

Appendix 1: Additional information on study methods

Parent study details and background

The Partners Demonstration Project was an open-label study of antiretroviral-based HIV prevention implemented at four sites in Kenya and Uganda. A total of 1013 HIV serodiscordant couples with high HIV transmission risk were enrolled with the goal of using PrEP to 'bridge' the couples until the HIV-infected partner became eligible for ART according to country guidelines, which were generally based on CD4 cell cut-offs or disease status as recommended by the World Health Organization. To be eligible for the parent study, HIV-infected partners could not be eligible for ART at the time of enrolment. After enrolment, ART-eligible HIV-infected partners were referred to local HIV facilities to initiate ART per country guidelines, while the uninfected partner was offered PrEP as a 'bridge' until the infected partner became eligible for ART and had confirmed plasma viral suppression six months after ART initiation. Findings from the study demonstrated that this integrated delivery approach resulted in a 96% reduction in HIV incidence (Baeten et al. 2016).

The Kisumu study site was located within the compound of a subcounty health centre named Lumumba that offers general primary care, antenatal care and HIV treatment and prevention services. The parent study's participants were recruited from a number of health centres throughout Kisumu City. All participants lived in or around Kisumu City at the time of enrolment, and a total of 281 couples were followed from May 2013 to June 2016. Generally, individuals in this area of western Kenya are self-employed or informally employed, via small businesses, farming or fishing activities, or housework, or unemployed.

Detailed description of participant sampling and recruitment

We assessed initiation of ART or PrEP by the third month of the study, anticipating that this was sufficient time for individuals to undergo counselling and decide on initiation of ART or PrEP. At the time of determining eligibility for this qualitative study in June 2014, ART eligibility was recommended for individuals with CD4 cell counts ≤ 350 cells/ μL or >350 cells/ μL with a WHO clinical disease stage III or IV (NASCOP 2011). After generating lists of potential participants in each of the four above categories, we randomly selected 20 participants from each of the four categories to sample with the goal of conducting at least 10 interviews in each category. From this random sample, we attempted to invite an equal number of male and female participants; however, some of the categories were highly skewed by gender, e.g. individuals who initiated ART were largely female. These potential participants were contacted by phone and, if interested, scheduled to return to the study facility with their study partner for an interview. All participants were encouraged to come for their interview with their study partner, so that we could better elicit dyadic dynamics amongst the couples, though it was ultimately the participants' choice if they came individually or with their partner.

Interview and interviewer details

The interviewers were hired locally in Kisumu and were native speakers of Dholuo; one was female and one male (with the male having more prior experience in research), and both had obtained bachelor's training in community/public health or social sciences. Study participants had minimal contact with the interviewers prior to the interviews, other than phone conversations to schedule the interview, and little information about the interviewers or researchers was provided to the participants, other than affiliations noted on the consent forms. The interviews lasted approximately 45–60 minutes. The interviewers took notes during the interviews and summarised their key reflections for each interview, which were included in each transcript. The interviewers transcribed the initial five interviews in Dholuo and translated these into English. Another member of the study staff verified the accuracy of the English translations against the audio file and Dholuo transcripts. Thereafter, the interviewers translated the interview audio files directly into English.

The same interview guide and questions were used for both individual and couple interviews, with the only minor variation in the couple interview guide being asking both partners their input on each

study question. The interviewers were trained to specifically elicit comments from both partners and reflections on each other's responses during couple interviews, for example, by asking the second partner how they felt about the topic or if they agreed/disagreed with the first partner's thoughts. The interviewers also attempted to ensure the women whose male partners were present during the interviews were able to fully express their views, including any dissenting views from the male partner, for example, by always asking the women, preferably first, for their opinions or seeking opposing views by using probes, e.g. 'Not everyone sees it the way your partner describes it. How do you feel about it?' No social harms were reported to the study staff by individuals who underwent couple interviews.

Appendix 2: Couple in-depth interview guide

Partners PrEP Demonstration Study
ACCEPT ART PrEP Sub-study, Kisumu

IDI guide for couples being interviewed together

Study Title: Why do individuals in HIV serodiscordant partnerships who qualify for antiretroviral therapy (ART) or pre-exposure prophylaxis (PrEP) accept or decline initiation of ART or PrEP in western Kenya? Antiretroviral Choices among Couples Eligible for Prevention of HIV Transmission (ACCEPT)

Partners PrEP Participant #1 (HIV-infected partner) ID:

Partners PrEP Participant #2 (HIV-uninfected partner) ID:

Date:

Has the participant #1 started ART or decided to start ART based on the Partners PrEP demonstration study chart?: Yes _____ No _____ Unclear _____

Has the participant #2 started PrEP or decided to start PrEP based on the Partners PrEP demonstration study chart?: Yes _____ No _____ Unclear _____

Interviewer name:

My name is _____ and I will be your interviewer today. Thank you for participating in our study. The goal of this interview is to understand your thoughts, opinions and beliefs about antiretroviral therapy or ART and pre-exposure prophylaxis or PrEP. The medications used for ART are called antiretrovirals or ARVs. Often people use these two terms, ART or ARVs, interchangeably. You should feel free to use whichever term suits you. When I use the term PrEP, it refers to the medications that the HIV-uninfected partner, like you (point to participant #2), can take.

During the interview, when I say 'your partner' I mean your partner with whom you are enrolled in the Partners PrEP demonstration study and who is here with us today. Another clarification I would like to make is about the phrase 'trying to get pregnant', which means having unprotected sex so that you or your partner can get pregnant.

Do you have any questions or concerns? Ok, let's start now.

Section 1: Perceptions of ART/PrEP, benefits and disadvantages

1. To start with, tell me some things you know about antiretroviral therapy or ART or pre-exposure prophylaxis or PrEP?

Possible probes: *Turn to each participant for the relevant question to that participant.*

- What do you think about ART or antiretrovirals (ARVs)? About PrEP?
- What have you heard other people say about ARVs? About PrEP?
- *Do you know anyone who is on ART? What has their experience been? On PrEP?*
- Have you ever taken ARVs before (e.g. AZT for PMTCT) or PrEP? If so, what was your experience?

2. In your opinion, what are the benefits of ART? Of PrEP?

Possible probes:

- Individual physical health –
 - For HIV-infected participant – reducing viral load, decreasing chances of opportunistic infections (e.g. TB), decreasing lifetime risk of cardiovascular disease (e.g. heart attacks) or cancers
 - For HIV-uninfected participant – reducing risk of acquiring HIV, uninfected partner in control of his or her life
- Individual mental health –
 - For HIV-infected participant – feeling healthier, less depressed
 - For HIV-uninfected participant – feeling healthier, less worried or stressed about acquiring HIV
- For others – reducing chances of transmitting HIV to sexual partners or infants
- Of these, which is the most important benefit to you, and why?
- Of these, which might be the most important benefit to your partner, and why? *Now, ask the partner, the same two of the above questions. If there is a discrepancy between their answers, ask: Why do you think you each have different reasons?*

3. In your opinion, what are the disadvantages of ART? Of PrEP?

Possible probes:

- Individual physical health – side effects of meds, costs of engaging in care (e.g. transportation costs, care payments, lost wages, time away from work)
- Individual mental health – burden of taking pills, distrust of Western medicine or medical systems
- Stigma –
 - For HIV-infected participant – associated with pills and others knowing your HIV status, partner knowing your status
 - For HIV-uninfected participant – partner perceiving lack of trust if using PrEP, partner perceiving promiscuity if interested in using PrEP
- Fears – reducing libido
- Of these, which is the most important disadvantage to you, and why?
- Of these, which might be the most important disadvantage to your partner, and why? *Now, ask the partner, the same two of the above questions. If there is a discrepancy between their answers, ask: Why do you think you each have different reasons?*

Section 2: Reasons for deferring ART/PrEP initiation
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4. *If the participant has decided to not start ART/PrEP yet, ask:* For what reasons did you decide to not start ART/PrEP just yet?

If the participant has decided to start or has already started ART/PrEP, ask: In general, why do you think some individuals decide not to start ART/PrEP?

If it's unclear if the participants are on ART/PrEP, ask: May I please clarify if you have decided to or started ART/PrEP? *And then ask one of the above questions accordingly.*

Possible probes:

- Stigma – internalised or external stigma
 - For HIV-infected participant – Are you worried about being identified as HIV-positive, and why or why not? Would people in your community treat you differently if they knew you were HIV-positive? Would people in your community want you to not have future children if they knew you were HIV-positive?
 - For HIV-uninfected participant – Are you worried about your partner being identified as HIV-positive, and why or why not? Would people in your community treat you differently if they knew your partner was HIV-positive? Would people in your community want you to not have future children if they knew your partner was HIV-positive?
- Perceptions of personal health – perceive current health or quality of life as already high

- Perceptions of HIV transmission risk – perceive current risk of HIV transmission to uninfected partner as low
- Medication factors – cost of treatment, side effects, number of pills
- Health facility factors – travel/transport to facility, long wait times, loss of income
- Fertility factors – wish to get pregnant and worried about ART/PrEP negatively affecting their ability to get pregnant or the health of the baby

Section 3: Reasons for initiating ART/PrEP

5. *If the participant has decided not to start ART/PrEP yet, ask: What possible factors would motivate you to initiate ART/PrEP?*

If the participant has decided to start or has already started ART/PrEP, ask: What factors motivated you to initiate ART/PrEP?

Possible probes:

- Perceptions of personal health – perceive current health or quality of life as low, maintain current health or HIV-negative status, specific benefits of ART outweighing disadvantages
- Perceptions of HIV transmission risk – perceive current risk of HIV transmission to uninfected partner as high
- Medication factors – ease of single pill, few side effects
- Health facility factors – easy access to facility, built relationship with providers, trust providers and their advice
- Fertility factors – wish to get pregnant and think that ART/PrEP will positively impact their ability to get pregnant or the health of the baby

Section 4: Prevention of HIV transmission to partner

6. What possible methods could you or your partner use to prevent your partner from getting HIV when you have sex?

Possible probes:

- What methods are you aware of? E.g. condoms, ART, PrEP
- Perceptions of efficacy of each method
- Perceptions of negative or positive effects on sexual desire of each method
- Ability to discuss each method with partner or to engage partner in that method use
- Perceptions of negative or positive effects of each method on ability to get pregnant or health of baby

7. How do you feel about protecting your partner from HIV? *For HIV-uninfected partner, can ask: How do you think your partner feels about protecting you from HIV?*

Possible probes:

- Feels responsible, shows care for my partner and our children, and future children
- Do you ever have conflicting feelings about protecting your partner from HIV?
- Whose responsibility is it to ensure that the HIV-negative partner remains HIV-negative?
- How do you feel about the fact that you have HIV but your partner is HIV-negative? Do you sometimes feel life is unfair, that you have HIV but your partner does not?
- How would you feel if your partner got HIV?

Section 5: Prevention of HIV transmission to partner when trying to get pregnant

8. What possible methods could you or your partner use to prevent your partner from getting HIV particularly when you are trying to get pregnant?

Possible probes:

- What methods are you aware of? E.g. ART, PrEP, non-intercourse insemination
- Perceptions of efficacy of each method
- Perceptions of negative or positive effects on sexual desire of each method
- Ability to discuss each method with partner or to engage partner in that method use
- Perceptions of negative effects of each method on ability to get pregnant or health of baby
- Perceptions of positive effects of each method on ability to get pregnant or health of baby

9. What has been your experience, if any, using a method to try to prevent HIV transmission to your partner while trying to get pregnant?

Possible probes:

- What methods are you aware of? E.g. ART, PrEP, non-intercourse insemination
- Perceptions of efficacy of each method
- Perceptions of negative or positive effects on sexual desire of each method
- Ability to discuss each method with partner or to engage partner in that method use
- Perceptions of negative or positive effects of each method on ability to get pregnant or health of baby

10. *If participants are taking ART or PrEP, ask:* How do you feel about using ART to prevent your partner from getting HIV particularly when you and your partner are trying to get pregnant?

If participants are not taking ART or PrEP yet, ask: How do you feel about using ART to prevent your partner from getting HIV particularly when you and your partner are trying to get pregnant?

Possible probes:

- Positive reactions – decreases risk of transmission to low, feel responsible, shows care for my partner or future child, feel like I'm in control or in charge, sense of relief
- Negative reactions – unprotected sex is uncomfortable since there is still a chance of transmission to partner, still face stigma of having children when HIV-positive, negative health effects of ART on self, effects sexual desire or libido

11. *For the female participant taking ART/PrEP, ask:* How do you feel about using ART/PrEP while you are pregnant to prevent your child from getting HIV?

For the female participant not taking ART/PrEP yet, ask: How would you feel about using ART/PrEP while you are pregnant to prevent your child from getting HIV?

Possible probes:

- Positive reactions – feel responsible, shows care for my future child because I will be less sick and my baby will most likely be HIV-negative, feel like I'm in control or in charge, sense of relief
- Negative reactions – still face stigma of having children when HIV-positive, still worry about transmitting HIV to baby, negative health effects of ART on baby, effects on sexual desire or libido

12. Studies in Africa and elsewhere have shown that HIV-infected individuals who regularly take ARVs rarely pass on the virus to their partner. In other words, if 1000 serodiscordant couples in which the HIV-positive partner is on ARV therapy with an undetectable viral load had sex for one year, only one or two of the HIV-negative partners could become infected with the virus. The remaining 998 or 999 HIV-negative partners would remain HIV-negative. How does your opinion of ART change now that you know that ART could help lower the chance of passing on the virus to your partner while you are trying to get pregnant?

Possible probes:

- Positive reactions – understand risks of transmission are low, perceive it as beneficial to baby, and beneficial to self due to better health on ARVs

- Negative reactions – still worried about negative side effects of ART for self or future baby, worried about low transmission risk
- Does your likelihood of starting ART or adhering to ART change?

13. Studies among couples in Africa have shown that HIV-negative women who regularly take PrEP have a reduced chance of getting the virus from their HIV-positive partners during unprotected sex. In other words, if 1000 serodiscordant couples in which the HIV-negative partner is on PrEP have sex for one year, about 995 will stay HIV-negative and about 5 will get HIV. How does your opinion of PrEP change now that you know that PrEP could significantly lower the chance that you get HIV while you are trying to get pregnant?

Possible probes:

- Positive reactions – understand risks of HIV transmission are lower if taking PrEP, perceive it as beneficial to self or to future baby
- Negative reactions – still worried about negative side effects of PrEP for self or future baby, worried about possibility of getting HIV even if taking PrEP
- Does your likelihood of starting PrEP or adhering to PrEP change?

14. Other studies in Africa and elsewhere have shown that HIV-infected pregnant women who regularly take ARVs during pregnancy very rarely pass on the virus to their baby. In other words, if 1000 HIV-positive pregnant women are taking ARVs, only one or two of their babies would be born with HIV. The remaining 998 or 999 babies would be born HIV-negative. How does your opinion of taking ARVs change now that you know that ARVs could help lower the chance of passing on the virus to your baby?

Possible probes:

- Positive reactions – understand risks of transmission are low, perceive it as beneficial to baby, and beneficial to self as stay healthier.
- Negative reactions – still worried about negative side effects of ART for self or future baby, still face stigma of having children when HIV-positive, effects sexual desire or libido
- Does your likelihood of starting ART or adhering to ART change?

15. Is there anything else you would like to share with me today?

Thank you for your time and participation. We have completed the interview and I will provide your travel reimbursement now.