Western HealthSciences

BEYOND IDEALS

An Analysis of Clinical Research Enrollment Decisions in Post-Ebola Guinea

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OBJECTIVES

In the aftermath of the West Africa Ebola outbreak, many grew familiar with the term "**Ebola business**"-a phrase serving as a shorthand for an assemblage of practices and possibilities that stood for the **profitability potential** of the deadly Ebola virus in the country. This is the backdrop for a CIHR-funded qualitative study aimed at advancing the understanding of whether and how those approached for **clinical research** post-Ebola, experienced those invitations and associated benefits. The study was co-developed with members of the Guinean National Health Research Ethics Committee and **expands evidence-based understanding** of when and on what basis, **participants** in **foreign-funded and remunerated studies** in **high poverty** and **health need** contexts, understand their **choice to opt in or out of research.**

METHODOLOGY

In 2019, we conducted **40 interviews** with adult participants following their completion of participation in an **Ebola-related study**: either the Russia-funded **Gam-Evac Ebola vaccine trial**, or the French-funded **Ebosex semen persistence trial**. Interviews were transcribed verbatim, translated, and inductively analyzed to **identify key patterns** within participants' **narratives of why and how they reached their decision to enroll in research**

FINDINGS

After **analyzing** the data, the following **key themes** were communicated by participants regarding their **decision-making processes** for **clinical trial participation.**

DISCUSSION and SIGNIFICANCE

A majority of those interviewed described careful consideration of numerous factors before enrollment.

- Many were living economically precarious lives and described their **research participation as providing access** to **health information** or **ancillary healthcare**.
- Most interviewed also cited observing **others emerging unscathed** from their participation as **crucial assurance** of limited or **no risk**.
- In all cases, decisions to enroll were contingent on the **endorsement** of **trusted male members** of the community, recognized through their education or in community elections as leaders in community decision-making, and with a reputation for **honesty** and **loyalty** to the community.
- **Optimizing** chances for **personal health** stood as the primary motivator to research participation once the risk was deemed minimal, with all but one interviewee **denying compensation playing any determining role**.

Despite Guinea representing a context of high economic and health need, participation in research in the country does remain experienced as a choice. The power entrusted to community leaders to recommend trial participation is notable. A Western bioethics perspective might denounce this power as problematic (e.g., coercive, paternalistic) however, this seems limited. **Relational autonomy** in the context of this collectivist society must be given consideration. We argue for the epistemic and ethical importance of recognizing that in contexts of limited literacy and rational distrust of outsiders, relying on educated leaders with track records of loyalty to the community *expands* the autonomy of 'vulnerable' research participants, especially when this reliance on leaders is coupled with observation of safe outcomes.

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