



# Social Science and Community Engagement in the Ebola Vaccine Trials in Sierra Leone

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# Overview

- The EBOVAC trials
- Social science & community engagement
- Setting up in an outbreak: social science perspectives on key challenges
- Motivations for joining & grounded ethics
- Lessons for future practice
- Future Directions

# The EBOVAC Salone Trial

- IMI funding of Ebola+ programme to support development, manufacturing and deployment of vaccines
- Consortium partners: LSHTM, Janssen, INSERM, COMAHS, Oxford
- Trial is assessing the safety and immunogenicity of the Ad26.ZEBOV/ MVA-BN-Filo prime-boost regimen
- Additional Phase 2 Studies in Europe and Africa
- EBOVAC Salone Study site: Kambia District, Northern Sierra Leone.
- Staged study, enrolment now complete:
  - Stage 1 (open label): 43 adults enrolled in October 2015
  - Stage 2 adults (RCT): 401 adults enrolled March – October 2016  
– RCT
  - Stage 2 minors (RCT): 192 adolescents aged 12-17; 192 children aged 4-11; 192 infants aged 1-3 enrolled March 2017 – July 2018

# Partners and funders



LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



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# Anthropological Involvement in Clinical Trials

1. Anthropology of Clinical Trials
  - Social relations between researchers and participants
  - Complex political economy questions & local effects of medical research on participants and their communities
  - Rumours and concerns/ hopes & expectations
  - Social life of a clinical trial
2. Anthropology during the Ebola outbreak: highlighting importance of understanding socio-cultural dimensions of disease and the historical/political contexts which shape them (context **NOT** a barrier)
  - Combining the two in a context of Ebola vaccine trials being set up in context of an epidemic

# Social Science Research in EBOVAC

- Main objectives:
  - To explore participant and community perceptions of clinical research and their decision-making around the trial
  - To understand the socio-cultural context in which the trial takes place
  - To explore local understandings of illness, disease and medical interventions.
- Methods: Participant observation, Exit Interviews, In depth interviews, Life narratives, Focus Group Discussions
- Research Team: Shelley Lees (PI), Luisa Enria, Shona Lee, Mike Callaghan, Angus F. Tengbeh, Mahmood H Bangura, Kadiatu Bangura, Rosetta Kabia, Alhaji Nyakoi

# Communications & Social Science

- The trial and the community
- 2 teams: social science & community liaison
- Research-driven communication strategy
- Rapid feedback mechanism between social science and community liaison team
- Rumour tracking and power mapping

# Challenges: Power, Fairness, Trust

- Who is “the community”? Contestations of power & diversifying communication strategies
- Trust & mistrust during Ebola: confronting rather than rejecting anxieties
- Fairness: local perceptions and recruitment strategies



# Motivations for Joining

- Usual focus on rejection but why do people join *despite* anxieties and atmosphere of mistrust?
- Perceptions of risk

*“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. “*

# Motivations for Joining

- Usual focus on rejection but why do people join *despite* anxieties and atmosphere of mistrust?
- Perceptions of risk
- Reasons in first stages:

## ***Altruism & Sacrifice***

“We are real heroes in this country [...] we are ready to die for this country”

## ***Curiosity & Hope***

“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.”

## ***Health-seeking & Vaccine powers***

“[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”

“it is a health seeking process, it’s good that we play an active part in it”

## ***Expectations & Notions of Exchange***

“We went, and we said: ‘If we die, we will die’, so what is [there] for us? What is the benefit? “

# Motivations for Joining

- Usual focus on rejection but why do people join *despite* anxieties and atmosphere of mistrust?
- Perceptions of risk
- Reasons in first stages:
  - Altruism
  - Curiosity and hope
  - Health seeking & beliefs in vaccine powers
  - Expectations and notions of exchange
- Grounded ethics

# Lessons

- Value of social science
  - In depth understanding of context & social norms
  - Social perspective on disease and medical intervention
  - Rapid insights into *changing realities*
- Close collaboration between community engagement and social science
  - Confronting political and social inequities and social relations
  - Dynamic engagement rather than correcting misinformation
- Close collaboration between social science and clinicians: rapid feedback mechanisms
- Mediating worlds: grounded ethics?

# Future Directions: AViD

- Anthropological exploration of facilitators and barriers to vaccine deployment and administration during disease outbreaks (AViD)
- PI: Dr Shelley Lees (LSHTM)/ Partners: LSHTM, Oxford, Bath, Anthrologica
- “Ecosystem” of vaccine deployment for outbreaks
- Multi-case study & multi-method:
  - Sierra Leone: political economy of emergency deployment/preparedness
  - India: healthcare systems and vaccine controversies
  - Brazil: Zika and public trust
  - Uganda: local knowledge for exploration of human and veterinary pharmaceuticals



# Publications

- Enria, L. et al. "Power, fairness and trust: understanding and engaging with vaccine trial participants and communities in the setting up the EBOVAC-Salone vaccine trial in Sierra Leone." *BMC Public Health* 16, no. 1 (2016): 1140.
- Tengbeh, A.F. et al. "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." *Social Science & Medicine* 203 (2018): 35-42.
- Enria, L. & Lees, S. "Citizens, Dependents, Sons of the Soil: Defining Political Subjectivities through Encounters with Biomedicine during the Ebola epidemic in Sierra Leone" *Medicine Anthropology Theory* (September 2018)