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## “We are the heroes because we are ready to die for this country”: Participants' decision-making and grounded ethics in an Ebola vaccine clinical trial

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### ABSTRACT

The 2014–2016 Ebola epidemic presented a challenging setting in which to carry out clinical trials. This paper reports findings from social science research carried out in Kambia, Northern Sierra Leone during first year of an Ebola vaccine trial (August 2015–July 2016). The social science team collected data through ethnographic observation, 42 in depth interviews; 4 life narratives; 200 exit interviews; 31 key informant interviews; and 8 focus group discussions with trial participants and community members not enrolled in the trial. Whilst research often focuses on why people refuse vaccination, we instead explore participant motivations for volunteering for the study, in spite of prevailing anxieties, rumours and mistrust during and after the Ebola outbreak. In so doing the paper contributes to on-going debates about research ethics and community engagement in resource poor contexts, offering reflections from an emergency and post-epidemic setting. We analyse participants' perceptions of the risks and benefits of participations, highlighting the importance of a contextual approach. We focus on four types of motivation: altruism; curiosity and hope; health-seeking; and notions of exchange, and argue for the role of social science in developing grounded research ethics and community engagement strategies that can take into account context and local realities.

### 1. Introduction

The 2014–2016 Ebola epidemic in Guinea, Liberia and Sierra Leone was the largest in history, with over 14000 cases and approximately 4000 deaths in Sierra Leone alone (Centers for Disease Control and Prevention (CDC), 2016). At the time of the outbreak, there was no licensed vaccine or treatment available for Ebola, leading to the rapid establishment of clinical trials of experimental products. The time pressure under which researchers had to work was complicated further by limited research experience in the affected countries, and a protracted history of structural violence having eroded trust in both national and international organisations across the region (Wilkinson and Leach, 2015).

As the disease spread, reports were rife of community resistance to medical intervention, mistrust of healthcare facilities, and stigmatisation of health workers and survivors (Chandler et al., 2015; Fairhead

et al., 2006). Rumours spread about the potential origins of the disease, including political conspiracies and international blood-stealing cartels (Bolten and Shepler, 2017; ICG, 2015; Leach, 2015). In a time of uncertainty, the establishment of clinical trials for experimental treatments and vaccines raised significant challenges for researchers and community engagement teams.

In this paper, we report findings from anthropological research carried out during an Ebola vaccine trial, EBOVAC-Salone, based in Kambia, Sierra Leone. This trial, funded by the Innovative Medicines Initiative, is evaluating the safety and immunogenicity of the Ad26.ZEBOV/MVA-BN-Filo prime-boost Ebola vaccine regimen in an affected population. Enrolment of healthy adults into a small, open-label initial stage of the study took place in October 2015. In March 2016, enrolment began into a randomised, controlled study stage, which first recruited adults before recruiting adolescents and lastly children aged 1 year and older. The discussion in this paper is based on

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research carried out in Kambia between August 2015, as the trial was being set up and as the epidemic was on-going but reaching its final stage, and July 2016, as the second stage of the trial had begun for adult participants and four months after the last official declaration of the end of the epidemic. Through ethnographic methods, interviews and life narratives, we explored the subjective experiences of participants in the early stages of this trial. We asked why, in an environment of fear, rumours and mistrust, Kambians volunteered to take part in the trial. The aim of this paper, therefore, is to analyse participant motivations for volunteering for an Ebola vaccine study, and to consider the implications of such motivations for clinical research ethics and community engagement in trials in low-resource settings.

Although research on motivations for healthy participants to volunteer in clinical trials has been limited, particularly in developing countries (Stunkel and Grady, 2011), there is a growing body of work on community engagement and research ethics in resource poor settings (Leach et al., 1999; Molyneux and Bull, 2013; Molyneux and Geissler, 2008). This literature has pointed to the complexity of context-specific social and economic factors that shape the experience of participants in clinical research and therefore the practical implications for seeking consent against this backdrop. In particular, a number of studies have pointed to the “subjective experiences of social and economic constraints on voluntariness” and the ways in which “inequalities and social power permeate all community engagement and consent activities” (Molyneux and Bull, 2013, p. 5; 10). There is also some evidence around decision-making in clinical research, including for example a number of studies that show the importance of access to healthcare in mothers' decisions to enrol their children in clinical studies in countries with limited service availability (Mtunthama et al., 2008; Nabulsi et al., 2011). We hope to contribute to this burgeoning literature by offering reflections from the context of an epidemic and emergency outbreak response.

Decision-making lies at the foundations of research ethics and how we think about informed consent. The essence of research ethics standards since their inception has been the notion that people should “not only decide freely whether to participate in clinical research, but decide with an understanding of the relevant facts” (Flory et al., 2008, p. 645). On-going debates in bioethics also address the basis of decision-making in terms of the implications of the potential “misconceptions” or “misestimations” of clinical study participants (Hornig and Grady, 2010; Kimmelman, 2007). Similarly, strong disagreements about whether participation in medical research ought to be remunerated or even considered as a form of labour—most starkly represented in the title of Dickert and Grady's (1999) provocative paper, *What's the Price of a Research Subject?*—reflect a preoccupation with the ethical implications of the motivations for taking part in clinical studies. These questions underpin the broader concern with how we define the social value of research and how this can be determined empirically (Rid and Shah, 2017).

Existing literature on immunisation programmes and risk communication also offers a useful framework for thinking through motivations. This body of work has focused in particular on the determinants of “vaccine hesitancy” along three domains: confidence (trust in the product and the provider), complacency (perception of need for the vaccine) and convenience (access) (Larson, 2013). Recent attempts to measure hesitancy to take vaccines across contexts have shown that confidence is the primary factor (Larson et al., 2015). In particular, intentions to take vaccines, especially newly introduced ones, have been found to correlate with trust in the broader healthcare system (Larson et al., 2015; Marlow et al., 2007; Ozawa and Stack, 2013). An emphasis on confidence in the context of vaccination campaigns highlights the need to engage with the concept of risk.

Over the years, scholars have increasingly asked for risk communication to take into account the social construction of risk (Larson et al., 2012; Slovic, 1994; Hobson-West, 2003; Abraham, 2009; Beck, 1992). This means firstly considering how different systems of

knowledge, and varying levels of trust in the sources of information provided, influence individual assessments (Hobson-West, 2003). In addition, it entails an appreciation of how risk is publicly perceived. Slovic (1994), for example points to a crucial mismatch between expert assessments of risk (measured for example by expected fatalities) and public perceptions of “riskiness” which rely on a much richer combination of assessments, including familiarity with the type of accident, the threat posed to future generations and so on. A train wreck that could kill hundreds of people may be perceived as less of a risk than terrorist attacks with far fewer victims. Similarly, Beck (1992) suggested that perceptions of how risk is distributed across society matters for how messaging around risk is received. These insights show that social, cultural and political dimensions of risk perception must be central to how we understand public attitudes to health interventions.

When transposed to the context of clinical studies during a complex emergency such as that produced by the Ebola epidemic in West Africa, these issues take on particular salience and raise questions for the ethics of medical research during outbreaks. Understanding why participants in the EBOVAC-Salome trial decided to put themselves forward to take an experimental vaccine during a time of uncertainty, despite significant ambivalence towards external intervention, and in a region with limited experience of medical research, thus presents an opportunity to revisit these questions in an empirically grounded manner. In so doing we build on existing literature on research ethics in resource poor settings to consider how experiences with an unprecedented emergency in West Africa can contribute to growing calls for ethical approaches that can take social, political and economic contexts seriously.

Whilst it may seem obvious why people would opt to take part in a study of a vaccine to protect from Ebola in the immediate aftermath of a deadly epidemic, we show that in fact the value of research and vaccination in a context of high levels of mistrust was socially contested. Indeed, as we have previously shown (Enria et al., 2016), the value of qualitative research alongside a clinical trial can help show how contextual factors shape perceptions of and attitudes towards biomedical interventions, including perceptions of risk that may be counter to those of clinical risk assessments. Taking subjective assessments seriously then, not only helps us understand possible tensions between clinical and social ethics but also to see what determines participation in a vaccine trial where vaccine hesitancy is prevalent. Our aim is not to assess the quality of informed consent on the EBOVAC-Salome trial on its own terms. Instead, we hope to show how, by taking into account individual participants' reflections on their motivations for joining a clinical trial in a post-epidemic setting, we can contribute to the development of a “grounded ethics” framework cognizant of local realities, and to suggest what the implications might be for community engagement for clinical research in developing countries.

Our approach stems from the anthropology of medical research, which explores social critiques and understanding of “postcolonial techno-science” (Fairhead et al., 2006). Through the lens of social narratives about science, anthropologists of clinical trials have shown the different “cultural worlds and material concerns” of researchers and communities hosting research (Fairhead et al., 2006). Applying this lens to the Ebola crisis and its aftermath, we show how EBOVAC-Salome participants' articulations of their motivations to join the trial were framed around socially shared and collectively negotiated meanings that were often external to the clinic.

After a methodological discussion, we explore the significance of rumours and mistrust in Kambia during and after the Ebola epidemic. This contextualizes participants' decision-making and lays the foundations for an analysis of how their perceptions of risk were shaped by history and social engagements with the epidemic. We then outline the four main motivations reported by vaccine trial participants: altruism; curiosity and hope; health seeking; and exchange. The paper concludes with reflections on how examining participants' decision making presents opportunities and challenges for research ethics grounded in

everyday realities and social worlds (grounded ethics) in resource-poor settings and for the increasingly central role of community engagement in clinical trials.

## 2. Methods

The EBOVAC-Salone study was funded by the Innovative Medicines Initiative's Ebola + programme in December 2014. The study is co-ordinated by the London School of Hygiene & Tropical Medicine (LSHTM), in collaboration with the College of Medicine and Allied Health Sciences (COMAHS) in Sierra Leone, and is sponsored by Janssen, who have developed the protocol and provided financial and in-kind support (e.g. cost of development, manufacture and shipping vaccines, cost of trial monitoring, funding to an international NGO to provide logistic oversight).

This paper is based on research carried out by the research team between August 2015 and July 2016, encompassing the trial's set up phase, and the first months of vaccination. This overlapped with the end of the outbreak, which was initially declared over in November 2015 and then again in March 2016 after a flare-up. The role of the social science team was to produce academic research on the acceptability of the vaccine trial; and to work in conjunction with a community engagement team to develop community-led approaches to participant recruitment. The community engagement team led on community and household-level meetings, in conjunction with community leaders, to explain the conditions for participation and participants underwent an informed consent process at the clinic (see [Enria et al., 2016](#); [Mooney et al., in preparation](#)).

Within EBOVAC-Salone the social science team contended with the tension between ensuring independence and providing critique whilst also generating impactful findings that can support the intervention. Whilst committed to supporting the running of the trial in a way that was responsive to socio-cultural context and participant experience, the team also put in place measures to maintain academic independence. One of these, for example, was the separation of social science and community engagement within the trial team, so that ethnographic observation was not coupled with volunteer recruitment drives. Similarly, systems were put in place to ensure the confidentiality of all data collected also within the team, so that anonymity was maintained for example when reporting rumours to be addressed by the community engagement team.

The social science component of the research project used qualitative research methods to explore community and participant perceptions and experiences of the trial. The methods included: ethnographic observation in Kambia's social grounds like *attaya bases* (tea shops), market places, local bars and other social gathering places, as well as in the vaccine clinics, to learn about participant experiences during clinic visits; exit interviews (200) conducted at the trial clinics with study participants immediately after visits; in-depth interviews (42) and life narratives (4) with participants. We also conducted focus group discussions with both trial participants (4) and community members (4) and key informant interviews (31) to explore community and participant perceptions and experiences of the EBOVAC-Salone trial. Interviews and discussions were carried out in Krio or Temne. The team used these qualitative research methods to explore the socio-cultural context and perceptions of illness, disease and medical interventions in Kambia. The data collected were transcribed and analysed using NVIVO 11. Ethical approval for this study was granted by the London School of Hygiene & Tropical Medicine Ethics Committee and by the Sierra Leone Ethics and Scientific Review Committee. Interviews were anonymised and names used in this paper are pseudonyms.

## 3. Findings

### 3.1. Rumours, mistrust and perceptions of risk

As the trial was being set up, Kambia was one of the last districts still recording new cases of Ebola in the country. A military deployment, Operation Northern Push, was under way to enforce state of emergency regulations to isolate the last cases. In order to understand the environment in which participants decided to join the EBOVAC-Salone trial, we consider widespread mistrust and rumours circulating about the vaccine during and after the outbreak. These narratives give a glimpse into the social meaning invested in science and the cultural and historical specificity of conducting a vaccine trial in the wake of a public health emergency. Further, prevailing anxieties surrounding the trial in Kambia highlight that the value (at the social, community and individual level) of research is contested and constantly negotiated. Because of widespread ambivalence towards biomedical interventions within communities during the outbreak, studying social perceptions of the trial and asking participants why they decided to join *despite* concerns surrounding the study offered an invaluable window into the complex questions around research ethics and engagement during emergencies.

During the outbreak, responders in West Africa identified mistrust as a major challenge, with resistance to interventions seen as a result of popular misunderstandings ([Chandler et al., 2015](#)). Anthropologists and community activists emphasised instead the social significance of rumours, understanding mistrust as emerging from histories of exploitation and extraction as well as contemporary realities ([Richards, 2016](#)). Rumours can accordingly be more productively seen as “modern commentaries” ([Geissler and Pool, 2006](#), p.975) and, as recognised by historians of medical research in Africa, can reflect “meandering epistemologies many Africans used to describe the extractions and invasions in which they [live]” ([White, 2000](#), p.5). Rumours then, are not simple misunderstandings but can convey “more generalised concerns about medical interventions” ([Enria et al., 2016](#), p. 8). The narratives surrounding the EBOVAC-Salone trial outlined below are windows into people's social and political realities, ranging from mistrust of a dilapidated national healthcare system to ambivalence regarding the role of international actors in Sierra Leone's affairs. Contextualising mistrust as well as hopes, dreams and expectations sets the stage for understanding how some people overcame fears, developed counter narratives, and decided to take the Ebola vaccine candidate as the new clinic opened in Kambia town in September 2015.

### 3.2. Mistrust of the healthcare sector during the Ebola outbreak

Mistrust of clinical research in Kambia has deep roots in the history of failed promises from the Sierra Leonean healthcare sector. As many commentators have noted, the Ebola epidemic tragically exposed the shortcomings of healthcare facilities in the three affected countries ([Dubois et al., 2015](#); [MSF, 2015](#)). The health care system in Sierra Leone was undoubtedly overwhelmed by the sheer magnitude of the outbreak, but the inability of the state to deliver health services had been apparent well before Ebola. Health outcomes amongst the worlds' worst ([WHO, 2017](#)) have been attributed to poor resource management, corruption and years of chronic under-spending on health and social care services ([Benton and Dionne, 2015](#); [Conteh, 2016](#); [Pieterse and Lodge, 2015](#); [Stubbs et al., 2016](#)). Against this backdrop, average Sierra Leoneans' experiences of healthcare, especially outside urban centres, tend to be characterised by long journeys, “Kafka-esque bureaucracies” and disappointing care, explaining widespread avoidance of health centres ([Ferme, 2014](#)). Indeed, in our ethnographic research in Kambia during and after the epidemic, perceptions of a lack of professionalism among healthcare workers and previous experiences of inadequate care were cited as key reasons for avoiding health centres even before the epidemic. Such mistrust was heightened during the epidemic by fears of

contracting Ebola in government hospitals and specialist treatment centres.

Healthcare workers were also implicated in popular theories claiming that Ebola was not “real” but a ploy by the government and/or the international community to reduce the West African population (Wilkinson and Leach, 2015; Bolten and Shepler, 2017; Enria et al., 2016; Shepler, 2017). The instruments of medical personnel came to symbolise these theories, for example as rumours circulated in Kambia about the use of chlorine to suffocate patients in ambulances and treatment centres. These rumours reflected deep-seated misgivings about national healthcare facilities and staff, as well as distrust in Western involvement. Outsiders were portrayed in popular discourse as potential saviours or as having ulterior motives. Rumours about people being murdered and having their blood taken in Ebola treatment centres mirrored those recounted by anthropologists and historians of colonial medicine across Africa (White, 2000). Such narratives, centred on mysterious extractions, have been related to histories of slavery, colonialism and the post-independence power of global capital (Comaroff and Comaroff, 1999). The stories about theft of blood and organs in Ebola treatment centres were thus part of a longer history of commentaries on inequality and expropriation, envisioned as drainage of life from Africa to the West.

The epidemic, in other words, did not generate, but exacerbated a profound sense of mistrust of healthcare facilities, health professionals and Western intervention. This is especially significant if we consider the evidence on vaccine hesitancy which points to linkages between trust in the healthcare providers and perceptions of immunisation drives (Larson, 2013; Larson et al., 2015; Marlow et al., 2007). The trust deficit evident during the outbreak created a difficult landscape for clinical researchers hoping to recruit individuals to come to a Western-funded clinic, to donate their blood for testing the safety and immunogenicity of an Ebola vaccine candidate. However, participants' motivations for joining the vaccine trial help us move beyond a single story of mistrust to see how people overcame fears and how they made sense of their decisions in the context of the outbreak.

### 3.3. Rumours about EBOVAC-Salone

In the context of the broader lack of confidence in the healthcare system, alongside anxieties about the interventions imposed in the Ebola response, it is no surprise that as the EBOVAC-Salone trial opened its doors in September 2015, several rumours circulated about what the new clinic and its staff might be doing. Many of the rumours were Sierra Leonean variations of social commentaries collected across research sites in different countries (Geissler and Pool, 2006).

One common rumour was that the vaccine was a form of “slow poison” that might give participants Ebola or another unknown disease:

Some were saying that we don't know the white men; that they can give slow poison to people for one month, two months, three months and nothing will happen to the person. And when it is ready to work in your system it will just happen (Male Participant 27.10.2015)

This rumour played on the widespread confusion about the origins of Ebola in West Africa and the fact that the arrival of the disease in the region had seemingly caught everyone off-guard. Kambians' concerns about the possibility of the future negative effects of the vaccine revealed anxieties among participants and community members that another outbreak might occur, rooted in broader uncertainty about the future of health security in the region.

The trial's requirement that participants give blood between eight and ten times similarly meant that the fears about blood stealing that emerged during the outbreak were easily transferred to the vaccine trial. For some, the rumour of a Western blood bank that needed replenishing to keep Europeans young through the blood of young Africans seemed to be confirmed by the trial's shipping of samples abroad. This was especially meaningful given the much discussed

discovery of containers of blood found at Sierra Leone's international Airport during the epidemic (Patasie, 2015; Thomas, 2015). A Kambian elder spoke of the affair in relation to the vaccine:

[They] are telling lies that [the vaccine] is Ebola, [it is here] to capture people, draw their blood, put it into a container and take it out. You see? They said they saw a lot of containers full of blood at the Airport, so that caused more fear. They said: ‘The white men need blood at their Bank, there is no blood there!’ (Key Informant 25.09.2015)

Blood-stealing rumours tend to be explained as metaphors of the occult, yet this can obscure the specific significance of blood in people's understanding of health and wellbeing (Fairhead et al., 2006). Participants and non-participants alike reported rumours about blood and related them to a general discomfort around giving blood and a feeling that it would leave people permanently weakened. The amount of blood in the body was associated with wellbeing, with illnesses such as malaria defined as being “short in blood”. Having enough and “good” blood was similarly associated with good health and self-care as a prospective participant explained:

It took me years to make this blood; I never drank alcohol, nor smoked marijuana, so I expect the trial to [compensate us] for the sacrifices we are making” (Male Participant 9.10.2015)

In addition to reluctance around the requisite blood taking (and later also around contraception), tensions emerged around the “incentives” offered for taking part in the trial. The EBOVAC-Salone trial offered participants compensation for transportation to get to the clinic. However, other trials taking place at other locations in the country at the same time, generally offered participants more money and sometimes a mobile phone. Discussions thus emerged around compensation, and some saw the provision of incentives as a worrying commodification that was tantamount to exchanging blood, one's life essence, for money. The notion that participants were “selling their lives” occasionally resulted in derision of those considering participation in the trial.

Memuna, a female teacher who decided to join the trial with a neighbour, described their experience as they walked to the clinic:

People made us afraid. [...] So on our way [to the clinic] they made remarks to us, saying: ‘Ah, two dead bodies are on their way’. I said: ‘God will protect us, that is what we pray every day, God will save us, let's go’. So we came. (Female Participant 5.04.2016)

Rumours need not be barriers to participation (Geissler and Pool, 2006) and indeed EBOVAC-Salone did not face significant problems in recruiting participants for the trial during the first stage of the study (see Enria et al., 2016). Yet Memuna's words, echoed by other participants, show how rumours, anxieties and mistrust surrounding the trial influenced participants' experiences as they decided to join. The fact that the study was taking place in the wake of a deadly epidemic and a militarised state of emergency cannot be ignored. Indeed, while participants did not necessarily believe the rumours, and often dismissed and ridiculed them, their subjective assessments were nevertheless shaped by the context of the crisis. We describe below how, in Kambia, rumours and anxieties were more than commentary: they informed how participants understood the risks they were taking, irrespective of the assessments presented to them by researchers.

## 4. Reasons for taking part in the EBOVAC-Salone vaccine trial

As rumours and apprehensions circulated, we explored participants' motivations to join the new vaccine trial in Kambia. We found that in participants' reflections on their decision-making processes, four main themes emerged: altruism; curiosity; health seeking and beliefs about the vaccine's powers; and expectations and notions of exchange.



#### 4.1. Altruism

Several participants framed their participation through notions of ‘sacrifice’. This must be understood first through an appreciation of the level of risk that participants felt they were taking when agreeing to enter the study. Several participants suggested that they thought there was a high probability that they might become seriously ill or die as a result of the vaccination. Mammy Isatu, an older female participant, recounted vividly in a focus group discussion the fear that she felt before taking the vaccine:

I held my body and prayed all the *suras* [verses of the Qu’ran] that I know, as the nurses prepared their papers, I said the *kalima* [Qu’ranic recitation] as they injected me (Female Participants Focus Group 12.05.2016)

In the face of such perceived risk, some participants talked about the feeling that taking part in the trial was their duty as a citizen, especially in the aftermath of Ebola and the devastation that the epidemic had brought to their communities. The notion of *sacrifice*, used by several participants, was emblematic of this convergence of altruism with a perception of high risks associated with the study (see also [Enria & Lees in preparation](#)). As one participant put it:

We are real heroes in this country [...] we are ready to die for this country”. (Male Participant 22.10.2015)

The language of “heroism”, used also to refer to those fighting Ebola as part of the response, was applied here to a sense that taking the vaccine in order to prove whether it would protect people from the virus was an act of altruism, a sacrifice with potentially deadly consequences.

The language of sacrifice was used especially by those who saw themselves, and were recognised by others, as leaders in the community, such as pastors and imams, traditional heads, and other respected personalities. Their descriptions of their own motivations emerged from a sense of responsibility to the community that they represented, as summarised by one Pastor:

As their spiritual father, I have come to build their confidence, if nothing happens to me, my congregation will join. (Male Participant 8.10.2015)

The idea that leaders should be the first to “sacrifice” for their communities was supported by assertions recorded throughout our ethnographic fieldwork that if community leaders put themselves forward for this study and came out unscathed, others would join. Sacrifice for others was described a key reason for taking part, especially amongst those who joined the first stage of the trial. The expectations placed on community leaders must be understood in the context of local moral economies, whereby personal power is expected to be balanced by material support and responsibility for those who made ascent to power possible ([Bolten, 2012](#); [Enria, 2018](#)). Furthermore, self-reporting morally virtuous motivations also points to the challenge of engaging with subjective descriptions, and highlights importance of considering a multiplicity of determining factors.

#### 4.2. Curiosity and hope

Notions of risk and sacrifice rest on particular understandings of and responses to uncertainty. Prevailing views about uncertainty, focused solely on vulnerability and precariousness, conceal the many ways in which uncertainty can be experienced as productive and as holding the potential for a better life ([Cooper and Pratten, 2015](#)). In a focus group with female participants on the notion of risk, the fear associated with taking a risk was counterbalanced by a sense of opportunity, the possibility that one might succeed. “Eagerness to know” was cited as one of the reasons why one might take a risk with uncertain outcomes. Indeed, when talking with study participants specifically about their decision to

take a vaccine with uncertain consequences, some emphasised an element of curiosity and a wish to explore something new and potentially dangerous. One respondent noted for example that his intention in coming to the clinic had been to test the rumours he had been hearing and to dispel his own anxieties:

I was afraid, so I decided to come and do research to see if this medicine is here to kill people as other people are saying. (Male Participant 12.04.2016)

Importantly, participants explained their personal strategies for dealing with risk in the trial by placing their decisions in the broader context of lives characterised by uncertainty:

Even the food that you eat is a sacrifice because you can eat it and anything can happen. (Male Participant 8.12.2015)

In this shifting, unpredictable landscape, many participants sought certainty in religion and explained their participation through faith in a higher power:

*Die nar wan tem* [You only die once], only God can mark your death. (Female Participants Focus Group 12.05.2016)

Although this might be interpreted as a form of fatalism or abandonment of agency, many respondents linked their faith purposively to their actions in life: “You should be ready to think positive, then God will do you good, if you sit and think bad, that is what God will give you” (Female Participants Focus Group 12.05.2016). This notion that good actions and intentions are rewarded by God, helped many participants overcome fear and see the risk they felt to be taking within the study as a potential opportunity. Others pinned their hope on a tentative expression of trust in “foreigners” or the government as gatekeepers of research, showing a more complex story about mistrust, whereby those who decided to join the study overcame fears and placed trust in the intervention despite high levels of perceived risk (see also [Enria & Lees in preparation](#)).

#### 4.3. Health-seeking and beliefs about vaccine's powers

The trial as an opportunity took different guises for different participants. Attitudes to vaccination include an assessment of the perceived likelihood that the vaccine will be necessary ([Larson et al., 2015](#)). For EBOVAC-Salone participants the first perceived opportunity, which made joining the study worth taking a risk, was the potential protection from a future outbreak:

[The Ebola vaccine] is very important looking at the disaster it has caused in the sub-region and our country in particular. With its presence in our bodies, it will stop the deaths, and [Ebola] will not disturb the economy again. (Male Participant 12.10.2015)

On some occasions this was expressed in terms of a hopeful conviction that the vaccine would be protective, as some participants felt that having not experienced any side effects proved the vaccine to be safe:

They said [that] when an Ebola outbreak happens in a country maybe in one or two or three years it will come back, and when it comes back it will be more dangerous. But when you complete taking the marklate you are free from [Ebola]. So that gave me more [confidence] that now that we have taken the first one and nothing happened to us. (Male Participant 17.12.2015)

It was more common, especially after the epidemic was declared officially over, to find participants' motivations to be rooted in a more generalised belief that the trial and the vaccine itself symbolised an ideal of good health and that participating therefore meant taking care of one's health.

In post-vaccination interviews, participants portrayed the trial as “fighting for [their] health”, and argued that they would recommend

that their families and friends join because: “it is a health seeking process, it's good that we play an active part in it” (Male Participant 19.10.2015). This must be understood in conjunction with the negative perception of government-provided healthcare noted above, in contrast to the trial's provision of a higher standard of care. The health-checks that participants had to undergo to determine their eligibility for the study were often perceived to be of higher value than the vaccine itself, given that the majority of Kambians entering the trial had never had a medical check-up before. “Knowing one's status” was thus frequently cited as a perceived benefit of participation:

What I enjoyed more, was the screening that I underwent with the doctor. They asked me a lot of question about my health, [and ...] they told me that I am really healthy and up to this time I am feeling healthiness in my body. (Male Participant 8.12.2015)

The provision of free healthcare for non-chronic conditions for those involved in the trial was similarly a significant motivation for Kambians to join. As one young man told us in an interview, he had been suffering from recurrent headaches and stomach aches and was hopeful that the trial team might be able to help him address these problems:

“[The trial] is good, it is free to us and also what made me become more interested [was that] if I have a head ache, after taking the injection, I can just inform them that my head is aching, so I thought that this will just make me get my health [...] These are the major things that made me join the trial. So I think I will get help from this people. (Male Participant 2.04.2016)

Participants' mention of access to higher standards of care as an incentive for joining is consistent with existing anthropological literature on participation, including in the MRC trials in The Gambia (Fairhead et al., 2006; Leach and Fairhead, 2008). This of course raises important questions around the social justice implications of a clinical study that provides healthcare to participants that are selected on the basis of their good health through a screening process. Participants who failed screening were treated for short-term conditions such as malaria or referred to the appropriate healthcare facility. EBOVAC-Salone also provided support to the Kambia government hospital, including refurbishing the paediatric ward. Nonetheless, as we discuss below, the role of healthcare provision in participants' motivations has important implications for how we think about ethics across contexts.

The conviction that the trial was associated with “good health” also went beyond the concrete ways in which the trial provided free healthcare. Some participants also reported having experienced special healing powers from the vaccine:

To me the vaccine does not only prevent Ebola, it also prevents some minor illnesses like rash etc. I have experienced it! (Male Participant 21.10.2015)

One participant reported that the first dose of the vaccine had led to his hernia disappearing:

When I used to cough, this place got swollen and I used to squeeze it, it was like a lump, so I asked and somebody told me that it was hernia, from the time after taking the first [vaccine] I noticed that it disappeared and there is no more pain like that (Male Participant 27.10.2015)

This apparent “misconception” surrounding the vaccine's role in the healing of ailments can be interpreted as a source of concern for the ethical conduct of a clinical trial, and as casting doubt over the informed consent process. However, as discussed below, we might instead consider the importance of differentiating formal informed consent processes from hope, especially in contexts characterised by great uncertainty.

Overall, these differing ideas of opportunity, perceived benefit and even the imputation of healing powers, to the perceptions of vaccine risks and benefits, and reflect the hope characterising participants'

descriptions of their motivations for joining.

#### 4.4. Expectations and notions of exchange

A final, often-cited reason for joining the trial was a different kind of perceived opportunity, expressed in terms of expectations about what might happen once the vaccine trial was over. These expectations were deeply rooted in notions of reciprocity, which suggested that one could reasonably expect altruistic behaviour or bravery to be rewarded in the future:

We went, and we said: ‘If we die, we will die’, so what is [there] for us? What is the benefit? (Female Participants Focus Group 12.05.2016)

This may appear to counter the notions of pure volunteerism that appear to be embodied by the altruistic motivations described above. However, as anthropological theories of gift-giving have long highlighted, altruism must be defined in relational terms that collapse the “liberal notion of autonomous choice” (Geissler, 2011, p. 47). Instead, these theories point to the norms of reciprocity that emerge from new collectivities, such as the trial community that participants entered. In this sense, expectations or hopes regarding what might happen once they had entered the trial, with full knowledge that these benefits had not been promised, are in line with expressions of altruism and sacrifice.

In some instances, especially at times when jobs were advertised by the trial, some participants articulated an anticipation that being a study participant might help them gain employment (even though the trial protocol forbids hiring participants). The arrival of the trial was often described as evidence of “development”, a source of various opportunities including increased demand for housing and commodities. Employment was one such opportunity. Expectations of material rewards have to be placed in the context of Sierra Leone's political economy and more specifically against the limited opportunities available in Kambia, a largely rural district with a 60% poverty rate (OCHA, 2015). Hopes that joining the trial might be rewarded with future employment thus simply reflected broader strategies for accessing opportunities through recognition and the creation of networks of reciprocity in an overcrowded market where labour supply far outweighs demand (Enria, 2018, 2015). Significantly, however, the most widely shared expectation or wish was the rather modest one that participants might be given certificates at a public ceremony the end of the process and thereby be recognised for their sacrifices. As Le Marcis (2012, p.488) argues, building on Honneth's (2008) work, struggles for recognition are central to the “self-realization of the individual”, and can thus be seen as the deepest and most fundamental motivations for human behaviour.

## 5. Discussion

The motivations that participants reported for joining the trial raise interesting questions that can contribute to on-going debates on how clinical trial ethics can be grounded in local realities. This is especially the case in the context of an epidemic whose social dimensions had significant implications for social perceptions of the risks posed by new biomedical interventions. By contributing novel empirical data from the West African Ebola outbreak, this paper speaks directly to the specific concerns of community engagement for medical research in outbreak and post-outbreak settings. The context of the Ebola outbreak allows us to flip the question driving research on vaccine hesitancy to ask why people decided to take the EBOVAC-Salone vaccine candidate given multiple levels of uncertainty, including that relating to medical research and deeper contextual mistrust arising from both historic and contemporary factors. Focusing on motivation for participating and how these emerge from social constructions of risk in an emergency context raises important questions about the nature of informed consent

and incentives for joining medical research.

Participant motivations to join show how rumours and mistrust that emerged during the epidemic influenced the landscape facing researchers. These concerns, even when participants dismissed them, informed their estimations of the level of risk they faced. At the same time, participants' self-reported motivations for joining reveal their efforts to create alternative, socially shared narratives based on hope, optimism and a sense of commitment to one's community. Community engagement teams and trialists cannot predict the acceptability of clinical research. However, they can take social acceptability seriously by engaging with rumours as social commentary, understanding how they shape fears but also how they are challenged through the creation of alternative narratives.

Studying subjective experiences reveals how narratives about science and specific research projects shape perceptions of both risks and benefits. This offers important insights for understanding the determinants of the acceptability of medical research. It suggests a grounded ethics approach to ethical standards in resource-poor contexts. Taking seriously fears and perceptions of risk *alongside* notions of hope, altruism, and expectations of exchange, helps us paint a more complex picture of motivation and choice somewhere between pure volunteerism and the participant as paid labour. Discussions of the practical ethics of incentivising participants for joining a clinical trial in low-income settings rarely take into account the intangible motivations (e.g. status) that shape individual decisions for taking part.

As scholars of risk have long pointed out, individual and collective evaluations of risk are influenced by a plethora of factors ranging from trust in the source of information to the nature of the event being evaluated and the distribution of risk in society (Abraham, 2009; Beck, 1992; Hobson-West, 2003; Larson et al., 2012). The experiences of EBOVAC-Salone participants similarly show how perceptions of risk in clinical research are rooted in specific social realities that extend far beyond the pages of informed consent forms, into households and communities where the value of the study is debated and vernacularized. Ideas about what is risky or beneficial are socially negotiated and contested, drawing on symbolic and material resources outside the research encounter. Contextualising rumours and anxieties around medical research also entails grasping the way in which these shape individual motivations, which remain socially situated even as individuals enter the clinic. This is also true for perceptions of benefits: while it may be unsurprising that quality healthcare and potential protection from the virus are incentives to join, what do we make of expectations, hopes or even seemingly unfounded beliefs about special healing powers and hopes about employment?

In contexts like Sierra Leone, characterised by acute crisis and widespread poverty, hope becomes a necessary resource, a means of imagining the future that is not necessarily tied to current realities but firmly reliant on leaps of faith. A grounded ethics approach would therefore need to take these emotional and belief-driven factors into account and consider how value is socially created at both the individual and collective level. The challenge in practice becomes how to integrate hopes, dreams and fears in our understanding of informed consent and of what ethics might mean in different contexts. Whilst keeping in mind the difference between consent and hope, incorporating social perceptions of risk and benefit can begin to advance and enrich our conversation on the social values of research (see Rid and Shah, 2017; Hornig and Grady, 2010).

This emphasis on a grounded form of research ethics that considers subjective assessments and local context also means contemplating how clinical trial protocols and ethical standards might interact with the realities of political economy in the places where they occur. The hope that participants held regarding employment by the trial might seem entirely misplaced in a resource rich context, but in Sierra Leone where the formal wage employment rate is below 10% and where employment is seen as being gained through recognition and reciprocity, this takes on a different meaning.

We would argue, in agreement with Scheper-Hughes (2003), that acknowledging the relevance of different ways of knowing the world and understanding self and others, need not amount to a suspension of 'the ethical'. Ethnographic research can help us understand the complexities of participation in clinical trials across different socio-cultural settings to better understand how context shapes decision-making. Understanding these dynamics can help make clinical trial protocols and ethical guidelines more socially relevant, ensuring that the fundamental principles that underpin research ethics are reflected in practice. Furthermore, emphasising context must also mean taking into account the implications of global hierarchies of power and the ways in which external interventions can reproduce inequality and injustice (for example providing healthcare only to healthy participants).

Recognising the global and local context can help us reconsider notions of fairness and volunteerism. For example, if we recognise that in a given context, decision-making does not happen at the individual level and that it often happens outside the clinic, informed consent processes can take this into account, through group informed consent processes to complement individual sessions. Involving communities in the design of clinical trial protocols from the very beginning can further contribute to a grounded approach to clinical trial ethics.

A grounded ethics approach need not be enacted solely through clinical trial protocols. Indeed, it may often be inappropriate for clinical practices to be moulded by subjective experiences and socio-cultural specificities. An example is the hope that participants expressed in the vaccine's healing powers, where participants argued that inoculation had cured them from a range of diseases, against clinical evidence. It would be clearly inappropriate to suggest that protocols ought to incorporate these perceptions. Community engagement for medical research, on the other hand, can exist in these liminal spaces between clinical trial protocols and communities' shared meanings. Community mobilisers are better placed than clinicians to think about whether and how to engage with subjective assessments of benefits in their campaigns. Notions of sacrifice, for example, were central to participants' motivations and to their struggle for social recognition and self-realisation, but they were developed in dialogue with a broader social context of fear and uncertainty rather than with the legalistic risk assessment provided by the clinical protocol.

An appreciation of the social constructions of risk and the importance of recognition for self-realization poses a complex but potentially productive challenge for those interested in developing messaging and engagement strategies that are responsive to local context.

## 6. Conclusion

Participant motivations for joining an Ebola vaccine trial in the immediate aftermath of a highly fatal disease outbreak offer important lessons for ethics and community engagement for clinical trial research across different contexts. Building on existing work on research ethics in developing country contexts, we have shown how experiences from an epidemic response can contribute to an on-going conversation about how to strengthen the context-sensitivity of guidelines and protocols in practice.

Participants in the EBOVAC-Salone trial joined for a variety of complex reasons, yet highlighting their articulations of motivations in terms of altruism; curiosity and hope; health seeking; and notions of exchange, underscores the situated nature of risk-benefit calculations. Studying motivations in a context as extreme as the West African Ebola outbreak gives important insights into the kind of factors that influence decision making in clinical research more broadly. More significantly, the reasons outlined by the EBOVAC-Salone participants emphasise the need to consider what motivates individuals to take part in a clinical trial, taking into account that these reasons are socially situated and context-specific. In particular, research during and after the outbreak revealed how perceptions of risk are influenced by social engagements with the epidemic. This has important implications for how we think



about research ethics across vastly different settings and how we design mechanisms for participant recruitment and messaging.

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