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Protection, health seeking, or a *laissez-passer*: Participants' decision-making in an EVD vaccine trial in the eastern Democratic Republic of the Congo

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ABSTRACT

During the 10th Ebola virus disease (EVD) epidemic in the eastern Democratic Republic of the Congo (DRC) (2018–2020), two experimental EVD vaccines were deployed in North Kivu. This province has been at the centre of conflict in the region for the last 25 years. Amidst ambivalence towards protracted foreign intervention and controversy about introducing two experimental vaccines, the existing literature has focused on mistrust and 'resistance' towards the Ebola response and vaccines. In this article, we examine why people in the eastern DRC *did* decide to volunteer for a trial of a second EVD vaccine in North Kivu, despite the controversy. Drawing on ethnographic observation, interviews, and focus groups with trial participants conducted between September 2020 and April 2021, we analyse three motivations for participating: protection, health seeking, and expectations surrounding travel requirements. We make three points. First, participation in vaccine trials may be understood locally to have advantages which have not been considered by the trial, because they go beyond medical considerations and are specific to a particular social setting. Second, despite much of the literature focusing on a causal relationship between rumours and 'vaccine hesitancy', some rumours may in fact *encourage* participation. Third, material objects associated with trial participation - such as participant vaccine cards - can hold social and political meaning beyond the confines of the vaccine clinic, and influence decisions surrounding participation. Empirical investigation of how medical interventions become entangled in political economies is essential to understanding the perceived *functions* of participation, and thus the reasons why people volunteer in clinical trials. Participants' narratives about their decision-making provide an insight into how international bioethical debates interact with, but may also stand apart from, the situated social and economic realities driving decision-making around clinical trials on the ground. This highlights the need for ethical approaches that foreground the political, social, and economic context.

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1. Introduction

Between 2018 and 2020, the second largest Ebola virus disease (EVD) epidemic unfolded in the eastern Democratic Republic of the Congo (DRC), resulting in 3481 cases and 2287 deaths. The epidemic began in North Kivu, a province in the eastern DRC which has been at the epicentre of conflict in the region for the last 25 years. The epidemic response was led by the Congolese government with support from international organisations led by the World Health Organisation (WHO). Two experimental EVD vaccines were deployed in North Kivu. The first vaccine, manufactured by Merck, was employed as part of a ring vaccination strategy to vaccinate contacts of EVD cases and healthcare workers in the epicentre of the epidemic. In November 2019, a second vaccine, manufactured by Johnson & Johnson, was trialled in Goma, the capital of North Kivu, which had only seen a few EVD cases. The aim of the second vaccine was to evaluate effectiveness of the vaccine against EVD and to create a protective 'curtain' by vaccinating people near but outside the outbreak zone (Watson-Jones et al., 2022).

The proposal for introducing a second vaccine sparked fierce debate about medical ethics in epidemic contexts (James et al., 2021; James and Lees, 2022). Whilst the WHO's vaccine advisory committee urged that other vaccine trials be conducted in the DRC with different target populations and eligibility requirements to enable more people to be vaccinated for EVD (SAGE, 2019), the Congolese Minister of Health at that time opposed the idea of deploying a second vaccine in the outbreak zone, arguing that it would 'confuse' the population. The minister accused the backers of a second trial of having no 'respect for ethics,' lobbying for their own interests without government support. This debate fed popular critiques in the eastern DRC that the epidemic was simply a business opportunity for responders to enrich themselves, and for pharmaceutical companies to test new vaccines (LUCHA, 2019; Bisoka et al., 2021). Despite the contentious debate, at the end of 2019, over 20,000 people had volunteered to participate in the DRC-EB-001 vaccine trial in Goma.

In this article, we examine the motivations for participating in the DRC-EB-001 EVD vaccine trial in a climate of distrust towards external intervention and controversy surrounding vaccine research. Drawing on ethnographic fieldwork, our approach focuses on the lived experience of 'post-colonial techno-science' (Fairhead et al., 2006). Our aim was not to assess the informed consent procedures of the trial, but to delve into individual participants' own reflections on their motivations for participating, which provide an insight into how biomedical protocols interact with political and economic realities in contexts of insecurity and uncertainty.

There were three key motivations for participating in the EVD vaccine trial. The first was protection: trial participants wanted to protect themselves from the ongoing epidemic, but also potential future Ebola outbreaks. The second motivation was access to free healthcare offered by the trial. Participation was seen as an exchange: participants described balancing the risks of receiving an experimental vaccine in exchange for the benefits of free medical care. Third, trial participants joined the trial because of the widespread belief that the EVD vaccination was already, or would soon become, essential to cross borders and to travel within DRC. These concerns surrounding mobility were shaped by experiences of containment during the epidemic.

Drawing on these participant narratives, we make three points. First, participation in vaccine trials may be understood to have advantages which have not been considered by the trial, because they go beyond medical considerations and are specific to a particular social setting. Second, despite an assumed relationship between rumours and 'vaccine hesitancy', some rumours and subjective assessments may in fact *encourage* participation. Third, material objects associated with trial participation - such as vaccine cards given to participants - can hold social and political meaning beyond the confines of the vaccine clinic, and influence decisions surrounding participation. To better understand why people volunteer in clinical trials, it is necessary to examine how medical research becomes entangled in specific political economies. Trial participants' narratives provides an insight into how international bioethical debates interact with, but may also stand apart from, the situated social and economic realities driving decision-making around clinical trials on the ground. This reemphasizes the need for ethical approaches that focus on political, social, and economic context (Tengbeh et al., 2018).

2. Methods

The DRC-EB-001 EVD vaccine trial (trial registration number NCT04152486) took place in Goma between November 14, 2019 and February 9, 2021 and was conducted by a consortium comprised of the *Institut National de Recherche Biomédicale*, the Congolese Ministry of Health, the London School of Hygiene and Tropical Medicine, Janssen Vaccines and Prevention B.V, Epicentre, *Médecins Sans Frontières* France, the Coalition for Epidemic Preparedness Innovations, Wellcome and World Vision. The trial was a non-randomised, open-label, single arm evaluation of the effectiveness, safety, and immunogenicity of a heterologous two-dose (Ad26.ZEBOV, MVA-BN-Filo) vaccine for prevention of EVD in adults and children aged 1 year or above. Phase 1 of the trial was conducted at six vaccination sites in two health areas of Goma, Majengo and Kahembe. These areas were selected based on their potential risk of EVD transmission given family and business links between these areas and the epidemic epicentre in the Grand Nord (Watson-Jones et al., 2022). All adults and children aged one year or above, including pregnant and breastfeeding women, were invited to participate in the trial. In April 2020, dose 2 vaccination in Goma was suspended for five months to prevent potential COVID-19 transmission in the vaccination centres. Vaccination restarted in Goma in September 2020 to ensure all existing participants could receive their second dose. The trial added an immunogenicity sub-study to assess the impact of the delayed second dose (Watson-Jones et al., 2022).

This article is based on ethnographic research conducted between September 2020 and April 2021, led jointly by the first and last author. The aim was to better understand perceptions and experiences of the EVD vaccine trial in Goma. Central to this was understanding why people volunteered. We conducted 45 interviews and 5 focus groups with trial participants, as well as 3 focus groups with citizens who were not participants of the trial, and 8 in-depth interviews with political and health authorities. All participants provided written informed consent. The conversations were carried out in Swahili or French and subsequently recorded and transcribed. All names have been changed. Swahili transcripts were translated into French, and Author 1 led thematic analysis of the French transcripts. Ethics committee approval provided by the London School of Hygiene and Tropical Medicine, *Médecins Sans Frontières*, the *Avis du Comité National d'Ethique de la Santé* and *Le Comité D'Ethique, Université de Kinshasa*. While James, Kasereka and Lees (2021) explore local controversy surrounding this trial and James and Lees (2022) examine the impact of the COVID-19 pandemic, this article focuses on understanding why people volunteered.

3. Decision-making around medical research

Discussion of public attitudes towards biomedical interventions is often framed in terms of 'hesitancy' and 'acceptance' (Vanderslott et al., 2022; Schneider-Kamp, 2022). The concept of 'ignorance' has historically been used to explain public 'hesitancy' (Nichter, 1995). In this framing, a supposed lack of scientific knowledge explains hesitancy: the cure is better 'communication' or 'public engagement' (Sturgis and Allum, 2004). This idea of knowledge 'deficit' has been widely critiqued (Geissler and Pool, 2006; Vanderslott et al., 2022; Chandler et al., 2015), as anthropological and historical approaches highlight how biomedical interventions can only be understood in political, social, and economic context (Enria and Lees, 2018; Geissler and Molyneux, 2017).

A broader body of work explores the social and political

'determinants' of mistrust (Larson, 2013; Blair et al., 2017). Rumours or misinformation are not manifestations of ignorance, but can instead be understood as vehicles of resistance in times of upheaval (Feldman-Savelsberg et al., 2000), or 'modern commentaries' on the workings of power in peoples' daily lives, including those embedded in medical research itself (Geissler and Pool, 2006, 980; White, 2000). Medical interventions are intimately entwined with political dynamics and understood in relation to them: attitudes towards vaccines and clinical research, for example, are shaped by state-society relations, imperial and post-colonial histories of medical violence, and contemporary geopolitical inequities (Tilley, 2011; Geissler, 2005). Clinical trials can also become new arenas for articulating broader concerns about inequality, exclusion, and social justice (Enria and Lees, 2018; Fairhead et al., 2006).

Yet, amidst recent public controversy about vaccine trials in the Global South (Tilley, 2020), fewer studies have examined why people *do* participate in clinical trials, especially in the context of widespread mistrust of foreign intervention (Tengbeh et al., 2018). 'Acceptability' is assumed to be 'common sense', the result of 'effective' communication, or passivity in the face of authority (Nichter, 1995). It is important to understand decision-making around clinical research because it is key to bioethical conceptions of informed consent. However, this requires looking beyond 'local acceptability' of medical procedures, to consider how clinical trial protocols 'interact with the realities of political economy in the places where they occur' (Fairhead et al., 2006, 1119; Tengbeh et al., 2018; James et al., 2021). For instance, financial rewards and free access to healthcare offered by a clinical trial can encourage people to volunteer (Mtunthama et al., 2008; Geissler, 2011). Consequently, anthropologists have argued for the importance of placing bioethics in their political and economic context, revealing the complexities of voluntariness amidst stark inequalities (Fairhead et al., 2006; Molyneux and Geissler, 2008).

Yet, motivations for participating in a clinical trial are more complex than financial gain or access to health services. For instance, ethnographic studies in Sierra Leone and Tanzania examine how engagement with clinical research is motivated by notions of materiality and exchange, but also curiosity and hope (Lees and Enria, 2020). Participation can become a means to perform notions of citizenship and to discuss the uncertainty of the present or hope for the future (Lees and Enria, 2020). In an EVD vaccine trial in Sierra Leone, for example, participants hoped for material rewards such as employment, but also for a public ceremony where they would be recognised for their sacrifices. Beyond access to free healthcare, people joined the trial because of beliefs that the vaccine itself symbolised good health (Tengbeh et al., 2018). Therefore, to better understand participant decision-making, there is a need to 'take seriously fears and perceptions of risk alongside notions of hope, altruism and expectations of exchange' (Tengbeh et al., 2018, 41). Given that attitudes towards clinical interventions are socially situated, these studies call for grounded research ethics which consider 'subjective assessments and local context' (Tengbeh et al., 2018:41).

In this article, we examine why people put themselves forward for a *second* experimental vaccine during an ongoing EVD epidemic, in an area that, at the time of the trial, that had experienced few cases. The question of decision-making is particularly salient in a context of epidemic 'emergency', when questions are raised about the ethics of medical research during outbreaks (Tengbeh et al., 2018). Indeed, the DRC-EB-001 EVD trial sparked international debate about the ethics of deploying multiple experimental vaccines in an outbreak (Monrad, 2020). Amidst existing distrust towards protracted foreign intervention and the central state, 20,000 people nonetheless volunteered for a second experimental vaccine that had sparked intense political controversy about the ethics of Western biomedical research in Africa. Participants' reflections provide a crucial insight into how these broader bioethical debates may influence but also remain remote from, the situated social realities motivating participation in clinical trials on the ground. This highlights the importance of understanding social, political, and economic contexts for ethical debates about clinical research (Tengbeh et al., 2018).

4. The 10th EVD epidemic in DRC

4.1. The response

The DRC-EB-001 EVD clinical trial took place in a setting of widespread mistrust of EVD epidemic response, historically strained state-society relations, as well as the contentious politics of international intervention. DRC has experienced recurrent EVD epidemics since the virus was discovered in the country in 1976. In 2018, the country's 10th EVD epidemic unfolded in Ituri, North Kivu and South Kivu provinces, in a context of political tensions and protracted insecurity. Eastern DRC has been at the centre of prolonged violent conflict since the 1990s. After Rwandan refugees fled across the border to the Kivu provinces, in 1996, a Rwandan-backed rebellion invaded and overthrew President Mobutu. The second war began when the new government expelled its Rwandan backers. The conflict escalated to involve eight countries and more than twenty-five armed groups. Although the war officially ended in 2003, violence has continued, with several armed rebellions: the *Congrès National pour la Defense du Peuple* (CNDP) between 2006 and 2009, and *Mouvement du 23-Mars* (M23) between 2012 and 2013, and most recently, since 2021. Today, the region is home to over one hundred armed groups. Eastern DRC became a regional hub for international NGOs and the UN's largest peacekeeping mission, which have radically reshaped the political economy (Buscher and Vlassenroot, 2010).

The EVD epidemic exposed and exacerbated existing distrust towards the state and foreign intervention, linked to the region's history of political marginalisation as well as contemporary violence (Groupe d'étude sur le Congo, 2020). The epidemic began in the Grand Nord territories of North Kivu, an opposition stronghold. Since 2014, there have been frequent attacks against the population by the rebel group the Allied Democratic Forces, leading to local discontent at the inability of the government forces or the UN's largest and most expensive peacekeeping mission to provide security. This has led to critique of the political economy of foreign intervention in the region, amidst continued insecurity for civilians and lack of state investment in services (Bisoka et al., 2021). In a context where attacks continue against civilians and basic services are underfunded, the introduction of a well-funded EVD response (approximately $1.2 billion) led by outsiders led to the impression that the disease was simply a business: a ploy to make money (Bisoka et al., 2021). The difference in salary between staff from abroad and from the capital, Kinshasa, compared with locally employed people, as well as instances of corruption, gave the impression that the response aimed to benefit intervenors rather than local populations. There was a widespread belief that responders had incentives to prolong the outbreak, or even invent EVD altogether to enrich elites and international NGOs (Bisoka et al., 2021; Groupe d'étude sur le Congo, 2020). The epidemic also unfolded at a particularly tense political moment. After long-delayed elections were then cancelled in EVD-affected areas, many in the region concluded that Ebola was a political invention to prevent the opposition stronghold from voting (Bisoka et al., 2021; Groupe d'étude sur le Congo, 2020). The suspicion and unrest prompted local opposition to the response, including attacks on treatment centres and responders.

4.2. Two vaccines

Within two weeks of the declaration of the epidemic, the Congolese Ministry of Health and the WHO began administering the experimental vaccine manufactured by Merck (rVSV-ZEBOV), which had not yet been licensed but had been shown to be protective in trials in West Africa. It was used under a 'compassionate use' protocol which allows for unlicensed treatments to be administered when there is no better alternative (Kelly, 2018). The vaccine was used in a ring-vaccination strategy,

vaccinating healthcare workers and close contacts of someone diagnosed with EVD. However, the case count continued to rise. By May 2019, the WHO Strategic Advisory Group of Experts recommended that another vaccine be introduced in order to expand coverage, especially given concern about 'potential shortages' of the Merck vaccine if the epidemic continued and also decided to adjust the recommended dosing by half to preserve existing supplies (SAGE, 2019; Branswell, 2019).

In July 2019, the WHO declared the epidemic a Public Health Emergency of International Concern, and global health institutions urged the adoption of a second vaccine to ensure more people could be vaccinated and to 'protect communities outside of the current outbreak zone who are likely to be affected next' (Arie, 2019). The Johnson & Johnson (J&J) vaccine, manufactured by Janssen Vaccines and Prevention B.V, emerged as the favourite option because of its more manageable cold-chain and because there was already sufficient supply of vaccines (Branswell, 2019). However, the proposed use of a second vaccine sparked debate, with vocal opposition from the Minister of Health (James et al., 2021). This discussion became imbricated in political tensions. In January 2019, after long-delayed elections, President Tshisekedi took over from Laurent Kabila after 18 years. After the transition, the position of ministers appointed by Laurent Kabila, such as the Minister of Health, was uncertain. After President Tshisekedi restricted the Minister of Health's mandate to non-EVD matters, the Minister resigned and attacked backers of the DRC-EB-001 trial who, he argued, 'have shown a clear lack of ethics by intentionally hiding important information from the health authorities' (Ilunga, 2019). In September, the former Minister was arrested for alleged misuse of EVD funds and in November, the DRC-EB-001 trial began.

4.3. Rumours about DRC-EB-001

There was popular debate in North Kivu about whose interests another vaccine served. Many in Goma concluded that vaccine trials were a profitable part of EVD business, whereby the Congolese government, health workers, foreign responders and pharmaceutical companies profited from testing vaccines on Congolese citizens. For example, a member of the civil society group, *Lutte pour le Changement* (LUCHA), explained 'our concern was that there had already been a vaccine!' When the trial began, LUCHA published an article entitled 'Ebola: vaccines or business?' questioning the ethics behind testing another vaccine, challenging the claim that there was a shortage of Merck: 'Is the priority for donors to quickly stem the current epidemic or to take advantage of the long duration of the epidemic to conduct all kinds of experimental tests on a wounded Congolese population?' (LUCHA,2019).

In Goma, a rumour circulated that the Ebola vaccine business was also a means for the Congolese state and foreign governments to exterminate the population:

> People say that the vaccine was a way for whites to exterminate us, it was a COP (business) of the Congolese government and American government to exterminate us, whites want to reduce the global population, they want to kill us, that was my impression (Interview, 17 October 2020)

Another participant of the trial was not concerned by these rumours, but explained the widespread perception of the trial:

> I wasn't worried, but members of the community were, because people knew that Ebola was a business, and then now they bring us yet another vaccine! People didn't understand that – they were scared that these scientists and the whites want to kill us, that's why they brought Ebola here in the first place (Interview 19 October 2020).

According to one rumour, the EVD vaccine infected people with a fatal disease: 'They come to plant these diseases in you and in the years to come you will all die and be exterminated', a trial participant explained (Focus Group, October 22, 2020). Another rumour spread that the EVD vaccine sterilised participants. In a focus group with people living in Goma who had not participated in the trial, a man from Majengo explained: 'you see, this vaccine, it was the whites who brought it to limit the number of births of Africans to stop the fertility of Africans so that they can no longer reproduce' (Focus Group, November 5, 2020).

This rumour reflected historically situated anxieties about the intentions of foreign intervenors, but also distrust in the central government (Feldman-Savelsberg et al., 2000). As one citizen in Goma explained, 'the same day we heard that there was going to be a Johnson & Johnson vaccine, we started to ask ourselves some questions: why did our government accept this, what do they want? With this miserable life we lead already, do they want us all to be exterminated?' (Focus Group, November 6, 2020). In Goma, rumours circulated as to why the two areas – Majengo and Kahembe – had been selected for vaccination sites. 'Is it only us here who can catch Ebola?!' one participant asked (Parent Interview, October 27, 2020). Many concluded that Majengo had been selected because it was predominantly inhabited by the Nande population from the Grand Nord. After the failure of the government to provide security for civilians in the Grand Nord, the EVD epidemic and then the election postponement, people in Majengo concluded that the government was now using the DRC-EBL-001 trial as another tool to exterminate Nande. A trial participant from Majengo summarised:

> People say, why have you only chosen here? Because there are 70–80 per cent Nande. See how they first banned us from voting … And now they are targeting us here with the undesirable consequences of the trial. If we are exterminated, so much the better (Interview, 15 October 2020.)

Another rumour associated the vaccine with "666," the sign of the beast or anti-Christ. Rumours circulated that the vaccination was a 'mark of the devil', injecting people with microchips of 666, or taking their souls for the anti-Christ. Trial participants were given a vaccine card, which included an identification number and photograph. As one participant in Majengo explained:

> According to the rumours, we were told about these vaccination cards that it is for the beast, 666. So, when the photos were taken and printed on the cards, they were also stored somewhere, and they form the relationship with the beast. So, we already had the mark of the beast. (Focus group, 23 October 2020).

The interpretation went that the end of the world was near, and those with vaccine cards had been marked out by the anti-Christ. 'My fear was that we could be brought to the second world by 666 because people said it was to bring us to the world of darkness with the mark of the beast,' a trial participant concluded (Adolescent Interview, November 12, 2020).

These rumours need to be understood in relation to historical and contemporary state-society relations, as well as past colonial extractions and biomedical campaigns (White, 2000). Rumours can be understood as reflections of asymmetries of power: 'modern commentaries' on social and political relations that go beyond clinical research (Geissler and Pool, 2006, 975). As White (2000, 5) describes in her history of colonial Africa, rumours are not necessarily misinformation, but epistemologies through which people describe the 'extractions and invasions' in their daily lives. Rumours about sterilization plots, for instance, have historically been a means to articulate concerns about collective survival (Feldman-Savelsberg et al., 2000). In the eastern DRC, rumours about EVD vaccines reflected existing distrust of foreign intervenors, drawing on a long history of imperial violence and post-colonial exploitation, as well as frustration toward the protracted presence of international NGOs and a UN peacekeeping mission which have created new forms of inequality, whilst failing to provide security for civilians (Bisoka et al., 2021). These rumours were also a reflection of distrust in the central government in a region where many felt neglected by the ruling class after decades of violent conflict.

5. Motivations for participating

Despite the public controversy, trial participants described three motivations in their decision-making process: protection, health seeking and because they believed that the vaccine card given by the trial would enable them to travel.

5.1. Protection

The first reason for volunteering for the trial was protection; although there were only a few confirmed EVD cases in Goma, people were afraid that the epidemic could spread south from the Grand Nord and devastate the city. A participant in Kahembe explained, 'At first I was not concerned, but when I saw the disease getting closer, I said to myself no, I must also go and take this vaccine so that I can also protect myself' (Interview, October 27, 2020). People with family connections or personal experience in the epicentre of the epidemic in the Grand Nord described being vaccinated after seeing the devastation of the disease. A participant in Majengo explained, 'People say Ebola didn't exist, but it really did. There are people we saw in Beni really suffering from Ebola. I have a big brother in Beni who told us it was real. There was also fear, seeing people die I told myself that I should also take the vaccine to protect myself' (Focus Group, October 28, 2020). A trial participant in Kahembe explained how seeing EVD first-hand in the Grand Nord changed her views about participating in the vaccine trial, despite her concerns:

> I lived where there was Ebola, and I saw for myself the people who suffer from Ebola. So that also helped me to agree to take the vaccine because I understood that it was a necessary precaution … But making the decision to participate in the first dose of the Ebola vaccine was difficult for me, because I knew that there are ulterior motives behind these vaccines, and according to what we hear, not all the vaccines that come are good for us. I considered it a risk for me to take the vaccine. But, when I saw the disease persist, that's when I decided to take the 1st dose (Interview, 15 October 2020).

Trial participants with family in the Grand Nord, or who travelled there frequently for work, described the vaccine trial as a means of potentially protecting themselves and their family. 'During the period when Ebola killed a lot of people in Beni and Butembo, I was scared because we have family in Butembo, and they often come to visit us. I also travel to Butembo often for work. Given that Ebola was already there, I thought it was best to be vaccinated,' a woman in Majengo explained (Interview, October 15, 2020).

Other trial participants did not articulate anxieties about the current epidemic but wanted to protect themselves against possible future epidemics. 'There aren't many cases here in Goma,' one participant explained, 'but they [the trial] are helping us because we never know, Ebola could return one day so that is why we need to be protected' (Adolescent Interview, October 26, 2020). Another participant in Majengo added, 'What really pushed me to take the vaccine was that I know that Ebola could disappear today or tomorrow but return again another day in the future. So, if I have the vaccine, it will be protected in the case of another epidemic' (Interview, October 19, 2020). Volunteering for the trial was a means for participants to access potential future protection in a context of recurrent epidemics.

How did the fact that this was the second experimental EVD vaccine deployed in the province influence participant decision-making process? In fact, despite the controversy and contrary to the initial assumptions that a second vaccine would confuse the population, most of the participants we interviewed said that they *did not know* that there was already an EVD vaccine which had been recently deployed under a compassionate use protocol in the province. When we asked whether participants knew of any other vaccines for EVD, many described the DRC-EB-001 vaccine, known locally as "J&J", as the only vaccine that existed. 'There isn't another one,' a focus group in Kahembe concluded (Focus Group, October 15, 2020).

It appeared that only participants of the trial with close links to the Grand Nord were more aware that DRC-EB-001 was the second vaccine to be deployed in the province. Exposure to the epidemic had persuaded them of the severity of the situation, and they had heard of the Merck vaccine which had been used in ring vaccination. Rather than confused by existence of two vaccines, these participants carefully considered the differences between the two. They believed that the DRC-EB-001 vaccine covered more variants of Ebola virus; they knew that the eligibility requirements were different; and that the Johnson & Johnson vaccine regimen was two doses rather than one. In addition, there was widespread perception that the DRC-EB-001 vaccine had fewer side effects (Focus Group, October 22, 2020).

For instance, a young woman living in Goma described how she had been identified as a suspected EVD case whilst in Butembo, in the Grand Nord at the height of the epidemic. After testing negative at a treatment centre, she was convinced that EVD was real: if it was just a business, the clinic would have declared her as a positive case in order to make more money. She explained 'I then saw people die in Butembo, I was scared. There was a vaccine called Merck but it was not available to everyone.' Like other participants, when she heard that a new vaccine was available in a trial with different eligibility requirements, she decided to volunteer. 'I was not even in the zone of Majengo, but I heard on the radio that the J&J vaccine was being given in Majengo even for those who lived elsewhere in Goma, so that is why I came to take the vaccine because I know that it is going to be protective when the epidemic arrives,' she explained (Focus group, October 23, 2020).

Trial participants volunteered because they hoped for protection in a context of uncertainty. However, not everyone had the same decision-making process. For some, the DRC-EB-001 trial was understood as the only means of accessing protection for future EVD epidemics. In contrast, for participants who had some knowledge about the Merck vaccine, the second trial was a way of accessing potential protection when they had found themselves ineligible for the Merck vaccine.

Yet, hope for protection and anxiety about uncertainty were not mutually exclusive, but co-exist (Lees and Enria, 2020). Many participants were concerned about the rumours circulating about the trial and expressed anxiety about potential side effects of the experimental vaccine. A trial participant in Majengo described his concerns:

> The concerns I have are that the vaccine itself has been brought in to reduce lifespan, so you can't reach 50 anymore … Another concern is that the vaccine will limit the fertility of people or to limit the births suppose if you were going to give birth to a lot of children, this vaccine limits that. These are the concerns we have; we still don't know what the reality is (Interview, 15 October 2020).

Trial participants described a lingering sense of uncertainty: 'I wonder if this vaccine will bring us problems later on in life,' a trial participant in Majengo concluded (Interview, October 16, 2020). Ultimately, many trial participants described participation as a trade-off between protection and potential danger further along in life. As one trial participant concluded in Kahembe, 'the advantage of this vaccine is that you will be immunised. The risk is that, if the trial goes wrong, you will be the first victim' (Interview, October 16, 2020). These narratives challenge the idea that anxieties and trial participation are somehow contradictory, illustrating the duality of vaccine 'hesitancy' and 'enthusiasm'.

5.2. Health seeking

The second reason for participating was access to free healthcare offered by the trial: participation was described as an exchange. Upon enrolment, trial participants received a vaccination card with their photograph, the first dose and a date for the second dose, individual ID number and toll-free phone to call for concerns. Participants described the advantage of having access to health advice through the trial's toll-

free number and the importance of the vaccination card to access free treatment. 'If you arrive with your card, you are treated. It becomes as if you have a voucher for medical care,' participants explained in Kahembe (Focus Group October 15, 2020). In a context where healthcare is expensive, this was a relief. When describing her decision to participate, one woman explained, 'There is free coverage of other diseases if you were vaccinated. This is an important aspect in a case like mine because if I happen to fall ill, I would not have to worry, I come here and I have access to care!' (Interview, October 16, 2020). Another trial participant in Majengo added, 'we are afraid and we often say to ourselves: oh my God the money! Where am I going to get the money in this crisis? But you are told that the care is free … And, so, if I feel sick, I have to come back to be treated!' (Interview, October 14, 2020). Trial participants in Majengo recommended that pregnant women they knew volunteered for the trial because they would have free health coverage until they gave birth, and the trial also covered the costs of the delivery (Focus group, October 22, 2020).

The decision-making surrounding trial participation, therefore, involved a risk-benefit analysis. For many, it was deemed worth the risk of participating in order to access the healthcare in the short term. However, these notions of exchange also led to frustration among participants who were disappointed with the treatment that they received from the trial – in particular, the fact that the trial only provided healthcare for one month after vaccination. If they had complications caused by the vaccine in the longer term, these participants argued, the trial should take responsibility and provide treatment. 'What happens if there are problem later on?' a participant from Majengo asked:

> We are frightened, because even after 10 years, 15 years, who knows what could happen, the observation period is too short … if the trial could continue to follow us even for a year, that would be better … I wonder if I will have any side effects later as a result of this vaccine? We do not know. (Interview, 15 October 2020).

Ultimately, trial participants described an uneasy tension between the fear of potential side effects, and the hope for protection.

5.3. Laissez-passer

The third motivation for participating in the trial was an impression that the EVD vaccination was already (or would soon become) essential to cross borders and travel within DRC. In Goma, many believed that the vaccine cards given to participants by the trial were necessary to travel internationally, just like a yellow fever certificate. 'It [the trial vaccine card] is like a *laissez-passer*, it allows us to travel from one region to another', a participant in Kahembe summarised (Interview, October 12, 2020). In Majengo, a participant explained 'apparently if you don't have the Ebola card, you can't travel to a foreign country. I participated in order to have the advantage of having the Ebola card,' (Focus Group October 23, 2020). In Kahembe, the view was much the same: 'I was vaccinated so that I could have the card and travel', a participant summarised (Focus Group, October 22, 2020).

Kahembe is a neighbourhood on the border with Rwanda and a centre for cross border trade. People in Kahembe were not concerned about EVD transmission but relied on cross border trade for their livelihoods. 'Lots of people accepted to be vaccinated because we heard that the vaccine card would help us cross borders and that we couldn't travel without it,' a participant explained (Focus Group, October 22, 2020). Another vaccine participant explained, 'many people were going to be vaccinated just so they wouldn't be refused to cross the border into Rwanda. It was said that one could not go to Rwanda without a vaccination card. So, people said to themselves, if you don't have a card you can't go to Rwanda. So, let's take the vaccine' (Focus group, October 23, 2020).

Majengo is a neighbourhood in the north of Goma, with trade links to the Grand Nord. Vaccine participants living in Majengo were concerned with their mobility within the province. The importance placed on accessing a vaccine card seemed to be shaped by experiences of containment in the province during the EVD epidemic. During a focus group, participants described how the government had put restrictions on movement in the province to restrict transmission: 'The government has done its best to have closed all the barriers in order to avoid this Ebola disease. The closing of all the barriers was to avoid people coming from Beni to cross into Goma' (Focus Group, October 28, 2020). A trial participant in Majengo working as a driver participated in the vaccine trial in order to access the vaccine card: 'We were bothered too much at the barrier to wash our hands each time. So, I showed my card saying I couldn't catch Ebola and walked through. This also made me take the vaccine' (Focus Group, October 23, 2020). Another trial participant had a similar experience when travelling north in the province, 'they started to ask us for the vaccination card in order to pass the barrier. I saw that people who had received the vaccine had an advantage, they could pass more quickly than those who did not' (Adolescent Interview, October 29, 2020). Some trial participants who thought the vaccine cards were essential for travel felt that they did not have much of a choice: 'I was vaccinated myself, it was more or less by force because I had to travel … We were vaccinated but saying in our hearts that it is God who always protects us in many things, but if it was up to me, I wouldn't do it' (Focus Group, November 12, 2020).

Other vaccine participants hoped that the card could enable them to travel *in the future*. 'I took the vaccine because we never know, maybe we will need it to travel to certain countries when the virus reappears. Then I'll have my card,' a participant in Kahembe summarised (Adolescent Interview, October 16, 2020). Another participant concluded, 'you never know when they [borders, customs] will start asking for it' (Interview, October 15, 2020). A trial participant living in Majengo told us: 'I advised my relatives to go and receive the Ebola vaccine so that they have easy access to walk around in the DRC, because … there was had a period during which, to go to another province and you did not receive the vaccine, it was really difficult; so we don't know what can happen tomorrow' (Focus Group October 22, 2020). 'When we travel, maybe there will come a time when we need to show the vaccine card against EVD, just like they ask for the yellow fever certificate', a participant in Majengo explained (Interview, October 13, 2020). In Kahembe, a participant exclaimed: 'I am very happy, no soldier can stop me, anywhere, let's go! I can hold up the card. I will hold up this (vaccination) card, and they will say "This card: ah! It's someone from the Ebola trial! *Botika ye, botika ye*! (Leave it, leave it!)" (Interview, October 13, 2020).

6. Discussion

The narratives of trial participants in Goma provide an insight into the socially situated motivations for joining a vaccine trial in a setting of conflict and recurrent epidemics, as well as contentious debate as to the ethics of introducing a second experimental vaccine. Whilst Congolese politicians expressed concerns about sovereignty or confusion among the population, the second vaccine was nonetheless described as a source of hope for many people living in a context of uncertainty. For some trial participants, volunteering was a means of accessing potential protection when they were ineligible for the first vaccine. The decision was primarily influenced by perceptions of future risk, given that there were few cases recorded in Goma. These participants invested in a 'political economy of hope,' whereby bioscience is not only about the production of truth but becomes invested in tentative notions of hope by 'citizens who have an active stake in their health and that of others' (Rose and Novas, 2004, 454). Yet, our research also illustrates that, in fact, many participants who volunteered for the EVD vaccine trial in Goma did not actually know that another EVD vaccine had already been introduced, let alone in the same province. This illustrates the stark disconnect between international bioethical discussions about availability of vaccines, risk, and epidemic response (Monrad, 2020) and the deliberations of actual trial participants.

This disconnect illustrates the need for ethical approaches to consider the political, social, and economic context (Tengbeh et al., 2018). To understand motivations for participating in clinical trials, it is crucial to examine the material realities of 'the lives of people involved in research, including political and economic inequality' (Molyneux and Geissler, 2008, 7). In the eastern DRC, participation was motivated by notions of exchange: a balance between the perceived risks of taking an experimental treatment and the benefits of access to healthcare and potential protection. This illustrates the complexities of voluntariness in contexts of inequality and poor access to basic healthcare. In fact, citizens in Goma critiqued the fact that the trial was only based in *quartiers populaires* on the periphery of the city rather than the affluent centre, where potential participants might be less interested in free healthcare (Focus Group, October 23, 2020). Ultimately, the focus on the 'demystification of science' in community engagement strategies overlooks the 'very real political economy of the global medical research industry' (Fairhead et al., 2006, 1119).

The experiences of trial participants also illustrate how participation in vaccine trials may be understood to have advantages which have not been considered by the trial, because they go beyond medical considerations and are instead specific to a particular socio-political context. In effect, 'ideas about what is risky or beneficial are socially negotiated and contested, drawing on symbolic and material resources outside the research encounter' (Tengbeh et al., 2018, 41). Crucially, rumours about a clinical trial are not always vehicles for communicating anxieties, nor barriers for participation – they can sometimes *encourage* participation. In Goma, the widespread belief that the vaccination card would soon be essential, or was already essential, in order to cross borders and travel in the province encouraged people to participate. For those who needed to cross the Rwandan border or travel to the Grand Nord to work, participation in the vaccine trial was seen as a tactical decision to continue working.

Indeed, material objects associated with trial participation - such as vaccination cards given to participants by the trial team - can hold social and political meaning beyond the confines of the vaccine clinic, and influence decisions surrounding participation. These vaccination cards became central to the construction of a new identity as a trial participant. As a participant in Kahembe summarised, 'It is an identity document that shows that you have made yourself protected and you cannot infect others' (Focus Group, October 22, 2020). This material proof of trial participant identity was perceived to hold important functions. The vaccination card became a material embodiment of the trial's obligations to provide free healthcare and advice – and proof of an individual's rights to make claims on the trial as a result of the exchange relationship underpinning participation. Here, a sense of belonging and rights claims are made on transnational actors, not based on biological injury or disease state (Rose and Novas, 2004) but based on the personal risk taken when participating for the greater good.

Yet, the importance of vaccination cards went beyond the trial's intentions and the biomedical encounter. Indeed, participants described volunteering for the trial in order to access the vaccination card for the benefits it held *outside of the clinic*. Due to the widespread belief that vaccination cards were essential (or would soon be essential) to travel, participation in the trial became a means for people to 'socially navigate' a context of uncertainty (Vigh, 2008). For participants, the trial card which proved their vaccination status and participant identity was seen as a form of capital: a means to access healthcare, and to remain mobile.

This raises important questions about how trial teams engage with subjective perceptions of the trial or rumours which may encourage participation. At the centre of research ethics is the idea that people should participate in a clinical trial based on a clear understanding of 'the relevant facts' (Flory et al., 2008, 645). Ethical discussions about participant decision-making are often focused on 'misconceptions' by clinical trial participants, such as conflating research with clinical care, or underestimating risk (Horng and Grady, 2003). 'Community engagement' activities for clinical trials are often geared towards countering these 'misconceptions', with the implicit aim of encouraging participation and informed consent. Yet, too often, rumours or misconceptions are seen as 'barriers' to participation when, clearly, this is not always the case. Instead, such community engagement activities must engage with rumours that encourage participation just as seriously as those that discourage it.

Participant decision-making takes place beyond the clinic's boundaries and informed consent procedures and is shaped by the particularities of a given social-political setting. Trial teams need to recognise the specific ways that clinical protocols interact with the political economy, because this shapes how and why people decision to volunteer. Rather than a means of ensuring participation, community engagement activities are an opportunity to explore the grey area between clinical trial protocols and participants' shared understandings (Tengbeh et al., 2018) and investigate the blurred line between the hopes that become invested in participation, and beliefs or rumours that could be characterised as a different form of 'misconception.'

7. Conclusion

The decision to participate in the DRC-EB-001 EVD vaccine trial was influenced by hope for protection, access to free healthcare offered by the trial and an expectation that the trial vaccination card could help participants to remain mobile in a context of uncertainty. Participant narratives provide an insight into how international bioethical debates interact with, but may also stand apart, from the situated social and economic realities driving decision-making around clinical trials on the ground. The international bioethical debate and political controversy surrounding the second EVD vaccine were focused on questions of vaccine availability, the possibility of unnecessary risk, and concerns about national sovereignty. Whilst this caused anxiety among some participants, the experience of most reveals a rather different set of material concerns on the ground. Indeed, participation in vaccine trials may be motivated by perceived advantages which have not been considered by the trial, because they go beyond the trial participant medical encounter. Crucially, rumours or subjective interpretations are not 'barriers' for clinical trials but may at times *encourage* participation. Material objects associated with trial participation, for instance, can hold meaning beyond the confines of the vaccine clinic, and influence decisions surrounding participation.

Decision-making around clinical research is core to thinking through bioethical research ethics. Yet, to better understand the reasons why people participate in clinical research, it is necessary to focus on how everyday trial processes interact with specific social and economic realities beyond the confines of the clinic. This reveals how vaccine trials not only become an arena for societal concerns, but also represent hope and possibility in uncertain strategies for getting by.

Credit author statement

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Data availability

The authors do not have permission to share data.

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