

Ethics of health research priority setting

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Pecha Kucha presentation

Ebola Virus Disease outbreak response in West Africa

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Brief description of the case study context

The Ebola virus disease outbreak that occurred in West Africa in 2014-2016 highlighted the power imbalances between HICs and LMICs in research priority setting. The initial response to the outbreak was criticized for being slow and inadequate, and the lack of effective treatments and vaccines reflected the insufficient investment in research and development for neglected diseases affecting LMICs. One example of the power imbalances in the response to the Ebola outbreak was the development of an experimental drug called ZMapp. The drug was developed by a small biotech company in the US, and initial clinical trials were conducted on American and European volunteers. However, the drug was not made available to the affected countries in West Africa, and it was only after significant public pressure and criticism that the drug was finally made available to some patients in the affected countries. Another example of the power imbalances in the Ebola response was the lack of LMIC representation in the decision-making processes for research priorities and resource allocation. Despite the outbreak occurring in LMICs, the majority of research funding and decision-making power was held by HICs. This resulted in research agendas that did not adequately address the health needs and priorities of the affected countries.

This case study was conducted using a qualitative research approach, based on a review of existing literature on the Ebola outbreak response and related issues. The study involved an analysis of key themes and issues related to power imbalances in research priority setting and the strategies proposed for reducing these imbalances.

Ethical issues

The analysis of the Ebola outbreak response revealed several key findings:

Lack of representation: The development and distribution of experimental drugs like ZMapp reflected a lack of transparency and equity in research prioritization and resource allocation. LMICs were underrepresented in decision-making processes for research priorities and resource allocation, resulting in research agendas that did not adequately address the health needs and priorities of the affected countries. This lack of representation can perpetuate power imbalances between HICs and LMICs in research and limit LMICs' ability to advocate for their own health needs and priorities.

Building LMIC research capacity was essential for promoting more equitable research prioritization and resource allocation, as it would increase the ability of LMIC researchers to participate in decision-making processes and conduct research that addresses the health needs and priorities of their countries.

Exploitation of research participants: Unfair power dynamics between HICs and LMICs led to the exploitation of research participants in LMICs, who were vulnerable to exploitation due to factors such as poverty, lack of education, and limited access to healthcare. Researchers from HICs took advantage of this vulnerability by conducting research without obtaining informed consent, failing to provide adequate compensation or treatment for research-related injuries, or conducting research that did not benefit the local community.

Control over funding: HICs exerted control over funding for research in LMICs, which limited LMICs' ability to conduct research that addressed their own health needs and priorities. HICs used funding as a means of exerting influence and control over LMICs, leading to the prioritization of research that benefited HICs rather than LMICs.

Unbalanced distribution of benefits: Unfair power dynamics between HICs and LMICs resulted in an unbalanced distribution of benefits from research. HICs benefited from research conducted in LMICs, such as the development of new drugs or vaccines, without adequately compensating or acknowledging the contributions of LMIC researchers or communities.

Conclusions and recommendations

The recommendations to policy makers highlighted that the Ebola outbreak response in West Africa called for a more equitable research prioritization and resource allocation, particularly for neglected diseases affecting LMICs. The strategies proposed in this case study, include increasing LMIC representation, increasing transparency in funding decisions, building LMIC research capacity, and prioritizing ethical considerations in research, represent important steps towards achieving this goal. By promoting more equitable research prioritization and resource allocation, it is possible to improve global health outcomes and reduce the power imbalances between HICs and LMICs in research priority setting. Some recommendations on how to reduce unfair power dynamics between HICs and LMICs in research priority setting:

Increase LMIC representation: LMICs should be included in decision-making processes for research priorities and resource allocation to ensure that the health needs and priorities of affected countries are addressed. This includes increasing the representation of LMIC researchers and policymakers.

Prioritize ethical considerations: Researchers and funders should prioritize ethical considerations in research, including obtaining informed consent, ensuring participant safety and wellbeing, and conducting research that benefits LMIC communities. Provide immediate and adequate compensation, along with necessary resources and protective gear, to frontline healthcare workers risking their lives during outbreaks. Prioritize their safety and well-being to ensure their continued commitment and motivation in managing such crises. Establish robust frameworks for rapid international response to outbreaks. Ensure swift deployment of essential resources, medical aid, and personnel to affected regions to prevent the escalation of the crisis and minimize casualties. Recognize the invaluable contributions of local staff and volunteers and ensure they receive equal compensation, acknowledgment, and support as part of the frontline response. Address disparities in resources and protective equipment to safeguard their health and effectiveness in combating the outbreak. Develop comprehensive support systems for communities affected by outbreaks. Prioritize timely and adequate assistance to mitigate economic hardships, address healthcare needs, and combat social stigma. Emphasize community engagement and collaboration to aid in the recovery process. Invest in preparedness measures, including training, infrastructure development, and early warning systems. Develop and implement rapid response protocols that prioritize the safety and well-being of frontline workers and affected communities, ensuring a more effective response to future public health emergencies.

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