Session	Session 9 Keynote 3
Name	Elysée Nouvet
Organisation	Western University School of Health Studies, London, Ontario and McMaster
Country	Canada
Title of presentation	Consent complexities, Ebola, and the fine line between collaboration and exploitation in research conducted during public health emergencies
Abstract	Background: There is significant and growing scholarship attending to the experiences and motivations of clinical Tx trial participants in Low and Middle Income Countries (LMICs). A smaller and newer body of research is emerging around perceptions and experiences of research conducted during public health emergencies. This presentation is based on one such Research on Research (RoR) study, the R2HC-funded qualitative study "Perceptions and moral experiences of research conducted during the 2014-16 West Africa Ebola outbreak." Objective: This presentation takes West Africans' first-hand accounts of decisions to support or enroll in EVD research as a point of departure for troubling normative parameters and markers of "consent to research". Methodology: Content for this presentation is based on team-based analysis of semi-structured interviews (N=99) with West African EVD study participants, members of research ethics boards, researchers, trial staff, and community leaders. Findings: Our interviews revealed diverse motivations and aspirations or participating or supporting trials, as well as some frustrations around limited options for engagement and impact. A number of researchers with whom we spoke experienced their decisions to "collaborate" on trials as coerced. Others – participants and community leaders – evidently embraced opportunities to enroll in and/or support trials, but simultaneously connected their voluntariness to conviction of their participation's impact on lives, to understandings of collective ownership over bio-samples, and/or to hopes for new political subjectivities. Mismatch between consent to trials (where consent includes both enrollment in or collaboration with) and the loaded significances of that consent for many with whom we spoke indicate a need for more localized and critical attention to the logics and significances of consent to research in particular humanitarian emergencies. Conclusion: Upholding ideals of free and informed consent to research in contexts such as ETCs, where those approached for research are sick, distressed, and quarantined, is never going to be easy. What our research flags is that the complexities of consent during the West Africa EVD epidemic extended beyond the walls of the ETC and beyond infected patients. This in turn supports broadening what normally gets included in discussion of and strategies to uphold consent and voluntariness in humanitarian heath emergency research.
Email address	nouvete@gmail.com