning concerns

Although 40% of KIs felt that young women are very concerned about preventing pregnancy, they highlighted some of the concerns that may prevent them from using family planning methods. KIs identified lack of education about family planning as a barrier for some young women. Other KI highlighted young women's concerns about side effects and the ability to return to fertility after long-term use as key barriers: some young women will not use family planning products for fear of side effects such as the implant causing bleeding, or becoming pregnant while using an intrauterine device (IUD). Many KIs mentioned young women's concerns, dislikes or fears of long-acting reversible contraception (IUD & implant) as a barrier to use. They also shared that young women hold many myths and misconceptions around family planning products. These included, but were not limited to, the belief that the products will cause them to gain weight, and will negatively impact their fertility in the long-term. Interpersonally, resistance from a male partner and stigma directed at young women who are sexually active were also described as barriers to family planning use. Finally, at the individual level, KIs mentioned that young women's "*laziness*," meaning their lack of motivation, is what prevents them from using family planning methods.

Three most promoted family planning methods

The most promoted family planning methods among the KIs were condoms, abstinence and long-term methods such as the injection, implant, or IUD. With condoms, resistance from a male partner and getting caught up in the moment during sex were identified as barriers to use. As a social worker in Johannesburg commented, "*when people are in the mood, they will put the condom aside.*" Although oral contraceptives were not identified as a widely promoted method, KIs nonetheless spoke to adherence issues that compromise this method. In Kenya, a number of KIs reported that although they do not widely promote emergency contraception or the withdrawal method, these two are frequently used by young women. One KI in Kenya suggested these two methods are used because male partners do not like or will refuse to use condoms.

KI Perspectives: HIV

KIs' perspectives about young women's HIV-related concerns

The KIs interviewed held a diversity of perspectives about young women's HIV-related concerns. Some felt that young women are definitely concerned about HIV, while others felt the opposite. A counselor and nurse for a mobile HIV prevention program in Cape Town shared that, "*these young*

women just live in the now.” Still others expressed more nuanced opinions that capture the range of potential experiences young women face. An outreach worker in Kisumu offered that:

Some are deeply concerned because they have seen some young girls their age get HIV and what they went through and challenges they face. Some are not concerned, they feel they are protected (use condoms), some are just not concerned because they don't have the right information.

In Kisumu a number of KIs felt that young women are more concerned about pregnancy than HIV because, “HIV is hidden and [in comparison] pregnancy comes out very fast and everybody would know and talk about it and that is their fear” (community health worker). KIs in Cape Town addressed the reality that even when young women are concerned about HIV, difficulties negotiating condom use with male partners leave them unprotected. A manager of HIV/ acquired immunodeficiency syndrome (AIDS)/tuberculosis (TB)/sexually transmitted infection (STI) programs in Cape Town explained that young women “feel a man has more right over their bodies than what they have.”

KIs' perspectives about HIV risk factors

When asked about factors that make young women more susceptible to HIV infection, KIs overwhelmingly addressed the environment of poverty in which most of these young women are immersed. A therapist in Johannesburg explained how young women:

have to go out there and find ways of surviving, and therefore they commit themselves to unprotected and unsafe sexual engagements. This is where it leads, because they want to provide bread and butter to their families. They wouldn't care about the other things because they want to survive.

As the quote illustrates, although young women who are living in poverty are concerned about HIV, those concerns often become secondary to concerns about basic survival. For some young women that means engaging in transactional sex or sex work to survive. Others will couple with older partners, or have multiple partners, primarily in hopes that these men will help provide for them.

HIV prevention methods promoted by KIs

KIs reported condoms as the HIV prevention method of choice for young women. Compared to condoms, about half as many of the KIs reported promoting abstinence and/or regular HIV testing (both for young women and their partners). In addition, one quarter of the KIs interviewed also promoted “being faithful” to one’s partner as a key prevention method.

KIs' perspectives on HIV testing services for young women

When asked what HIV testing locations young women prefer, KIs most commonly reported general health facilities, mobile testing sites and “youth-friendly” testing sites. A founder of a community-based organization in Kisumu also noted, “I have seen very good results and very good environment when

we do it [testing] in the house.” This echoed other KIs in Kisumu who also suggested self-testing as a preferred method due to its convenience and discretion.

KIs suggested the main barrier to testing services access by young women is a fear of being observed and judged by community members. KIs also noted young women’s concerns regarding negative, judgmental attitudes of nurses and other clinic staff as a significant barrier to testing uptake. Across testing locations and methods, KIs highlighted young women’s preference for discretion and non-judgement, noting that young women prefer to test at home where they may be assured privacy or at clinics far from where they live to avoid fellow community members recognizing them.

KI suggestions for improving HIV testing services

When asked about how to improve HIV testing services for young women, KIs described needed improvements in service provision. They underscored the need to make testing sites and services more youth-friendly. One Kisumu social worker reported that, *“it’s a challenge for young people because when they come there and see grandmothers as counsellors, they just walk away.”* KIs also suggested improving not just the skills and knowledge of HIV counsellors, but also the education provided about HIV and testing. They underlined the importance of messaging around knowing one’s HIV status, and addressing partners’ belief in testing by proxy (i.e., having one partner test for HIV and assuming the results are indicative of the other partner’s status). To facilitate improved testing uptake, KIs also suggested making testing services more convenient by offering integrated HIV testing services with family planning, and providing testing services closer to where young women live and prefer to spend their time.

KI Perspectives: PrEP

KIs’ knowledge of oral PrEP

Almost one third of those interviewed reported they had never heard of PrEP. Some KIs stated that they had heard of PrEP prior to the interview; however, as some of these KIs went on to describe PrEP, it became clear that they had mistaken PrEP for post-exposure prophylaxis (PEP) or antiretroviral (ARV) medication. Few KIs stated that they had a decent understanding of how PrEP works, and some admitted they didn’t know very much about it. Comparing the sites, KIs in Kisumu were the most likely to have heard of PrEP, while those in Cape Town were the least likely. It is unclear what is associated with these different levels of awareness.

KIs’ support of oral PrEP

After asking about whether the KI knew about PrEP, all of those interviewed received a brief explanation of how PrEP functions as a daily pill to prevent HIV infection, along with its level of effectiveness. KIs were then asked to share their opinions about PrEP and if they would promote it to young women. Of those asked, 16 KIs explicitly stated that they support offering PrEP. One Kisumu religious leader explained his enthusiasm by stating:

Yes, 100%, because this one gives them [young women] the power in their hands so they don't need to worry about anything. This is so good because you don't have to worry whether you get an HIV [infected partner] person or not, even a sex worker will feel safe with it.

One HIV/AIDS/TB/STI manager in Cape Town who had heard of PrEP said she had previously only thought of it for sex workers, and had never thought about offering it to young women in general. Yet, she offered, *"I want for the next generation to be savvy and stand up for themselves and not take crap from anybody, to be strong,"* and saw PrEP as an opportunity for giving young women more "power." These two KIs' responses reflect those shared by others; namely, their support of women-controlled prevention.

Although KIs reacted very positively to PrEP overall, they also expressed a few important concerns about providing PrEP to young women: young women's anticipated adherence, side effects and effects on risk behavior. Across sites, over one third of KIs voiced concerns about the daily burden and possibility of young women forgetting to take pills. KIs in Kisumu and Johannesburg were especially concerned with motivating adherence when a patient is not sick. One clinic manager in Johannesburg voiced her concern that young women would have difficulties with PrEP adherence, expressing, *"I'm still battling with the sick to make them comply, then to make a non-sick [person] comply, it's climbing Kilimanjaro."* Due to experience and knowledge of ARVs, KIs across sites also anticipated young women taking PrEP would experience side effects. Noting the need to improve their knowledge around PrEP, one Johannesburg non-governmental organization manager expressed, *"I will really need to understand it [PrEP] because anything that is good has its own side effects and long term results."* Regarding risk behavior, six KIs from the Cape Town area were supportive of PrEP, but also worried that it would cause young women to stop using condoms and become "reckless" because they believed young women would feel protected enough to start taking more sexual risks.

In addition to concerns about the end users of PrEP, KIs also expressed concerns about PrEP accessibility and staffing needs for PrEP provision. Chief among these concerns were the cost of PrEP to providers and patients, and consistent PrEP medication supply. KIs worried about facilities' ability to maintain sufficient stock to meet their anticipated high demand. In terms of staffing, KIs noted the limited time available for existing staff to take on a new responsibility, as well as staff's limited knowledge of PrEP. They also spoke about known issues with staff stigmatizing young women who are sexually active.

KIs' perspectives on young women's interest in PrEP

Thirty-three percent of KIs explicitly said they think young women would be interested in PrEP. When asked which young women would be interested in PrEP, KIs anticipated that the young women who would want PrEP would include those who may be at greatest risk of exposure to HIV. In particular, KIs mentioned women engaged in casual or transactional sex, those who are "unfaithful" or have multiple partners, those who do not want to use condoms, or those who have a partner who is HIV positive. Few KIs suggested that young women who are simply sexually active would want to take PrEP, although

some did mention that women in stable relationships would be interested in PrEP. When asked what age range of young women would be interested in PrEP, KIs suggested varying age ranges starting as young as 14 years and going through adulthood.

KIs suggested a variety of reasons why young women would be interested in PrEP. Some felt that young women would want to use PrEP to be *“in charge”* and enable their protection against HIV without partner consent. Another reason noted was young women will simply want to use PrEP to *“stay safe”* in relationships when they are unsure about their partner’s fidelity. KIs also felt that young women would like PrEP because of its reversibility; that is, young women are able to stop taking PrEP when they feel they are no longer at risk, or no longer wish to take a daily pill. One KI also pointed out that once PrEP becomes well-known, young women may use it to *“advertise”* that they are HIV-negative. Some KIs predicted young women will want to use PrEP because it will allow them to continue to forego using condoms.

KIs’ views on young women’s possible issues with PrEP

When asking KIs what issues young women may have with PrEP, they primarily identified issues with daily pill adherence and stigma surrounding pill use because of associations with ARV use and promiscuity. KIs highlighted how young women struggle to adhere to daily pill use especially when, such as is the case with PrEP, the pill is not treating an existing illness with conditions that would remind them of its necessity. KIs also thought that young women would have fears of PrEP side effects. In addition, KIs foresaw potential stigma associated with PrEP use among young women. They worried that family, partners, or others would find out about their use of PrEP and either confuse it with ARVs and assume the person has HIV, or associate PrEP use with promiscuity and unfaithfulness. One project coordinator/therapist in Johannesburg said *“women don’t want to be seen taking a pill on a daily basis”* because of these stigmatizing views. Also related to community viewpoints, KIs voiced apprehensions around low community awareness and misconceptions of PrEP, foreseeing issues with a *“fear of the unknown”* and community members questioning whether *“they [clinics are] using us as guinea pigs.”* KIs also thought that low community knowledge of PrEP would be an access issue for young women.

KIs also believed that young women would be concerned about service logistics; that is, clinic access issues surrounding clinic locations and hours, long waits and inconsistent PrEP stock. Some KIs interviewed also believed young women would have trouble with the PrEP requirement of being tested for HIV every three months; but an equal number of KIs interviewed believed testing requirements would not be an issue for young women.

KIs’ views on influencers of PrEP uptake and PrEP messaging for young women

When asked who would influence young women to use PrEP, KIs most commonly suggested young women’s peers and male partners as the greatest influencers. KIs thought parents (particularly mothers) would also be an important influence, along with clinical providers, traditional healers and herbalists, celebrities and religious healers.

To relay messages to young women regarding PrEP, KIs recommended the use of young CHWs and peer ambassadors (who have successfully used PrEP and could offer support to others who want to start PrEP). They felt that these people could educate young women on PrEP in an accessible and relevant manner. KIs emphasized the need to ensure staff interacting with young women are also young because community health workers who most commonly have this role are stereotyped as older, judgmental and lacking adequate training.

KIs proposed a variety of PrEP promotion techniques including using slogans, videos, pamphlets in local languages, t-shirts, demonstrations and awareness events, as well as local newspaper and radio station coverage. KIs suggested messages for PrEP should highlight the need to 1) *“be responsible”* (use PrEP consistently, with contraceptives/condoms to prevent pregnancy/other STIs); and, 2) have a positive tone to avoid stigma. Positive message suggestions included highlighting PrEP use as a way of being empowered and in control, healthy, having choices, *“never be[ing] in the position of testing HIV positive,”* and protecting women in case of sexual violence. KIs also mentioned the importance of highlighting that PrEP can be used discreetly and is not for people with HIV.

KI suggestions regarding PrEP clinical staff, facilities and mode of administration

Similar to KIs’ suggestions regarding staff involved in PrEP education, they also addressed the need to have clinical staff who can relate to young women. In particular, they favored the idea of young, friendly, non-judgmental staff delivering services to young women. KIs also suggested hiring and training staff specifically for PrEP implementation to ensure they have adequate time and training for their role.

KIs recommended that facilities supplying PrEP be convenient to young women, with well-known, consistent schedules. They also advised multiple facility options to fit the needs of different women. Recommended facility types included general clinics and health centers, as well as youth-friendly or campus clinics. KIs also shared that young women prefer the convenience of pharmacies/chemists and mobile clinics. KIs suggested many outreach locations for mobile clinics, including group meetings (for youth groups, women’s groups, arts and sports groups), community halls and centers, schools and campuses, churches (although two KIs thought churches infeasible) and rural areas. Shopping malls were also suggested by those interviewed in Johannesburg.

Four KIs asked whether PrEP would be available in the form of a 3-month injection, and suggested that if available, this form of PrEP would enable women to be tested for HIV and receive contraception injections at the same time as their PrEP injection.

KI suggestions regarding PrEP counseling

KIs also highlighted the need for PrEP counseling and recommended specific approaches. Again, KIs suggested using staff who can relate to young women, namely peer educators or young counseling staff. KIs in Kisumu suggested counseling support groups, and that these support group meetings could provide PrEP refills to young women for convenience.

KIs recommended counseling sessions focus on dispelling myths; educating about how to routinize pill-taking (i.e., using alarms, taking pills with a regular meal and suggesting storage options); coaching around disclosure to parents and partners; and continuation of condom use while on PrEP.

Cross Data Analysis

A comparison of data from the KIs and interviews with young women revealed that the two groups understand each other and are in agreement about the potential barriers for PrEP uptake and implementation. Overall, general consensus existed about the levels of interest in PrEP, barriers to PrEP use, and who are the influential people in young women's lives. Across the two groups, they both identified the ways in which PrEP accessibility and adherence, interpersonal dynamics, poverty and gender norms will likely be barriers to PrEP use. They also were in agreement that interpersonal issues encompass young women, their intimate partners and family members and also healthcare providers. The examination of these two data sets did not reveal any salient divergence of opinions.

Conclusions: Mental Models and Key Informant Interviews

In conclusion, in terms of clinic interactions, the analysis confirmed some of what experts know: young women feel judged and dismissed in negative interactions with health providers. It also expanded on young women's attempts to avoid those negative interactions can disrupt access to sexual health services (and PrEP), or lead young women to seek informal consults with individuals who may not be as knowledgeable or resourced. The analysis also revealed two major differences between the expert and lay models of PrEP initiation and adherence. The first difference involves how experts and young women view the value proposition of PrEP. While the expert decision model emphasized the influence of social stigma in the decision calculus, the model's overall focus tended to be on risk assessment and the health costs and benefits of taking PrEP. In contrast, young women spoke frequently about the relational, moral and even identity-oriented uncertainties that deciding to take PrEP would introduce, e.g., potentially losing close loved ones (romantic, friendly or familial) due to mistrust or judgment; the pressure of consistently lying to close others; uncertainties about whether they'd need to be on PrEP for their whole lives, and what that possibility said about their character as well as life stability. The second difference between the expert and lay models came from young women's (and men's) inaccurate understanding of HIV risk and mechanism. Women and men vastly overestimated their risk for contracting HIV from unprotected sex. Moreover, given years of messaging that claimed one exposure would likely lead to HIV, interviews showed that some who know or suspect they've been exposed but did not contract the virus ascribe their HIV- status to "being immune." Indeed, the interviews seemed to call into question the idea that risk perception is the pathway motivating PrEP initiation in young women. A follow-up survey, however, found that women's assessment of their one-year HIV risk helped to predict their interest in trying PrEP. Women's one-year personal risk assessment correlated significantly with more objective markers of HIV risk in the survey (such as frequency of sex, side partners and condom usage), thus, while it is not clear how honestly women reported their sexual behaviors, it is possible that these assessments reflected actual risks to some degree. Thus, while we conclude that risk assessment is an important part of women's motivation to use PrEP, we would highlight that individual risk perception is a complex and contextually dependent. Qualitative elements

of this report which revealed means of distancing one's self from risk (e.g., immunity narratives), while the mental models follow up surveys showed that both attractiveness and character appraisals could influence how one assessed the HIV risk of others.

KIs interviewed included counselors, social workers, community health workers, clinicians and community leaders. These individuals primarily felt that young women are very concerned about preventing pregnancy, but they highlighted some of the reasons that may prevent them from using family planning products. These included limited education about family planning, concerns about side effects and impacts on fertility after long-term use, as well as resistance from male partners. KIs held diverse perspectives about young women's concerns about HIV. Some identified that young women are concerned about HIV infection, while others felt they are not because of present bias. Additionally, KIs noted young women's difficulties negotiating condom use with male partners and how addressing survival needs often results in young women not being able to use condoms when having sex.

Few KIs, even among those interviewed working in HIV-related fields, were knowledgeable about PrEP. Once informed, they were enthusiastic about offering PrEP to young women, and thought demand would be high, but they also expressed concern about potential challenges with adherence, side effects and stigma. These challenges were similar to those identified for use of family planning, and there may be lessons from successful pregnancy prevention programs for youth that can be applied to PrEP delivery. KIs emphasized the need for PrEP training that would enhance provider and stakeholder knowledge and address common concerns and misconceptions about PrEP. Specifically, they asked that training address how to promote adherence, promote end-user acceptability and ensure PrEP does not increase young women's risk behavior.

KIs highlighted concerns around HIV testing and PrEP service accessibility and convenience for young women, underscoring issues around staff biases against sexually active young women. To address accessibility needs, KIs encouraged discreet services be offered in close proximity to where young women live and spend time, with well-advertised, consistent schedules. KIs recommended ensuring service approachability by having staff who can relate to young women and provide nonjudgmental health services. In addition to training about how to relay messages to young women in an effective and non-judgmental manner, KIs proposed that those best suited to accomplish this would be peer educators/counselors, young community healthcare workers, support groups and PrEP ambassadors. They also noted the importance of having consistent PrEP stock supplies.

Recommendations

Marketing. PrEP holds strong interest for young women because it engenders in them two positive feelings of security and empowerment. As the mental models interviews and follow up survey have demonstrated, these emotions are given high value in a romantic and sexual environment that is uncertain and sometimes uncontrollable. Marketing campaigns should feature the immediate, positive emotional returns of PrEP usage (e.g., control, empowerment, health, strength) and seek to establish PrEP as a norm. While our formative work has also demonstrated that women feel a great deal of uncertainty and negative affect in relation to the relational and identity questions raised by PrEP, we

recommend leaving these issues off the table for marketing and initial decision-making surrounding PrEP.

According to KIs, future messaging around PrEP should be positively oriented to garner community buy-in and prevent stigmatizing views of PrEP users. Peer, male partner and family support may be particularly important for PrEP uptake and adherence, so along with young women, these influencers should be targeted for messaging.

Clinic. In terms of risk assessments, despite the fact that participants in this sample vastly overestimated the risk of contracting HIV from a single exposure, we do not recommend giving people better information about the single-exposure risk of HIV sexual transmission as it may undermine efforts to control the spread of the disease. However, we do recommend that providers give PrEP participants cumulative risk information—perhaps 1-year, 5-year, or 10-year estimates. Individual counseling, similar to what is provided in family planning services, might be able to tailor the behavioral patterns of specific individuals (e.g., frequency of sex, degree of protection, partners from different risk groups) in order to provide accurate cumulative risk information.

Descriptions of PrEP need to be kept simple in order to be understood. At the same time, a simple and clear description of how PrEP works—including its HIV-specific role in the immune system, how long it takes to be optimally protective in the body, and how long it takes to leave the bloodstream—might help PrEP users feel more protected in times of missing a pill, and encourage them to stay the course. User instructions could explicitly address PrEP's effectiveness at 4+ pills per week, the safety of taking concurrent medications (including over-the-counter medications for flu and cold) and why experiencing side effects is not a sign of long-term harm in the body. Lastly, PrEP's inability to protect against STIs must be emphasized.

Input into Decision Tool. Perhaps the largest finding in this formative work is that the relationship and identity uncertainties raised by PrEP initiation play a large role in the value proposition of PrEP. To some extent, given the inability to predict how PrEP might affect one's relationships and the negative and aversive feelings conjured by considering the possibilities, it might be best to limit these considerations from entering into the formal decision calculus. A decision tool would be a useful way of focusing attention on the items that matter most for determining whether PrEP makes sense for an individual. Once that judgment is made other measures can be employed to mitigate against the fears related to relationship uncertainties, etc. This formative work identified a variety of factors that young women perceive as relevant in decision-making about PrEP, among them: routine stability, having access to a private space, willingness to experience temporary side effects, etc.

Delivery. Several themes emerged for how best to move forward with PrEP implementation.

- *Structure of waiting rooms and services.* PrEP programming should work to address concerns about the convenience and accessibility of HIV testing and clinical services for young women, to facilitate PrEP uptake and adherence. Many young women reference the lack of anonymity

(regarding purpose of clinic visit) that accompanies visits to the clinic. Efforts should be taken to structure services anonymously. Youth-friendly spaces and providers need to be identified. To be youth-friendly, they should offer private services near young women, with well-promoted, consistent scheduling.

- *Create service environments that are professional (confidential), friendly and judgment-free.* The young women in this sample spoke highly about their experiences at mobile and adolescent clinics—environments that cater to being patient-centered for youth. Work needs to be done that addresses the deeply embedded biases and judgments providers hold regarding young women, to make them more approachable. PrEP providers should draw on lessons learned from the family planning field in determining how best to reduce bias and make services youth-friendly. If resource constraints make it difficult to design PrEP-delivery sites for this purpose, training for nurses (in particular) and/or setting up a youth advocate at each site could be helpful.
- *PrEP Ambassadors:* Both young women and the KIs suggested the importance of PrEP ambassadors for outreach and education to each group as well as having peers, whether they are young women or health providers, to make information about PrEP more accessible and engaging. To address provider and stakeholder gaps in knowledge around PrEP, training should attend to their common concerns around improving PrEP adherence, end user acceptability, risk behavior compensation, PrEP stock maintenance and staffing for PrEP provision. These conclusions are strengthened by the fact that young women interviewed shared many of the same perspectives as KIs and had many of the same recommendations.

Limitations and Next Steps

While illuminating, this formative work is limited by several factors. First, our interview and survey participants spent much of their interviews doing something people in general don't do well: forecasting how they feel or think about uncertain futures. While it is useful to know how people *think* they will feel and act once PrEP is made available, it is plausible that their actual attitudes and behaviors will evolve differently than they expect.

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APPENDIX A. POWER Key Informant Demographic Form

_____ / _____ / _____
Participant ID (PTID)

Staff Initials

____ / ____ / ____
Date of Interview (dd/mm/yy)

POWER Study Key Informant Demographic Form

<p>INSTRUCTIONS: Please fill out the form so that we can have a little more information about you before the interview. Remember that this information will remain confidential and will not be linked to your name in any way or shared with anyone outside the research team.</p>	
1.	What year were you born? <div style="float: right; text-align: center;"> _____ </div>
2.	What is your gender? (circle one) <div style="float: right; text-align: center;"> Man / Woman </div>
3.	What is your highest level of education?
4.	Name of organization where you work:
5.	Type of work you do:
6.	What neighborhood and city do you work in?
7.	What is your primary role? <ul style="list-style-type: none"> <input type="checkbox"/> Provide services directly to clients <input type="checkbox"/> Advocacy/activism <input type="checkbox"/> Religious Leader <input type="checkbox"/> Traditional Healer <input type="checkbox"/> Other (specify): <hr style="border: 1px solid black; margin-top: 5px;"/>
8.	What is your current job title (select all that apply)? <ul style="list-style-type: none"> <input type="checkbox"/> Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Medical officer/clinical officer <input type="checkbox"/> Counselor <input type="checkbox"/> Outreach Worker <input type="checkbox"/> Pharmacist <input type="checkbox"/> Religious Leader <input type="checkbox"/> Traditional Healer <input type="checkbox"/> Youth group leader or member <input type="checkbox"/> Women's group leader or member <input type="checkbox"/> Sex worker group leader or member <input type="checkbox"/> Other (specify):

		<hr/>
9.	<p>What types of people do you work with/serve (check all that apply):</p>	<input type="checkbox"/> Children <input type="checkbox"/> Young women (age 16-25) <input type="checkbox"/> Young men (age 16-25) <input type="checkbox"/> Adult women <input type="checkbox"/> Adult men <input type="checkbox"/> People living with HIV/AIDS <input type="checkbox"/> Family planning clients <input type="checkbox"/> Sex Workers <input type="checkbox"/> Drug Users <input type="checkbox"/> Other (specify): <hr/>

APPENDIX B. POWER Key Informant Guide

Key Informant Interview Guide

Note to interviewer: Text in *italics* is instruction that should not be read aloud to the participant.

NOTE: Please have the participant fill out the demographic form

Introduction:

(Interviewer read): Thank you for agreeing to participate in this interview. Let me remind you that whatever you say will not be connected to your name. You may refuse to answer any of these questions. There are no right or wrong answers and your opinion is really important for this research, so you should speak freely.

Do you have any questions for me before we begin?

As you were told when you provided your consent, I will be audio-recording this discussion. This is to make sure I capture accurately everything we will be discussing. Is it okay to turn on the recorder now?

[Once you have answered participant's questions, turn on recorder.]

I've just turned on the audio recorder. I will let you know when I turn it off as well. Can you confirm you agree to be recorded?

I. Background Questions (5-10 minutes)

I would first like to ask you some background questions. These questions will help us understand more about your work. They will also help us learn from you about HIV and family planning practices among people in your community. When we use the term "family planning" we mean pregnancy prevention or birth spacing.

1. To get us started, please tell me about the work you do.
 - a. How long have you been doing this work? How did you end up in your current role?
2. What is the community like where you do this work?
3. What is your role in the community?
 - a. *[For HIV doctors, clinicians and outreach workers]* What is your clinical setting like?
 - i. How many staff work there?
 - ii. What types of services do you provide?
 1. Is your work mostly focused on HIV prevention, treatment, or both?
 2. Do you also provide family planning services?
 - a. If yes, what types of services?
 - iii. What types of clients do you see?

1. How many of your clients are young women aged 16 – 25?
 2. What type of work do you do with young women (ages 16-25)?
 3. What types of sexual relationships are these young women involved in? (for example: are they married? Involved with multiple sex partners? Are they having sex with other women? Are they doing sex work or transactional sex?)
 - a. How many sex partners do they typically have?
 4. What are the reasons why these young women come in to see you?
 - a. What makes it difficult for them to come in for an appointment? (for example: do they have money for transportation? Money to pay for the visit? Fears about getting health services? Does their work schedule make it hard to come in when the clinic is open?)
 5. Thinking about the young women you work with/provide services to, what types of life goals and dreams do they have?
 - a. Do you think they see your services as assisting them towards those goals?
 6. Thinking about the young women you work with/provide services to, what are some of the worries or concerns they have?
 - a. *[Note to interviewer: If no concerns mentioned about HIV or family planning ask the following]* What about concerns they have about HIV? How about concerns about family planning??
 - i. What does the current clinical system do to address these concerns?
- b. *[For NGO staff]* What is your organization setting like?
- i. How many staff work there?
 - ii. What types of services do you provide?
 - iii. What types of clients do you see?
 1. How many of your clients are young women aged 16 – 25?
 2. What type of work do you do with young women (ages 16-25)?
 3. What types of sexual relationships are these young women involved in? (for example: are they married? Involved with multiple sex partners? Are they having sex with other women? Are they doing sex work or transactional sex?)
 - a. How many sex partners do they have?
 4. What are the reasons why these young women come in to see you?
 - a. What makes it difficult for them to come in for an appointment? (for example: do they have money for transportation? Money to pay for the visit? Fears about getting health services? Does their work schedule make it hard to come in when the clinic is open?)
 5. Thinking about the young women you work with/provide services to, what types of life goals and dreams do they have?

- a. Do you think they see your services as assisting them towards those goals?
 - 6. Thinking about the young women you work with/provide services to, what are some of the worries or concerns they have?
 - a. What is being done to address these concerns?
 - b. *[Note to interviewer: If no concerns mentioned about HIV or family planning ask the following]* What about concerns they have about HIV? How about concerns about family planning??
- c. *[For Advocacy Group Leaders]* What is the mission of your group?
 - i. When was your group formed? How many people work for or volunteer with your group?
 - 1. How many of the leaders of your group are young women aged 16-25? How about group members?
 - ii. Please tell me about some of the current work your group is doing.
 - 1. How much of this work relates to the needs of young women aged 16-25?
 - iii. Thinking about young women, what types of life goals and dreams do they have?
 - a. How does your group's work try to help them achieve these goals?
 - iv. What are some of the worries or concerns that young women have?
 - a. What is your group doing to address these concerns?
 - b. *[Note to interviewer: If no concerns mentioned about HIV or family planning ask the following]* What about concerns they have about HIV? How about concerns about family planning??
- d. *[For religious leaders and traditional healers]* What types of people do you work with?
 - i. Please tell me about some of the current work you are doing.
 - 1. How much of this work relates to the needs of young women aged 16-25?
 - ii. Thinking about young women, what types of life goals and dreams do they have?
 - a. How does your work try to help them achieve these goals?
 - iii. What are some of the worries or concerns that young women have?
 - a. What types of work are you doing to address these concerns?
 - b. *[Note to interviewer: If no concerns mentioned about HIV or family planning ask the following]* What about concerns they have about HIV? How about concerns about family planning??

II. Family Planning (15 minutes)

I now want to ask you some questions about family planning, specifically about preventing unplanned pregnancies and spacing births.

1. How concerned do you think young women (aged 16-25) are about unplanned/unintended pregnancies?
2. When you talk to young women about family planning, what do you tell them?
 - a. How do you bring up a conversation about family planning?
 - b. What do you think are the most important things for young women to know about family planning?
 - i. Do you think when young women know these things that they make different decisions? Why or why not?
 - c. What do you think are the most important things for young women to know about what happens if they have an unplanned or unintended pregnancy?
 - i. Do you think when young women know these things that they make different decisions? Why or why not?
3. What types of family planning methods and behaviors do you encourage young women to use?
 - a. Do you encourage the same methods to all young women? If no, what helps you decide which product or method to tell a young woman about? (For example: whether she has multiple partners; whether she has paying partners; her level of education; whether she is married)
4. How are young women protecting themselves against unplanned/unintended pregnancies?
 - a. What makes it hard for young women to protect themselves against unplanned/unintended pregnancies? [for example: don't have access to certain prevention products like condoms, injectable contraceptives or implants; sexual violence; Male partners won't let them consistently use condoms]
 - i. What types of suggestions or counseling do you (or your organization) give young women on how to address these challenges?

III. HIV (30 minutes)

I now want to ask you some questions about HIV.

5. How concerned do you think young women (ages 16-25) are about getting HIV?
6. Are young women in your community at risk for getting HIV? [if someone says no, ask why they think they are not at risk. If someone answers yes, ask why they think they are at risk]
 - a. Are certain groups of young women more likely to get HIV?
 - i. If yes, which groups of young women? What puts them at a greater risk?
7. When you talk to young women about HIV Prevention, what do you tell them?
 - a. How do you bring up a conversation about HIV prevention?
 - b. What do you think are the most important things for young women to know about preventing HIV?
 - i. Do you think when young women know these things that they make different decisions? Why or why not?
 - c. What do you think are the most important things for young women to know about what happens if they test positive for HIV?

- i. Do you think when young women know these things that they make different decisions? Why or why not?
8. What types of HIV prevention methods and behaviors do you encourage young women to use?
 - a. Do you encourage the same methods to all young women? If no, what helps you decide which product or method to tell a young woman about? (For example: whether she has multiple partners; whether she has paying partners; her level of education; whether she is married)
9. Where do young women go to get tested for HIV?
 - a. How do you think they choose the location where they go for testing? (For example: is it whatever place is closest to where they live; is it a place where people won't know them; is it a place where they can get other services in addition to HIV testing; geographical location, discreetness, integrated services...)
 - b. What do you think young women like about their HIV testing locations? What do you think they dislike?
 - i. *[Note to interviewer: Ask this ONLY for people who work somewhere that offers HIV testing]* What do you think young women like about your clinic/setting? What do you think they dislike?
 - c. Do you think that young women are using HIV testing as a prevention technique? [for example: are they getting tested with a male partner before they start to have sex; are they testing on their own and then talking to their male partners about the results]
 - d. What suggestions do you have for making HIV testing easier for young women to do? [for example: locations that are easier to get to; mobile testing sites; hours when HIV testing is offered; self-testing]
 - e. Are young women getting tested for HIV on a regular basis?
10. How are young women protecting themselves against HIV? Anything else?
 - a. What do you think makes it hard for young women to protect themselves against HIV? [for example: don't have access to certain HIV prevention products like condoms; Male partners won't let them protect themselves against HIV; They are trying to get pregnant so don't use condoms; They do not use condoms regularly]
 - i. What types of suggestions or counseling do you (or your organization) give young women on how to address these challenges with protecting themselves against HIV?
 - ii. How do you think their male partners influence their decision and ability to protect themselves from HIV, if at all?
11. In addition to what you shared about how young women are protecting themselves against HIV, what other products and methods do you know about that may protect against HIV infection?
 - a. *[only ask this if the person mentions other products or methods]* How aware do you think young women in the community are about these other products and methods?
 - i. For those who are aware of these products/methods, please tell me how you think they feel about them? [for example: likes, dislikes, any rumors about the products or methods]
12. *[Note to Interviewer: If traditional herbs have not been mentioned already, ask this question].* Have you heard about traditional herbs that can prevent HIV?
 - a. *[If yes]* What do you think about this potential way to prevent HIV?
 - b. *[If no]* Traditional herbs are traditional harvested and prepared by a nyanga. What do you think about this potential ways to prevent HIV?

13. Young women in this community may have beliefs about how HIV is transmitted, or how they can protect themselves from getting it, that differ from what you believe. Have you experienced this before?
 - a. If yes, please describe the different beliefs.
 - b. When these differences come up, how do you deal with them?

IV. PrEP (35 minutes)

Earlier we talked about the different ways that young women can protect themselves from getting HIV. I now want to ask you questions specifically about PrEP.

1. Have you heard about PrEP before?
 - a. If yes, what do you know about PrEP?
 - b. What do you know about how PrEP works?

[Note to Interviewer, if person says they have not heard about PrEP, read the following information; also read the following information if they say “yes” but after person answers above questions]

“PrEP stands for **Pre-Exposure Prophylaxis**. PrEP is a medication that, when taken daily by people who do not have HIV, can prevent HIV infection. PrEP is safe and contains some of the same medicines used to treat HIV. The World Health Organization (WHO) recommends PrEP for persons at risk of HIV.”

2. Do you think young women would want to take PrEP? Why or why not?
 - a. What do you think would make young women want to take PrEP?
 - b. What types of young women do you think will be most likely to use PrEP (For example: would certain ages be more interested; if someone is in a committed relationship or multiple relationships or having transactional sex)
3. What would make young women not want to use PrEP?
 - a. What suggestions do you have for how to deal with these things?
 - b. What else could make more young women want to use PrEP?
4. Some people have a hard time taking a pill every day. What may make it hard for young women to take a PrEP pill every day?
 - a. What suggestions do you have for how to make it easier for young women to take a pill every day?
 - b. What else or who else might make it hard for young women to use PrEP every day?
 - i. What suggestions do you have for how to make it easier for them to use PrEP?
5. Once a young woman starts PrEP she will need to be tested for HIV every 3 months to make sure PrEP is protecting her against HIV. Do you think this will influence a young woman’s decision about whether she wants to use PrEP? Why or why not?

Now I'm going to read all the things we've discussed as possibly influencing a young woman's decision about whether to use PrEP, [*Note to Interviewer: Write out all items mentioned, including pill every day and HIV testing every 3 months and ask the following question for each one.*]

6. Is this very important, somewhat important, or not important? Why?
7. How do you personally feel about PrEP?
 - a. Would you encourage young women to use PrEP? Why or why not?
 - b. What concerns do you have about this product?
 - c. What help would you need if you were going to encourage young women to use PrEP?
8. What do you think is the best way to describe PrEP to a young woman?
 - a. What questions do you think young women will have about PrEP?
9. Who are the types of people who influence young women?
 - a. If these people spoke about the importance of PrEP, would it make young women more likely to use PrEP? Why or why not?
 - b. If these people used PrEP openly, would it make young women more likely to use PrEP? Why or why not?
10. Where might the best locations in your community to offer PrEP so that it will be easy for young women to get it? (For example: clinics, mobile sites)
 - a. What do you think about the idea that a community health worker could bring PrEP to young women somewhere in their communities?
 - b. What do you think about offering PrEP through churches, mosques, or other religious centers?
 - c. How about through youth groups or women's groups?
 - d. Thinking creatively for a moment, what other ideas might be possible?
11. Once a young woman has started PrEP, what locations in your community would be the best for providing refills of the pills? [For example: should it be the same sites you mentioned above or would other sites be appropriate such as hair dresser salons and other non-medical sites]
12. [*For respondents who are in a clinic/healthcare setting*] Please tell me what it would be like to offer PrEP at your organization.
 - i. What would make doctors and other healthcare workers want to give PrEP to young women?
 - ii. What barriers might doctors and other healthcare workers have in giving young women PrEP? (For example: do they have the time needed to meet with a young woman and talk about whether PrEP is a good option for the young woman; would the doctors and health workers need special training; time available for follow-up with the young woman and support around taking PrEP every day)

V. Wrap-up (2 minutes)

I want to thank you for doing this interview with me.

1. Are there any additional things you want to share about what we've talked about?
2. Anything you thought would come up in our discussion but didn't?

Thank you for your time. I know there are many types of leaders in the community, both official and unofficial. Can you suggest anyone else I might talk to who works closely with young women around HIV prevention?

APPENDIX C: Six Steps to Mental models Research

Table 1: Six steps to mental models research

Steps	Description
1. Expert Model & Interviews	Identify the relevant aspects of a problem (uptake of and adherence to PrEP), as known to science and providers.
2. Lay Model Interviews	Characterize how members of the target audience frame and understand the problem to reveal their “mental models,” in the terms comparable to Step 1.
3. Comparative Analyses	Identify where users need help in understanding, negotiating and implementing strategies (i.e., uptake and scale-up of PrEP) by identifying divergences between the mental models & the expert model.
4. Survey	Using the language of lay participants in the interviews, design and implement a survey that will establish the prevalence of beliefs and attitudes within the population, pre-test potential communications and identify linkages between sub-populations and specific beliefs.
5. Intervention	Inform and design interventions to facilitate making and implementing informed choices amongst various subpopulations.
6. Evaluation	Evaluate the effectiveness of implemented interventions on decision-making and relevant outcomes.

APPENDIX D: Expert Survey Questionnaire

Expert Survey Questionnaire (Online)

Our Mission

We are decision scientists at Carnegie Mellon University, working collaboratively with partners in both the US and Africa, on the USAID-funded Prevention Options for Women Evaluation Research (POWER) project.

Drs. Connie Celum and Jared Baeten of the University of Washington are Co-Project Directors of this work. The goal of this work is to develop and evaluate effective, scalable strategies that are context-specific and gender responsive and address critical gaps in oral pre-exposure prophylaxis (PrEP) delivery for African women in high HIV incidence settings.

Expert Survey

You are receiving this survey because you have been identified as an expert in your field. We believe that your expertise will be invaluable to us as we strive to: 1) understand the lives and needs of young African women at risk of HIV and 2) inform the development of appropriate, effective oral PrEP delivery strategies.

To help us ensure the success of the POWER project, please complete this short, 15 minute survey. Please note that your responses are anonymous and we will only report aggregate data. We thank you in advance for your help!

Click <next> to begin the survey.

Q93 Please explain briefly how you came up with that estimate.

Q94

On a scale from 1-10, where 1 means “Not at all” and 10 means “ A great deal,” how much do you think each of the following would influence her decision to take PrEP?

	1 Not at all (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)	9 (9)	10 A great deal (10)
How far she has to travel to pick up her PrEP (5)	m	m	m	m	m	m	m	m	m	m
How much PrEP costs (4)	m	m	m	m	m	m	m	m	m	m
The size of PrEP pill (12)	m	m	m	m	m	m	m	m	m	m
The packaging of the PrEP pill (e.g. if it looks like ARV packaging) (13)	m	m	m	m	m	m	m	m	m	m
How her partner feels about PrEP (6)	m	m	m	m	m	m	m	m	m	m
How her family feels about PrEP (16)	m	m	m	m	m	m	m	m	m	m
Whether any of her friends took PrEP (11)	m	m	m	m	m	m	m	m	m	m
Social stigma related to HIV (14)	m	m	m	m	m	m	m	m	m	m
The possibility of being recognized at the clinic (15)	m	m	m	m	m	m	m	m	m	m
Having to take her PrEP every single day (8)	m	m	m	m	m	m	m	m	m	m
Whether she will have a suitable place to “store” or “hide” her PrEP medication (7)	m	m	m	m	m	m	m	m	m	m
Whether PrEP caused her to gain weight (9)	m	m	m	m	m	m	m	m	m	m
Whether PrEP had side effects like nausea, dizziness, or headaches (10)	m	m	m	m	m	m	m	m	m	m

Q95

Are there any other factors that might make a young woman MORE LIKELY to try oral PrEP?

Q96

Are there any other factors that might make a young woman LESS LIKELY to try oral PrEP?

Q98

Imagine a young African woman decided to take oral PrEP. On a scale from 1-10, where 1 means “not at all” and 10 means “extremely,” how likely would she be to tell her partner of her decision to take oral PrEP,

m 1 Not at all likely (1)

m 2 (2)

m 3 (3)

m 4 (4)

m 5 (5)

m 6 (6)

m 7 (7)

m 8 (8)

m 9 (9)

m 10 Extremely likely (10)

Q97

If a young woman decided to take PrEP, and told her sexual partner, how would her partner feel about her decision?

Q49

If you were in charge of figuring out a way to encourage people in African communities to take PrEP, what would be your strategy? Imagine that you have unlimited funds to realize your idea.

Q50

On a scale from 1-10, where 1 means “not at all effective” and 10 means “extremely effective,” how effective do you think each of the following strategies would be at increasing oral PrEP adherence among young African women?

	1 Not at all effective (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)	9 (9)	10 Extremely Effective (10)
Individual financial incentives for adherence (1)	m	m	m	m	m	m	m	m	m	m
Group level financial incentives for adherence (12)	m	m	m	m	m	m	m	m	m	m
Lotteries for adherence (2)	m	m	m	m	m	m	m	m	m	m
Informational campaigns about PrEP (3)	m	m	m	m	m	m	m	m	m	m
Informational campaigns about HIV risk (11)	m	m	m	m	m	m	m	m	m	m
Subsidizing the cost of pills (4)	m	m	m	m	m	m	m	m	m	m
Multiple access point (clinics, pharmacies, other healthcare sites) (5)	m	m	m	m	m	m	m	m	m	m

Incorporating PrEP use into television story lines (7)	m	m	m	m	m	m	m	m	m	m
Peer mentoring or support groups (10)	m	m	m	m	m	m	m	m	m	m
Highlighting PrEP use among socially prominent figures (e.g. celebrities, community leaders, or key members of a social network) (13)	m	m	m	m	m	m	m	m	m	m
Combination PrEP and birth control (9)	m	m	m	m	m	m	m	m	m	m

Q57

Are there other strategies, not mentioned above, that you think would be effective at encouraging PrEP use? Please explain them here.

Q61

Are there any strategies that you believe are just not worth trying at all for encouraging PrEP use among young African women? Please list each of these strategies below and briefly explain 'why it is not worth trying'

Q101

If a young African woman had unprotected sex with a single HIV positive partner ONE TIME what is the percent chance that she would become HIV positive? Please drag the slider bar back and forth to indicate your response. Remember, "0" means there is absolutely no chance she would become HIV positive and 100 means that she would definitely become HIV positive

_____ % chance she would become HIV positive (1)

Q54

If a young African woman had unprotected sex with a single HIV positive partner TEN TIMES what is the percent chance that she would become HIV positive?

_____ % chance she would become HIV positive (1)

Q55

If a young African woman had unprotected sex with an HIV positive partner ONE HUNDRED TIMES what is the percent chance that she would become HIV positive?

_____ % chance she would become HIV positive (1)

Q52

Please explain briefly how you came up with each of these estimates.

Q103

What are some things a young African woman can do to decrease her chances of contracting HIV?

Q104

If a young African woman is already HIV positive, is there any action she can take that will make her HIV worse?

Q105

What are some places a young African woman can currently go to have an HIV test done?

Q106

Please list some challenges she might face in seeking out an HIV test.

Q32

If a young African woman really trusts her same-age male sexual partner, what percentage of the time do they use a condom? Remember, "0%" means absolutely never and "100%" means every single time.

_____ % of the time they use a condom (1)

Q34

Please explain briefly how you came up with that estimate.

Q35

How does your estimate change if the man is older than she is? Please check all that apply.

q My estimate increases if the man is older than she is (4)

q My estimate decreases if the man is older than she is (5)

q My estimate remains unchanged (6)

Q59

How does your estimate change if the man is younger than she is? Please check all that apply.

q My estimate increases if the man is younger than she is (4)

q My estimate decreases if the man is younger than she is (5)

q My estimate remains unchanged (3)

Q36

On average, how many sexual partners do young African women usually have at any given time?

m 0 (1)

m 1 (2)

m 2 (3)

m 3-5 (4)

m 6-10 (5)

m >10 (6)

Q38

On average, how many sexual partners do young African men usually have at any given time?

m 0 (1)

m 1 (2)

m 2 (3)

m 3-5 (4)

m 6-10 (5)

m >10 (6)

Q39

On average, how many sexual partners do older African men usually have at any given time?

m 0 (1)

m 1 (2)

m 2 (3)

m 3-5 (4)

m 6-10 (5)

m >10 (6)

Q40 Our last questions are about you.

Q41

Do you professional treat individuals with HIV (as a physician, counsellor, etc)?

m Yes (1)

m No (2)

Q42

Do you personally know anyone who is HIV positive?

m Yes (1)

m No (2)

Q43

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What is your sex?

m Male (1)

m Female (2)

Q44

What is your age?

m 18-24 years old (4)

m 25-34 years old (5)

m 35-44 years old (6)

m 45-54 years old (7)

m 55-64 years old (8)

m 65-74 years old (9)

m 75 years or older (10)

Q46

What is your highest level of educational attainment?

m High school diploma (1)

m Some college or technical school (2)

m Associate degree (5)

m Bachelor's degree (6)

m Master's degree (7)

m Professional degree (JD, MD) (8)

m Doctorate degree (Psy.D, PhD) (9)

Q56

What is your primary country of residence?

APPENDIX E: Mental Models Interview Guides

MM Interview 1 & 2 Young women and men

INTERVIEW 1 (Female) Mental Models Interview Guide

PURPOSE

One aim of this initial IDI guide is to understand those factors that affect the following decisions that young South African women make, specifically:

- 1) the decision to start and continue dating someone
- 2) the decision to engage in sexual intercourse and unprotected sexual intercourse

Another aim is to better understand the daily lives of young South African women.

This includes understanding their:

- Daily routines and range of travel
- Social and cultural lives, including: the music they like, the social events they attend, who their friends are, how their time is spent, and the technology (phone apps etc.) they use
- Life goals and dreams
- The role played by family, friends and partners in terms of informing their decision-making and values

INSTRUCTIONS

There are 2 levels of questions:

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- Initial topic questions: these questions will be numbered. They address the topics that you as the interviewer must ask and discuss with participants. The questions are suggestions for getting the discussion going. You are not required to read them exactly as they are written, but they are written to ensure some consistency across IDIs. You may adapt the questions and/or ask them in a different order, depending on how the interview develops. However you will have to ensure that by the end of the interview, all the topics and key themes have been covered. Local-language translations of these questions will be available.
- Probes: they are indicated with a bullet. The interviewer should ensure that key topics listed in the guide have been addressed/discussed during the interview; however the probes are meant to serve as suggestions for the interviewer to draw from rather than a strict list of questions that *must* be asked. So, depending on what has already been discussed, and the IDI context, you may ask these probes or not or may phrase probes differently to try and better understand what the participant is trying to communicate.
- Instructions/suggestions to interviewer are in *italics*.

Beginning the Interview

[Warmly.] Good morning/afternoon. My name is . Thank you so much for your willingness to be a part of this discussion. You are one of a small group of women that we have invited to work with us to explore which ways would be best to provide young people with the information they need to make informed decisions about their sexual and reproductive health. By helping us to understand you and your world, you can help us design outreach and services for HIV prevention that can help all the people in *[specify community of the participant]*.

We will only be able to cover half of our topics today, so, as you know, we will meet once more within a week's time. For today, I am interested in learning more about who you are, your family and life experiences, your daily life, your experiences around relationships and sex and the ways that you use technology such as Internet and phones. As you read in the consent form, everything you say in this interview is both anonymous and confidential; what you share will not be linked to your name.

There are no right or wrong answers to the questions I'll ask, I'm only interested in understanding your honest perspective. If I ask anything that makes you uncomfortable or that you don't want to discuss, let me know and we'll move on to the next question.

Do you have any questions before we begin?

Great. At this point, then, would you be able to turn off your phone? This will allow us to talk without interruption. *[Wait for them to turn off phone.]* Thanks.

Lastly, to help remember what we discuss, I'll turn on the recorder now. *[Start Recorder]*

PART I (15 minutes)

To start our discussion today, our first questions will deal with what sorts of things you like, who you care about, how you spend your days and what are your goals and dreams. Let's start by talking about home.

Home (5 minutes)

1. Tell me about where you live.

- Who lives with you?
- What is your home like?
- What do you like about living there? What don't you like?
- Do you have a private place to keep things that you don't want others to see or use?

2. What neighborhood do you live in?

- What do you like about it? What don't you like about it?

- Would you feel comfortable walking alone in your neighborhood at night? Why or why not?
 - [If yes] Is there anyone in your community that looks out for everyone's safety? Who is that?
3. Tell me more about your relationship with your family.
- Who in your family are you closest with?
 - What do you wish for this person?
 - Do members of your family influence your life decisions? If yes, how so?
4. From day to day, what are your household responsibilities?
- How many hours a day do you think you spend on these responsibilities?
 - What happens if you are not able to do them?

Thanks. That concludes our questions about family. Is there anything else you would like to say about your family or the impact it has on your life?

Okay. Let's move on. Now let's talk about your goals.

Goals/Aspirations (5 minutes)

5. What is most important to you in life?
- Can you share an example of how this has been a priority for you?
 - What is important to your friends? (Similar / different?)
6. What would you like your life to look like five years from now?
- What steps do you need to take in order to achieve this?
 - What challenges do you see along the way?
 - What resources or support do you have to help you?
 - Do you know anybody who wanted to achieve this but couldn't?
 - Why couldn't they?
 - Do you know anybody that wanted to achieve this and did it?
 - How did they do it?
7. How would you define success?
- Tell me about the most successful person that you know personally.
 - How did they achieve their success?

Great, thank you. Now I'd like us to talk about some social and cultural influences on your life.

Social & Cultural (5 minutes)

8. What do you like to do with your free time?
- Tell me more about why you enjoy that?
 - How often do you get to chill?
 - Who do you most often go out with?
 - Where do you go when you go out?
 - What are the most exciting places for you and your friends in [site area]?
 - Are there places that you try not to go, or to walk near? Why is that?
9. What tv shows do you watch?
- How many hours a day do you watch them?
 - Why do you like these shows?
10. Which music artists do you like the most?
- What do you like about them?
11. How do you communicate with your friends? [text, whatsapp, facebook, phone, etc]

Now I'd like to ask you a bit more about your friends.

12. Do you have a particular person or a group you like to hang out with?
- Tell me about them.

- How did you meet?
- What are some of the good things happening in life/lives right now?
- What are some of the challenges, in their life/lives right now?

13. Are you involved in any other groups or activities?

14. Are there any places where people your age hang out that we didn't discuss? These might be places where you don't go but you've heard that other people do.

PART II

Daily Life Map (25 minutes)

[Have MAP Form available.]

We've spoken about your life and about some of the people who are important to you. Now I would like to get a sense of your daily routine. Understanding the daily tasks and travel that make up young women's lives can help us figure out how to provide health services in a way that would be easier for young women. To do this, we are going to map out a day in your daily life. We'll start by thinking about how you spent your day yesterday *[If it is a Monday, start with last Thursday]*. We will create two maps—one for a normal weekday and one for a normal weekend day.

Was yesterday *[or last Thursday]* a normal day for you? *[If it was not, then begin with the last typical day.]*

Okay, before we start, know that I am going to ask for the most accurate addresses that you can provide for each of the locations you visited yesterday. Except in one case: please do not tell me the exact address for where you live, or for where any other individuals you may visit live. This is to make sure that I respect your privacy and the privacy of the other people. For those two types of places, just a general neighborhood area will be fine.

Great, let's begin. *[Interviewer should take notes using the MAP FORM.]*

A. Let's start with waking up yesterday *[or last normal day]*. What is the neighborhood where you woke up?

- Is this where you normally wake up? *[If not, ask for normal location and use that instead.]*
- Thinking about the order of events after you woke up but before you left the house, what did you do?
- Who else was also there? *(relationship, age)*
- How many hours did you spend at home after waking up and before you left the house?

B. Where did you go next?

- What did you do there?
- Who were the people you interacted with most while you were there? *(relationship, age)*
- How many hours did you spend at this location after arriving and before you went to your next destination?

- How did you travel from point [A] to point [B]?

- How much time did that take, from door to door?

- If public transport, how much did that cost?

C. Where did you go next?

- What did you do there?
- Who were the people you interacted with most while you were there? *(relationship, age)*
- How many hours did you spend at this location and before you went to your next destination?
- How did you travel from point [B] to point [C]?

- How much time did that take, from door to door?
- If public transport, how much did that cost?

Continue like this—D, E, F, G, etc.—until two maps (weekday and weekend day) have been completed.

PART III (20 minutes)

Romantic Relationships & Sex

Ok, great. In this section, we are interested in your thoughts and experiences surrounding romantic relationships and sex. Again, please keep in mind there are no right or wrong answers; your honest answers can help us better serve other young South African women.

15. To begin, what qualities do you look for in someone you would date?

16. I'm interested in how romantic relationships work for you and your friends.

- How do you and your friends meet the people you date?
- How do you know when someone likes you? ...And then what happens?
- How do you know when the relationship is over?

17. Are you in a relationship with anyone right now?

[If no]

- How do you feel about that? *(Probe about whether they would like to be or not, if they see a reason for their not being in a relationship)*

Tell me a little about your last relationship.

- How did you meet that partner?
- How long were you been together?
- What did you like about them?
- What about them bothered you? How often did you see each other?
- Did you spend time alone together?
- Were you having sex with them?

○ *[If yes]*

§ When did you start having sex with them? *[how long after starting to date]*

§ How did you decide to start having sex with them?

§ Where were you able to have sex together?

§ When you did have sex together, how often did you use a condom?

- Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
- Why did you use a condom *[repeat whatever answer P chose]*?

○ *[If no]*

§ Was there a particular reason why not? *(Probe about whether they would like to in the future, what would need to happen for them to want to, etc)*

- Did you see this partner in your long-term future?
- Did you have any reason to believe that your partner had side partners?

○ *[If yes]*

§ How did you feel about that?

§ Did this influence how you acted in the relationship? Had you thought about quitting the relationship because of it?

§ If your friends found themselves in that position, what would they have done?

○ *[If no]*

§ How would you have felt if he had side partners?

§ Would it have influenced how you acted in the relationship? Would you have thought about ending the relationship because of it?

§ If your friends found themselves in this position, what would they do?

· Did you have any side partners in that relationship?

○ *If 1 or more, ask these questions for each:*

§ Tell me a little about your relationship with them...

§ When you had sex together with the side partners, how often did you use a condom?

· Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?

· Why did you use a condom [*repeat whatever answer P chose*] with your side partner?

· [*If answer differed for main and side*] Why did you use a condom [more/less] with your main versus your side?

[*If yes*]

· Tell me about them.

· How did you meet?

· How long have you been together?

· What do you like about them?

· What about them bothers you? How often do you see each other?

· Do you spend time alone together?

· Are you having sex with them?

○ [*If yes*]

§ When did you start having sex with them? [*how long after starting to date*]

§ How did you decide to start having sex with them?

§ Where are you able to have sex together?

§ When you do have sex together, how often do you use a condom?

· Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?

· Why do you use a condom [*repeat whatever answer P chose*]?

○ [*If no*]

§ Is there a particular reason why not? (*Probe about whether they would like to in the future, what would need to happen for them to want to, etc*)

· Do you see this partner in your long-term future?

· Do you have any reason to believe that your partner has side partners?

○ [*If yes*]

§ How do you feel about that?

§ Does this influence how you act in the relationship? Have you thought about quitting the relationship because of it?

§ If your friends found themselves in this position, what would they do?

○ [*If no*]

§ How would you feel if he had side partners?

§ Would it influence how you acted in the relationship? Would you think about ending the relationship because of it?

§ If your friends found themselves in this position, what would they do?

· Do you have any side partners?

○ *If 1 or more, ask these questions for each:*

§ Tell me a little about your relationship with them...

§ When you have sex together, how often do you use a condom?

- Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you use a condom [*repeat whatever answer P chose*] with your side partner?
 - [*If answer differed for main and side*] Why do you use a condom [more/less] with your main versus your side.
18. What different kinds of sexual partners are there?
- What types of partners have you had?
 - How many partners have you had at one time? [*make sure you get a number*]
 - [*If more than 1*]
 - Did your different partners know about each other?
 - What were the benefits for you in this/these situation/s?
 - How is or was it difficult?
 - Have any of your friends ever had side partners?
 - [*If yes*]
 - § Did their different partners know about each other?
 - § What were the benefits for them in this/these situation/s?
 - § How is or was it difficult?
19. How many sexual partners do most young women have at one time?
- [*If more than 1*] What are the benefits in that?
 - What are the difficulties with that, if any?
20. How many sexual partners do young men usually have at one time? [*make to get a number*]
- [*if more than 1*] What are the benefits for them?
 - Are there disadvantages for them?
 - What if the guy is older than 25 [*or 30, if P > 20*]?—how many partners do you think he is likely to have then? [*make sure you get a number*]
 - Why do you say that?
21. Can main relationships succeed when one or both partners have side relationships?
- Do you believe that men can have just one partner? Why or why not?
 - Do you believe that women can have just one partner? Why or why not?
 - Imagine that 10 average couples from [*name participant's township*] were standing before us. Out of these 10 couples, in how many would neither person have a side partner?
22. Now I have a few questions about sex.
- How old were you when you first had sex?
 - Tell me about that situation.
 - What do you like about having sex? Dislike?
 - Once you've had sex with someone, how do you decide whether to have sex again?
 - Are some kinds of sexual partners more special than others?
 - Are [LM1] there some sexual experiences that you'd be more likely to do in some situations, or with some partners?
 - Are there certain sexual practices that you wouldn't do the first time you have sex with someone?
 - Are there things you won't do with a side partner that you might with a main partners?
23. Now let's talk about trust.
- What does trust mean to you?
 - Do you trust the main partner you're having sex with?
 - Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - How do you know if you can trust him?

- What role does trust have when deciding whether to use a condom with someone?
24. Now I want to know how often you think other people use condoms.
- When a woman like you has sex with a trusted main partner, how often does she use a condom?
 - Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you say that?
 - What if her partner is older, say older than 25 [*If P > 20, then say 30*]?
 - Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you say that?
 - Now imagine that this woman like you is the side partner of a man that also has a main. How often do you think he would use a condom with her?
 - Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you say that?
 - Would this be different if the man is 25 or younger [*or if P is > 20, '30 or younger'*]?
 - [*If yes*] Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you say that?
 - Would this be different if the man is older than 25? [*If P is > 20, 'older than 30'*]?
 - [*If yes*] Would you say: never (1), not very often (2), sometimes (3), usually (4), or always (5)?
 - Why do you say that?

Okay, we just have a few more questions for you before we end.

Education, Jobs & Technology

25. Do you currently go to school?

- Do you think school can help people in life? Tell me more.

26. You mentioned earlier that you [do / do not] currently have a job.

[If yes]

- How many hours a week do you work?
- Does it provide you with enough money to pay for what you need?
 - How do you get the things you want that it doesn't pay for?

[If no]

- How do you get money to pay for things you need?
- [*if they say from parents or other caregiver or boyfriend*] What about things that [caregivers/boyfriends etc] won't pay for?

27. What about your friends:

- How do your friends get the money they need to pay for things?
- [*if they say from parents or other caregiver or boyfriend*] What about things that [caregivers/boyfriends etc] won't pay for?

28. Do you have a cell phone?

[if yes]

- Can your phone connect to the internet?
- How much time each day do you spend on your phone?
- What do you mostly use your phone for?
- What social media do you use?

Thank you. We are reaching the end.

29. How has it been to participate in this interview?

- Are there any issues we discussed that you would like to talk more about?
- [*If < 18*] Would you have agreed to participate if we had required parental consent?

POWER Formative Report

10 August 2017

[Turn off recorder]

Demographic Form

Lastly, I'd like to get a little basic information about you, to make sure we speak to a range of young women of different ages and backgrounds.

Go through demographic form.

· Do you know of anyone else who might be interested in participating in this research?

[If yes, give your phone number or the number of a recruiter from their area] Please ask them to get in touch with us if they are interested.

OR

○ Would you like us to contact them? If yes, you can give me their number and I will contact them to discuss the study.

Those were all the questions that I had today. Thank you so much for reflecting on your life with me.

Payment

Provide participant with R70 for participation and ask for signature.

Confirm Interview #2

I'm looking forward to seeing you again at _____ *[insert date/time of interview within one week]*.

Thank you again!

INTERVIEW II (Female) Mental Models Interview Guide

PURPOSE

One aim of this second in-depth interview guide is to understand those factors that affect sexual and reproductive health decisions that young South African women make, specifically:

- 1) the decision to become pregnant (or avoid becoming pregnant)
- 2) the decision to seek out reproductive health services, including HIV prevention

Another aim is to better understand how young South African women will respond to oral PrEP when it becomes available to them through various sources. This includes understanding:

- 1) the way they perceive the risks and the benefits associated with taking a medication like PrEP; and,
- 2) their attitudes towards PrEP after learning more about it.

INSTRUCTIONS

There are 2 levels of questions:

- Initial topic questions: these questions will be numbered. They address the topics that you as the interviewer must ask and discuss with participants. The questions are suggestions for getting the discussion going. You are not required to read them exactly as they are written, but they are written to ensure some consistency across IDIs. You may adapt the questions and/or ask them in a different order, depending on how the interview develops. However you will have to ensure that by the end of the interview, all the topics and key themes have been covered. A local-language translation of these questions should be provided on this document in the space provided.
- Probes: they are indicated with a bullet. The interviewer should ensure that key topics listed in the guide have been addressed/discussed during the interview; however the probes are meant to serve as suggestions for the interviewer to draw from rather than a strict list of questions that must be asked.

So, depending on what has already been discussed, and the IDI context, you may ask these probes or not or may phrase probes differently to try and better understand what the participant is trying to communicate.

- o Instructions/suggestions to interviewer are in *italics*.

Beginning of the Interview

[*Warmly.*] Good morning/afternoon. It is good to see you again! As a reminder, my name is

. Thank you so much for returning to complete the second interview.

I'm going to repeat a few things from last time, to remind you about why we are meeting. First, you are one of a small group of women that we have invited to work with us to explore which ways would be best to provide young women with the information they need to make informed decisions about their sexual and reproductive health. Please think of yourself as our team member. By helping us to understand you and your world, you can help us think about how to provide better services for HIV prevention that can help all the young women in [*P's township*].

Today is our last interview. Last time, we talked about values and relationships in your life, we drew a map of your daily schedule, and we discussed your views on romantic relationships and sex. Today, I am interested in hearing about your experiences with health clinics, and your thoughts around pregnancy, HIV and HIV prevention. Like last time, as you read in the consent, everything you say in this interview is confidential and anonymous. Your name will not be linked to you responses.

Lastly, like last time, know that all of your thoughts are important to us. There are no right or wrong answers – we just want to hear your perspective. However, if you feel uncomfortable answering a question, just let me know and we'll move on to the next question.

Do you have any questions before we begin?

Great. Before we begin, can you turn off your phone once again? This will ensure we are not interrupted.

Like last time, to help me remember what you've said, I'd like to record our conversation. Is it OK if I start recording our conversation now? [*Start Recorder*]

Great. Let's begin.

PART I: Clinics (15 minutes)

I'd first like to talk to you about your experiences with health and health clinics.

1. What do you usually do if you get sick?

- At what point do you decide to go to a clinic?

2. How many times have you visited a clinic—any clinic—in the past 12 months? [*request a number*]

- What medical reason/s brought you to the clinic [each time]?
- How did you originally learn about this clinic or clinics?
- Did you bring anyone with you for help or company?

o [*If yes*], Who? Was it helpful to you to bring them?

- Which clinic do you usually go to if you get sick? [*request clinic name and neighborhood*]
- How do you feel about this clinic?

Now I'm going to ask you to rate this clinic [*if they listed more than 1 clinic, ask for ratings for each*].

3. How *friendly* would you say the staff at [*name clinic*] is? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)

- Why do you say that?

4. How *knowledgeable* would you say that the staff at *[name clinic]* is about medicine and health? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- Why do you say that?
- 5.. How much do you *trust* the staff at *[name clinic]* to act in your personal best interest? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- Why do you say that?
- 6.. How do you get to *[name clinic]*?
- How long does it take you to travel there? (*in minutes*)
 - How long is the wait? (*in hours*)
 - What are the challenges in getting there, if any?
 - How does visiting the clinic affect your routine that day?
6. Is *[name clinic]* the place you would go to ask about contraception or sexual health matters (for example, if you were worried you might have an STI or wanted to find out if you were pregnant)?
- Why is that?
 - What other places, or what other people might you see to ask about contraception or sexual health matters? *[request clinic/person name and neighborhood]*
 - Have you ever gone to any of these places for sexual health matters? Can you tell me about what happened?
- [If a clinic or individual was mentioned for sexual health]*
8. How *friendly* would you say that the staff and healthcare professionals are at *[name of new clinic/person mentioned for sexual health]* is? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- Why do you say that?
9. How *knowledgeable* would you say that the person/staff at *[name of clinic/person mentioned for sexual health]* is about sexual health issues? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- What makes you say that?
10. How much do you *trust* the person/staff at *[name of person/clinic mentioned for sexual health]* to act in your personal best interest? Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- Why do you say that?
11. How do you get to *[name of person/ clinic mentioned for sexual health]*?
- How long does it [or would it] take you to travel there and back? (minutes)
 - How long is the wait? (in hours)
 - How does visiting there affect your routine that day?
12. How do you think other young women your age generally feel about going to clinics when it comes to sexual health issues?
- Are there other people they prefer to ask first if they have questions about sexual health?
 - What about if they have questions about reproductive health?
13. Are there any other people or places that you would go to for health information, places that we haven't spoken about? [If they are unsure, prompt with suggestions, e.g. mobile clinics, traditional healers, religious leaders, friends, etc.]
- [For each person or place, prompt for why they list them, and use the same rating scale as above - i.e. friendly, knowledgeable, trust]

· [For each person or place, prompt for how easy it is to go there, i.e., How long does it [or would it] take you to travel there and back? How do you [or would you] travel there? How long is the wait? How does it affect your daily routine that day?

Great, thanks. Now I'd like to talk to you about your thoughts surrounding risks of pregnancy.

PART II: Pregnancy (15 minutes)

In our last interview, we talked about your romantic relationships and now we are interested in your feelings about pregnancy.

14.

[If no children mentioned in previous interview]

Have you ever been pregnant?

· [If yes]

○ Tell me about the pregnancy.

○ How did you find out?

§ Where did you get a test done?

○ How did the pregnancy turn out?

○ Do you ever think about getting pregnant again?

○ How would you feel if you thought you might be pregnant now?

○ If you thought you might be pregnant, who would you tell first? Why?

○ Who would you not want to tell? Why?

[If children mentioned in previous interview]

You mentioned when we last met that you have a child/children.

○ How did you find out you were pregnant at the time?

§ Where did you get a test done?

○ Do you ever think about getting pregnant again?

○ How would you feel if you thought you might be pregnant now?

○ If you thought you might be pregnant, who would you tell first? Why?

○ Who would you not want to tell? Why?

[If currently pregnant]

Tell me about this pregnancy

· How did you find out you were pregnant? Where did you get the test done? Why there?

· How are you feeling about it?

· Who did you tell first? Why?

· Was there anyone you did not want to tell? Why?

· Was this pregnancy planned?

15. If you did not want to get pregnant, what things do you think you can do to avoid getting pregnant?

· Do you do any of these things?

· *[If yes – for each contraceptive method]*

○ Why did you choose that method?

○ What do you like about it? Dislike?

○ Where do you get your [contraceptive product] from?

○ Do you have any difficulties getting the [contraceptive] you need? If so, what would make it easier to get it?

16. Think of a young woman like you. How likely do you think she would be to get pregnant if she had sex ONE time without using any kind of birth control?

[Point to the line on the Quantitative Form] I'd like you to answer by marking on this line.

Let me explain the line. If you marked the very left side *[point to the left side of the line]* you would be saying it is "IMPOSSIBLE" that a young woman like you would become pregnant. If you marked the very right side of the line *[point to the right side of the line]* you would be saying that it is "CERTAIN" that a young woman like you would become pregnant. You can mark anywhere on this line. As you move from the left side of the line to the right side, you are saying that the chance someone like you will become pregnant is becoming larger.

To summarize: At the left it is IMPOSSIBLE to become pregnant, then it is UNLIKELY. In the middle there is an EQUAL CHANCE—they might become pregnant but they might not. Moving more to the right, it is LIKELY but not yet CERTAIN. And at the very right, it is CERTAIN. Do you have any questions?

Here is a pen. *[Make a pen available to the participant.]* Again, the question is: If a young woman like you had sex ONE TIME without using any birth control, how likely do you think she would be to become pregnant? Please mark what you think on the line.

- Tell me more about why you chose to mark the line there.
- Where would your mark be if it was *you* that had sex ONE TIME without using any birth control?
 - *[If different, prompt for why it would be different for them, personally?]*
- 17. What do you think would be worse: getting pregnant when you do not want to, or getting HIV?
 - Tell me more about why you say that.

Thank you for sharing these thoughts with me. Now let's turn to HIV and HIV testing.

PART III: HIV (15 minutes)

18. First, can you tell me what you know about HIV?

- How can people contract it?
- Who is most likely to get it?
 - Can you describe someone who is very likely to get it?
 - Can you think of any other things that make people more or less likely to get HIV?
- When someone is infected with HIV, how does it affect them or their body?
 - What is the disease doing that makes them sick?
 - What are some ways you know of to treat HIV?
 - *[If not mentioned]*, prompt here for ARVs, herbal remedies, others
 - *[For each method mentioned]*
 - § What do you take that for?
 - § How do you think *[method mentioned by P]* works in the body to treat HIV?
 - § How do you think *[method mentioned by P]* works in the body to treat symptoms of HIV?

19. Do you know anyone who has HIV?

[If yes, read below; If no, ask in general.]

- How do you think that person got it?
- How has his/her life changed?
- How do his/her friends feel about them now?
- What were the impacts on their family?

20. How likely do you think a young woman like you would be to become HIV positive if she had unprotected sex with an HIV positive partner, one time?

[Point to line on Quantitative Form] I'd like you to answer by marking on this line.

Let me explain the line. If you marked the very left side *[point to the left side of the line]* you would be saying it is "IMPOSSIBLE" that a young woman like you would become HIV positive if she had unprotected sex ONE time. If you marked the very right side of the line *[point to the right side of the line]* you would be saying that it is "CERTAIN" that a young woman like you will become HIV positive if she had unprotected sex ONE time. You can mark anywhere on this line. As you move from the left side of the line to the right side, you are saying that the chance is becoming larger.

In summary, at the left it is IMPOSSIBLE to become HIV positive, then it is UNLIKELY. In the middle there is an EQUAL CHANCE—they might become HIV positive but they might not. Moving more to the right, it is LIKELY but not yet CERTAIN. And at the very right, it is CERTAIN.

Here is a pen. *[Make a pen available to the participant.]* Again, the question is: If a young woman like you had unprotected sex with an HIV positive person ONE TIME, how likely would she be to become HIV positive? Please mark what you think on the line.

- Ok, great. Tell me more about why you chose to mark the line there.
- Where would you put the mark if it was you that had sex ONE TIME with an HIV positive partner?
- *[If different, prompt for why it would be different for them, personally.]*

21. Now think about if a young woman like you had unprotected sex with an HIV positive partner TEN times. How likely do you think she would be to become HIV positive?

[Point to the line on the Quantitative Form, and make the pen available.] Again, I'd like you to answer by marking on the line.

- Tell me more about why you chose to mark the line there.
- Where would you mark the line if it was *you* that had unprotected sex TEN times with an HIV positive partner?

○ *[If different, prompt for why it would be different for them, personally.]*

22. Now, imagine that a young woman like you had unprotected sex with an HIV positive person 100 times over the course of a year. How likely do you think she would be to become HIV positive?

[Point to the line on the Quantitative Form, and make the pen available.]

- Tell me more about why you chose to mark the line there.
- Where would you mark the line if it was *you* that had sex 100 times with an HIV positive partner?
- *[If different, prompt for why it would be different for them, personally.]*

23. Now, imagine that you have a partner who is HIV negative, but your partner has unprotected sex with another woman who is HIV positive ONE time and *then* has unprotected sex with you. What is the likelihood that you will become HIV positive?

[Point to the line on the Quantitative Form, and make the pen available.]

- Tell me more about why you chose to mark the line there.
24. Do you think any of your friends are at risk of getting HIV? Why or why not?
25. How much control do you feel you have over whether you will become HIV positive? Would you say: none (1), a little (2), somewhat (3), quite a bit (4), total control (5)
- Tell me more about why you say that.

26. What are some things that you think you can do to lower your chances of getting HIV? Anything else?

- *[Follow up on what they answered, item by item]*
- How or why does this decrease your chance of getting HIV?
- Are you doing this?
- Why or why not?

27. If someone is already HIV positive, is there any action they can take that will make their HIV worse?

28. Have any of your friends ever had an HIV test done?

- *[If no],* why not?
- *[If yes]* What made them decide to do it?
- Where did they get tested?
- What do you think their thoughts and feelings were when they got tested?
- What were their results?

- What were their feelings when they received the results?
- Do you think getting a negative result leads to more careful behavior or less careful behavior?
Please explain.

29. Have you ever had an HIV test done?

- [If no], why not?
- [If yes] What triggered you to do it?
- Where did you get tested?
- What were your thoughts and feelings when you got tested?
- What were your feelings when you received the results?
- How many times have you been tested?

30. If you wanted to have a test done today, where could you go?

31. If you were getting a prescription for birth control pills and someone at the clinic suggested an HIV test while you were there, how would you feel?

32. When do you think young women *should* get an HIV test done? Why do you say that?

33. Who do you think she should she tell about the result if it's positive?

- If it's negative?

34. In the relationship you're in, have you ever talked about HIV with your partner?

- Have you talked about testing for HIV?
- Who brings the conversation up?
- What kinds of things do you say?
- How does it make you feel to talk about it?

PART IV (15 minutes)

PrEP

35. Have you heard of PrEP?

IF YES:

What have you heard? [*You might need to distinguish PrEP from PEP*]

- How do you think PrEP works?
- Do you think it is safe?
- What do you think happens if you miss a pill, or forget to take one?
- What are some reasons someone might miss taking a pill?
- Do you think there are any side effects to PrEP?
- Who do you think this pill helps?
- Do you know anyone who has taken PrEP?
- If a friend wanted to take PrEP, what is some advice you might give her?
- If she decided to take it, how do you think her (husband/boyfriend) would feel?
- What about her family?

IF NO: [insert standardized explanation and show picture of the size of the pill]

- How do you think PrEP works?
- Do you think it is safe?
- What do you think happens if you miss a pill, or forget to take one?
- What are some reasons someone might miss taking a pill?
- Do you think there are any side effects to PrEP?

- Who do you think this pill helps?
 - Do you know anyone who has taken PrEP?
 - If a friend wanted to take PrEP, what is some advice you might give her?
 - If she decided to take it, how do you think her (husband/boyfriend) would feel?
 - What about her family?
36. If you were offered the chance to use PrEP, how interested would you be in trying it? Specifically, would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)
- Why did you say that?
37. What would make it difficult for you to take PrEP? Tell me more.
- Can you think of other challenges that you might face if you took PrEP?
38. Imagine that you did take PrEP. Can you imagine some good ways that it would affect your life?
- How might it affect your romantic relationships?
39. Now I'm going to list some things that might influence you to take PrEP.
- If you had to pay for PrEP?
- Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - If you had to travel far to pick up PrEP
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - If your partner would not be supportive of you taking PrEP?
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - If you did not have a suitable place to keep your PrEP?
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - The fact that you have to take it every single day?
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - If PrEP gave you side effects like nausea, diarrhea, or headaches?
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
 - If one or more of your friends also took PrEP?
 - Would you say: not at all (1), a little (2), somewhat (3), quite a bit (4), extremely (5)?
 - § Why did you say that?
40. Are there some other things that we didn't talk about that might affect your decision to take PrEP?
41. Earlier we talked about how much control you feel you have over whether or not you will become HIV positive. Now, imagine that you are taking PrEP. How much control do you feel you have over becoming HIV positive? Would you say: No control at all (1), A little (2), Some (3), A lot (4), or Total control (5)?
- Tell me more about why you chose to mark the line there.

Open Label Demonstration Participation

42. Soon PrEP will be made available at various places, like clinics and maybe hospitals or pharmacies. However, to be able to take PrEP, you will have to do a couple of things. The first would be to take an HIV test to make sure that you don't already have HIV. Then, you will have to take it every day, at approximately the same time every day, in order for it to work.

- How does that sound to you?
 - Do you think you would be able to take it every day around the same time? Why or why not?
 - What are some things that would make it easier for you to take it consistently?
 - Are there places you'd rather get PrEP than a clinic?
- 43.If you decided to try out PrEP, how do you think your [main] sexual partner would feel?
- Would you tell him? If yes, what would you say?
 - Would you tell your family? If yes, what would you say?
 - Your friends? What would you say?
- 44.If you found out your main partner was taking PrEP, how would you feel?
- Would you want him to tell you?
 - Would you trust him more or less?
 - Would his taking PrEP make you want to take PrEP, too?
45. Think about the most popular person you know...someone that everyone knows and likes. Do you have someone in mind?
- If you found out that they were taking PrEP, what would you think about them? Would it make you think differently about PrEP?
46. How would your feelings about PrEP change if most of the people you knew were taking it? Please explain.
47. How would your feelings about PrEP change if most of the people at risk for HIV in the United States were taking it? Please explain.
48. How would your feelings about PrEP change if the South African government said that people in this country should take it? Please explain.
49. *[If there is time to ask]* Science studies conducted here in South Africa have shown that if people take PrEP the number of cases of HIV will go down. If you were in charge of figuring out a way to encourage people from your community to take PrEP, what would be your strategy?
- CLOSING**
50. Before we finish, are there any thoughts or questions that you would like to share with us?
Thank you. *[Turn off recorder]*: Do you have any further thoughts that you think may be helpful to the project?
Do you know anyone else who might be interested in participating in this research?
There will be a study that makes PrEP available to young women like yourself. Would you be interested? If you wish, we can contact you when that study is getting ready to begin.

APPENDIX F: Mental Models Demographic Tables

Demographics Tables

Demographics for Coded Mental Models Sample

Participant Attributes	DTHF (f=10) (m=10)	WRHI (f=9) (m=9)	KEMRI (f=8) (m=9)	All Sites (f=27) (m=28)

Age (median)	20 (17-23)	23.5 (20-46)	20 (18-24)	23 (19-34)	20.5 (18-23)	28 (23-31)	20 (17-24)	24.5 (19-46)
Highest level of education:								
Primary school			1			1	1	1
High School	9	10	7	8	6	4	22	22
University	1		1	1	2	2	4	3
Graduate						2		2
Marital Status:								
Single	9	8	9	9	6	4	24	21
Single but living together	1	1					1	1
Married		1				4		5
Children:								
0	7	7	7	6	7	4	21	17
1	3	2	2	2	1	5	6	9
2		1		1				2

Demographics Table for ALL Participants

Participant Attributes	DTHF (f=15) (m=15)		WRHI (f=15) (m=15)		KEMRI (f=15) (m=12)		All Sites (f=45) (m=42)	
Age (median)	19 (16-23)	26 (20-51)	20 (18-25)	23 (19-34)	20.5 (16-25)	27.5 (19-41)	20 (16-25)	25 (19-51)
Highest level of education:								

Primary school	1	2	1		1	2	3	4
High School	13	13	13	13	10	5	36	31
University	1		1	1	3	3	5	4
Graduate				1	1	2	1	3
Marital Status:								
Single	14	12	15	15	14	6	43	33
Single but living together	1	1				1	1	2
Married		2			1	4	1	6
Children:								
0	9	7	10	10	12	6	31	23
1	6	4	5	4	3	6	14	14
2		3		1				4
6		1						1

APPENDIX G: Respondent Responses (Additional)

Women's and men's responses to questions about relationships and sex (averages)

Variable	Cape Town		Johannesburg		Kisumu		Total	
	F	M	F	M	F	M	F	M
<i>First sex (age)</i>	15.8	15.1	17.9	16.3	17.4	18.3	17	16.5
<i>Main partner: Length of relationship (yrs)</i>	2.1	8	2.0	2.2	2.6	2.2	2.2	4.13
<i>Main partner: Frequency of condom use? (1-5, 5=always)</i>	3.6	2.4	4	3.6	2.8	3	3.5	3
<i>Main partner: How much do you trust them? (1-5, 5=totally)</i>	4.4	3.5	3.9	3.3	3.8	4.5	4	3.8
<i>How many partners have you seen at one time?</i>	1.4	4.6	1.3	2.9	2.5	2.6	1.7	3.4
<i>Do you have a side partner now? (0=no /1= yes)</i>	0	.93	.33	.67	.4	.5	.24	.7

<i>Side partner: Frequency of condom use? (1-5, 5=always)</i>	.	4.1	3	3.7	3.57	4.7	3.3	4.2
<i>Most women: How many partners?</i>	2.9	4.2	3.1	3.9	3.2	4	3.1	4
<i>Most men: How many partners?</i>	4.7	5.4	4.8	4.6	4.9	4.3	4.8	4.8
<i>Of 10 regular couples, how many do you think are monogamous?</i>	2.9	2.9	4.4	5.9	4.8	2.8	4	3.9

APPENDIX H: Survey Data Tables

Demographics

Participant Attributes	Cape Town (f=87 m=52)		Kisumu (f=82 m=72)		Johannesburg (f=75 m=76)		All Sites (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
Children:								
0	58	33	54	36	55	59	167	128
1	19	16	18	10	16	13	53	39
2	5	2	9	12	4	3	18	17
3+	0	0	1	13	0	1	1	1
Religiosity (average):	3.56 (1.24)	3.25 (1.31)	3.54 (0.96)	3.51 (1.17)	3.52 (1.36)	3.12 (1.41)	3.54 (1.17)	3.29 (1.29)
Know anyone using/has used PrEP:								
No	81	47	75	70	72	74	228	191
Yes	5	3	6	2	3	2	14	7

Sex and Relationships

Variable	Capetown		Kenya		Johannesburg		All Sites	
	F	M	F	M	F	M	F	M
Sex frequency 1 (1-8) <i>Thinking back on your sex life the past 3-6 months, how frequently have you had sex?</i>	-	-	-	-	3.39 (1.51)	3.17 (1.22)	3.39 (1.51)	3.17 (1.22)
Sex frequency 2 (1-8) <i>How frequently do you have sex?</i>	3.05 (1.45)	2.63 (0.97)	3.96 (1.51)	3.17 (1.07)	3.53 (1.61)	3.16 (1.25)	3.51 (1.56)	3.03 (1.14)
Age sexually active (median) (yrs) <i>At what age did you first become sexually active?</i>	16 (12-20)	16 (11-21)	16 (12-24)	17 (8-30)	17 (13-22)	16 (9-22)	16 (12-24)	16 (8-30)
How often condom used with main partner? (1-5) <i>Think about your main sexual partner (or, if you do not currently have a partner, think about your most recent partner). When you have sex with them, how often do you use a condom?</i>	3.16 (1.16)	3.19 (1.24)	3.10 (1.56)	2.68 (1.65)	3.79 (1.20)	3.88 (1.23)	3.33 (1.35)	3.27 (1.49)
Does main partner have sides? (1-6) <i>Do you think your main partner (or last main partner) has side partners?</i>	3.70 (1.54)	3.31 (1.58)	4.07 (1.30)	3.25 (1.56)	3.64 (1.70)	3.30 (1.64)	3.81 (1.52)	3.29 (1.59)
Have a side now? (0/1) <i>Do you currently have more than one sexual partner?</i>	0.22 (0.42)	0.69 (0.47)	0.34 (0.48)	0.57 (0.50)	0.15 (0.36)	0.54 (0.50)	0.24 (0.43)	0.59 (0.49)
How often condom used with side partner? (1-5) <i>When you have sex with your side partner(s), how often do you use a condom?</i>	4.15 (0.93)	3.69 (1.11)	3.54 (1.35)	4.02 (1.13)	4.27 (1.10)	4.38 (1.03)	3.88 (1.20)	4.04 (1.11)
How many partners most women have? (1-5) <i>How many sexual partners do you think most women your age have at one time?</i>	2.76 (1.17)	2.84 (1.12)	2.29 (1.09)	2.39 (1.19)	2.55 (1.03)	2.66 (1.11)	2.54 (1.12)	2.61 (1.15)
How many partners most men have? (1-5) <i>How many sexual partners do you think most men have at one time?</i>	3.65 (1.21)	3.41 (1.37)	3.61 (1.15)	3.10 (1.15)	3.79 (1.13)	3.17 (1.18)	3.68 (1.16)	3.20 (1.22)
Out of 10 couples in neighborhood, how many have sex with sides? (1-10) <i>Imagine that 10 couples from your neighborhood were standing before us. In how many of these 10 couples would at least one partner be having sex with someone else?</i>	4.25 (2.49)	4.78 (2.16)	6.37 (2.59)	5.56 (2.76)	4.43 (2.09)	4.63 (2.38)	5.02 (2.59)	5.01 (2.50)

HIV Risk

Variable	Capetown		Kenya		Johannesburg		All Sites	
	F	M	F	M	F	M	F	M
1x (1-100)								
Self <i>Imagine that you, who are HIV negative, had condomless sex with someone who has HIV, one time. How likely is it that you would get HIV?</i>	62.18 (31.65)	67.84 (20.46)	70.74 (19.58)	71.04 (18.05)	56.92 (39.94)	57.38 (33.86)	63.43 (31.39)	65.01 (26.07)
Other <i>Imagine that another wo/man, HIV negative like you, had condomless sex with someone who has HIV, one time. How likely is it that s/he would get HIV?</i>	73.62 (26.44)	52.64 (39.37)	67.60 (21.86)	61.38 (28.88)	59.58 (28.10)	56.62 (29.53)	67.37 (25.93)	58.08 (31.20)
Narrative <i>Imagine a young woman/man named [Mary/John]. [Mary/John] is 20 years old. One night, [Mary/John] meets a [woman/man] called [Mary/John] and they got along [Mary/John] is HIV positive. If Mary and John have sex without a condom one time, how likely is it that [Mary/John] will get HIV?</i>	65.23 (29.38)	71.11 (32.32)	72.64 (25.00)	65.38 (25.95)	60.60 (28.73)	69.92 (27.04)	66.41 (27.85)	68.82 (27.81)
10x (1-100)								
Self <i>Now, imagine that you had sex without a condom with someone who has HIV ten times. How likely is it that you would get HIV?</i>	79.86 (28.58)	88.91 (11.35)	84.07 (15.18)	81.92 (16.50)	79.00 (28.15)	81.62 (21.23)	81.01 (24.51)	83.94 (17.21)
Other <i>Now, imagine that same wo/man had condomless sex with someone who has HIV ten times. How likely is it that s/he would get HIV?</i>	82.03 (28.04)	85.00 (22.41)	81.88 (17.14)	76.29 (21.22)	88.08 (20.26)	91.85 (19.13)	83.82 (22.48)	82.50 (21.59)
Narrative <i>Now, think that Mary and John have sex without a condom ten times. How likely is it that [Mary/John] will get HIV?</i>	84.37 (23.76)	86.00 (24.57)	82.38 (22.49)	81.04 (21.09)	90.44 (15.03)	90.42 (18.08)	85.49 (21.08)	86.52 (20.71)
100x (1-100)								
Self <i>Lastly, imagine that you had sex without a condom with someone who has HIV one hundred times. How likely is it that you would get HIV?</i>	88.54 (20.37)	90.50 (18.37)	92.26 (5.77)	84.29 (18.18)	90.63 (22.50)	89.92 (22.07)	90.44 (17.51)	88.22 (19.65)
Other <i>Lastly, imagine that same wo/man had condomless sex with someone who has HIV one hundred times. How likely is it that s/he would get HIV?</i>	90.55 (21.27)	88.45 (14.81)	90.27 (10.10)	89.04 (13.21)	94.88 (10.31)	87.69 (30.51)	91.77 (15.19)	88.54 (19.23)
Narrative <i>Lastly, think that Mary and John have sex without a condom 100 times within a year. How likely is it that [Mary/John] would get HIV?</i>	85.00 (26.50)	82.39 (25.92)	87.29 (20.83)	87.42 (15.28)	97.24 (10.19)	93.81 (16.07)	89.43 (21.18)	89.21 (18.90)

HIV Risk: 1 Year Self and Karma

Variable	Capetown		Kenya		Johannesburg		All Sites	
	F	M	F	M	F	M	F	M
1 Year HIV risk perception (0-100) <i>Think for a moment about your current situation and sexual behaviors. How likely is it that you will get HIV in the next year?</i>	34.17 (31.24)	36.02 (29.15)	24.64 (28.47)	19.57 (24.75)	22.11 (23.75)	26.61 (20.87)	27.24 (28.53)	26.52 (25.33)
Female Good Karma (0-100) <i>Akinyi is 20 years old. She is a good person, and always helps at home. Akinyi tries hard to think about how her actions affect those around her. People say Akinyi is a good person. One night, Akinyi meets a man called Odhiambo and they get along. Odhiambo is HIV positive. If Akinyi and Odhiambo have unprotected sex one time, how likely is it that Akinyi will get HIV?</i>	79.20 (24.71)	53.86 (37.93)	67.71 (19.12)	61.53 (18.14)	62.85 (27.25)	57.33 (29.66)	69.89 (24.44)	57.86 (28.50)
Female Bad Karma (0-100) <i>Akinyi is 20 years old. She can be bad to others, and doesn't help out at home. Akinyi doesn't think about how her actions affect those around her. People say that Akinyi is not a good person. One night, Akinyi meets a man called Odhiambo and they get along. Odhiambo is HIV positive. If Akinyi and Odhiambo have unprotected sex one time, how likely is it that Akinyi will get HIV?</i>	81.57 (23.40)	61.58 (36.90)	72.17 (24.05)	72.67 (17.99)	55.95 (35.11)	64.72 (28.54)	67.00 (29.96)	66.16 (27.84)
Male Good Karma (0-100) <i>Odhiambo is 20 years old. He is a good person, and always helpful at home. Odhiambo tries hard to think about how his actions affect those around him. People say Odhiambo is a good person. One night, Odhiambo meets a woman called Akinyi and they get along. Akinyi is HIV positive. If Odhiambo and Akinyi have unprotected sex one time, how likely is it that Odhiambo will get HIV?</i>	58.18 (32.70)	61.82 (33.03)	68.56 (29.06)	73.74 (25.96)	66.68 (26.19)	58.31 (28.92)	62.70 (30.38)	66.02 (28.94)
Male Bad Karma (0-100) <i>Odhiambo is 20 years old. He can be bad to others, and is not helpful at home. Odhiambo does not think about how his actions affect those around him. People say Odhiambo is not a good person. One night, Odhiambo meets a woman called Akinyi and they get along. Akinyi is HIV positive. If Odhiambo and Akinyi have unprotected sex one time, how likely is it that Odhiambo will get HIV?</i>	58.24 (31.06)	57.36 (32.66)	75.60 (21.65)	61.44 (26.76)	58.61 (32.06)	87.00 (20.27)	64.24 (29.24)	66.65 (29.44)

PrEP Interest

Variable	Capetown		Kenya		Johannesbur g		All Sites	
	F	M	F	M	F	M	F	M
Know of PrEP (0/1) <i>There is a new pill that can prevent HIV. Had you heard of PrEP before taking this survey?</i>	0.43 (0.50)	0.32 (0.47)	0.22 (0.41)	0.24 (0.43)	0.69 (0.46)	0.59 (0.49)	0.44 (0.50)	0.39 (0.49)
Interest 1 (1-5) <i>Now that you have learned a little more about PrEP, how interested would you be in learning more?</i>	3.60 (0.58)	3.37 (0.69)	3.16 (0.78)	3.11 (0.93)	3.53 (0.50)	3.39 (0.59)	3.44 (0.66)	3.29 (0.76)
1-4 (Average)	0	0	2	0	0	0	2	0
5 (Don't know, not included)								
Interest 2 (1-5) <i>Having learned more about PrEP, how interested would you be in trying it?</i>	3.41 (0.68)	3.02 (0.89)	2.66 (0.98)	2.65 (0.96)	3.08 (0.89)	2.97 (0.77)	3.06 (0.90)	2.87 (0.88)
1-4 (Average)	1	2	4	0	1	1	6	3
5 (Don't know, not included)								
Self-Efficacy (1-5) <i>As you learned above, PrEP is supposed to be taken every day around the same time for it to be effective. How good do you think you would be at taking it every day around the same time?</i>	3.85 (1.17)	3.62 (1.14)	3.46 (1.33)	3.10 (1.31)	4.05 (1.14)	3.74 (1.23)	3.78 (1.24)	3.47 (1.27)
PrEP & Condom Use – Self <i>If you took PrEP, do you think you think you would use condoms less often (even though PrEP would not protect you against other STIs or pregnancy)?</i>	0.34 (0.48)	0.57 (0.50)	0.32 (0.47)	0.40 (0.49)	0.31 (0.47)	0.45 (0.50)	0.33 (0.47)	0.46 (0.50)
0-1 (average)	14	15	8	9	8	12	30	36
2 (Don't know, not included)								
PrEP & Condom Use – Others <i>If other people took PrEP, do you think they would use condoms less often (even though PrEP would not protect them against other STIs or pregnancy)?</i>	0.67 (0.47)	0.74 (0.45)	0.55 (0.50)	0.62 (0.49)	0.72 (0.45)	0.61 (0.49)	0.64 (0.48)	0.64 (0.48)
0-1 (average)	22	22	17	21	25	22	64	65
2 (Don't know, not included)								

PrEP Value Proposition

Variable <i>(How much would each of these influence your decision to take PrEP?)</i>	Capetown		Kenya		Johannesburg		All Sites	
	F	M	F	M	F	M	F	M
Safe from HIV (1-5, 5 = extremely)	3.83 (1.26)	3.54 (1.30)	4.27 (1.19)	4.00 (1.38)	2.89 (1.59)	3.31 (1.43)	3.69 (1.46)	3.61 (1.41)
Empower self (1-5)	3.52 (1.43)	3.18 (1.26)	3.93 (1.21)	3.73 (1.44)	2.93 (1.57)	3.29 (1.44)	3.47 (1.46)	3.42 (1.41)
Empower community (1-5)	4.02 (1.32)	3.76 (1.45)	3.47 (1.47)	3.33 (1.46)	3.22 (1.64)	3.53 (1.54)	3.58 (1.51)	3.52 (1.49)
Community support (1-5)	3.71 (1.41)	3.41 (1.44)	3.42 (1.47)	3.25 (1.40)	3.01 (1.56)	3.28 (1.57)	3.40 (1.50)	3.30 (1.47)
Friends on PrEP (1-5)	3.65 (1.43)	3.34 (1.35)	3.27 (1.53)	3.33 (1.53)	2.76 (1.64)	2.91 (1.56)	3.25 (1.57)	3.17 (1.50)
PrEP delivered (1-5)	3.33 (1.53)	2.73 (1.40)	3.64 (1.51)	3.15 (1.48)	2.95 (1.51)	2.91 (1.49)	3.32 (1.54)	2.95 (1.47)
Nice clinics (1-5)	3.43 (1.48)	3.49 (1.49)	3.75 (1.29)	3.75 (1.27)	2.65 (1.59)	2.72 (1.47)	3.30 (1.52)	3.29 (1.47)
Fear about relationships (1-5)	2.45 (1.21)	2.52 (1.15)	3.43 (1.55)	3.59 (1.42)	2.08 (1.27)	2.58 (1.39)	2.67 (1.46)	2.93 (1.43)
Clinic Visits (1-5)	2.85 (1.30)	2.92 (1.29)	3.56 (1.23)	3.56 (1.38)	2.52 (1.47)	2.63 (1.35)	2.98 (1.40)	3.04 (1.40)
Clinic Stigma (1-5)	2.70 (1.46)	2.90 (1.36)	3.56 (1.57)	3.62 (1.46)	2.67 (1.45)	2.37 (1.40)	2.98 (1.54)	2.95 (1.51)
Daily effort (1-5)	2.73 (1.36)	2.88 (1.32)	3.40 (1.40)	3.15 (1.54)	2.44 (1.32)	2.71 (1.32)	2.87 (1.41)	2.91 (1.41)
PrEP effectiveness (1-5)	3.17 (1.34)	3.27 (1.07)	4.38 (1.04)	3.93 (1.42)	2.77 (1.32)	2.78 (1.31)	3.45 (1.41)	3.31 (1.38)
Side effects (1-5)	3.10 (1.15)	2.82 (1.13)	3.63 (1.30)	3.74 (1.36)	2.55 (1.21)	2.72 (1.38)	3.11 (1.30)	3.11 (1.39)
Partner violence (1-5)	2.47 (1.25)	-	3.86 (1.39)	3.00 (2.83)	2.21 (1.28)	-	2.86 (1.49)	3.00 (2.00)
Which is worse: pregnancy or HIV (0/1)	0.69 (0.47)	0.73 (0.45)	0.84 (0.37)	0.88 (0.33)	0.87 (0.34)	0.79 (0.41)	0.79 (0.41)	0.81 (0.40)
Which is worse: losing job or HIV (0/1)	0.66 (0.48)	0.55 (0.50)	0.91 (0.28)	0.85 (0.36)	0.81 (0.39)	0.72 (0.45)	0.79 (0.41)	0.72 (0.45)
Which is worse: being isolated or HIV (0/1)	0.56 (0.50)	0.67 (0.48)	0.90 (0.30)	0.88 (0.33)	0.81 (0.39)	0.64 (0.48)	0.75 (0.43)	0.73 (0.44)