

A research alliance

Tracking the politics of HIV-prevention trials in Africa

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Abstract

This article explores a research alliance across fields and continents in the wake of the early and controversial HIV-prevention clinical trials of pre-exposure prophylaxis (PrEP). Our research set out to understand why three trial arms prematurely closed while another was refused approval from the relevant institutional review board. We conducted ethnographic research on ‘what happened’ at two of the sites. Over time our research strategy cohered around unearthing and exploring rapidly disappearing knowledge. We analyze insider/outsider politics, the power of global public-private partnerships, and the forms of scientific knowledge (located in African countries) that get left behind in the process.

Keywords

research alliances, HIV prevention trials, PrEP, Malawi, Nigeria

Introduction

In August 2004, a message was posted to the national Nigeria AIDS listserv – ‘the AIDS Eforum’ – that announced the closure of a clinical trial located ten thousand kilometers away in Phnom Penh, Cambodia. The poster, a Nigerian AIDS advocate working on behalf of sex workers, described to her readers a new HIV-prevention technology known as ‘PrEP’ – pre-exposure prophylaxis. The trial tested whether taking one anti-HIV pill a day could prevent

HIV transmission in adults who are HIV negative. Readers learned that women being recruited for this trial were members of a national Cambodian sex workers' union. For reasons we did not quite understand at that time, the union protested the trial, which was subsequently shut down by the Cambodian minister of health.

It was the first time that most working in the Nigerian AIDS advocacy sector had even heard of PrEP. Indeed, the Eforum – created by a Nigerian nongovernmental organization (NGO), Journalists Against AIDS – is one of the first places to hear news about AIDS in Nigeria and elsewhere, which travels among the 2,000 subscribers who are HIV-positive advocates, workers in multiple levels of government, international funders, and Nigerian AIDS NGO staff. The question put to the listserv that day was whether anyone had information about the Cambodian trial closure because an arm of an identical PrEP trial was simultaneously taking place in Nigeria. At first the question was met with silence. But in a very short amount of time, the AIDS Eforum became home to the longest-standing national debate on any issue pertaining to AIDS in Nigeria.¹ Both of us posted individually to these discussions. And it was through these posts that we met each other and decided to jointly pursue HIV prevention research in Africa.

In this article, we explore the dynamics of 'research alliances'. We have chosen to use 'alliance' rather than 'collaboration' because the latter has two opposing meanings: 'partnership' and 'traitorous participation'. Given the sensitive and challenging nature of the politics that emerged out of our research together, 'alliance', in our view, allows for multiple iterations of relationships, ethics, and research possibilities. We reflect on our long-term alliance, established between Folayan, a Nigeria-based public health academic trained in dentistry, and Peterson, a US-based anthropologist. We also discuss our dialogical alliance with research scientists and members of Nigerian AIDS NGOs whose analyses of events and their structural contexts were pertinent to our concerns. Finally, we analyze how our research interfaced with the broader global PrEP community made up of research scientists, powerful funding agencies, and global AIDS activists.

¹ AIDS advocates, scientists, journalists, academics, FHI, NHVMAS, and Tenofovir trial coordinators participated in this debate about the Nigerian PrEP trial from 30 August–11 October 2004, with the majority of remarks posted in September 2004. A total of thirty-one posts on the Nigeria Eforum pertained to this issue.

The 2004–05 PrEP Trials

In the summer of 2005, we met at a fast food joint, Mr. Bigg's, in Ibadan, Nigeria, where Folayan was living at the time, where Peterson was once a university research fellow, and where a number of HIV-prevention trials had taken place, including the Nigerian PrEP trial. Peterson had conducted dissertation research on AIDS activism in Nigeria four years prior and was familiar with AIDS politics as well as activist networks in the country. In addition to being a university professor, Folayan was a member of the New HIV Vaccine and Microbicide Advocacy Society (NHVMAS), an NGO that is made up mostly of research scientists along with a few leading national AIDS activists. In tracking HIV research, the organization had optimistically kept abreast of new biomedical HIV-prevention technologies that were emerging at that time.² As an independent organization not affiliated with any institution, it also scrutinized 'overseas' (Molyneux and Geissler 2008) trial protocols that governed clinical practices for HIV-prevention research. In this sense, NHVMAS filled an institutional gap because there was no national ethics committee in Nigeria during the 2000s.

By the time we met in person, the Nigerian PrEP site had prematurely closed. Another arm of the trial located in Cameroon had also shut down early. In Malawi, the national ethics committee refused institutional review board (IRB) approval for the trial (Chigwedere 2009; Peterson et al. 2015). The global AIDS community, made up of policy makers, activists, and research scientists, was in a swirl because the future of what was deemed promising PrEP research was in trouble. And so, the private–public partnerships that organized these trials – the Centers for Disease Control, the National Institutes of Health, The Centers for Disease Control and Prevention, University of California San Francisco, Family Health International (FHI), and the Gates Foundation – scrambled to put things back together.³ Several institutions and universities were contracted to conduct the trials at other sites.⁴

Like most involved at that time, we were trying to make sense of these closures, and we found ourselves tracking how varying analyses of 'what happened' were circulating on a global level. In doing so, we had to pay attention to AIDS advocate and scientific networks

² These included vaccines, microbicides, and PrEP. Microbicides, made up of multiple chemical substances, are no longer being pursued due to a lack of efficacy found in clinical trials conducted in the late 1990s and early 2000s.

³ Gilead Sciences, the manufacturer, agreed to donate Tenofovir medication.

⁴ These included: in Ibadan, Nigeria: FHI and the University of Ibadan; in Bangkok, Thailand: the CDC, the Bangkok Metropolitan Administration, and the Thailand Ministry of Public Health; in Gabarone and Francistown, Botswana: the CDC and the federal government of Botswana; in Tema, Ghana: FHI and Virtual Access; and in Doula, Cameroon: FHI and the Care and Health Program.

across the world. In the early 2000s, listservs like the Eforum were not limited to just AIDS activists: they included multiple stakeholders who held a new sensibility in the AIDS world of activism, one that pursued partnerships with funders like the Gates Foundation as well as global brand-name drug companies. AIDS activists in Nigeria and other parts of Africa are also on multiple other AIDS listservs that are global in scope. When the first PrEP site closed in Cambodia, news of it took less than twenty-four hours to reach the Nigerian Eforum. Watching how information traveled so quickly, we became interested in what got highlighted and left out of these stories, and what structures and partnerships of power were mediating these movements.

We first noticed that the discussion of the PrEP closures took a polarizing turn. Trial coordinators blamed AIDS activists for obstructing what was deemed ‘humanitarian’ research that would save poor women from future HIV infection. But local actors – sex worker unions, AIDS activists, ethicists, and research scientists – listed numerous problems with the trial protocol across sites (Ako 2005; Jintarkanon et al. 2005; Ukpong and Falobi, n.d.; Ukpong and Peterson 2009). The principal investigators (PIs) and the PrEP trial funders were afforded prominent space in high-profile medical journals to tell their own stories of what went wrong (Grant et al. 2005; Mills et al. 2005; Mack et al. 2010). We found it curious that these stories pertained mostly to the Cambodia and Cameroon sites, where sex workers and AIDS activists had pushed the PIs to address the problems that each group had found with the trial protocol. Sex workers in Cambodia were concerned about side effects that could obstruct their day-to-day work and that therefore could lead to economic precarity for them and their families (Forbes and Mudaliar 2009; Sandy 2012). They asked for long-term health insurance for trial-specific injuries. While the PIs appeared sympathetic, the demand was not implemented into the trial protocol (Forbes and Mudaliar 2009). In Cameroon, AIDS activists raised concerns pertaining to the protocol design, including the fact that the informed consent documents they had reviewed appeared to be only available in English (Cameroon’s two official languages are French and English), female condoms were not included in the protocol, no provisions were made for the care of trial participants if they became HIV positive during the trial, and there were no stipulations on future access to drugs if proven effective (Akoa 2005; Yombe 2009). As in Cambodia, Cameroonian activists suggested modifications to the protocol to allay these concerns, which did not materialize.

Local actors who raised concerns ultimately were portrayed as unable to understand HIV clinical science. Specifically, scientists outside these countries and working within international public-private HIV-prevention consortiums insisted that communities required more AIDS science education. It was thought that once sex workers and AIDS activists better understood the principles of HIV clinical research, the implementation of PrEP trials would proceed apace (UNAIDS 2005; Grant et al. 2005; Mills et al. 2005).

The disjuncture between ‘what happened’ and how the stories of these trials were being narrated on a global scale prompted us to historicize events where there was very little media attention: Nigeria and Malawi. Crucially, university ethicists and research scientists led the debates at these sites. In Nigeria, discussions were heated and very public, and were documented in detail by members of NHVMAS (Ukpong and Falobi, n.d.). In Malawi, the debate took place very quietly among university ethicists and research scientists. At both sites, these extended discussions were largely invisible to academics analyzing HIV clinical research as well as the broader global AIDS activist communities (Ukpong and Peterson 2009; Peterson et al. 2015).

And so, in many ways our research alliance cohered first and foremost around a politics of visibility. We were motivated by two histories: the marginalization of African research scientists and the history of clinical trial research in Africa. Usually rendered junior partners in overseas trial relationships, African research scientists may lack access to the data that they produce and may be afforded little opportunity to be included as coauthors on research publications. Such marginalization can also include institutional inequalities, where overseas researchers have established more or less permanent centers of research that exceed the funding and research opportunities of neighboring university- and state-run research organizations (Crane 2013; Elliott 2014; Kingori 2015; Fairhead et al. 2006; Farmer 2002).

When designing trials in the United States, from which a huge number of trials are conducted overseas, it is not often imagined that junior partners will scrutinize the trial protocol for clinical ethics and scientific rationales; rather they are imagined as implementers of these trials. In interviews, Nigerian researchers characterized these expectations and roles as ‘contract labor’ rather than as partners in research. Moreover, HIV-prevention trials were largely characterized by some of the same researchers as less urgent than other needed studies, such as the rising problem of multidrug-resistant tuberculosis or research on the correlation between HIV infection and neglected tropical worm infections. These concerns had somewhat fallen off of the radar of global health organizations and thus less funding exists for long-term sustained research on such issues.

We also studied the history of clinical trial research, especially in Nigeria. While some trials caught national and/or international attention, many others were not noticed beyond the complaints made by trial participants to either social workers or AIDS advocates. Most notable was Pfizer’s 1996 unregistered Trovan study that sought to create new uses for an existing product. It was marred by multiple ethics violations and the death of eleven children (Goldstein 2011; Khan 2008). The study recruited children with meningitis at the same hospital in the northern city of Kano where tens of thousands of people were seeking emergency care in the midst of an outbreak. A class-action suit was filed against Pfizer in a Nigerian court but the company never bothered showing up for trial. The suit was filed in

and thrown out of courts across continents, a fact that was widely reported in the Nigerian media. Documents released by WikiLeaks in 2013 indicate a backroom deal was made between Pfizer and the Nigerian government that settled for substantially less damages than what the plaintiffs were seeking. But Trovan was exceptional in its infamy. In our interviews with both AIDS activists who were former trial participants and staff from Nigeria's federal drug administration, we found that a number of HIV trials were never officially registered – and therefore never regulated – in Nigeria. When NHVMAS conducted its own research on the state of overseas HIV-prevention research in Nigeria in early 2004 (Ukpong and Falobi 2004), it discovered an unregistered feasibility study of the potential of douching with lime juice as an HIV-prevention tool. As Folayan, Peterson, et al. (2015) show, multiple ethical problems with overseas trials persisted even after the initial PrEP trials.

In our minds, the broader impacts of making local PrEP stories visible meant highlighting the voices of African researchers who had plenty of epidemiological and other experience that could help to inform the shape of future HIV research. We also felt that it could help to stretch the meaning of research ethics. But we were unprepared for just how sensitive it would be to correct, much less add to, the official story of the initial 2004–05 PrEP trials.

The PrEP debate in Malawi

We constructed a research project that could build on and, more importantly, talk across our very different disciplines and expertise. Folayan best understood clinical ethics and HIV science and Peterson best understood the political economy of global trials. Peterson obtained a National Science Foundation grant and then created research teams in both Nigeria and Malawi where we both had existing professional networks. All six team members had advanced training in their disciplines, which included bioethics, pharmacy, anthropology, and public health. Additionally, all team members were paid at international rates for their expertise and the critical work that each was able to do on the research project; most were coauthors on subsequent publications.

The local team, especially in Malawi, was quite critical in helping to assess the very sensitive politics of PrEP on the ground. Even though both Folayan and Peterson had long-established contacts in Malawi who were familiar with the PrEP debates, folks were keeping quiet about why the IRB approval was denied. The local team had to spend a great deal of time trying to understand what was at stake for both ethicists and research scientists. Once we arrived to spend time conducting interviews and hanging out in offices and research spaces, the doors had clearly been opened up by the local team.

In Malawi, we learned that research scientists and university ethicists (many of whom were also research scientists) engaged in a number of conflicting PrEP discussions for about a year. The researchers worked for a large-scale research center that was owned and operated by foreign universities and used as a site for overseas clinical research. They argued that PrEP was important to developing cutting-edge HIV biomedical solutions. Moreover, they felt that foreign partnerships play a key role in keeping skilled labor employed, bolstering the integrity of public and population health programs, and providing an ‘equalizing effect’ (often via state-encouraged technology transfers through data sharing, publication opportunities, and equipment provisions) between wealthy research institutes and Malawian scientific institutions (Peterson et al. 2015).

While ethicists shared these sentiments, they were worried about the prospect of trial participants developing resistance to the experimental drug, Tenofovir. They were concerned about the fact that in Malawi, a country that provides universal access to antiretroviral treatment for HIV infection, Tenofovir was second-line therapy, the last tool available in the national HIV-treatment policy. HIV-positive patients usually begin with one treatment combination and when HIV becomes resistant to this first-line therapy, the patient will switch to a new HIV-drug combination, or a second-line treatment. If a trial volunteer were to develop a Tenofovir-resistant strain of HIV, no treatment would be available to him or her in Malawi (Peterson et al. 2015).

Ultimately, it came down to a choice between holding on to opportunities for cutting-edge research or defending the integrity of a national HIV-treatment policy – a forced choice made possible in the context of the political-economic location of Malawi’s AIDS research and treatment infrastructures. Even though IRB approval was refused in 2004, two more PrEP studies, each utilizing Tenofovir as part of the study drug, were submitted again in 2009. Both were denied. We wondered what it meant for a Malawian ethics committee to say ‘no’ to PrEP research, not once but three times, and especially when these refusals were made because of Malawi’s existing lack of capacity to execute national AIDS policies.

Our commitment to making visible African researchers’ views of these trials was hampered by what we discovered in Malawi. The PrEP debates were tied to multiple and perhaps even long-standing politics driven by the structural conditions of overseas research, only some of which were clear to us. We suspected that some (although not many) researchers and ethicists chose not to talk to us for two reasons. First, as one ethicist explained to us, foreign research often gets published without the knowledge of the national ethics committee that either approved or did not review a research protocol. For example, as had happened in the past, the minister of health might suddenly get a call from the BBC in London asking about controversial research that took place in Malawi, and the minister might never have heard about that research. Given the sensitive nature of PrEP, our study was playing with fire.

Second, the ramifications of the IRB decision had profound institutional ripple effects even several years after the fact. We chose not to discuss these issues in publications because we knew that there were and could continue to be serious consequences for people's careers. And so we had to rethink what we meant by making visible African researchers' views on HIV clinical research. In this case, the best we could do was highlight a structural conundrum. But we were far less able to discuss contrasting epistemologies that were mediated by various forms of local and extranational institutional power that sustain overseas research agendas.

The polarization of the PrEP debates slowly gave way increasingly to a moral and doctrinal claim made about PrEP within activist–researcher–funder communities: a growing consensus, especially undergirded by its most prominent funder, the Gates Foundation, established that PrEP had to be the next-generation solution for African populations, especially women. In fact, we witnessed how activists who continued to raise questions and concerns over PrEP got discredited in multiple ways especially at international AIDS conferences, and, as we noted in the beginning, we saw how they were depicted as unable to understand clinical research. When we first started this research in Malawi, we wondered why it was the least understood trial site that closed prematurely. But as time passed it became clear that less and less discursive room was available to debate potential unwanted epidemiological outcomes, as scientists in Malawi had done.

We found ourselves in an unusual research situation. We imagined we were making visible concerns of African researchers that would help to understand why the PrEP trials closed prematurely. But the objectives quickly became about unearthing subjugated knowledge that was rapidly disappearing. We worked to gather these stories with advocates from the different sites (Ukpong and Peterson 2009). For Folayan, especially, it became about dedicating time to working with Nigerian AIDS NGOs on developing and increasing ethics and research literacy, from 'knowing your rights' to how to read and interpret a research protocol. Our research alliance, between an anthropologist and a public health academic/dentist, thus extended to include AIDS advocates and African researchers who had extensive experience with PrEP and other clinical trials. It became about documenting stories that were either not being told or were being entirely rewritten. We discovered that attempting to share these stories encountered their own political difficulties.

The PrEP debate in Nigeria

In Nigeria, we actively participated in the PrEP discussions taking place on the AIDS Eforum; spent time with NHVMAS members listening to their analyses of PrEP, their stories of clinical research, and their takes on ethics; and heard their opinions on what kind

of studies are needed for neglected local biologies. Unlike Malawi, where we had to piece together ‘what happened’, we were involved with the Nigerian PrEP debates as they were happening in real time.

Unlike most others on the Eforum, NHVMAS was already very familiar with the trial. The organization had held a National Advocates Meeting on New HIV Prevention Technologies in Nigeria in Abuja, Nigeria, in May 2004. Attendees included HIV-prevention researchers working in the country, ethicists, community advocates, policy makers, regulatory agency staff, and journalists. Also in attendance was the Nigerian PI for the proposed Tenofovir PrEP trial to be conducted by Family Health International and administered by the College of Medicine, University of Ibadan, in Ibadan, Nigeria (Ukpong and Falobi n.d.). All of them presented on the progress of their HIV-prevention trials. The PrEP trial PIs’ presentation generated discussion on the use of existing antiretroviral drugs for HIV prevention, including questions about potential drug resistance. The PI assured meeting attendees that findings of the phase I study showed good and promising results. NHVMAS attempted to obtain more information without success.

Three months later, tension over PrEP erupted on the AIDS Eforum. Several members of the listserv, which also included members of NHVMAS, asked to view the trial protocol, knowing that FHI key workers were members of the Eforum. Instead of supplying the protocol, FHI responded by attempting to reassure forum participants that the PrEP study ‘has been designed according to the most ethical international standards, and with stringent review within Nigeria’.⁵ It was also stated that those who became HIV positive on the trial would be referred to treatment sites. The responses to these statements were instant. Participants reported having little trust in most African ethics review boards, and they highlighted well-known health care system referral problems, which aroused a lot of anger. As a result, more detailed requests came up on the listserv that pertained to community preparedness, care of trial subjects, study design/rationale and implementation, and the informed consent process. Some participants we knew posted about their personal stories of past clinical trial abuses (see also Folayan, Peterson, et al. 2015). These were meant to appease and ensure FHI and the PIs that there were ways to learn about the details of the trial without jeopardizing participant confidentiality. Despite these pleas, FHI did not hand over the official trial protocol or the informed consent document forms. Members of NHVMAS turned to colleagues at SIDACTION, a Paris-based AIDS NGO that at the time funded literacy training on clinical research in African countries. SIDACTION did not have the protocol. But it asked colleagues at Réseau sur l’Ethique, le Droit et le Sida (REDS), an

⁵ Posted to the Eforum by Beth Robinson on 13 September 2004.

AIDS advocacy organization based in Douala, Cameroon, for the protocol. REDS was able to locate it and shared it with NHVMAS.

After analyzing the documents, the scientists and ethicists at NHVMAS produced a list of concerns, which they sent via private communication to the PrEP PI and IRB at the University in Ibadan in October 2004. In brief, the concerns focused on: a) disagreement over the protocol's safety profiles; b) the use of Tenofovir pills instead of a Tenofovir vaginal gel (Tenofovir needs to be taken daily in pill form, and NVHMAS could show evidence that an analogous uptake of a daily contraceptive pill was very low in Nigeria; even if Tenofovir was efficacious as a prevention technology, NHVMAS felt that it would not be widely used); c) the adverse effects scale, a categorized breakdown of low-to-high health problems related and unrelated to the trial, was disputed in terms of when a participant should be withdrawn from the study if problems arise in an already health-compromised population; d) the lack of preclinical data on Tenofovir drug resistance in HIV-negative individuals and that drug resistance was not being monitored in the trial; e) malarial coinfection was not monitored, yet NVHMAS felt there was a need to understand the role of malaria and anti-malarial drugs with an antiretroviral like Tenofovir; f) the lack of care provided to trial participants who seroconverted during the trial, as both NHVMAS and Eforum members argued that referrals did not lead to actual treatment; g) no female condoms were provided to trial participants; h) the lack of post-trial follow-up of research participants, given the slight potential for liver failure and other side effects; i) the lack of community advocates involved in monitoring the trial; and j) the lack of any memo of understanding with the government of Nigeria, and agreement on future distribution if Tenofovir PrEP was found to be effective (Ukpong and Falobi, n.d.).

In October 2004, the University of Ibadan's IRB agreed to make changes to the trial protocol, which satisfied NHVMAS. But FHI did not take action. It offered no comments during this discussion between the university and NHVMAS, and no parties ever met face to face. In March 2005, NHVMAS drafted another letter to the university IRB requesting the same protocol modification. Even though it claimed that future HIV-prevention trials were important and needed to be pursued, NHVMAS argued that the Tenofovir PrEP trial was 'not necessary' because the evidence to support it was not strong enough to warrant its implementation in Nigeria. Two days before the letter was sent, FHI shut down the trial claiming it 'determined that the study team was unable to comply with the required operational and laboratory procedures at the level necessary for conducting this study' (Singh and Mills 2005).

We interviewed one person working on this arm of the PrEP trial who concurred that there were several problems with trial implementation. We consulted Nigerian clinical trial

regulatory officials at the National Agency for Food and Drug Administration and Control (NAFDAC) to substantiate whether the irregularities to which FHI referred were standard in clinical trials in Nigeria. NAFDAC claims that during their three PrEP trial monitoring visits, no in-process reports were made available to NAFDAC. Both Nigerian and US federal drug regulatory agencies use and require these documents for official monitoring of clinical trials from start to finish. Because they were unavailable to NAFDAC, the regulatory agency was unable to monitor the trial. It is entirely possible that documents were submitted by FHI to NAFDAC, but when we asked FHI for its final report submitted to NAFDAC, none was forthcoming. NAFDAC claimed that FHI never submitted a final document explaining why the trial closed prematurely and for that reason did not know why the trial was shut down. Over the years at conferences, we witnessed members of PrEP international public-private consortia echo FHI's reasons for shutting down the Nigerian trial site. In this sense, FHI's reasons silenced the Nigerian discussions raised about the trial that were critical of the ways overseas trials are managed. It also disregarded NAFDAC's regulatory authority governing clinical trial conduct.

International deliberations over PrEP

After three trial closures (Cambodia, Cameroon, and Nigeria) and another IRB application was denied (Malawi), the Gates Foundation, FHI, and others became concerned about future HIV-prevention research. In May 2005, the International AIDS Society and Gates held a 'consultative meeting' among researchers, ethicists, government officials, and community members (AIDS activists, and potential trial participants such as sex workers, men who have sex with men, and injection drug users) in Seattle, Washington. Ahead of this meeting, the United Nations Programme on HIV/AIDS (UNAIDS) also organized a series of 'regional consultations' in Abuja, Nigeria, Pattaya, Thailand, and Durban, South Africa. We attended the meeting in Abuja, interviewed others who attended meetings in Geneva and Seattle, and studied the documents from these consultations (Collins 2005; UNAIDS 2005; Mellors 2005).

The meetings' objectives were to learn more about trial failure, local community concerns, and ways to move forward on future research. The discussions circled around 'what happened' at each of the sites. All actors had their views, their regrets, their insights, and their newly acquired education (IAS 2005). At the regional meeting in Abuja that we attended, AIDS advocates and some of the PIs from Nigeria, Cameroon, and Ghana presented their own views of what happened. On our end, we helped collate all the data and information from the Nigeria PrEP debates (as well as discussions between the university and NHVMAS), which were presented by Nigerian advocates at the meeting. A significant item of agreement was that there needed to be new ways to incorporate appropriate

community advocates and advisory boards from the beginning to the end of the trial process, so that protocols and clinical ethics can be well monitored.

But by the time that all the ‘stakeholders’ headed to Seattle, the overall tone of the meeting was geared toward a new language of ‘effective partnerships’, which was about getting past the trial closures and ‘working ‘together’ to continue PrEP research (IAS 2005; UNAIDS 2005; Mellors 2005). ‘Working together’ meant getting on board with a new paradigm that sought to accommodate expanded ideas of ethics in the form of ‘community engagement’, which could be newly implemented in protocol designs. Community engagement was important because it included forms and mechanisms for independent community input and monitoring of clinical trials. However, 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 scrutinizing process because such a response disrupts ‘effective partnerships’.

It is important to note that the scientists and ethicists in Nigeria and Malawi who critiqued the protocol did not belong to the public–private partnerships that brought PrEP trials into being. Regardless of the numerous platforms that these scientists and ethicists used (via IRB deliberations in Malawi, the Eforum listserv, the private correspondence between scientists and the university IRB, the UNAIDS Abuja stakeholders meeting, and extensive documentation in Nigeria), their views remained illegible to public–private PrEP partnerships. By the time the Seattle meeting took place, their concerns pertaining to the appropriateness of PrEP for African trial communities began to fade as discourses about activists’, sex workers’, and certainly the African media’s HIV research ‘ignorance’ gained more attention.

Over the last fifteen years, we have attended numerous AIDS- and HIV-prevention conferences. Folayan has especially contributed to the HIV-prevention consortiums by developing new ethics paradigms to be incorporated into trial protocols. She also continues to work with community-based organizations in Nigeria on clinical research ethics. (We have taken what we have learned and applied it to analyses of research ethics during the 2014 Mano River States Ebola outbreak; see for example Yakabu et al. 2014; Folayan, Brown, et al. 2015). As much as this work continues, we still encounter pervasive beliefs echoed by international HIV research scientists at conferences. Some continue to reference the early PrEP trials as a time when activist obstruction and ignorance contributed to research delays; some have gone as far to say that these delays have contributed to countless loss of life (see also Nguyen 2011).

These turns of events have been disappointing if not quite devastating to those who wish to make subaltern scientific knowledge count for something. A critical thing we have had to understand in our research alliance was that revealing a counter-story does not in any way guarantee its prominent location or its disruption to the making of an official story. Rather we have come to recognize that all these stories must be located in broader structures of power, made up of pharmaceutical value, the geopolitics of neoliberal humanitarianism, and the contrasting dreams that African AIDS advocates and research scientists hold for their own futures.

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