



'There is nothing to hide': Disclosure of PrEP use by young women in South Africa and Tanzania – qualitative findings from a demonstration project

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3 ***‘There is nothing to hide’*: Disclosure of PrEP use by young women in South Africa and**
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5 **Tanzania – qualitative findings from a demonstration project**
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10 **Abstract**
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13 Investigating how young women disclose oral pre-exposure prophylaxis (PrEP) use is important given
14 evidence that disclosure is associated with higher adherence. We report qualitative results on PrEP
15 disclosure among adolescent girls and young women (AGYW) in South Africa and Tanzania who
16 participated in a PrEP demonstration project (EMPOWER). In total, 81 in-depth interviews were
17 conducted with 39 AGYW aged 16-24 years—25 from Johannesburg and 14 from Mwanza—at
18 approximately 3, 6, and/or 9 months post-enrolment. Analysis of data was thematic and inductive.
19 Most Johannesburg participants were students in the inner-city; in Mwanza, all worked in recreational
20 venues, occasionally engaging in sexual transactions with customers. A continuum of approaches was
21 evident. Partner disclosure was common in Johannesburg but less so in Mwanza, where many partners
22 were feared as judgmental and potentially violent. In both sites, AGYW commonly disclosed to
23 family to secure support, and to friends and work colleagues to advocate about PrEP and encourage
24 uptake among at-risk peers. Adherence clubs appeared helpful in building AGYW’s skills and
25 confidence to disclose, particularly in gender-inequitable sexual relationships. PrEP counselling for
26 AGYW should focus on strengthening communication skills and help develop strategies for safe
27 disclosure.
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48 **Keywords:** oral pre-exposure prophylaxis; disclosure; young women; east and southern Africa
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Introduction

Nearly three decades have passed since the idea of female-controlled HIV prevention methods was first advanced, when it became apparent that women in sub-Saharan Africa were disproportionately affected by HIV (Stein 1990). Women need methods that they can initiate and control themselves—unlike male condoms—and which could potentially be used without partner knowledge or participation (Becker et al. 2004; Heise 1999). From the earliest commentaries on vaginal microbicides and the diaphragm, to more recent studies of oral pre-exposure prophylaxis (PrEP) and long-acting methods such as the vaginal ring, injectables and implants, these products have held the promise for women, at least theoretically, of independent and covert use.

Currently, we have a better understanding of the social and relational dynamics that shape how women use trial products and integrate them into their everyday lives (Stadler et al. 2014; Montgomery et al. 2015; Mngadi et al. 2014; MacQueen et al. 2014; Lanham et al. 2014; Montgomery et al. 2008). Social science research has shown that the question of independent and covert use is more complex than first thought. While early work on the use of female-controlled barrier methods suggested that women favoured covert use (MacPhail et al. 2009), recent studies have shown that overall, the risks of secrecy are often burdensome, with many women participating in HIV prevention trials in sub-Saharan Africa having pro-actively chosen to disclose product use to their sexual partners (Montgomery et al. 2012; Montgomery et al. 2015; Mngadi et al. 2014). Some product characteristics may make covert use inherently difficult to achieve (Woodsong 2004). In some settings there may be social expectations of partner involvement in the decision to use a product (Gafos et al. 2015; Woodsong 2004), especially where product efficacy is unknown. Women may want to pre-empt the anger of a partner discovering the product himself—an especially likely motivation in violent or inequitable relationships and in highly patriarchal societies (Lanham et al. 2014; Sahin-Hodoglugil et al. 2009).

Research in southern and east Africa has further suggested that disclosure tends to involve more negotiation than merely providing information. This often involves permission-seeking as well as cajoling, persuading, and justifying, as women skilfully weigh the risks and benefits of disclosure, and

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3 strategically tailor communication with partners to maximise support for ongoing use (Gafos et al.
4 2015). These observations, together with emerging evidence of the positive impact of disclosure on
5 adherence, have increasingly prompted trials and demonstration projects to support product use
6 disclosure (Woodsong et al. 2013).
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12 To date, most research on disclosure has involved topical microbicides (Succop et al. 2014; Gafos et
13 al. 2015), which have shown limited efficacy in trials (Baeten et al. 2013). Oral PrEP marks a
14 departure from these earlier methods on several levels. Firstly, it is known to be effective when used
15 consistently during periods of high risk (Marrazzo et al. 2015), and it is the first woman-initiated new
16 product for HIV prevention to be licensed. Secondly, PrEP signals the shift to systemic rather than
17 topical methods of HIV prevention, and thirdly, its physical form—a daily pill that can be discretely
18 swallowed—may have implications for disclosure that are quite distinct from vaginal products. These
19 novel dimensions to oral PrEP warrant closer investigation, especially given evidence showing
20 associations between disclosure and higher adherence (Montgomery et al. 2015; Ware et al. 2012;
21 Corneli et al. 2015). Understanding how and why women choose disclosure over covert product use
22 could help inform interventions to support disclosure, particularly in settings where young women
23 face stigma or gender-based violence (GBV), both of which remain extremely common in southern
24 and east Africa (Decker et al. 2015).
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40 In this article we report on results from a qualitative study among adolescent girls and young women
41 (AGYW) in South Africa and Tanzania who participated in a demonstration project that included
42 daily oral PrEP. Much of the literature on novel HIV prevention methods for women has focused on
43 negotiation of product use with male partners. We describe how participants approached product use
44 disclosure to sexual partners, but also to family members and friends. Broadening the scope of
45 enquiry to include others beyond sexual partnerships recognises that social networks may be critically
46 important for young women as they attempt consistent daily pill use.
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Methods

Between February 2017 and February 2018, we conducted serial in-depth interviews (IDIs) with a sub-sample of study participants in the EMPOWER (Enhancing Methods of Prevention and Options for Women Exposed to Risk) demonstration project, which sought to assess the acceptability and feasibility of an HIV prevention package, including oral PrEP. Women aged 16-24 years were recruited in inner-city Johannesburg, South Africa, and Mwanza city, Tanzania. At the time, PrEP was licensed in South Africa, with government focussing its introduction to prioritised populations. In Tanzania, PrEP was not yet licensed. In both countries, PrEP outside of this study setting was largely unheard of as an HIV prevention method.

Women who were HIV negative, not pregnant and interested in taking daily PrEP were enrolled, offered Truvada, and followed up for 6-15 months. At quarterly clinic visits, women received HIV testing and counselling, screening for GBV, and sexual and reproductive health services. Referrals were provided as needed. All women received PrEP adherence counselling with follow-up messaging through SMS. Additionally, half the participants were randomly chosen to participate in monthly adherence support clubs, which included a four-session empowerment curriculum. These clubs were designed to offer additional PrEP adherence support, and build resilience to stigma, GBV, and relationship conflict. Possible disclosure scenarios were discussed in club sessions and further disclosure support was offered during individual counselling at study visits.

The study was approved by the Human Research Ethics Committee of the University of the Witwatersrand, the London School of Hygiene and Tropical Medicine Ethics Committee, and the Tanzanian National Health Research Ethics Committee of the National Institute for Medical Research.

Qualitative sub-study: sampling and data collection

Participants enrolled for at least three months, who had accepted PrEP, were purposively sampled to capture a spread of PrEP experiences and be representative of the study population. Efforts were made to sample participants who had: initially declined PrEP at enrolment, disclosed experience of GBV at screening, or been placed on product hold for medical reasons, including pregnancy. Participants were

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3 approached by telephone or in person by a member of the qualitative research team and invited to
4 participate in the IDIs. The target sample size was 25 participants in each site.
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8 Serial IDIs aimed to capture how participants' overall experience of PrEP-taking changed over time.
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10 In Johannesburg, participants were interviewed 1) after three months, about motivations for PrEP
11 uptake and initial challenges experienced with product use; 2) after six months, focusing on barriers to
12 adherence; 3) around nine to twelve months after enrollment about participants' experiences of the
13 study interventions. In Mwanza, interviews were held after three and six months only.
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19 Detailed IDI guides were developed by the qualitative research team, then field tested and refined
20 with members of the Johannesburg Youth Community Advisory Board. The guides were reviewed
21 after the first interviews and adapted to include new questions and refine probes. In all interviews,
22 PrEP disclosure was discussed using probes that encouraged participants to talk about their decision
23 to disclose or not, whether disclosure had been intentional, and the reaction to disclosure. Three
24 trained interviewers conducted the interviews in private at the clinic in the participant's preferred
25 language (English, isiZulu, seSotho or Swahili). Interviews lasted between 20-60 minutes, were
26 audio-recorded, transcribed verbatim, and translated into English, where necessary. Quality and
27 accuracy of transcriptions were checked against audio recordings by the interviewers, before being
28 uploaded to a secure database. Interviewers received refresher training as necessary.
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41 ***Data analysis***

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43 Analysis followed a thematic, inductive approach (Glaser and Strauss 1967), with key themes
44 identified directly from interview data. A provisional codebook was developed following open coding
45 of a small selection of transcripts by members of the qualitative team. Two coders then independently
46 coded the same transcript and inter-coder reliability (ICR) was assessed using QSR NVivo V.11. ICR
47 was set at 0.75 and re-coding of a common transcript continued until this level of agreement was
48 achieved. Thereafter, the codebook was finalised and remaining interview data inductively coded by
49 four coders (FS, NK, LR, EM). Coding was reviewed regularly by FS, and discrepancies discussed
50 with the relevant coder until agreement was reached on the best applicable code. Reports were
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3 generated for specific nodes and summary matrices developed to examine intersecting themes. Two
4 coding and analysis workshops were held to discuss interpretation of the data.
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8 A matrix of summarised information on PrEP disclosure patterns across all qualitative participants
9 and interview rounds was developed. ‘Full disclosure’ was defined as telling another person that one
10 is taking oral PrEP to protect oneself from HIV, while ‘partial disclosure’ was defined as revealing
11 only some of this information.
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16 17 ***Study settings***

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19 In Johannesburg, EMPOWER study participants were recruited from the inner-city neighbourhood of
20 Hillbrow and surrounds. This is a densely populated neighbourhood characterised by high-rise
21 apartment blocks, which are overcrowded and often unsafe, with frequently interrupted power and
22 water supplies. With a number of schools and tertiary education colleges nearby, many young people
23 reside in or travel into the area daily.
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30 Mwanza, Tanzania’s second largest city, is located on the shores of Lake Victoria. Around 10% of the
31 city’s population (approximately 500,000) are estimated to have migrated from rural areas.
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33 Opportunities for poorly educated migrant women are often limited to setting up small businesses or
34 engaging in petty retailing (Ellis et al. 2007). More formal employment may be found in bars,
35 guesthouses, and clubs across the city, where many of the women in this study were recruited.
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42 **Results**

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44 In Johannesburg, 25 participants were recruited, of whom nine women completed three interviews, 12
45 completed two, and four completed one interview. In Mwanza, 12 participants were interviewed
46 twice, and two interviewed once.
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51 ***Key characteristics of study sample***

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53 Overall, the qualitative sample reflects the demographics of the overall study and captures key
54 differences by study site (Table 1). Median age across both sites was 20.5 years old (IQR 19-22).
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57 Around half the Johannesburg sample were tertiary-level students, while a third had completed high
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3 school and were seeking employment. All were living with parents, other relatives or in student
4 residences. By contrast, most of the Mwanza participants had completed primary school only. All
5 worked in recreational venues or in food and alcohol outlets, where occasional sexual transactions
6 with customers are the norm. Most were living alone or with family members.
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12 Prevalence of GBV was high, with roughly half (both sites) reporting ever experiencing physical,
13 sexual or emotional violence. PrEP uptake was also high: 23 of the 25 participants in Johannesburg
14 and all 14 participants in Mwanza accepted PrEP at enrolment.
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19 [Table 1 about here]
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22 ***Disclosure to sexual partners***

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24 Sixty-four percent (16/25) of Johannesburg participants had disclosed PrEP use—fully or partially—
25 to partners by the first interview, compared to two of the 14 Mwanza participants. This pattern did not
26 significantly change during the study. At both sites, a range of approaches towards partner disclosure
27 of PrEP was evident, from reluctance and prevarication to pragmatism and bold decisiveness. This
28 continuum from non-disclosure to full disclosure is similar to that used in studies of other candidate
29 HIV prevention methods (MacPhail et al. 2009; Lanham et al. 2014; Sahin-Hodoglugil et al. 2009). In
30 disclosing to partners, participants tended to explain PrEP use as a procedure required for study
31 participation, and thereafter as '*a pill that prevents HIV*'. In some cases, extra care was taken to
32 distinguish PrEP from ARVs as treatment.
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44 Full disclosure was mostly evident at the Johannesburg site (Jhb), where a number of women framed
45 the decision to start PrEP as a choice already made—a *fait accompli*—with no need for partner input
46 and apparently little regard for what his response might be. Portia's¹ view on this was unambivalent:
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51 *If I want to take [PrEP], I can take it whether he likes it or not (laughs) because it's me, it's my*
52 *body.* (21 years, Jhb; IDI-113B)
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56 Buhle told her partner within a week of starting PrEP:
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3 *I didn't fear anything, actually. I didn't care what people said, after all, it's my life. His*
4 *response was 'OK, it's fine'. (18 years, Jhb; IDI-153F)*
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8 In many cases, this confident approach was driven by a desire for honesty and openness in the
9 relationship. Most Johannesburg participants reported that their partners were supportive of their PrEP
10 use, with some apparently asking if they, too, could join the study and access PrEP, while others
11 helped by reminding women to adhere to their daily regimen. Some partner responses were reported
12 to be less positive, especially where partners were sensitive to doubts about their fidelity and HIV
13 serostatus. Disclosure had the potential to bring latent mistrust in the relationship into sharp relief,
14 potentially triggering conflict and counteraccusations.
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23 Women at both sites navigated these situations with enormous skill, developing tactics to manage
24 their partner's response and retain control of the narrative when met with resistance or anger. One
25 such tactic involved openly asserting one's right to be protected from infection, mobilising arguments
26 about self-preservation. Portia, for example, acknowledged her partner's other relationships, but did
27 not back down on asserting her right not to be infected.
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34 *He was like, 'so you don't trust me, you think that I'm not faithful?' and all that. And then I told*
35 *him, like, that because he once cheated on me...I told him that 'I trust you but I don't want*
36 *mistakes. What if you get tempted and cheat and cheat with a wrong person and you come and*
37 *infect me?' And then that's how he understood. (21 years, Jhb; IDI-113B)*
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44 Similarly, Olivia—one of only two women in Mwanza (Mwz) to disclose PrEP use to a sexual
45 partner—claimed her husband's untrustworthy behaviour posed a threat to her wellbeing.
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48 *He had two other girls out there...I continued using the pills and I made sure that he knew*
49 *about it and I told him that he wasn't settled and so it's better if I protected myself. He asked*
50 *me where I got the pills, I explained, then he allowed me. (24 years, Mwz; IDI-ET0017D)*
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55 Part of this strategy involved justifying PrEP use as an act of self-care or as a step they were
56 compelled to take in order to *'be safe'*. When Lerato's partner questioned her decision to take PrEP,
57 she responded:
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3 *...it's just PrEP but I'm just taking care of myself, at the end of the day I have to think about*
4 *myself and not another person. (23 years, Jhb; IDI-235Z)*
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8 Other strategies involved suggesting how her PrEP use could benefit him. Theresa used this approach
9 to win her partner's support:

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13 *Eh, at first he was like, 'why are you taking PrEP?' [I said] 'I want to prevent myself.' 'From*
14 *what? [he asked] – am I HIV positive?' I said 'no, I don't think so. At the end of the day I'm*
15 *protecting you from your side', So when I told him 'I'm protecting you', ja, he started being*
16 *happy and said 'fine, at least I'm not gonna be infected'. (18 years, Jhb; IDI-440G)*
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22 Another approach—and one that falls closer to the 'non-disclosure' than the 'full disclosure' side of
23 the continuum—involved strategically guiding a partner's attention to something *other* than PrEP.
24 Katleho, for example, told her boyfriend she was taking PrEP but said she had been motivated by the
25 benefits of study participation, rather than access to PrEP itself.

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31 *...he was a bit angry, 'how come you don't trust me?' Then I said I wanted to be in the study...I*
32 *want to be checked [for HIV and other health conditions] after every 3 months. (20 years, Jhb;*
33 *IDI-206G)*
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38 Nsekelwa managed to secure her partner's permission to use PrEP by diverting attention away from a
39 potentially uncomfortable discussion of sex and trust.

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43 *On the first day when I told him he asked why I didn't trust [him], to begin using the*
44 *medicines... And I also told him 'Aaaah! [No] it's not that HIV can be caught in sex only, it*
45 *could happen maybe by sharing sharp objects then you catch HIV. After that explanation, he*
46 *allowed me because I explained and he understood and agreed. (22 years, Mwz; IDI-ET00831)*
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52 A fourth strategy involved partial disclosure through the telling of a 'half-truth' or simply not
53 correcting a partner's misperception. For example, a handful of women in Johannesburg allowed their
54 partners to assume that the pill they were taking was for contraceptive purposes. In South Africa,
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3 contraception is often colloquially referred to as ‘prevention’, making it possible to exploit this
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5 slippage of terms to conceal PrEP use.
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8 In most cases, it was the fear of conflict, stigma and judgement that necessitated evasive approaches
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10 to disclosure; these were prominent themes in the interviews, regardless of setting. Rosemary
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12 remarked that if her partner found out she was taking PrEP, ‘*he may even beat me up*’ (20 years,
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14 Mwz; IDI-ET0079Q). Fear of partner response also appeared as a strong motive for non-disclosure
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16 among the Johannesburg participants; about a third had not disclosed to their partners by the second
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18 (six-month) interview. They anticipated a range of angry responses from partners; one woman said he
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20 would ‘*throw the pills away*’; another said, ‘*World War III will start*’. Cecilia insisted she would
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22 never disclose to her partner and maintained that by doing so, ‘*I’m avoiding many problems...it would*
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24 *be a long conversation...I don’t even touch the subject*’ (18 years, Jhb; IDI-346Z). Unsurprisingly,
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26 non-disclosure of PrEP use was more common in relationships with low levels of trust, and where
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28 women feared violence. Dikeledi described her partner of six years as jealous and controlling and said
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30 he had tried to strangle her in the past. She was adamant that disclosure was out of the question and
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32 that by staying HIV negative through taking PrEP, she could avoid conflict and recriminations later.
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36 *I don’t tell him that I am taking PrEP because if he is doing things outside [having other*
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38 *partners] ...I don’t expect him to say I am the one who made him sick because I will be safe*
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40 *and he will be the one who is sick at that time.* (22 years, Jhb; IDI-084Q)
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43 Importantly, not all decisions to use PrEP secretly were based on fear of partner response. In
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45 Johannesburg, sharing such sensitive information would be considered inappropriate in a relatively
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47 new relationship. Maria had not disclosed to her partner of two months: ‘*if I see that things now are*
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49 *getting too serious....Then I will tell him the truth*’ (20 years, Jhb; IDI-418D). Zukiswa (Jhb), having
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51 recently reunited with her partner after a break-up, felt relations between them were too fragile for her
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53 to disclose, although she planned to do so eventually to pre-empt his suspicion about her multiple
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55 clinic trips. So, partner type – new or casual versus stable, long-term partner – in part determined
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3 whether women considered covert use of PrEP to be necessary, an assessment that could shift as the
4 relationship changed.
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8 These findings on the challenges of communicating about PrEP use within relationships raise the
9 question of whether the study interventions had any impact on women's ability or willingness to
10 disclose to partners. In these interviews, most commentary focused on the experience of participation
11 in the clubs. In Johannesburg, we explored whether partner disclosure patterns were shaped by study
12 arm allocation. Here, almost all (11/13) of the qualitative participants assigned to the club arm had
13 disclosed PrEP use to their partner, compared to only half (6/12) of the participants receiving standard
14 adherence support. Club participants reported boosted confidence levels and strengthened
15 communication skills, often using practical role-play exercises, which in turn may have facilitated
16 disclosure to an intimidating partner. Additional support for disclosure may have come from the
17 strong emphasis in club sessions on open communication and shared responsibility for decision-
18 making within sexual partnerships:
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32 *In terms of relationships, eh, I have learned that communication is key, you see when you*
33 *communicate, you do not do something just because another person wants you to do it, you*
34 *both need to take decisions as a couple, you need to be responsible for those decisions.*
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38 (Nomzamo, 21 years, Jhb)
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41 ***Disclosure to family members, friends, and work colleagues***

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43 Compared to partner disclosure, with family members there were clear shifts in the patterns of
44 disclosure across time, i.e. between the first and the final interviews. Full disclosure to trusted female
45 family members (mothers, aunts and sisters) featured prominently in the first interview; participants
46 described being “close” to these family members and actively seeking to share their decision about
47 PrEP with them. Parents and other family members believed to be potentially disapproving or
48 judgemental were usually not told until much later in the study. Xoliswa initially only told her mother
49 and sisters about her PrEP use, and delayed telling others in her family as she feared their response.
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3 *My father, my grandmother, okay, ja, all of them because I was scared that maybe they will*
4 *think I am doing something like...maybe I am sleeping around or that's why I am doing that.*
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7 (21 years, Jhb; IDI-200I)
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10 By the 6-month interview, Xoliswa reported having disclosed to her grandmother. Still nervous of
11 how her father might respond, Xoliswa had asked her grandmother to inform her father about her
12 using PrEP.
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17 In Mwanza, the strongest motivation for disclosing PrEP use to family members was overwhelmingly
18 women's need to explain their frequent clinic visits and the presence of pills in the home. In keeping
19 with a social norm of children displaying respect for parents and older relatives, women believed they
20 needed "permission" for PrEP uptake, particularly if living with their parents. Rosemary, who works
21 as an attendant at a hotel, told her father, mother and sister, and explained:
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28 *How do I go out from home without permission and I must explain where I am going? ...I also*
29 *chose consciously not to hide because I live with them. (20 years, Mwz; IDI-ET0079Q)*
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33 Agnes also told her mother, because:
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36 *When I thought of what she would think if she was to find the medicine in the house and she*
37 *asks me about them, so I thought it was wise to tell her. (21 years, Mwz; IDI-ET0082A)*
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41 At both sites, however, some women had hidden their PrEP use from parents. Nomzamo had used
42 PrEP in secret for a month. But adherence was difficult under such circumstances. She recalls, 'I had
43 to hide the pills...ya, you are not free in the house' (21 years, Jhb; IDI-112Y).
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48 Like Nomzamo, other participants initially found it difficult to be open about PrEP with family
49 members, but at the same time struggled to conceal PrEP in the home. Phindile started to take PrEP
50 surreptitiously after initially showing her mother the study pamphlet:
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54 *I told her that they want me to take PrEP and she just said no, she said 'if you do it, then just*
55 *know that you would be doing it against my will.' You know when a parent says that, yoh, yoh,*
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3 *it's heart-breaking, she makes you feel bad". [But] I just had no say. She just said that that was*
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5 *it. (19 years, Jhb; IDI-26U)*
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8 Phindile would watch her mother's movements and *'look if there is anybody watching, and...sneak*
9 *into the room [to take PrEP]. It's a bit difficult...exhausting'*. In Johannesburg, participants who
10 attempted covert PrEP use at home did so largely because they wanted to hide from their parents that
11 they were sexually active. Refiloe, a 19-year-old student, hid her PrEP pills among her clothes in her
12 wardrobe to conceal them from her mother. She reflected on the consequences of being found out:
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19 *I don't want to see their reaction, first of all, they would ask, they will be shocked that I am*
20 *even sexually active...That would lead to so many questions. (Jhb; IDI-095X)*
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24 In Mwanza, however, having sexual partners was not something participants needed to conceal from
25 parents, who often knew about the kind of work they were doing in local bars, taverns and other food
26 and entertainment venues. Both participants and their families seemed acutely aware of the
27 heightened risk of HIV acquisition they faced in the workplace and the lack of alternative
28 employment options for women in this setting. Being open about their PrEP use to family members
29 thus became a way for women to reassure them that they were safe. Rodia used this approach with her
30 mother:
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39 *I told her the environment where we work is filled with risks...You might be caught up in a*
40 *relationship with an infected person, so the pills help you prevent the risks of infections. (24*
41 *years, Mwz; IDI-ET0089N)*
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46 For the same reason, many participants were motivated to disclose PrEP use to female peers and
47 colleagues at work, in the hope that they, too, would join the study and protect themselves from
48 infection. Indeed, this is often how PrEP was pitched to this group. Wakuru advised her co-workers at
49 the bar that PrEP offered an alternative to male condoms.
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55 *For example, you have a lover and maybe he doesn't want to use condoms...Since there is PrEP*
56 *which helps you; even if he has his own other doings, when you rightly focus on taking the pill*
57 *everyday...even if they meet with their lovers and they are infected, but due to the immunity that*
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3 *is already built up with PrEP, it'll be a safe way to avoid infections.* (20 years, Mwz; IDI-
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5 ET0018E)
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8 Participants in Johannesburg were equally aware of the elevated HIV risks faced by young women in
9
10 their environment, citing their peers' (and partners') reluctance to be HIV tested and the high rates of
11
12 sexual assault as motivations for PrEP use. Telling friends about PrEP therefore often involved
13
14 directly pointing out *their* risk and encouraging them to take PrEP. Tumi, who joined the study
15
16 because she once had a friend who was HIV positive and didn't want to see herself '*in the same*
17
18 *situation*', told all her friends she was taking PrEP and urged them to do so as well. Being open about
19
20 this strengthened Tumi's sense of purpose in being among the first among her peers to adopt PrEP: '*I*
21
22 *feel proud about myself. So that they know that we are bringing change*' (21 years, Jhb; IDI-085K).
23
24

25 Refiloe similarly turned disclosure to friends into an opportunity to educate:
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27

28 *I know we are all sexually active so I told them so that they could think about joining...Ja, and*
29
30 *they always complaining about HIV, pregnancies and all that. So I was like, 'let me just give*
31
32 *you one option to think about so that you could decrease your worries'.* (19 years, Jhb; IDI-
33
34 095X)
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36

37 Indeed, some of these participants went beyond mere disclosure to embrace pro-active promotion of
38
39 PrEP among peers and even among strangers in the broader community. Alice, for example, felt
40
41 strongly about this advocacy role.
42
43

44 *There is nothing to hide...It's PrEP, it's for everyone, so I shouldn't wait for people to ask me*
45
46 *'hey what are you doing?'* No, it's a feeling like I should let people know about this. It should
47
48 *be all over the world, people should be asking about it... 'cos it's not for myself, it's for*
49
50 *everyone else...I feel very open, like I should be having a mic[rophone] and telling everyone*
51
52 *about PrEP (laughs).* (22 years, Jhb; IDI-446R)
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54

55 Disclosure to a friend was extremely common (23/25 in Jhb, 10/14 in Mwz), and tended to happen at
56
57 an early stage of taking PrEP. By the final interview, several participants had also disclosed to a much
58
59 wider circle, such as church members, work colleagues, and acquaintances.
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3 There were reportedly mixed responses from family members and friends. The novelty of PrEP and
4 its relatively unknown status, especially in Tanzania, meant that some family members simply did not
5 believe in its existence. Rosemary maintained that her mother and brother insisted that she was living
6 with HIV and taking antiretrovirals, even challenging her to bring ‘documentation’ back from the
7 clinic to prove her HIV-negative status. Responses of outright disbelief were reported as less common
8 in Johannesburg but there was scepticism that a pill alone could prevent HIV infection, and general
9 mistrust in clinical research. While in most cases, friends expressed interest in PrEP and in joining the
10 study, some had apparently teased the participants about taking antiretrovirals or about being tested as
11 ‘guinea pigs’ in research.
12
13

14 Negative responses from family and friends appeared to be the exception rather than the rule. The
15 omnipresence of HIV in the broader environment meant that family members more often openly
16 welcomed participants’ decision to use PrEP. In both sites, overwhelmingly, parents reportedly
17 expressed relief that their daughters were actively doing something to protect themselves from HIV.
18 Xoliswa’s mother responded ‘*aah, at least you are safe*’ (21 years, Jhb; IDI-200I), while Amina’s
19 grandmother was happy the clinic was providing PrEP to young women because ‘*many girls are*
20 *ruined*’ (22 years, Mwz; IDI-ET0013Q).
21
22

23 In Johannesburg, the response of parents and other family members was often shaped by their direct,
24 personal experience of HIV. Zama’s mother is living with HIV; she apparently understood
25 immediately when her daughter told her about PrEP and saw it as ‘*a good thing*’ (24 years, Jhb; IDI-
26 192H). When asked by her mother why she was taking PrEP, Dikeledi recalled that her response was:
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*Remember one of your cousins passed on because of HIV and got it from the boyfriend? So I
don’t want history to repeat itself, my child is still young. (22 years, Jhb; IDI-084Q)*

61 Karabo told her parents about PrEP because ‘*they know this container...I don’t want them to think*
62 *otherwise*’ (22 years, Jhb; IDI-08J). Her mother was not surprised and saw Karabo’s decision as
63 positive, setting her apart from the actions of a cousin, ‘*the one they trusted so much*’, who had
64 contracted HIV. A number of the Johannesburg participants mentioned that their decision to initiate
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3 PrEP was praised by their mothers, who appeared to interpret this as a sign of maturity. Naledi
4 described her mother's response:

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8 *She said it's best to protect yourself... 'I'm very proud you are doing something, you have a*
9 *child now, now you know what's wrong, what's right'. (22 years, Jhb; IDI-263J)*

10
11
12 Similarly, Theresa's mother, a nurse, had approved her daughter's decision to take PrEP saying, '*now*
13 *you are actually grown up, you decided to go there by yourself'* (18 years, Jhb; IDI-440G). When

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15
16 Buhle told her sisters,

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20 *'They were proud of me actually, 'cos they didn't know about the pill, ja and I was seen as this*
21 *responsible young lady. I was very happy. (18 years, Jhb; IDI-153F)*

22 23 24 25 **Discussion**

26
27 In assessing patterns of and motivations for PrEP disclosure among AGYW in South Africa and
28 Tanzania, we found important distinctions that likely derive from socio-demographic differences
29 between the two study sites. In Johannesburg, there was evidence of autonomous decision-making
30 about HIV prevention—possibly a function of higher education levels—and a strong trend towards
31 disclosing PrEP use to sexual partners. Disclosure to a broader network of family and friends was
32 partly influenced by acute awareness of HIV risk and sexual violence at community level, and was
33 often received with empathy and support, particularly by those directly affected by HIV. By contrast,
34 the dominant pattern in Mwanza was non-disclosure to partners, who considered highly likely to
35 judge and condemn women taking PrEP. This may reflect the participants' relative lack of power vis-
36 à-vis male partners, as well as local stigmatising discourses about sex, gender and disease. We saw a
37 strong trend of women disclosing PrEP use to friends and work colleagues, mainly as a way to
38 encourage PrEP uptake among this broader, at-risk group. As in Johannesburg, disclosure to parents
39 was common in Mwanza, with women appearing to seek parental permission as well as offering
40 reassurance that—as young women working in a high-risk environment—PrEP made them 'safe'. In
41 both sites, there seemed to be a pattern of first disclosing to supportive female family members, and
42 later to older and male family members, or those initially feared as potentially judgmental of young
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3 women's sexuality. More 'public' disclosure became easier for women in the later months of the
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5 study.
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8 This was a relatively young cohort of women, with many unmarried and living with family, which
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10 likely shaped their disclosure decisions. For younger women, their parents seemed to be more obvious
11
12 'gate keepers' to PrEP uptake than their partners. This may point to shifts in inter-generational
13
14 relations between adolescents and adult caregivers that facilitate more open discussions about
15
16 sensitive issues like sexual activity and HIV than was possible in the past. It is significant, perhaps,
17
18 that in Johannesburg some parents approved of PrEP use and regarded it as a positive sign of maturity
19
20 and responsibility—a possible framing that could help to counteract PrEP stigma against young
21
22 women. In Mwanza, family dynamics appear to be shifting together with recent rural to urban
23
24 migration, with evidence that sexual education now tends to be administered by mothers in urban
25
26 areas, whereas, in the past, it was largely administered by grandmothers and female elders (Lees
27
28 2013).
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31
32 Participants' experiences of attempted covert use of PrEP illustrate the social obligations and
33
34 gendered norms that young women—especially in the Johannesburg site—are under pressure to
35
36 respect, namely, the expectation that they delay sexual debut. These experiences also bring to light the
37
38 practical challenges of daily pill-taking under the watchful eyes of others who share the same living
39
40 space. Since residences in these settings are often cramped and overcrowded (Scorgie et al. 2018), this
41
42 may have restricted privacy for those who wished to hide their PrEP, ultimately forcing disclosure to
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44 household members. Arguably, PrEP's 'visibility' in this context is increased by its resemblance to
45
46 antiretrovirals, its daily regimen, and need for pill storage, suggesting that the physical characteristics
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48 of the product itself may also have shaped disclosure within households. Other, more discreet, forms
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50 of systemic PrEP currently under development may be less visible by comparison, thereby removing
51
52 this challenge altogether.
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56 The high proportion of participants who told at least one friend or colleague about their PrEP use
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58 points to the 'social and connected lives' (Haberer et al. 2019) of AGYW, where decisions and
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2
3 experiences are frequently shared with peers. Increasingly, peer relations in these settings are shaped
4
5 by widespread use of social media, with young people increasingly attuned to the crafting of new,
6
7 gender equitable identities—even if social norms and institutions lag behind. The importance of these
8
9 early PrEP adopters sharing their experiences with peers who are similarly at high risk of HIV cannot
10
11 be overstated. Through participation in projects such as EMPOWER, they have the potential to
12
13 influence future uptake among peers and male partners, and to shape attitudes at community level,
14
15 potentially normalising women’s autonomous use of HIV prevention methods. Given the prevalence
16
17 of PrEP stigma in both study sites, this aspect of disclosure potentially gives it a potency beyond
18
19 impacting on the individual PrEP user alone.
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23 Across the continuum of approaches used when disclosing to partners, it was evident that women
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25 considered the nature of the relationship, anticipated their partner’s response, and skilfully controlled
26
27 what information to convey, even resorting to deceit if needed. For most participants, low levels of
28
29 trust and partners’ controlling behaviours determined how much communication about PrEP use was
30
31 possible, if at all. This was particularly true for Tanzanian participants, where sexual relationships are
32
33 marked by stark gender inequalities and women’s economic dependence on male partners.
34
35 Consequently, there was more covert use with sexual partners than in South Africa, where gender
36
37 norms are more in flux. In Johannesburg, the framing of PrEP use as an act of legitimate self-care to
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39 which women are entitled, speaks to the prominence of discourses about gender equality and women’s
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41 empowerment in this fast-paced urban environment, where independence and agency are highly
42
43 valued among young people. In this context, it makes sense that PrEP use should be claimed by them
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45 as an individual right. More broadly, the trend of a new generation of young women becoming more
46
47 aware and assertive about their sexual and reproductive health rights is partly attributable to the long
48
49 history of research on HIV prevention products for women in the region.
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53 Along with PrEP advocacy in PrEP naïve communities, adherence clubs appeared to be helpful in
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55 building positive social norms around women’s use of this new HIV prevention technology. Although
56
57 not examined here in detail, there were signs that through the use of practical scenarios to rehearse
58
59 safe disclosure with partners, clubs strengthened confidence and communication skills, thereby
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1
2
3 supporting women who chose to disclose. Indeed, PrEP adherence clubs in other studies have been
4 effective in offering peer support for adolescents taking PrEP, including support to disclose to others
5 and overcome stigma (Celum et al. 2019). Initiatives that include participants' support networks and
6 those that help participants to convey simple, factual information about PrEP are also potentially
7 important (Toledo et al. 2015).
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14 There were limitations to the study. Interviewing participants at the clinic may have led them to avoid
15 saying anything negative about the study or about PrEP use. The small study samples make it difficult
16 to be definitive about trends such as the apparent association between club attendance and disclosure
17 to partners. We also did not interview the partners, family members and friends of study participants,
18 and our conclusions about *their* responses to PrEP disclosure should be read with caution.
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25 Understanding young women's decision-making around PrEP disclosure may help inform PrEP
26 delivery services and scale-up, as well as efforts to 'normalise' PrEP use among young women more
27 generally. Where possible, PrEP counselling should enhance communication skills and develop
28 strategies for safe disclosure. In doing so, the risk of partner violence must be recognised in
29 relationships with controlling behaviours, insecure partners or a history of violence. Women require
30 support in such situations and careful discussion of their fears. Future messaging around PrEP may
31 also need to address the assumption that a male partner of a woman taking PrEP is directly protected
32 from acquiring HIV. Not only is this perception potentially harmful, it could unfairly place the onus
33 for *men's* HIV prevention on women.
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45 Finally, our study findings support recent recommendations that PrEP be marketed to AGYW as an
46 empowering 'lifestyle choice' rather than more narrowly as a biomedical HIV prevention tool
47 (Haberer et al. 2019). Where young women can see PrEP initiation as a self-affirming, positive step,
48 there is potential for the claiming of a new, socially empowered identity. Supporting women to talk
49 openly about their PrEP use and spreading the word about its efficacy lays a foundation for scaling up
50 and introducing future technologies—like long-acting injectables or implants—moving us closer to a
51 time when young women's use of HIV prevention is regarded as unexceptional.
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Declaration of interest

The authors have no conflicts of interest to declare.

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Table 1. Baseline demographic characteristics of participants in the qualitative sub-samples and in the overall EMPOWER sample

	Qualitative sub-study		EMPOWER		
	South Africa (n=25) n (%)	Tanzania (n=14) n (%)	South Africa (n=379) n (%)	Tanzania(n=52) n (%)	Total (n=431) n (%)
Age					
16-19 years	9 (36)	4 (29)	93 (25)	14 (27)	107 (25)
20-24 years	16 (64)	10 (71)	281 (75)	38 (73)	319 (75)
Highest education completed					
Primary school or less	0 (0)	6 (43)	7 (2)	24 (46)	31 (7)
Some Secondary School	3 (12)	3 (21)	41 (11)	10 (19)	51 (12)
All Secondary School	8 (32)	5 (36)	228 (61)	18 (35)	246 (58)
Some Tertiary education	14 (56)	0 (0)	98 (26)	0 (0)	98 (23)
Employment					
None	22 (88)	1 (7)	309 (83)	7 (13.5)	316 (74)
Full time	0 (0)	12 (86)	26 (7)	38 (73.0)	64 (15)
Part-time	3 (12)	1 (7)	39 (10)	7 (13.5)	46 (11)
Residence					
Alone*	6 (24)	5 (36)	91 (24)	12 (23)	103 (24)
Parents	12 (48)	3 (21)	200 (53)	16 (31)	216 (51)
Partner	0 (0)	1 (7)	0 (0)	6 (11)	6 (1)
Other relatives	7 (28)	5 (36)	84 (23)	18 (35)	102 (24)
Number of sexual partners					
None	0 (0)	1 (7)	0 (0)	1 (2)	1 (0)
One	19 (76)	10 (71)	306 (81)	36 (29)	342 (79)
Two or more	6 (24)	3 (21)	73 (19)	15 (29)	88 (20)
Relationship status					
Single (not married)	25 (100)	12 (86)	345 (91)	42 (81)	387 (90)
Living with partner	0 (0)	1 (7)	23 (6)	6 (11)	29 (7)
Married	0 (0)	0 (0)	10 (2.8)	0 (0)	10 (2)
Separated or divorced	0 (0)	1 (7)	1 (0.2)	4 (8)	5 (1)
Screened positive for GBV	13 (52)	7 (50)	121 (32)	20 (38)	141 (33)
PrEP uptake					
Accepted PrEP at enrolment	24 (96)	14 (100)	356 (94)	52 (100)	408 (95)
Accepted PrEP by M12	1 (4)	0 (0)	8 (2)	0 (0)	8 (2)
Still declining PrEP by M12	0 (0)	0 (0)	15 (4)	0 (0)	15 (3)

*Includes women living in student residences