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“Let’s say it wears an Ebola Coat, but it’s not Ebola”
The Rhetoric and Politics of Reframing a Vaccine for a Transnational Clinical Trial

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Article abstract

Focusing on how disease, health and vaccine research take on different forms, meanings and interpretations in diverse contexts, we examine the use of rhetoric to recruit people living with HIV in sub-Saharan Africa for an Ebola vaccine clinical trial. Conducted after the West African Ebola outbreak in a country that had not been affected by Ebola, the urgency, relevance and materiality of disease, health and biomedical research takes on different shapes, meanings and understandings. The limitations of multilateral initiatives to address inequalities in associated healthcare and access to essential medicines and vaccines highlight the tensions created when neither local researchers nor patient communities have been involved in the design or planning of the trial, and when the pathologies targeted by experimental technologies are either inappropriate for the people they are aimed at, or unfold without the knowledge of a social consensus.

By deciphering the metaphorical discourse on an Ebola vaccine candidate and the erasure of a viral ontology from the hybrid technology to which it gives rise, we understand that the discourse of clinic staff makes it possible to establish a scientific truth in the service of instrumental productivity: manufacturing consent and recruiting arms for vaccine shots.

In this article, we show that the closure of biomedicine to an esoteric discourse reflects the weakness of science in communicating what it actually does and the techniques it produces. It also addresses the failure of community engagement in the field of emerging infectious diseases.

“Let’s say it wears an Ebola Coat, but it’s not Ebola”

The Rhetoric and Politics of Reframing a Vaccine for a Transnational Clinical Trial

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Keywords: manufacturing consent; community engagement; vaccine clinical trial; Ebola; HIV

Résumé : En se concentrant sur la façon dont la maladie, la santé et la recherche vaccinale prennent des formes, des significations et des interprétations différentes dans des contextes variés, nous examinons l'utilisation de la rhétorique pour recruter des personnes vivant avec le VIH en Afrique subsaharienne dans le cadre d'un essai clinique d'un vaccin contre Ebola. L'urgence, la pertinence et la matérialité des maladies, de la santé et de la recherche biomédicale prennent des formes, des significations et des compréhensions différentes en contexte de post épidémie dans un pays non affecté par Ebola. .Les limites des initiatives multilatérales visant à remédier aux inégalités en matière de soins de santé associées et d'accès aux médicaments et vaccins essentiels soulignent les tensions créées lorsque ni les chercheurs locaux ni les communautés de patients n'ont été impliqués dans la conception ou la planification de l'essai, et lorsque les pathologies ciblées par des technologies expérimentales ne sont soit pas appropriées pour les personnes qu'elles visent, soit se déploient à l'insu d'un consensus social. En décryptant le discours métaphorique sur un candidat vaccin Ebola et l'effacement d'une ontologie virale de la technologie hybride dont elle donne lieu, on comprend que le discours du personnel de clinique permet d'instaurer une vérité scientifique au service d'une productivité instrumentale : fabriquer des consentants et recruter des bras à vacciner.

Dans cet article nous montrons que la fermeture de la biomédecine dans un discours ésotérique dénote de la faiblesse de la communication de la science sur ce qu'elle fait réellement et sur les techniques qu'elle produit. Elle traite également de l'échec de l'engagement communautaire dans le domaine des maladies infectieuses émergentes.

Mots clés : fabrique du consentement ; engagement communautaire ; essai vaccinal ; Ebola ; VIH

The West African Ebola outbreak, which began in December 2013 in the countries of Guinea, Sierra Leone, and Liberia, was declared a Public Health Emergency of International Concern in August 2014. The declaration occurred after the disease had threatened the Global North and spread in several countries. By 2015, a revised research and development (R and D) strategy for infectious threats and pandemics carved a central place for vaccine

development in emergency preparedness and humanitarian response (Henao-Restrepo 2016). Reflecting on ethical practices, and "appropriate" regulation, as well as innovative financing processes, the World Health Organisation (WHO) Roadmap established a more favourable environment for experimentation in the context of epidemics by accelerating R and D processes (Kieny 2018). Decades ago, Canadian scientists developed a special vaccine using a safe virus that can carry the Ebola proteins. This artificial virus, called vesicular stomatitis virus (recombinant VSVs), required a special technique developed at Yale University. The Kikwit strain of the Ebola virus was isolated from a patient during the 1995 outbreak in the Democratic Republic of the Congo. Monkeys given a single shot were shown to be protected through the production of a strong immune response and it worked prophylactically. In 2010, the Canadian government sold the marketing rights of the vaccine to the American biotechnology company, NewLink Genetics, who marketed it to Merck (Graham 2019)

By the beginning of our anthropological fieldwork in September 2018, sixty-one Ebola vaccine trials had been registered on the ClinicaTrials.gov website. As the epidemic waned, emergency research that had been organized for compassionate purposes in the affected countries of Sierra Leone, Liberia and finally Guinea (Maurice 2014; Graham 2019) had given way to more conventional trials aimed at the safety and efficacy of the experimental vaccine candidates. Post-emergency clinical trials were necessary to meet the official (non-emergency) licensure pathway that involved recruiting larger populations and targeting sub-populations (for example, women, children and immunocompromised people) under normal and favourable conditions.

The West African Ebola vaccine trials had blurred the line between conventional and emergency trials, not only because of the continuation of outbreaks after the West African epidemic but also because of the ease with which other clinical trials continue to be set up under the compassionate use of experimental measures (Benton 2018). It became necessary to complete the full range of clinical trials to approve the safety and efficacy of the vaccine beyond emergency use.

Our inquiry into *global vaccine logics* examines the social, political and technological processes and practices of vaccine development and deployment in northern and southern countries. We report here on our ethnographic study of the Canadian African Trial for an Ebola Vaccine (CATEbola),[1] a transnational phase 2/3 clinical trial of the effectiveness of an Ebola vaccine.

The trial was designed to provide evidence of safety and immunogenicity in immunocompromised individuals (specifically people living with HIV (PLHIV)) to support the licensing of the Ebola vaccine candidate by the Food and Drug Administration (FDA). Despite efforts at standardizing a common transnational platform to establish comparability across North and South research sites, we found evidence of ethical variability in the inclusion criterion for recruitment at a Canadian site (David and Mathiot 2021). For example, opportunistic diseases such as Hepatitis B were excluded in the northern site but included in the South where Hep B is far more common; otherwise, recruitment excluding those with Hep B would have tanked. Additionally, the number of white blood cells required for the inclusion of individual subjects in the North was difficult to attain in the southern settings, resulting in the need for multiple screenings for some participants until they obtained the necessary count. We corroborated what others before us, including various researchers and analysts, had found: assumptions in clinical trial protocols of universal biological commensurability are only assumptions, often failing to account for the complex variability in human biology and individual responses to treatment (Lock and Nguyen 2011: 176). So, too, financial remuneration in the offshoring of research designed in the North also came with lower compensation for southern participants (Kingori 2015, David and Mathiot 2021).

Our ethnographic fieldwork in Africa took place over fourteen months, between September 2018 and December 2019. OT, coordinated the anthropological study with assistants: HS and IB. She liaised with the PI of the clinical trial to negotiate a formal position neither inside nor outside the trial. With the clinical workers' confidence, she integrated seamlessly into the trial staff, enabling her to observe various stages of the trial: recruitment, training of staff, clinicians meetings, vaccination, and follow-up. Observation took place at various locations, including the hospital, the clinic, the home of HIV/AIDS study participants, and the office of the PLHIV associations. We recorded the meetings, took notes during medical consultations, and identified key informants for interviews. A total of five cohorts were recruited, starting with HIV- healthy adult participants (Cohort 1) with subsequent cohorts having lower CD4 counts (a biomedical indicator of immune function) and a final adolescent cohort. The fieldwork encompassed participation in trial recruitment and meetings, formal interviews and informal conversations with clinical researchers, participants, and HIV representative associations both within and outside the clinic setting. To obtain a comprehensive understanding

of the experiences of the patients and clinicians and the overall infrastructure of the CATEbola study at the African site, anthropologists OT and HS performed participant observation. Patient informants were selected based on their willingness to participate in a trial cohort and all national clinicians were interviewed. Informal conversations during coffee breaks, meetings or in the waiting room prior to medical consultations or blood screenings were meticulously recorded in OT's ethnographic diary. OT and HS conducted 27 semi-structured interviews with eight staff and 19 patients at the clinical trial site.

The interviews and group discussion fieldnotes, having been transcribed by IB, were imported into NVIVO 11 software. In order to identify emerging themes, as is commonly done in grounded theory analysis, a codebook was developed that captured the themes, with modifications made as new themes surfaced. The codebook was then cross-referenced with both interview data and our observational fieldnotes, for triangulation purposes.

We analyzed the activities and discourse of clinical investigators during vaccine trials and explored how these narratives reconfigure the ontology of the Ebola vaccine, favouring its image as effective and acceptable for the study participants. We suggest that in various domains, including clinical trial laboratory and community perceptions, the vaccine progressively assumes an ontology specific to a new imaginary, understanding, and scientific narratives. This ontology does not always align with the regulated process of standardization. The rationale, objectives and details of the original study design are instead negotiated in the context of local conditions with conceptual "bricolages" (Lévi-Strauss 1962: 27) being used to create narratives that reshape and realign the vaccine's attributes alongside local reasoning, conditions and usage.

Our study crosses epistemological and ontological borders between two major viral contagions and epidemiological and social dramas, namely the eighteen-month West African Ebola epidemic, and four decades of the AIDS pandemic. Although Ebola and AIDS have different pathogeneses, narrative temporalities, and epidemiological and interventional histories (Lauer and Shenton, 2017), they both have been subject to similar social reactions that include discrimination, violence, and stigmatization, which have resulted in a significant reduction in quality of life (Gausset et al. 2012; Davtyan 2014). The experiences of PLHIV with Ebola disease have been poorly described, particularly in the context of vaccine trials and in their everyday lives following the epidemic (Thiongane and Graham 2021).

HIV associations have long worked on and monitored the conditions for inclusion in therapeutic clinical trials of PLHIV (Couderc and Sall 2012). These trials have been marked by controversy and struggle, leaving unresolved ethical concerns about study participation, such as the risk balance of benefits and harms, but also the relevance of the studies in relation to participants given their determinants of health (Bosia 2011). Activists have worked to enable free access to diagnosis, antiretroviral treatments (ARTs) and medical follow-up, and several HIV associations and coalitions advocate for the health, reproduction, gender and sexual rights of PLHIV in West Africa (Nguyen 2005). Initiatives to have expert community groups provide input to medical experiments have taken place, but without guarantee of implementation (Berthé 2013). Moreover, the activities of these associations have changed considerably with the decline in international funding, accompanied by a reduction in actors and preventive actions, and the normalization of AIDS by the biomedical community and international organizations (Benton 2015b; Colvin 2011; Murray 2021; Nguyen 2010).

Social Justice as a Pretext for a Vaccine Trial

The WASite Research Centre, located in one of the first Ebola-free countries in West Africa, was created to collaborate on experimental Ebola vaccine research. Having established an epidemic preparedness program, this site is active in several international clinical trials. Another trial targeting the Ebola Zaire strain overlapped[2] with the CATEbola trial. This, along with a previous study on a multi-filovirus Ebola vaccine, conducted between 2016 and 2018, led to an influx of international funding that provided significant positive externalities, including material and professional infrastructure, that greatly benefitted the Centre. The Principal Investigator led the first antiretroviral drug regimens trial to prevent mother-to-child transmission. For him, conducting an Ebola vaccine trial allowed his country to participate in a global health initiative that was contributing to scientific knowledge production about the vaccine. He echoed the words of a renowned African historian, Joseph Ki Zerbo, when he said, "To sleep on someone else's mat is akin to sleeping on the ground." The principal investigator of the trial emphasized: "If you want others to find solutions for you, you will always be subject to their solutions" (interview conducted on 20 September 2019).

The clinical researcher from WASite acknowledged a desire for autonomy as motivation in their decision to join the Ebola vaccine trial consortium. It is worth noting that the criticism of dependency and the value of autonomy were

the only concerns. A member of an HIV association expressed broader worries about access following the study, fearing that his country and the WASite study team had not negotiated future Ebola vaccine access for the trial participants. Regrettably, the man passed away in a car accident a mere three months after he had signed the consent form for the study and prior to the commencement of the clinical trial.

The PI narratives of ending dependency by collecting data from black bodies manifest throughout African researchers, who welcome the opportunity to contribute to international scientific projects. Asked to identify several key motivators that drive African researchers to participate in international research, a Médecins Sans Frontières epidemiologist one motivator as the opportunity to build local and national institutional capacity. Additionally, the partnerships provide African researchers with an opportunity to enhance their own profiles, thereby turning the clinical trial into a self-promotional tool (Boum 2018). Notably, the activities we observed and the discourses we heard about setting up the transnational clinical trials added other dimensions that complemented Boum's statements.

None of the reasons highlighted by Boum were mentioned in informal or formal interviews; instead, our informants articulated a motivation to co-construct knowledge as equals in the research pursuit.

Still, Community Advisory Boards (CAB), recognized as structures to promote and improve the protection of research participants, are often not sufficiently implemented in many countries (Berthe et al. 2009; Couderc and Sall 2012).

Structural Conditions of the Vaccine Clinical Trial

The majority of participants (65%) were female, single, married or widowed, averaging 50 years of age, and were solely responsible for the well-being of their children or grandchildren. They worked as cleaners, waitresses, or traders. The earliest positive diagnosis of HIV had been made in 2009, and the majority of participants worked as cleaners, waitresses, or traders. Many of the widows worked in the home, supporting their children or grandchildren. The medical files of potential study participants were closely screened. A convocation ceremony was held to celebrate those who met the inclusion criteria. Much work went into this process (around 500 patient files were assessed, their personal history was cross-checked with their CD4 count and viral load, and

in the end, only 10 patients met the inclusion criteria). Much of the clinical trial work for the earliest (healthy) cohort was strategically focused on ensuring the PLHIV were "healthy enough" to participate in the clinical trial by reinforcing positive living, that is, supplementing food and care that could contribute to a higher CD4 count (OT and JG 2021).

Recognized and often described by the medical researchers at WASite as "sensitive" and "stigmatized," the participants were recruited without widespread publicity or the involvement of their representative associations. Instead, PLHIV were approached formally in the hospital where they obtained their routine treatments. In contrast, the MakonaVac Study, the first Ebola vaccine trial conducted at the WASite two years earlier, had carried out a large public communication campaign during recruitment, targeting public health and nursing students, where, notably, PLHIV were included in only one cohort. A member of the mobilization team reported that the National Technical Advisory and Ethics Committee operated under significant pressure to approve the trial due to Ebola's exceptional/emergency circumstances. This led the committee to authorize ethical approval for a study, even though there was insufficient evidence available for a comprehensive review. Social scientists responsible for the mobilization of recruits had knocked on the doors of elected officials and neighbourhood residents surrounding the clinical trial site. Despite the high-profile public campaign, concern arose around the implementation of MakonaVac when the results of the first phase of the study were not disclosed at the onset of the phase 3 trial.

The results of the MakonaVac mobilization were presented during a bi-annual scientific meeting, two years before the implementation of the CATEbola study. At that meeting, the social science team highlighted uncertainties and rumours surrounding the MakonaVac Ebola vaccine. The researchers refrained from reporting any detailed information that could reveal the inclusion of an HIV cohort. The researchers contributed to a knowledge gap and to furthering the lack of acknowledgement of PLHIV as a valuable part of the study and of society.

Importantly, these trials were located in a country where PLHIV still hide their status from the general public in genuine fear of social rejection, stigmatization, and violence given their disease's association with what many consider to be the "deepest evil." People we interviewed included those who took their ARTs in great secrecy, and had experienced countless discriminations,

including banishment, disinheritance, and having their children and property taken away. Some were supporting their HIV-positive children, teenagers and spouses, who often suffered from various physical and mental health depressive disorders. So, the inclusion of undeserving communities in medical research presents significant ethical and medical obligations and challenges. Poverty and crippling stigmatization remain prevalent, as demonstrated by the historical and current therapeutic activism of NGOs and AIDS organizations in the South in their struggle to make ARTs accessible (David and Mathiot 2021; Eboko and Mandjem 2011; Nguyen 2010). The CATEbola clinical trial was framed radically from the previous MakonaVac study in terms of labour and research pluridisciplinarity. The MakonaVac social scientists were excluded from the CATEbola trial, officially on the grounds of the high costs claimed for their expertise. Funding was in the hands of medical teams, and they held the power to manage grant allocation that led to relations of hierarchy between social and medical sciences. When we arrived at the WASite, a sociologist involved in the MakonaVac study expressed concerns about the lack of communication for the CATEbola trial, which was exclusively recruiting HIV-positive individuals. We were informed that a member of the PLHIV association had approached them, concerned that the study could be undermined, given confidentiality issues that might inevitably be raised. The anger was palpable; the sociologists felt that decades of community mobilization work had been for naught and secret testing practices were still taking place. Significant precautions had been taken, more to control rumours and misinformation than to include PLHIV in the clinical research decision-making process.

Clinical trial participants expressed various motivations for participating in the experimentation; some mentioned their expectations of better care and a diagnosis, and the prevention of some unknown disease, while others expected to be injected with a vaccine that cured HIV AIDS. Despite harbouring fear and initially refusing to be injected, one individual reluctantly participated, expressing their motivation through an illuminating metaphor: "I played the dead goat; when a goat is dead it is not frightened by a knife." A physician associated with the study was a particularly charismatic influencer. He successfully persuaded his patients by appealing and gently goading them to take part in the vaccine trial.

In the wake of Ebola, the enrolment of PLHIV operated in a landscape of confidentiality, fear of disclosure, and self-sacrifice.

Defusing Rumours through Artificial Community Engagement

The particular circumstances and contexts for protective measures to ensure the safety and security of HIV community members are seldom included in clinical study designs or in recruitment guidelines. It is as if the study clinicians and investigators had never read the countless publications, research reports, and advocacy on the key importance of community engagement, transparency and trust building (Abramowitz et al. 2015; Faye and al 2018;, Ryan et al. 2019). Responsibility to the PLHIV in the CATEbola trial was taken in its narrowest sense to mean keeping participation in the trial discreet if not secret. Regarding communication, posters were created and disseminated within the confined space of the clinic. The discreet advertisement is justified by the communication officer in the following terms: "*Africans often view clinical trials as experiments that exploit them as guinea pigs. However, the situation is more complicated, we can't execute advertising campaigns akin to those in Europe*." (OT fieldwork journal, WASite 1, 26 September 2018)

Paradoxically, decades of contestation and criticism of the instrumentalization of racialized bodies in pharmaceutical trials in the Global South have resulted in the interiorization and erasure of health communication (Peterson and Folayan 2018). The health professional's general anxiety about clinical trial participation was reinforced by news of a controversial malaria study that involved the release of a genetically modified (GM) strain of the malaria mosquito *Anopheles coluzzi* during the time of the CATEbola trial. Ecology activists opposed to the release of the GM mosquitoes into the environment mobilized a wide sociotechnical debate on genetic manipulation at the national and international levels. Prompted by environmentalists and members of local civil society, they declared that the country has become a laboratory for the "sorcerer's apprentice." The ethics committee suspended the approval of the malaria study. This controversy over the release of genetically modified mosquitoes generated concern among CATEbola trial staff, particularly the head of communications, who believed that "lack of communication and unclear explanations" led to controversies over the malaria study. The potential for such bad publicity needed to be carefully avoided in the CATEbola study. Heightened risk awareness within civil society prompted the clinical researchers to step out of their comfort zones and adopt a more pragmatic approach to communicating about the clinical trial process, particularly when engaging with potential participants they aimed to recruit.

During the recruitment of participants, the CATEbola study suffered from the poor image of Ebola in general. An unpublished social science report

surfaced indicating that people were concerned that the vaccine harboured the virus, underscoring existing fears and sparking conspiracy theories. Notably, these rumours were not specific to the WASite Research Centre and led to the failure of several vaccine trials in the African sub-region (Kummervold et al. 2017).

An initial incident at the onset of the CATEbola study was sparked by a participant's decision to withdraw from the study just as he was about to receive the shot. He complained that PLHIV were being vaccinated to be exterminated and raised concerns about the trustworthiness of both the study and the research team. A few days prior, rumours began circulating within the HIV associations, alleging a secret trial was being conducted on PLHIV. Rumours spread along the corridors of the research centre where the physicians alleviate patients' fears. To defuse the crisis and keep participants in the trial, the research staff wavered between adopting the same protocol used in the Makonavac trial study, which incorporated a crisis management mechanism, and directly engaging in discussion with the HIV associations. The first strategy would involve informing and mobilizing all the administrative and religious authorities, most of whom had not yet been informed about the CATEbola study. Such a strategy would be costly and time-consuming. The second option was chosen. Three months after the start of the vaccine experimentation and the completion of the first cohort, in order to defuse the rumours and prevent any further distrust, the HIV associations were invited to a meeting by clinicians. Per diems were given to participants even though they all lived nearby, and a buffet was set up by the clinical trial team who attended in large numbers to mark the event. All the arrangements were scripted.

The meeting began with a PowerPoint presentation by the clinical researchers, who provided a brief history of the Ebola vaccine, and an explanation of its features and molecular characteristics. The presentation concluded with an outline of the trial's design and objectives. This was the same presentation given to the trial staff a few months earlier during their first training session about the vaccine trial. No effort was made to adapt the contents to this new audience. The clinicians' explanations retained a technical content more appropriate for medical experts than patients. They clarified that the trial targeted patients with the HIV-1 strain, and that clinical trials were taking place in North America, Europe and other African countries. During epidemic times, it was not possible to include HIV patients. Now they had the opportunity.

At the end of the presentation, the head of communications, who was taking pictures and operating the presentation equipment, distributed flyers. He then opened the floor to questions from the audience. The clinicians were confronted with the incomprehension of association members regarding a vaccine trial targeting people with immune deficiencies. Confusion stemmed from the fact that the vaccine in question was not directly related to their HIV condition, coupled with the fear of vaccine-induced infection.

To address inquiries regarding the specific experiences of patients during the Ebola vaccination in Guinea, the clinicians called upon the anthropologist (OT). Being the only one with prior experience confronting the Ebola epidemic in another African country, OT was tasked with fielding questions about the risk of sexual transmission associated with Ebola, particularly among men who have sex with men. Additionally, OT was asked to provide information about the risk of transmission by Ebola survivors. The list of questions was long, and two central concerns emerged. The first centred around the rationale for an Ebola vaccine trial for PLHIV, and the second crystallized the most persistent anxiety and rumour about the vaccine substance itself: its materiality: Does the vaccine contain Ebola? Are vaccinated people injected with the Ebola virus?

Justification of the clinical trial was grounded on the aim of preventing Ebola and on the need to know whether the vaccine prevented PLHIV from getting Ebola. The clinicians explained that the Ebola epidemic does not choose its victim; therefore, it would be unfair and discriminating to vaccinate everyone and exclude PLHIV from the protection of vaccination. In this light, access to vaccination was introduced as a new biotechnology advancing social justice principles of health equity for all.

Throughout the exchange, the study clinician repeatedly explained the trial in multiple allegorical ways, more reminiscent of a litany than an information session:

> You need to know that this vaccine doesn't carry the virus, another virus is used and changed. It's not Ebola virus. Let's say it wears an Ebola coat, but it's not Ebola.
>
> It is trying to kill, you can stand back and see the shape of Ebola, it is a coat, but not really Ebola.
>
> It's a fragment of a chimeric vaccine. (OT fieldwork journal, WASite, 16 December 2018)

The virus anthropomorphism suggests the closeness between human and non-human, while the rhetoric contains the virus in figuration and allows it to remain in a state of debris. During the discussion, a study clinician twice made the Freudian slip of "we inject a virus." He also promised that all participants would be vaccinated after successful competition of the trial and final regulatory approval by health authorities. A colleague cautiously corrected him, emphasizing that they only know what happens in the context of the study and that they do not have control over the future.

Amidst the complex web of concerns and misunderstandings surrounding vaccine experimentation, it becomes evident that the narratives are deeply influenced by specific circumstances and contexts. To delve deeper into the dynamics surrounding vaccine acceptance, it is essential to explore the underlying factors that shape these narratives.

What lies Behind Narratives of Vaccine Acceptance?

Both the implementation of a local research study involving genetically engineered mosquitoes and the CATEbola vaccine trial had actively engaged communities and led to confusion, disputes, and mistrust. At the public presentation of the gene drive research by a medical anthropologist, an entomologist expressed his disappointment to us about the adoption of a top-down approach. This method is recognized as outdated and largely ineffective, he noted. When controversies blew up, the medical anthropologist involved in the gene drive implementation started to plan community engagement, communicating directly to us that he suspected the European political ecology movement had influenced local people. Both this example and the information session organized by the researchers of the CATEbola trial illustrate how local scientific elites misunderstood the capacity of lay people to make their own critical judgement, attributing it instead to activism from the North. These two trials, one about Ebola, and the other about malaria, expose the complexities of transnational pharmaceutical research contexts and reveal the political role clinical scientists in the South play in situating their research.

Both the context and the particular researcher's narratives shape understanding of the vaccine. In scientific publications and explanations, the recombinant vesicular stomatitis virus (rVSV) is well described as a live, attenuated virus, used as a vector system. The rVSV has been widely explored as a promising platform for the development of multiple vaccines (for example,

it is used as a chimeric vaccine for HIV-1). The Ebola vaccine is one of many that have taken advantage of reverse vaccinology and genomics. The most advanced rVSV vector currently in development, for example, is a vaccine against Ebola virus disease in which the VSV glycoprotein (G) is entirely deleted and replaced with the corresponding glycoprotein (GP) of the Zaire Ebolavirus (rVSVΔG-ZEBOV-GP). This vaccine, currently designated V920, is in development by Merck and Co. in Kenilworth, New Jersey, and is in the registration process (Government of Canada 2023). Simply put, the rVSV Zebov contains protein from the Ebola virus, the protein carries the GP gene, and the gene carries heredity, dealing with transmission (Alazard-Dany et al. 2006).

The clinician discourses conveyed several ambiguities that shed light both on the work of translation as the complex entanglement between human and non-human relationships, and epistemic challenges when facing zoonotic disease technologies. While the presence of Ebola can be discussed in a hybrid vaccine technology, discomfort with the rhetoric can result from a lack of North-South cooperation in the scientific vaccine design and the failure to communicate science efficiently.

While most researchers take the objective positivism of the clinical trial study as an authoritative object, we document how clinicians were not only keen to play a role in changing the rules of the clinical trial, but also in the way in which the vaccine was assigned an identity, and serve as platform of new regime of truth (Adams 2013). Although the vaccine trial protocol was designed in the framework of Evidence-Based Medicine, both the recruitment criteria and the trial participants had to be refashioned to fit. Lacking practical and empirical knowledge or experience with Ebola viral disease, the study participants had little relevance for Ebola in their already difficult everyday lives with HIV and all that it entailed socially and physically. The MakonaVac study had included only a few PLHIV and the results have yet to be published by the transnational research team. Indeed, the lack of reporting the results once the data had been collected and sent to the investigators outside of Africa may signal some trouble with time, space, and context. While study results circulated among local study team members, they did not participate in any subsequent analyses. So, too, this vagueness surrounding the study details and the results lingered for the participants even when the trial was over.

It seems the case that the majority of clinical study teams include the southern partner only partially, usually in relation to its local feasibility and on issues that may be perceived as spurious in terms of study implementation.

Scholars highlight the divide in North/South research partnerships, noting that the South often provides sites and raw materials while the North funds, analyzes and owns the data and determines how it will be used and commercialized in the advancement of knowledge and health (Pollock 2019). During one meeting among clinical trial researchers, the coordinator of the study stated: "Even if it is contrary to our reasoning, we give them what they want to be quiet." This attitude of service provider gives the North authoritative avenue to command and the South to obey, even if a range of alternative strategies might be deployed to situate the clinical trial locally. Bringing that research back to improve the circumstances in the communities from which it came is, at best, an afterthought.

Issues of equivalent epistemologies in the design of transnational clinical trials are only discussed informally, and even though this is at the local level, difficulties in adapting international knowledge to the biological realities of southern patients are striking (Thiongane and Graham 2021). The meeting brought out a narrative surrounding the Ebola vaccine that captures both the role of African clinicians in the imaginary of vaccine technologies and the communications that manufacturing consent to on behalf of innovative biopharmaceutical companies (Herman and Chomsky 2011).

The metaphorical discourse of an Ebola vaccine was a way of constructing social distancing with Ebola itself. Local people saw this vaccine as competing for resources in a time of Ebola or its aftermath. Community engagement was only brought in as a last resort when rumours threatened patient recruitment. By doing so, clinical trial staff ensured the acceptability of an Ebola vaccine by giving attributes that make it accessible to human perception and depicting the vaccine as an "ecological charismatic" technology (Lorimer 2007). In fact, for this community, Ebola remains in the shadows of HIV.

Many study participants experienced significant discomfort from not only the fear of disclosure and stigmatization fueled by their HIV status but also by another highly stigmatized disease, Ebola, that had uncertain sexual transmission. Some provided testimony about their expectation for an HIV vaccine, challenging the staff as they replaced those expectations with an undesirable and unwanted object. The claim that "the vaccine doesn't contain the Ebola virus" strengthened the persuasive power of the study team to meet recruitment objectives and instill trust while awkwardly invalidating the fears of the vaccine as a necropolitical instrument (Gomez-Temesio and Le Marcis 2017). The study staff's objective was to convince the PLHIV of the acceptability

of the experimental vaccine to be injected. The rhetoric called upon in the CATEbola trial reconnected with Ebola vaccine as a local anthropomorphic chimera, a new hybridity (Nading 2015), a vaccine utopia connected to the staff's own representations.

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Notes

The area of study, the site, and all names are anonymized to maintain and respect confidentiality.

1 CATEbola is a pseudonym for the clinical trial that we followed during our fieldwork. MakonaVac study is the previous Ebola vaccine trial conducted before the CATEbola trial.

2 We use a pseudonym to protect the confidentiality of study participants and clinical trial staff.

References

Abramowitz, Sharon Alane, Kristen E. McLean, Sarah Lindley McKune, Kevin Louis Bardosh, Monger Fallah Mosoka , Josephine Kodjo Tehoungue, Patricia A. Omidian. 2015. "Community-Centered Responses to Ebola in Urban Liberia: The View from Below." *PLOS Neglected Tropical Diseases* 9 (4). https://doi.org/10.1371/journal.pntd.0003706.

Adams, Vincanne. 2013. "Evidence-Based Global Public Health: Subjects, Profits, Erasures." In *When People Come First: Critical Studies in Global Health*, edited by Joao Biehl and Adriana Petryna, 54–90. Princeton: Princeton University Press.

Alazard-Dany, Nathalie, Michèle Ottmann Terrangle, and Viktor Volchkov. 2006. "Ebola et Marburg : les hommes contre-attaquent." *Médecine/Sciences* 22 (4): 405–410. https://doi.org/10.1051/medsci/20062244405.

Benton, Adia. 2018. "Why We Should Be Cautious about the 'Game-Changer' Ebola Vaccine." *Aljazeera*, 30 May. https://www.aljazeera.com/opinions/2018/5/30/why-we-should-be-cautious-about-the-game-changer-ebola-vaccine (accessed 23 May 2023).

Benton, Adia. 2015b. *HIV Exceptionalism: Development through disease in Sierra Leone*. Minneapolis: University of Minnesota Press.

Berthé, Abdramane, Nicolas Meda, Isidore T. Traoré, Jérôme Some, Souleymane Salouka, Lalla Sanou, Felicien Some, Jeremy Rouamba, Djenaba Ouedraogo, Gilles M'Boutiki, Philippe Mayaud, Nicolas Nagot, Philippe Van de Perre. 2009. "Preparation for HIV Vaccine Trials in Africa: Barriers and Facilitators for the Establishment of a Community Advisory Board in Burkina Faso." *Retrovirology* 6 (3) (22 October): 226. https://doi.org/10.1186/1742-4690-6-S3-P226.

Bosia, Micheal. 2011. "SIDA et politiques postcoloniales. Act-up face à la science et à l'idéologie universaliste en France." In *Les Suds face au SIDA: quand la société civile se mobilise*, edited by Fred Eboko, Frédéric Bourdier and Christophe Broqua, 333–369. Marseille: IRD.

Boum II Yap. 2018. "Is Africa Part of the Partnership?" *Medicine Anthropology Theory* 5 (2). https://doi.org/10.17157/mat.5.2.527.

Colvin, Christopher J. 2011. "HIV/AIDS, Chronic Diseases and Globalization." *Globalization and Health.* 7 (1): 31. https://doi.org/10.1186/1744-8603-7-31.

Couderc, Mathilde and Caroline Desclaux Sall. 2012. *Du patient au réseau : construction de la dynamique communautaire*. Dakar. https://halshs.archives-ouvertes.fr/halshs-00712808/document.

David, Pierre-Marie, Benjamin Mathiot, Oumy Thiongane, Janice E. Graham. 2021. "Under Consent: Participation of People with HIV in an Ebola Vaccine Trial in Canada." *BMC Medical Ethics* 22 (1): 42. https://doi.org/10.1186/s12910-021-00606-6.

Davtyan, Mariam, Brandon Brown, and Morenike Oluwatoyin Folayan. 2014. "Addressing Ebola-related Stigma: Lessons Learned from HIV/AIDS." *Global Health Action* 7 (1): 26058. https://doi.org/10.3402/gha.v7.26058.

Eboko, Fred and P.Y. Mandjem. 2011. "ONG et associations de lutte contre le sida en Afrique : incitations transnationales et ruptures locales au Cameroun." In *Les Suds face au sida : quand la société civile se mobilise*, edited by Fred Eboko, Frédéric Bourdier, and C. Broqua, 205–230. Marseille: IRD. http://www.documentation.ird.fr/hor/fdi:010051858.

Faye, Sylvain, Birane Landry, Waly Diouf, Papa Ndiaga Cisse, Alexandre Quach, Malick Minkael Sylla, Moussa Makalo Koita, Simon Gbanamou, Billy Sivahera Muyisa, Éric D'Ortenzio, Abdoul Habib Beavogui. 2018. "Engager (avec) les communautés dans un essai vaccinal en contexte post-Ebola (Guinée Conakry) : un modèle basé sur les 'champions'." *Sciences et Actions Sociales* 10 (2): 112–141. https://doi.org/10.3917/sas.010.0112.

Gausset, Quentin, Hanne Overgaard Mogensen, Maurice Evariste Yameogo Wambi, Berthé Abdramane, and Konaté Blahima. 2012. "The Ambivalence of Stigma and the Double-Edged Sword of HIV/AIDS Intervention in Burkina Faso." *Social Science and Medicine* 74 (7): 1037–1044. https://doi.org/10.1016/j.socscimed.2011.11.044.

Gomez-Temesio, Veronica and Frédéric Le Marcis. 2017. La mise en camp de la Guinée : Ebola et l'expérience postcoloniale. *Homme* 222: 57–90. https://shs.cairn.info/revue-l-homme-2017-2-page-57?lang=fr

Government of Canada. 2020. *National Advisory Committee on Immunization Interim Statement on the Use of the rVSVΔG-ZEBOV-GP Vaccine for the Prevention of Ebola Virus Disease*. Government of Canada. https://www.canada.ca/en/public-health/services/publications/vaccines-immunization/interim-statement-vaccine-prevention-ebola-virus-disease.html.

Graham, Janice E. 2019. "Ebola Vaccine Innovation: A Case Study of Pseudoscapes in Global Health." *Critical Public Health* 29 (4): 401–412. https://doi.org/10.1080/09581596.2019.1597966.

Henao-Restrepo, Ana Maria, Marie-Pierre Preziosi, David Wood, Vasee Moorthy, and Marie Paule Kieny. 2016. "On a Path to Accelerate Access to Ebola Vaccines: The WHO's Research and Development Efforts during the 2014–2016 Ebola Epidemic in West Africa." *Current Opinion in Virology*, 17: 138–144. https://doi.org/10.1016/j.coviro.2016.03.008.

Herman, Edward S. and Noam Chomsky. 2011. *Manufacturing Consent: The Political Economy of the Mass Media*. Knopf Doubleday Publishing Group.

Kingori, Patricia. 2015. "The 'Empty Choice': A Sociological Examination of Choosing Medical Research Participation in Resource-Limited Sub-Saharan Africa." *Current Sociology* 63 (5): 76378. https://doi.org/10.1177/0011392115590093

Kummervold, Per Egil, William S. Schulz, Elizabeth Smout, Luis Fernandez-Luque, and Heidi J. Larson. 2017. "Controversial Ebola Vaccine Trials in Ghana: A Thematic Analysis of Critiques and Rebuttals in Digital News." *BMC Public Health* 17 (1): 642. https://doi.org/10.1186/s12889-017-4618-8.

Lauer, Helen and Joan Shenton. "Counterproductive Contributions to African Epidemiology." 2017. *Madridge Journal of Immunology* 1 (1): 28–39. https://doi.org/10.18689/mjim-1000108.

Lévi -Strauss, Claude. 1962. *La pensée sauvage*. Paris: Editions Plon.

Lock, Margaret, and Vinh-Kim Nguyen. 2011. *An Anthropology of Biomedicine*. 2nd edition. Oxford: Wiley Blackwell

Lorimer, Jamie. 2007. "Nonhuman Charisma." *Environment and Planning D: Society and Space* 25 (5): 911–932. https://doi.org/10.1068/d71j.

Maurice John. 2014. "WHO meeting chooses untried Interventions to defeat Ebola." *The Lancet* 384 (9948): e45-e46.

Nading, Alex M. 2015. "Chimeric Globalism: Global Health in the Shadow of the Dengue Vaccine." *American Ethnologist* 42 (2): 356–370. https://www.jstor.org/stable/43867914

Nguyen, Vinh-Kim. 2005. "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship." In *Global Assemblages. Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier, 12444. Malden: Blackwell Publishing.

———. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham: Duke University Press.

Peterson, Kristin and Morenike Oluwatoyin Folayan. 2018. "Ethics and HIV Prevention Research: An Analysis of the Early Tenofovir PrEP Trial in Nigeria." *Bioethics*, https://doi.org/10.1111/bioe.12470.

Pollock, Anne. 2019. *Synthesizing Hope: Matter, Knowledge, and Place in South African Drug Discovery*. Chicago: University of Chicago Press.

Ryan, Molly J., Tamara Giles-Vernick, and Janice E. Graham. 2019. "Technologies of Trust in Epidemic Response: Openness, Reflexivity and Accountability during the 2014–2016 Ebola Outbreak in West Africa." *BMJ Global Health* 4 (1): e001272. https://doi.org/10.1136/bmjgh-2018-001272.

Thiongane, Oumy and Janice Graham. 2021. "Who's Positively Healthy Enough for an Ebola Vaccine Trial in West Africa?" In *Beyond the Endgame: Living with HIV in Post Crisis Times*, edited by David Murray, 105-121. Washington: Lexington Books.