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Beyond remedicalisation: a community-led PrEP demonstration project among sex workers in India

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ABSTRACT

Global health policy-makers have called for demonstration projects to better understand pre-exposure prophylaxis' (PrEP) effectiveness across geographies and populations. *Ashodaya*, a sex worker collective, initiated a PrEP project in Mysore, India. We conducted a project ethnography to explore the role that community participation played within the project. Although the project proved immensely successful in terms of retention and adherence, to explain these findings we point towards *Ashodaya's* history of collectivisation around sexual health—a history of community action that has given rise to new spaces of belonging and accumulated knowledges that became instrumental in the formulation of strategies to confront anticipated challenges during the project. These strategies included: (1) the participation of community leaders as the first participants to take PrEP, followed by the sharing of their experiences through testimonials to their peers; (2) the endorsement of PrEP among community leaders living with HIV, to avoid social divisions around HIV status; and (3) ongoing community-level support from outreach workers that went beyond administering PrEP to address the various needs of the community. These community-led approaches demonstrate that communities hold key insights into the delivery of clinically-oriented interventions, suggesting the vital role they continue to play in planning and implementing new prevention technologies.

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Background

In recent years, there has been what some social scientists have termed a “remedicalisation” of the HIV epidemic—that is, the shift away from activism and “a return to the early 1980s view of the epidemic as a medical problem best addressed by purely technical, biomedical solutions whose management should be left to

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biomedical professionals and scientists” (Nguyen et al. 2011, 291). Playing into this paradigm are attempts to scale up pre-exposure prophylaxis (PrEP), a prevention strategy that administers antiretroviral medication (usually a combination of tenofovir and emtricitabine) to HIV-uninfected individuals to reduce the transmission of HIV (World Health Organization 2012). These individuals, defined in epidemiological terms as being at-risk, take a daily pill to prevent acquiring the virus. The clinical efficacy of PrEP has been well documented through randomised control trials across geographies and populations (e.g. Okwundu et al. 2012). In 2015, the World Health Organization called for PrEP to be offered to individuals at “substantial risk” of HIV infection as an option within comprehensive HIV prevention services (World Health Organization 2015).

Despite PrEP’s demonstrated clinical efficacy as a new prevention technology, its history of development was embroiled in controversy, especially during early oral tenofovir trials with sex workers in Cameroon, Nigeria, Malawi and Cambodia. Between 2004 and 2005, sex worker and activist protests culminated in the halting or cancelation of trials amidst concerns about a lack of community consultation and involvement, questions concerning the safety of tenofovir use as a prevention drug and the failure of researchers to ensure the provision of treatment in cases of HIV infection during study participation (Haire 2011; Ukpong and Peterson 2009). The transnational collectivised power of activist networks through these protests resulted in more ethical research practices.

Following these highly publicised protests, the International AIDS Society and the Bill & Melinda Gates Foundation (Gates Foundation) held a stakeholder consultation to identify a way forward with biomedical HIV prevention research (Peterson and Folayan 2017). UNAIDS and the AIDS Vaccine Advocacy Coalition (AVAC) also organised regional consultations. These meetings resulted in the preparation of the *Good Participatory Practice (GPP) Guidelines*, intended to provide systematic guidance on how to effectively engage all stakeholders in the design and implementation of HIV prevention trials (UNAIDS/AVAC 2007, 2011). The document points to the need for community engagement, but in the words of Peterson and Folayan (2017):

..., community engagement was not imagined to extend to independent assessments that evaluate whether the trial and its objectives are actually beneficial to trial participants. In other words, ‘saying no’ to a clinical trial, as was done in Malawi and Nigeria, is not imagined to be part of an independent scrutinising process because such a response disrupts ‘effective partnerships’ (29).

Clinical trials continued to be rolled-out between 2007 and 2013, but sex workers have largely been left out as participants in these trials (Shannon et al. 2018).

While documents such as the *GPP Guidelines* provide “systematic guidance on how to effectively engage” with all stakeholders (UNAIDS/AVAC 2011, 5), “effective engagement” is often deployed in order to move public health research forward, as Peterson and Folayan (2017) state in their critique of the guidelines. Alliances, such as the Global Network of Sex Work Projects, have released their own recommendations for moving forward with PrEP, calling for the active engagement of sex workers in all levels of PrEP policy and programme discussions, including in the design, implementation and monitoring of programmes, stressing that the demand for PrEP must come from sex workers themselves, rather than pressure or force from governments, researchers or funders (NSWP 2016). In this way, PrEP builds on the legacy of community activism in early HIV research,

whereby people living with HIV demanded a say in the shaping of clinical trials and access to early treatment.

During the early years of the HIV epidemic, people living with HIV organised to negotiate access to early treatment options. In what Epstein (1996) has called “impure science”, treatment activists began to influence the design and roll-out of early clinical trials as members of regulatory boards, reviewed ethical study procedures and advocated for access to new and experimental drug regimes. Community activism continues, including during a demonstration at the 2004 International AIDS Society conference in Bangkok that brought global attention to the controversies surrounding the early tenofovir trials, and social scientists warn researchers against adopting a purely biomedical approach to the HIV epidemic (Lorway 2016; Nguyen et al. 2011). During a keynote address at the 2nd International Conference for the Social Sciences and Humanities in HIV in Paris in 2013, Richard Parker, a medical anthropologist and critical social scientist, argued that current approaches to HIV prevention fail to pay attention to community-based approaches, and that complex political and social issues have been generally ignored and require attention (Hyde and Lees 2013).

In reflecting on the third decade of HIV, Mykhalovskiy and Rosengarten (2009) call for a “revival of the sort of scholarly innovation that characterised the early years of the HIV epidemic” where multidisciplinary theoretical approaches “emphasised the ‘social’ for understanding the significance of AIDS and opened up new avenues for critiquing and reimagining scientific, cultural and social responses to infectious disease” (187). Similarly, the sociologist Adam (2011) has stated that, “all biomedical prevention technologies are also social interventions” (5); for they must account for, respond to, and navigate an array of social and political realities.

Following the documented efficacy of PrEP, the World Health Organization called for demonstration projects to better understand the use of PrEP outside of clinical trials (World Health Organization 2013). Responding to these social complexities, *Ashodaya Samithi*, a sex worker-led organisation based in the South Indian city of Mysore, ran a Gates Foundation-funded demonstration project. The Gates Foundation selected *Ashodaya* as one of only two sites in India, the other being the *Durbar Mahila Samanwaya Committee* (DMSC) in Kolkata. Both organisations comprise internationally renowned sex worker collectives, known for their leadership in sex worker-led mobilisation and innovation in community-based sexual health interventions that have led to high rates of condom use, reductions in HIV and STIs, and a strong sense of community ties (e.g. Jana et al. 2004; Reza-Paul et al. 2008).

In an attempt to move beyond the distinction often assumed between biomedical and social interventions, we conducted an ethnographic study that ran alongside the *Ashodaya* PrEP Project to explore the role that community participation played across the life cycle of the project. This paper demonstrates how the PrEP project results need to be interpreted against the broader backdrop of *Ashodaya*’s history of community mobilisation, activism, research and support. Like Catherine Campbell (2003), whose ethnographic work sought to understand how the outcomes of the Summertown Project failed to address the HIV epidemic affecting a small mining town in South Africa, we are also concerned with the social processes that lead to programme outcomes—in our case success. In terms of retention and adherence, the

demonstration project proved immensely successful, with 640/647 participants retained for the 16-month project, and participants reporting high adherence to the drug regimen, confirmed by serum tenofovir testing (Reza-Paul et al. 2020). In an effort to explain these findings, we go beyond biomedical understandings of adherence, pointing towards Ashodaya's history of collectivisation around sexual health—a history of community action that has given rise to new spaces of belonging for sex workers.

Site setting and methods

Ashodaya Samithi

Beginning in 2004, the Gates Foundation funded Ashodaya Samithi as the first organisation supported under their Avahan initiative, which aimed to address the HIV epidemic in six high prevalence states across India (e.g. Ramakrishnan and Alexander 2006; Rao 2010). Members of our team, as public health researchers, travelled to Mysore to understand the local sex work context, with the initial goal of setting up clinical services to test and treat STIs and HIV. During these visits by the team, it became clear that while many sex workers operated in the city, little sense of community existed. Despite initial resistance from NGOs working to “rehabilitate” sex workers, and rumours from within the community that the researchers were in the business of selling organs, the research team was able to build trust, initially among male sex workers, who then helped provide a link to the women with whom they shared networks. Priorities shifted from a biomedical focus on testing and treating STIs, to a focus on addressing the needs of sex workers. A drop-in centre was opened in a location chosen as convenient by sex workers that provided them with a safe space to spend time between clients. This space provided an informal place for women to gather, leading them to share their experiences with each other and cultivate solidarity. These relationships soon spilled out to the street, with women working more collaboratively to ensure their physical and health protection. Sex workers also shared their experiences of violence at the hands of police, clients and intimate partners with the public health staff, and told of avoiding health services due to fears of discrimination. The team began to address these immediate needs of sex workers, by speaking with police to curb harassment and arrests, responding to client and partner violence, and providing accompaniment on healthcare visits (see Reza-Paul et al. 2012). The drop-in centre provided a space for the community to both collectivise and problem solve. Uniquely, male, female and transgender sex workers all came together to form the Ashodaya community. Within the drop-in centre site, Ashodaya opened a community-based clinic in the first year of the organisation, with community members playing a key role in designing the clinic and selecting healthcare providers (Dixon et al. 2012). By the end of that year, according to the team, almost 75% of the estimated sex worker population had begun to access services at the clinic, creating new norms around community-based healthcare.

Sex work leaders established a board of governance comprised of elected representatives from the sex worker community. Based on a philosophy of building community capacity, sex workers were paired with project managers to learn their roles, with the expectation of taking over the operations of the organisation. Sex workers played key roles in all organisational activities, which over the years were expanded to include

outreach and advocacy, sexual and reproductive health services, cooperative banking, addressing sexual and gender-based violence, and community-based research. Beginning in 2010, Avahan began transferring funding responsibility over to the government (Rao 2010), which led to significant funding delays and a scaling back in activities. Within this context of funding cuts, the PrEP demonstration project unfolded.

Study design and analysis

The findings in this paper are based on an ethnography of the PrEP Demonstration Project, with fieldwork taking place between January 2015 and April 2018. Evans and Lambert (2008), in asking the question: “why do some community-based HIV prevention projects succeed whereas others falter?”, point to the importance of ethnographic research in uncovering the “complex and inter-dependent dynamics of context, practice, agency and power that are specific to a project and shape the course of intervention implementation in ways that may be ‘hidden’ in conventional techniques of project reporting” (467). The first author conducted the ethnography as part of a doctoral research (Lazarus 2019). This ethnographic work began in January 2015 during the feasibility study, an awareness-raising and acceptability phase prior to the demonstration project (see Reza-Paul et al. 2016). The demonstration project began enrolment in March 2016.

As part of the research, we invited demonstration project staff and participants to take part in in-depth interviews. The first author conducted interviews with project staff, which includes sex work leaders, community outreach workers, and programme support personnel, towards the start of enrolment in September/October 2016, and closer to the project end in November/December 2017. After obtaining informed consent, the staff interviews were conducted in English or in Kannada (the local language), with simultaneous translation done by the third author, one of the programme officers, who played a significant role in this study. We invited all core members of the Ashodaya project team to participate in an interview. In consultation with the community leaders and programme personnel, we purposively recruited community outreach workers who represented women working across different networks in different geographical areas of the city. Twenty-one interviews were undertaken during the first round of data collection and 16 interviews during the second round. Project staff interviews aimed to capture the demonstration project processes, including successes and challenges.

Trained community researchers were responsible for conducting the participant interviews in Kannada. Participants were invited to participate in a longitudinal cohort that included three rounds of in-depth interviews in September/October 2016, April 2017 and November/December 2017. The project team and community outreach workers assisted in purposively sampling participants for the interviews to ensure the representation of women of different ages, belonging to different networks, who practised sex work in different contexts (such as home-based versus street-based) and who had been connected to the organisation for varying lengths of time.

We invited 40 participants to take part in the first round of interviews in September/October 2016. Community researchers and outreach workers attempted to

reach all participants for the second round of interviews, with 30 of the women returning to participate in the second round. Additionally, community researchers interviewed two extra participants who they believed to be part of the original cohort and we collectively decided to include these interviews. Community researchers interviewed 36 women in the final round of interviews in November/December 2017. As in the previous round of interviews, we included one new participant in the cohort. The questions we posed explored experiences taking PrEP, as well as experiences as a member of Ashodaya. Participant demographics at the time of the first interview are presented in [Table 1](#).

The first author coded all the interviews for emergent themes and thematic analysis (Braun and Clarke 2006) using NVivo 11 software. A group analysis session took place with peer researchers in April 2018, in which selected interview segments were discussed for community contextualisation and member checking (Creswell and Miller 2000). While coding, we paid special attention to themes related to the community-based processes employed in the rolling-out of the demonstration project.

The University of Manitoba Health Research Ethics Board and the Institutional Ethics Committee (IEC) at Durbar Mahila Samanwaya Committee (DMSC) granted ethics approval for the larger PrEP demonstration project. The first author obtained secondary ethics approval as part of her doctoral research through the University of Manitoba Health Research Ethics Board in relation to the work presented in this paper.

Table 1. Socio-demographic characteristics of qualitative study participants at baseline.

Characteristic	n (%)
N (all participants)	40
Age (years)	
Median (Range)	31 (22–47)
≤20	0 (0)
21–25	6 (15)
26–30	13 (32.5)
31–35	5 (12.5)
>35	16 (40)
Number of years registered with Ashodaya	
Median (Range)	5 (1–11)
≤5	21 (52.5)
6–10	15 (37.5)
11–15	4 (10)
Number of years in sex work	
Median (Range)	8 (1–20)
≤5	18 (45)
6–10	13 (32.5)
11–15	4 (10)
>15	5 (12.5)
Education	
Illiterate	21 (52.5)
Literate	19 (47.5)
Marital status	
Never married	1 (2.5)
Married	18 (45)
Widow/divorced/separated	21 (52.5)

Lessons from a sex worker-driven PrEP demonstration project

The PrEP Demonstration Project began in March 2016, with 647 women enrolled into the project over the ensuing months. Community outreach workers provided ongoing support for PrEP, which the women received free of charge for 16 months. The clinic team screened participants quarterly for any health concerns or complications. By the end of the project, 640 women had completed their follow-up and high self-reported adherence was confirmed by serum tenofovir testing (Reza-Paul et al. 2020). These findings differ significantly, particularly in terms of retention, from other demonstration project sites among sex workers (see Cowan et al. 2018; Eakle et al. 2017) and raise the question as to what processes or circumstances led to the high retention rates. To understand these findings, we examine the community-led strategies implemented by Ashodaya to confront anticipated challenges in the project.

Going slow: the role of testimonials in obtaining community consent

The demonstration project posed a new challenge for Ashodaya's programme team, comprising sex work leaders and the programme support personnel, as it was the first biomedical study undertaken by the organisation. Although not a clinical trial, the demonstration project shared many of the same characteristics, in terms of recruitment targets, regular medical screening visits and extensive adherence monitoring. Despite the scope of the project, Ashodaya leaders were able to draw on their expertise in community-based healthcare delivery, support and research, particularly drawing on their experience in condom distribution and other HIV and STI prevention interventions, in order to minimise potential risks and challenges when rolling-out the project.

As PrEP was a new intervention, the team developed a deliberately slow recruitment plan, first enrolling senior community leaders into the project, who then shared their experiences taking PrEP with their networks. Over the years, community mobilisation programmes have "produce[d] specific dimensions of sociality—subjectivities; social connections, affinities and tensions; organisational allegiances and oppositions; and cultural politics" (Lorway 2016, 91), creating space for new "truths" to emerge, such as the introduction of PrEP as a new prevention technology, and shape identities in relation to illness while also opening up new opportunities for activism.

It is within this context of shared socialities that testimonials become highly influential means of recruitment and retention. According to Boellstorff (2009), testimonies "emphasise form over content", and call to the dynamics of belonging (351), compelling "listeners to constitute themselves as persons "at risk" and thus as persons who would take action to prevent becoming infected with HIV" (359). This is mirrored in the testimonial examples at Ashodaya, where testimony from trusted community leaders to members of their networks at the start of the project drew on collective experiences of shared risk and normalised the pill-taking process. Saumya, a community outreach worker who had been with the organisation since its start, described the testimonial process:

So the community is already ready for this because we had done a lot of group works and other things. And simultaneously when this PrEP enrolment started, the screening and other things, we have not done it with the community first. We identified leaders of

the community. They first took the tablets and they went through the testing and they started taking [PrEP] and they had shared their experiences by saying that “Okay, first we went through this. This is useful for us. See nothing has happened to us.” They [the community] started watching them and based on that, community has come so that we have not faced much difficulties in mobilising them (Saumya, outreach worker, October 2016).

As described by Saumya, enrolment was deliberately slow and began with senior community leaders as the first to take PrEP, which worked to dispel initial doubts surrounding the introduction of a new prevention technology. Deepa, a participant enrolled in the study, explained how she watched community leaders take PrEP, before deciding to take the medication herself:

They said this tablet is good for you and will keep you healthy. Then I asked them to take it and show it to me that they are also taking it. In front of me they took the tablet and so I also started taking the tablet. Then they followed-up with me to see if I am taking it regularly. I was taking it regularly (Deepa, participant, November 2017).

Furthermore, as more women began to take PrEP, they too started to provide testimonials across their networks. Gayathri, another participant and a member of Ashodaya, explained how she decided to take PrEP in order to encourage other women to take it.

I did not know about PrEP, then they told me about it. Then I thought if I take it then I can tell others also. If I take it and I am fine, then I can tell other women also to take it. I can tell them to take it and they will not get any diseases, they will not get HIV, STIs or any such thing. So I am taking it and so are the other women.... (Gayathri, participant, December 2017).

Mitigating divides: the endorsement of PrEP among community leaders living with HIV

Research projects by their very nature create groups of exclusion. Ashodaya leaders were sensitive about creating tensions among members left out of the project. In order to maintain unity, Prisha, a community leader, explained how leaders living with HIV offered testimonials linking PrEP to the benefits that they experienced from ART and provided their endorsement of the project.

I have trust that okay all are continuing and all had a tablet every day without failing. I will give my own testimonial to many of them by saying that “Okay you guys are lucky ones because you are getting at least PrEP tablet and you are able to prevent yourself from getting infected but we unfortunately got infected. Now as you can see my life. We had got infected. If we might have got the PrEP, we also [might have been] safe.” So like that also I will mobilise many of them and motivate others... (Prisha, outreach worker, October 2016).

Communal experiences of loss of friends and fellow sex workers to AIDS produced a shared sociality, in which members of the organisation came together to support and deliver PrEP, regardless of their HIV status or desire to individually take PrEP. An early endorsement from community members living with HIV further served to

mediate some of the tensions that exclusions of some members from the study could have caused and helped compel Ashodaya members to enrol in the project and use PrEP.

That said, the study did cause some to feel being left out. Saanvi, a senior outreach worker, described the pushback she witnessed by some Ashodaya members who did not receive PrEP:

Those who are a little bit elderly age persons they are saying that “This is not right that you are giving [PrEP] only [to some] people. You have to give this tablet to all others also, whoever are present sex workers who are doing sex work. We are also entertaining the clients. We are also under risk. We may also fall under infections and other things. Why you are not providing the tablet to all other sex workers also? Why are you limited to this particular one?” These kinds of questions are coming because [Ashodaya] until now has served for everybody. ... (Saanvi, outreach worker, December 2017)

In such a situation, the project team shared how they emphasised that while the research nature of the intervention limited enrolment, hopefully the study findings would lead to greater PrEP availability in the future. Although the demonstration project created divisions within a closely-knit community, project leaders, through their knowledge of the membership and protecting shared solidarities, were able to mitigate this risk through testimonials and the endorsement of the project by senior community leaders, as well as by drawing on the community’s research knowledge to explain enrolment restrictions.

Revitalisation: reconnecting to community

As community leaders and other project team members expected that a biomedical intervention such as PrEP might create friction between those taking and not taking the drug, they used the study as an opportunity for community members to come together and reconnect to the organisation. The Ashodaya project team made strategic efforts to ensure that all members were linked to Ashodaya’s array of services, stressing that PrEP was one of a number of services that people could take advantage of regardless of whether they were part of the PrEP project. This worked to minimise possible tensions and divisions among their membership. Ramesh, a long-term member of Ashodaya’s programme team, described how through the PrEP project Ashodaya had been able to reconnect members to a variety of services.

Because of new community members... They are also getting information about [Ashodaya]. Once they came not only to get PrEP, they came and they can get the other services also. They link with the cooperative [bank], they link with some social and treatment programmes, they link with [Ashodaya] programmes ... (Ramesh, programme personnel, September 2016)

In order to understand the full scope of the project, it is necessary to situate PrEP within the intervention life of Ashodaya. The project came at a time when the organisation had been forced by budget cuts to pare down previous outreach activities. Moving beyond simply delivering a drug, Ashodaya leaders were able to use the project as a catalyst to reconnect to their members and provide services reaching out beyond PrEP. Conversations extended beyond PrEP and led to opportunities to

reconnect members to social, health and financial support programmes available through Ashodaya. This approach is quite similar to what Rhodes et al. (2019) have termed “care beyond the virus” when discussing HIV care, where “care of the virus” requires responding to “vital concerns” beyond simply treating HIV (18).

Ishaan, a senior community leader, described how calling participants to check on adherence led to conversations of this kind.

After that when we came back and we started the process, first we thought that one-month trial we will do with those who are taking it. We will do the very close watch with them for a month, like every three days we'll do personally visiting and every day we are calling and getting information, collecting information and details from them like that. Then I realised that I started calling them every day just to know, “You started taking the tablet. How are you feeling? What is going on?” Like that. So definitely, when we'll start a conversation, we will not only talk about PrEP but a lot of things we will discuss about their personal life and other things also. So, what happened is slowly, slowly this conversation after second week or third week, I started realising that they're waiting for my call (Ishaan, community leader, December 2017)

PrEP, in this case, was the catalyst needed to encourage community and leaders back into the field at a time when funding had cut programme activities. The demonstration project created excitement and new hope for the organisation. The project office now bustled with daily visits as previously disengaged members came in for their PrEP screening and follow-up. As time progressed, outreach workers proudly described how they no longer needed to remind their networks about picking up pills or following-up with appointments, with ownership of the study gradually passing to participants. Saanvi explained:

Actually, the community has come very close to the organisation because of this project. Until now there is no other way of getting prevented from HIV. Only one device is there that is called condom, but there is no medicine Along with that, during this time actually, our attention level, not “our,” [our] means everybody, whoever is working in our organisation also started showing extra concern towards the community members and we are always ready for serving them at any moment of time. We are addressing all their needs and other things Because this procedure is so that they need to visit frequently and it has developed as a habit that whenever they feel like anything, they will walk directly to the office and they started consulting us even when they have any doubts or anything like that. Not necessary that they need to come for a particular health reason So this has definitely given us good bondage between the community and the organisation because of this project. (Saanvi, outreach worker, December 2017)

Marrying science to community

The Ashodaya PrEP Project provides important insights for moving biomedical research into community-led spaces, demonstrating that communities can play a vital role in collaboratively leading biomedical interventions. PrEP here builds on an earlier legacy of AIDS activism in which, in the words of Epstein (1996), “lay experts” conducted their own community-based trials and learned new languages to be able to advocate for their right to access innovative therapies. According to Vijay, a member of the programme team, blending together community engagement and science was what led to project success.

Yeah definitely. When these two [community and science] are coming together then definitely it's going to be a success because if you go only with the community agenda and not following the science and not following the methodology, not following this one then there will be no success. And if you go only with the scientific research and not keeping the community interest and community together, then there will be no results out of that. So we need to marry both and we need to keep them together always ... (Vijay, programme personnel, October 2016)

Although community empowerment and mobilisation have long been recognised as central to HIV prevention among sex workers (e.g. UNAIDS 2012; Vijayakumar 2018), community wisdom still continues to be left out of more biomedically-oriented research. Ishaan and Saanvi, both Ashodaya staff, described the pride they felt in playing an active role with the project.

So, I feel very proud because I gained a lot of knowledge and gained a lot of skills about this one. I know the loop and corners about this particular project. I can say with my gut feeling what is the screening processes and what is happening in screening and why it is essential and how the tablet needs to be preserved and how they need to distribute it and how they need to keep a track record and other things. I know about all that. I have become a master trainer now. I can train on PrEP about this here. In that way I feel very much proud. One more thing that makes me proud is [that] I'm HIV positive and during this project and particularly from last one year this one, I have contributed many of them to get prevented from HIV ... (Ishaan, community leader, December 2017)

As I'm working here for the last 13 years, so I used to attend a lot of district level meetings and other NGO meetings ... When onwards PrEP has started, I am very proud that no other person has any information, any clue about PrEP and I'm talking about PrEP that, "Okay this is a tablet, this is what is going to be happening and we are giving it for so many people and we had done this, this time. We had done so many follow-ups like that." By presenting these things I feel really proud in front of other organisations because they don't know damn about this particular PrEP and I am the one who is talking about this ... (Saanvi, outreach worker, December 2017)

Discussion

In this era of remedicalisation, the Ashodaya PrEP Project furnishes a unique example of a community-led biomedical intervention that is not unlike Epstein's (1996) depiction of activists leading clinical trials in the USA during the early years of the HIV epidemic. However, while Epstein depicts the scientific entanglements of activism and science between people with considerable social, political and economic capital, Ashodaya provides an example of a community-driven project in the global South driven by a working-class community with much less direct access to political power and prestige. Ashodaya's expertise emerged from 14 years of leading structural HIV interventions, which laid the foundations of knowledge, experience and wisdom from which leadership was able to anticipate new challenges and formulate novel strategies to confront problems encountered during the project.

The project started with a deliberately slow roll-out, to build acceptance and trust. Community leaders, as the first to take PrEP, used testimonials as a means of sharing experience of risk and motivating others to take PrEP. This testimonial sharing, and the forms of sociality that it cultivated, spread throughout the community, as more

members began taking PrEP and sharing their experiences. Participants professed an interest in PrEP in part due to their shared experience of the loss of friends and fellow sex workers to AIDS (Reza-Paul et al. 2016). Their shared sociality created a collective experience of risk and trauma.

Attention was also paid to whether the project would lead to the creation of excluded groups. Clinical trials, and by extension demonstration projects, can create divisions by differentiating between members who are eligible for inclusion in the study and those who are not (Biehl 2004; Montgomery and Pool 2017). In the Ashodaya project, only female sex workers were eligible to participate, despite the trial taking place in an organisation providing services to female, male and transgender sex workers. Through their intimate knowledge of community dynamics, Ashodaya leaders pre-emptively employed strategies such as the testimonials of peer leaders and members living with HIV, to minimise tensions that could have disrupted community solidarity throughout the project. While frustration was expressed early on by some members left out of the study, an understanding of research and scientific rationalities among sex workers, in the form of what Lorway (2019) has termed “evidentiary politics”, ultimately channelled support for the project to move on. Although significant portions of Ashodaya’s membership were left out of the study, endorsement of the project by Ashodaya leaders and an understanding that “evidence” was needed to advocate for wider PrEP access, led to support from Ashodaya’s membership, including male and transgender sex workers, with the expectation that project “success” would lead to PrEP availability for all of Ashodaya’s members. At a time when public funding for HIV prevention was in decline, the effect of which began to erode community solidarity networks, Ashodaya leaders seized upon the resources furnished by the project to build a renewed position of relevance in the sex worker community. Along with delivering PrEP, Ashodaya outreach workers re-engaged with their networks to provide other services and supports. In this way, the project revitalised a sense of collective belonging between diverse community members.

While in this paper we focus on the community-led processes implemented at the initiation of the Ashodaya PrEP Project to mitigate challenges surrounding the roll-out of a new biomedical HIV prevention technology, problems arising during the course of the study are explored in detail elsewhere (e.g. Lazarus 2019; Reza-Paul et al. 2020). In particular, challenges surrounding adherence early in the project were linked to demonetisation in India which greatly affected sex work income (Reza-Paul et al. 2020). Mid-study serum tenofovir testing results also showed some dips in adherence that led the project team to rethink the need for tailored adherence support strategies throughout the course of the demonstration project. These ongoing support strategies, which resulted in higher levels of adherence during the end-of-project tenofovir-level testing, will be explored in a forthcoming paper.

Conclusion and policy implications

Through this study, we aimed to push beyond current discussions of participation and engagement in HIV biomedical research to reveal communities as possessing key insights for the making of scientific knowledge itself. Grass-roots approaches such as this

demonstrate how communities hold key insights into the delivery of clinically-oriented interventions, suggesting the vital role they can play in planning and implementing new prevention technologies. Building on the work described here, sex workers and sex worker organisations should be called upon to formulate context-specific community priorities for PrEP access and help lead these interventions in the future.

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