

*Data Sharing in Public Health Emergencies:
Anthropological and Historical Perspectives on Data Sharing during the 2014-2016 Ebola
Epidemic and the 2016 Yellow Fever Epidemic*

Final Report

Submission date: November 26, 2018

Research Team:

Sharon Abramowitz, Independent anthropologist

Tamara Giles-Vernick, Institut Pasteur

Jim Webb, Colby College [emeritus]

Jennifer Tappan, Portland State University

Elanah Uretsky, Brandeis University

Jorge Varanda-Ferreira, University of Coimbra

Katherine Mason, Brown University

Molly Beyer, University of North Texas

Claire Collin, London School of Hygiene and Tropical Medicine

Amadou Sall, Institut Pasteur-Dakar

I. STUDY DETAILS

Principal Investigator; Study coordinator	Sharon Abramowitz saabramowitz@gmail.com
Co-Principal Investigator; Supplier	Tamara Giles-Vernick tamara.giles-vernick@pasteur.fr
Funder	Alice Jamieson Wellcome Trust 215 Euston Road, London NW1 2BE +44 (0) 20 7611 8446 A.Jamieson@wellcome.ac.uk Through the Wellcome-DfID joint initiative on epidemic preparedness
Institut Pasteur Ethics Committee Protocol	IRB2018-07
Key words	Yellow fever virus (YFV), ebola virus disease (EVD), data sharing, open access, epidemic, preparedness, response, case study, public health emergency

II. ACKNOWLEDGEMENTS

We thank Wellcome-DfID joint initiative on epidemic preparedness for its generous financial support. We thank the Wellcome Trust, the U.K. Department for International Development, and particularly Alice Jamieson, Katherine Littler, and Lenio Capsaskis for the opportunity to investigate these case studies and for their stimulating questions, and Helena Wilcox for her support. Our thanks, too, to the Institut Pasteur for its support of this project and particularly Marie-Laurence Meignan for her valuable administrative help. Katherina Thomas provided invaluable and rapid transcription of our interviews, which we truly appreciate. Finally, we are grateful to all those who patiently and frankly responded to our questions.

This work was funded through the Wellcome-DfID joint initiative on epidemic preparedness and does not represent the views of the funders.

Table of Contents

I.	STUDY DETAILS	2
II.	ACKNOWLEDGEMENTS	3
III.	ABBREVIATIONS	5
IV.	SUMMARY: DATA SHARING DURING EPIDEMICS	6
	<i>A. Executive Summary</i>	<i>6</i>
	<i>B. Key Findings</i>	<i>9</i>
	<i>C. What are data in a public health emergency?</i>	<i>13</i>
	<i>D. What is sharing during a public health emergency?</i>	<i>15</i>
	<i>E. Data Sharing During Public Health Emergencies: Histories and Precedents.....</i>	<i>16</i>
	<i>F. Data Sharing: A Comparison of the Cases.....</i>	<i>22</i>
	<i>G. PEARLES</i>	<i>23</i>
	<i>H. Ethics.....</i>	<i>28</i>
	<i>I. Lessons learned: How could more data sharing have helped?</i>	<i>32</i>
	<i>J. Who is Responsible?</i>	<i>33</i>
	<i>K. Our Approach</i>	<i>34</i>
V.	CASE STUDY: YELLOW FEVER EPIDEMIC 2016.....	36
	<i>A. Summary</i>	<i>36</i>
	<i>B. Yellow Fever: A Historical Overview.....</i>	<i>36</i>
	<i>C. Yellow Fever Epidemic in Angola and Democratic Republic of Congo (2016).....</i>	<i>39</i>
	<i>D. Data sharing during the Angola-DRC-China Yellow Fever epidemic.....</i>	<i>40</i>
	<i>E. Post-epidemic data sharing</i>	<i>55</i>
	<i>F. Key barriers and facilitators to data sharing</i>	<i>57</i>
VI.	CASE STUDY: WEST AFRICA EBOLAVIRUS EPIDEMIC 2014-2016.....	67
	<i>A. Summary</i>	<i>67</i>
	<i>B. Ebolavirus disease: A Historical Overview.....</i>	<i>68</i>
	<i>C. West Africa Ebola epidemic (2014-2016).....</i>	<i>71</i>
	<i>D. China’s Response to Ebola in West Africa</i>	<i>74</i>
	<i>E. Data Sharing during the West Africa Ebola Epidemic.....</i>	<i>75</i>
	<i>F. Post-Ebola Data Sharing.....</i>	<i>100</i>
	<i>G. Key barriers and facilitators to data sharing</i>	<i>103</i>
VII.	WORKS CITED	108

III. ABBREVIATIONS

(DRC) Democratic Republic of the Congo

(EVD) Ebola virus disease

(ETC/ETU) Ebola Treatment Center, Ebola Treatment Unit

(EOC) Emergency Operations Center

(ERF) Emergency Response Framework

(ECDC) European CDC

(IMS) Incident Management System

(INSP) Instituto Nacional de Saúde Publica, Angola

(IHR) International Health Regulations

(LMIC) Low- and middle-income countries

(MSF) Médecins Sans Frontières

(MINSÁ) Ministério de Saúde, Angola

(MOH/MOHS) Ministry of Health, alt. Ministry of Health and Sanitation

(PHEIC) Public Health Emergency of International Concern

(US CDC) U.S. Centers for Disease Control

(WHO) World Health Organization

(YFV) Yellow fever virus

IV. SUMMARY: DATA SHARING DURING EPIDEMICS

A. Executive Summary

The EVD and YFV epidemics demonstrated two radically different models for data sharing during epidemic response - a routine data sharing environment, as compared to an extraordinary event classified as a Public Health Emergency of International Concern.

Business as Usual vs. PHEIC

In our analysis, the YFV epidemic of 2016 that affected Angola, the Democratic Republic of the Congo, and China constituted a case of “business as usual” in epidemic response, with the routine stakeholders frequently engaged in disease outbreaks in LMIC countries (see Table 1). During the YFV outbreak, data access was strictly regulated by government authorities. WHO actors were able to mobilize informal persuasive measures to gain access to data, but they had little authority to circulate that data beyond their own carefully constricted inner circle of data stakeholders (ex. WHO Collaborating Centers, response partners), and even within that circle, implementing partners had inconsistent access to data. Countries with close bilateral relationships with the national governments – like Cuba and Angola - were able to gain access to data by leveraging long histories of public health response partnerships that bypassed routine mechanisms of information coordination for outbreak response.

In contrast, the West Africa EVD epidemic of 2014-2016 constituted a critical moment in global health history. The epidemic, which was declared a Public Health Emergency of International Concern (PHEIC) in 2014, mainly affected Liberia, Guinea, and Sierra Leone, but also resulted in smaller outbreaks in Senegal, Mali, Nigeria, and several European and North American countries. Prior to the PHEIC declaration on August 8, 2014, data sharing in the EVD epidemic was characterized by the engagement of data stakeholders that typified routine epidemic response activities. Data sharing was restricted to stakeholders who were regarded as relevant for operational response, and access to data was deeply restricted and shaped by pre-existing governmental and institutional arrangements.

However, in the EVD epidemic, routine data sharing practices (and the lack thereof) gave way to a radical shift in expectations, supply, and demand for data sharing. With the PHEIC declaration, and the media-visible, public failure of conventional approaches to epidemic containment of the Ebola virus appearing on the front pages of newspapers around the world, conventional standards, norms, and agreements regarding the legitimacy of data stakeholdership were deeply tested by a range of insurgent data claimants and data sharers, both globally and on the ground in West Africa. With these drivers, insurgent actors within and outside conventional stakeholder relationships moved to share data informally with “outsiders,” to create open-source mechanisms for creating and circulate data, and to put pressure on core response actors to increase data access and transparency. At the same time, the question of data sharing between response pillars became important. Data was segmented between response pillars (e.g. epidemiological was sent to WHO collaborating centers for modelling and analysis; while social mobilization data stayed within the social mobilization pillar for response), and pre-existing data sharing agreements between the WHO, collaborating centers, and unspoken expectations with implementing partners sustained these divisions.

In all this, the role of the nation-state as a focal point in arbitrating data access was subject to continuous testing and was managed quite differently by different national governments. This is addressed more completely in the case studies.

Table 1: Key Stakeholders

Stakeholders	YFV	EVD (a PHEIC)
National governments in affected countries	x	x
WHO	x	x
WHO Collaborating Centers	x	x
WHO/epidemic response NGO implementors (IFRC, MSF)	x	x
National research partners	x	x
International research community (not WHO CCs)		x
International global health community		x
Multilateral agencies and funders (e.g. World Bank, IMF)		x
Foreign governments	x	x
Private donors/philanthropists		x
Commercial/for-profit entities		x
Humanitarian response actors		x

Data: What was important?

In all epidemics, specific types of data are routinely prioritized for collection and circulation to inform response activities. During the YFV epidemic, these routinized practices were on display. Prioritized data included epidemiological data, clinical data, laboratory/diagnostic data, genetic data, and vaccination data. There were capacities created to conduct research during this epidemic due to the need to distribute fractional dosages of the YFV vaccine to local populations, due to a global vaccine shortage.

During the EVD epidemic, the first eight months of the outbreak were marked by a dependence on these routine sources of data collection. However, as the epidemic grew in scale, visibility, risk to wealthy countries, it exceeded the capacity of responders to contain the disease. When the PHEIC was declared, conventions regarding needed data were tested. While routine actors like WHO collaborating centers were subjected to strict limitations on the kinds of data they could access and circulate, external actors – from ‘star’ scientists to philanthropists – were brought to the region to look at sensitive data. Dispensations were made on informal and formal bases.

The chaotic conditions were unfavourable to structured data sharing (and even supported data hoarding actions); but it was also remarkably facilitative of informal sharing and open source data sharing. There was also an enormous surge of data sharing innovation from unconventional data stakeholders demanding access to and input into the EVD response. Anthropological, geospatial, clinical, and political and economic data were highly demanded – and were generally unavailable due to a lack of existing and integrated platforms for collection and sharing. People working within the region felt morally compelled to share data outside of institutional norms and conventions in order to raise international awareness about the impact of the epidemic. And researchers outside of West Africa worked intensively on the limited data emerging from the region to make it accessible and useful to unrecognized, informal “response actors,” including data consumers that ranged from the U.S. White House Office of Science and Technology Policy to college classrooms.

Was there a Therapeutic or Vaccine?

We learned that the presence of a vaccine substantially impacts attitudes towards data sharing during an epidemic. When a vaccine or therapeutic is available, the overwhelming focus of epidemic response is oriented towards *action*, mainly the effective distribution of the vaccine or therapeutic. In the absence of a vaccine or therapeutic, a more expansive approach is taken towards *learning*, and *learning* is conducive to a response environment that supports data sharing.

In our analysis of the 150+ year history of YFV epidemic response, we discovered that historically, both sociocultural and entomological data were more prioritized for YFV epidemic response than they currently are. The shift towards dependence on a vaccine has resulted in a corresponding decline in response prioritization of vector control; which has in turn resulted in a decline in research capacity and interest in vector data and sociocultural data. Vector control, however, is still an important and effective part of YFV response, and social mobilization continues to be a major priority for response activities (though not data collection or data sharing). This marks a marginalization of key data areas that should be reconsidered.

In the absence of a rapid diagnostic, therapeutic, or vaccine, governments around the world mobilized vast research networks and resources to target responses to the Ebola outbreak. To find vaccines and rapid diagnostic tests, public/private partnerships involving government funds, WHO coordination, pharmaceutical development, and international research community intellectual property and licensure were negotiated through closely guarded meetings and public statements. On the other hand, scientific journals tried to facilitate the flow of data and analyses by opening up rules around publishing pre-printed data, removing paywalls, and increasing expectations regarding shared attribution.

Barriers

Different types of data were associated with different barriers to sharing, and often these barriers existed on a country-by-country basis and changed over time. Further details on barriers and facilitators are presented in the report.

The Relevance of History

Much attention has been paid – and rightly so – to the role of specific historical relationships between governments, between African governments and formal colonial powers, and between wealthy and LMIC countries prior to epidemics. Less attention has been paid to how the history of the WHO itself has informed some of these relationships and capacities. We found that the deep history of the WHO’s relationships with collaborating centers continues to create privileged access to a limited number of public health agencies, research institutions and research communities. Long-standing relationships with the WHO are associated with greater data restrictiveness overall and may reproduce relationships of ‘data colonialism’ observed by others. This situation is likely to be tested, as nearly 2/3 of all WHO collaborating centers have become so in the last 15 years, and most are located in non-Western countries. We can anticipate frictions around data sharing as formerly privileged relationships are expected to give way to a more inclusive collaborative public health emergency response environment.

China

China played a unique and distinctive role in each of these outbreaks, and we believe that a dedicated analysis was needed to understand the growing role[s] of non-traditional government actors in disease response. During the YFV outbreak, China was a government affected by the outbreak in that it had several hundred thousand migrant workers based in Angola and became a

site of YFV spread through the migration of mobile laborers between Angola and China. China did not intervene in Angola, and instead chose to identify suspected cases at its border, implement rapid isolation and containment measures, and ended the potential outbreak in just a few days.

In contrast, during the EVD outbreak, China deployed a major mobilization of human resources, funds, infrastructure, and expertise to support the EVD response. It partnered with local coordination actors in Sierra Leone, worked closely with the U.S. CDC, and made clear through public statements that it was doing so as part of its *Belt and Road Initiative* to engage globally in public diplomacy through health diplomacy.

Lessons Learned

Although the EVD outbreak received an enormous level of international attention, investment, and structural change emphasis for data sharing during epidemics, in this analysis, we regard YFV as the more significant of the two studies. In many ways, the story of data sharing during the YFV outbreak *was* the story of data sharing during the EVD outbreak, until the EVD outbreak became unmanageable, a PHEIC was declared, and radical efforts were taken to change the entire approach to public health emergency response, research, and learning --- for Ebola in West Africa in 2014-2016. For the most part, however, the norm for disease response remains the YFV model – which was, in fact, deployed chronologically after the EVD outbreak, in involved many actors who had worked in both scenarios. The YFV model is likely to continue to remain the dominant model for data sharing during epidemic response unless specific measures are taken to change the overall approach to epidemic response.

B. Key Findings

Overview

- WHO policy statements on data sharing privilege certain kinds of data, including surveillance, epidemiology, and emergency response data, genetic data and clinical trials. These priorities pre-empt other kinds of data collection and slow their integration during epidemics.
- There has been a growing recognition among nation-states that during epidemics, certain kinds of data have value to the international community.
- For privileged data, there are known informal and formal rules for data production, data sharing, and data publication in the international community. These rules are specific to the types of data, and the types of knowledge required for data generation and analysis.
- National leadership strongly impacted data sharing. Emergency Operations Centers based in government ministries facilitated the logistical aspects of formal and informal data and analytical exchanges.
- Data sharing is not a costless common good. Data has value for nations, institutions, and persons, and effective data sharing strategies recognize this value rather than try to erase it.
- Long historical experience with epidemics facilitated specific institutional expertise in both EVD and YFV research and the forging of multinational institutional collaborations with strong historical affiliations with the World Health Organization.

The types of data needed and used during epidemics are probably too limited. As new frameworks of ‘essential disciplines’ have emerged, the utility of some earlier approaches has

been forgotten or side lined. This appears to have been the case, for example, with vector control in yellow fever outbreaks.

- During public health emergencies, recent historical data – including entomological data, ecological data, clinical data, and the testing of biological samples collected prior to the outbreak – came to be seen as valuable and important. Additionally, data collected prior to the outbreak, or for non-epidemic purposes (e.g. census data, monitoring and evaluation data) can provide valuable insights.
- The rules, guidelines, and procedures for data sharing during public health emergencies differ widely by data class and can be opaque or confusing. Data specific considerations need to be taken into account in data sharing.
- During public health emergencies countries like China, Cuba, and Russia drew upon distinct historical and institutional relationships to negotiate data sharing.
- China is emerging as a major global player in epidemic response and is building global health surveillance and laboratory infrastructure in hot spots around the world as part of its “One Belt, One Road” soft power strategy. But as China’s very different engagements in the YFV and EVD epidemics demonstrate, national governments have quite distinct needs and objectives for engaging in public health response; and these specific considerations can inform data sharing differently during different epidemics.
- Nation-states’ approaches to, and understandings of, effective data sharing may not resemble those of Western powers. The workings of its authoritarian yet decentralized government may both help and hinder data sharing during public health emergencies.

YFV Case Study

- During the 2016 YFV epidemic, officials found it more challenging to gain access to the full epidemiological databases in Angola than in DRC. Angola refused to share epidemiological data or provide access to raw data and national databases. In DRC, access to this type of data was “simpler,” but was limited by a net dearth of data.
- Data sharing had a mixed record. Delays in reporting diagnostic results were significant at the outset of the epidemic and may have had consequences for the spread of the epidemic. In Angola, it galvanized the creation of laboratory capacity for YFV diagnosis, helped to identify new outbreaks, and assisted Angola in developing new differential diagnostic tools for febrile syndromes.
- Angola, through MINSA, maintained strong state control over data sharing. Through the tightening of formal procedures between June and August of 2016, MINSA increased its control over data sharing among collaborating partners. MINSA data sharing procedures were regarded by respondents as confusing or rigid.
- Political considerations and social ties facilitated data sharing. Shared experiences of prior outbreak responses and material support forged “trust”, which was a prerequisite for sharing. Sharing itself cultivated and reinforced trust and facilitated other kinds of support.
- In Angola and DRC, the lack of trained personnel translated into significant delays and non-sharing in multiple ways, particularly for response coordination, clinical, epidemiological and vaccination data. The quality (timeliness, accuracy) of shared vaccination data suffered

because of a dearth of accurate complementary data, including epidemiological data. Delays and inaccuracies in vaccination data and census data hampered the production of estimates of vaccination coverage.

- In Angola, early response coordination was hampered by a lack of personnel and infrastructural capacity. Angola’s surveillance system was weak, and it initially had no laboratory capacity for detecting YFV; it did not have sufficient people or capacity to collect reliable epidemiological data. This made it difficult to quickly produce the data needed to mount an effective response via vaccination campaigns. The main blockage in Angola was in reporting diagnostic results from the national laboratory to the provinces and districts.
- In DRC, some data was shared with the WHO, but the lack of data that resulted from insufficient detection and reporting prevented consistent sharing.
- In China, all YFV data was held by the state, and the state was able to mount an effective response. The epidemic was identified among traveling migrant workers at the Chinese border (airports), and immediate measures were taken to isolate YFV cases. The epidemic concluded in several days.
- The Cuba Cooperation had a decades-long history of vector control in Angola. It followed different, perhaps less-restrictive data sharing procedures.
- Procedures for data sharing posed barriers to sharing, either because they were not always clear to those involved or because they were perceived as too rigid.
- After the YFV epidemic, most data were never published.

EVD Case Study

- National actors were under enormous international pressure to share data. MOHs were confronted by the international press about epidemic response operations, and by international scientists demanding original epidemiological data.
- As the epidemic escalated, it brought together “the usual suspects” in Ebola response, the World Health Organization, academic research institutions, medical NGOs, and governments. When individuals didn’t know each other, credibility for data sharing was conferred by their organizational institutions. Informally, many the key data stakeholders were people who were known to each other, who had worked together before, and were able to presume a certain set of common understandings about epidemic response priorities. These people were “elites” in the EVD response. They were the data stakeholders because they held the data.
- The vertical working groups/pillars structure of the IMS defined the lines of authority and accountability within the system.¹ This response architecture facilitated flow of data within pillars, but created barriers between pillars.
- Access to information was initially severely restricted. WHO SitReps needed to be circulated in machine-readable formats. Without this capacity, NGOs, senior government officials, and response actors were unable to interact with the data in order to use it for response planning, activities, or research.

- A crucial gap in governmental coordination was inter-governmental coordination around border areas. This was managed directly through informal mechanisms (cell phones, email) between actors in neighboring districts who bypassed their chains of command to share case counts, suspected movements of potentially infected individuals, and other public health activities.
- Data sharing depended on one's positionality. Many responders wore multiple hats at the same time, each with distinct ethical frameworks, priorities, and decision-making and there were no clear super-ceding logics or discourses that lead to a natural preference for one over the other.
- When it became clear that routine systems for epidemic management were failing to keep pace, marginal experts, or experts not trained in traditional public health fields, like anthropologists and modelers eagerly engaged in informal data sharing in order to influence the course of the epidemic.
- Clinical trials data sharing was constrained by ethics, protocol, and confidentiality agreements. This raised serious problems for healthcare workers who were frequently required to be a frontline interface between EVD suspected cases and healthcare access. Secrecy about clinical trials research findings also raised alarm and frustration among local populations.
- All actors working in open-source platforms struggled with issues of citation and attribution (this included anthropological data, and GenBank). It was through these processes, or other open-science approaches that abuses between researchers and concerns about exploitation were more likely to be reported. However, it was also recognized that these platforms were enormously impactful for a huge global audience.
- The small network size of some research communities resulted in the concentration of large quantities of data with just a few international stakeholders during the EVD epidemic. Individuals functioning in those nodes made *ad hoc* decisions about how to manage data access and data sharing based on the situated knowledge of those individuals.
- Research on biological specimens took precedence over transmission, ecosystems, reservoirs, and diagnostics, which were more critical for a conventional public health response.
- Ethics review processes were slowed down by a lack of information and clarity about the rules and procedures for sample ownership, and uncertainty about how results would be shared with participants and their communities.
- Researcher-originated conflicts over sharing data regarding PCR thresholds lead to implementation problems for epidemiologists and clinicians.
- Infectious disease cartography was implemented in several ways during the Ebola outbreak, and nearly all efforts depended on open-source shared data.
- The barriers to private sector data use (e.g. mobile phone data) were substantial, and largely hinged on the legal requirement for private sector partners to prioritize individual privacy concerns; the ethics of using private sector data for unapproved purposes, and difficulties establishing the contractual foundations for data sharing.
- Funding, logistical support, and institutional support for data collection and data sharing did not keep pace with the expansion of social science demands.

- KAP studies were delayed due to their status as a research activity. When KAP-like data was mapped onto operational research, data was collected more frequently, and disseminated more widely across practitioner networks.
- Data on community engagement was widely available and accessible to all actors involved, but it was not seen as a priority data area, and no formal consideration was given to its distribution or preservation.
- After the epidemic, the rewards for data sharing were not distributed evenly. Those with close proximity to key decision makers received credit and recognition for their efforts, while informal contributors, within-organization advocates, and volunteers were rarely recognized for their work.
- Long-term data custodianship has become a crucial issue in regulating access to data and biological specimens from the West Africa Ebola epidemic. Key post-epidemic decisions are being distributed across stakeholders in a more haphazard manner. In some cases, it's unclear if the governments themselves continue to hold the data. The development of an EVD biobank has become mired down by a lack of consensus about governance mechanisms. Respondents remarked that some key stakeholders were “happy with the status quo.”

C. What are data in a public health emergency?

Data sharing in the context of health emergencies has posed a major challenge to epidemic responses since the SARS outbreak in 2003.^{2,3} During disease outbreaks, data sharing allows for a better understanding of the pathways of infection, epidemiologic spread, categorization of disease, and more – and more effective and humane - prevention, treatment and care.^{4,5} But what is “data” during a public health emergency? What is sharing? How does it work? Whom does data sharing privilege, and who derives benefits? Why don't people and countries share data? How can data sharing – or the lack of sharing - cause harm?

For this comparative case study, the first case examined the Yellow fever virus (YFV) outbreak in Democratic Republic of the Congo (DRC), Angola, and China in 2016 which represented a *known pathogen with a licensed intervention* (a vaccine). The second case the West Africa Ebolavirus disease outbreak of 2014-2016, which represents a *known pathogen without a licensed intervention*.

These cases demonstrate that the presence of a licensed intervention is a critical factor in determining the total ecology for data sharing during an epidemic. We determined that in the YFV epidemic, the usual playbook of case identification and vaccinations was mobilized, a limited number of core response actors were tapped to provide support, and there was a “usual playbook” of response activities. Data needed to be shared to facilitate response activities. Outside of the fractional dosing of YFV vaccine, which resulted from a global stockpile shortage of YFV vaccine in 2016, there wasn't an active learning environment that demanded data sharing during the YFV epidemic. While much attention from our respondents was focused on the strict centralization of data at national government levels, we found that this dependence on routinized approaches lead

to overlooking key lines of inquiry, particularly with regard to vector control and socio-cultural contexts¹.

In contrast, the Ebola epidemic involved a high-visibility response environment where learning was prioritized. Early failures during the outbreak meant that key response actors at the most senior levels of government and the WHO were forced to recognize that the usual epidemic response playbook was failing, and new thinking and learning was required. This necessitated data sharing. There were so many uncertainties about Ebola virus disease, prevention, control, treatment, and basic research questions that data sharing was a necessary practice. As a result, this epidemic saw a kind of global renaissance of global health research and data sharing. An enormous diversity of agreements, technologies, platforms, and lines of communications were opened to share data; and many of these practices continued well into the aftermath of the epidemic.

As a group of anthropologists and historians, we bring a unique perspective to the question of data sharing during public health emergencies. We premise our research on the understanding that data are shared by people – many of whom play multiple roles and hold multiple positionalities during disease outbreaks, and situate themselves in multiple networks of obligation, reciprocity, norms, and ethics around data production, use, sharing, and dissemination. At the same time, data are claimed by institutions including governments, universities, multilateral agencies, and research labs that are each governed by their own interests. The factors that inform the use, production, and dissemination of data during epidemics are embedded in deep historical relations that inform modes of production, extraction, sovereignty, and dependency. These historical, institutional, and individual factors result in new configurations of data networks, use, agreements, and policy that tell a new story for every epidemic.

In the development of these two case studies, we were compelled to develop a definition for data that was as imprecise as our respondents' interpretations: *Data*, we observed, was situated information that can be shared and understood by others. It may or may not be standardized. It always involves dynamics of inclusion and exclusion. In public health, data are frequently collected with an eye towards purposive use, to inform or validate policies or actions, or to test the validity of the relationship between anecdotal narratives and empirical events at scale.

This definition of data fits poorly with existing legal and policy frameworks for defining data, which frequently position data as a *good* or as *property* – either institutional or individual. If *data* are property, then data sharing should accord with philosophical and legal precedents for property ownership and transfer, or for the production and consumption of communal and public goods. From the International Health Regulations to individual institutions' legally prescribed data sharing agreements to Europe's new General Data Protection Regulations (GDPR), an intellectual property approach to individual, institutional, and government data ownership provides the framework for governing data. As a result, determinations about whether data are "public" or "private" are particularly salient in contexts of public health emergencies. An exclusive "data as property" approach, however, aligns poorly with how producers, users, and consumers value, use, and distribute data.

Two other approaches were presented by our informants, which we describe as "data as labor" and "data as speech." In "data as labor," respondents characterized their time, effort, and work on data

¹ For example, there was a mass social mobilization campaign to respond to the YFV epidemic, but there was almost no data – beyond operational information – developed around that work.

—through the production of data by transforming information and observations into an entity that is readily discernible as a new kind of data; or through standardization, analysis, and dissemination—as meriting compensation. This kind of compensation was frequently sought through authorship on publications, credit or recognition among professional peers, and the establishment of scientific and professional credibility or capital for future work.

In “data as speech,” data stakeholders characterized their duty to share data as a matter of moral obligation to “tell the truth.” They described their intention to raise awareness, invite the attention and support of the world, and inform research and policy for humanitarian benefit, for the benefit of science, or for the public good. Informants who characterized data as speech were likely to share Dropboxes™ or Microsoft Excel™ spreadsheets of data with individuals who might be in a position to broadcast that data; position the data for analysis by the widest possible audience; or use the data to raise the visibility of public health emergencies to key stakeholders who controlled financial and policy decisions. Alternately, an individual researcher might regard the publication of data as “speech” in his or her professional milieu or discipline; by depriving a person of the right to share “data as ‘speech’” through conventional pathways, data sharing principles might effectively silence a researcher and deprive them of a voice in their professional conversations.²

For each interpretation of data – property, labor, or speech—there exists strikingly different principles of law and policy that inform individual and institutional regulations, protections, and obligations. Our view is that during public health emergencies, data is a hybrid of property, labor, and speech; and data stakeholders treat data as such in any situation in which there is not a pre-existing, strong data sharing agreement. This results in the widespread *informalization* of data sharing across epidemic response networks; the larger the network, and the more varied the types of data in use, the more informal it is. We do not view this as a misuse of data; instead, we view it as an application of the core principles of property, labor, and speech that each stakeholder carries with them to an outbreak scenario. Again, these historical, institutional, and individual factors result in new configurations of data networks, use, agreements, and policy that tell a new story for every epidemic.

D. What is sharing during a public health emergency?

The term “sharing” encompasses a wide range of actions and activities ranging from the informal to the rigidly bureaucratic (see Figure 2). It entails a variety of interactions and social and technical practices: collaboration, trust and reciprocity, legal and transportation and technological regimes, publishing data, uploading data onto an open-access database, providing data to institutions implicated in epidemic response prior to publication, or even allowing research collaborators to see data. Data sharing is also entangled with issues of ownership, credit, responsibility, obligation, and power. As some analyses have shown, debates over data sharing and insistence over the unambiguous values of “common good” need additional nuance.^{6,7} Whether to share, at what moment to share, what data to disclose and hide, and with (or from) whom are shaped by the institutional social conditions and the contemporary and historical relations from which they emerge.⁶

² There are implications to a “data as speech approach” for nation-states as owners and sharers of data as well. This was not a key theme in our findings and requires further attention.

Unfortunately, for many actors involved in epidemic response, the legal framework for data sharing during epidemics offers limited guidance. According to the International Health Regulations³, World Health Assembly member states commit to sharing with the World Health Organization (WHO) and submitting for inspection public health, surveillance,⁴ and personal [individual] data.⁵ The WHO has elaborated its stance on data sharing with reference to specific categories of data in public health emergencies in its 2016 *Policy Statement on Data Sharing by the World Health Organization in the Context of Public Health Emergencies*.⁸

In this policy statement, certain types or classes of data are privileged in data sharing guidelines. In workshops and publications, academics⁹ and policy makers¹⁰ with insider access to data and decision-making in public health emergencies have identified the following types of data as priorities for collection and sharing:

- Surveillance, epidemiology, and emergency response data, including “data from surveillance and monitoring (informing epidemiology), from the emergency response (e.g. contact tracing, vaccination, treatment), and data concerning health facilities (e.g. the numbers and locations of in-patient and out-patient centers, and the staff and medical facilities available at these centers).”
- Genetic sequence data/information
- Observational studies and clinical trials

By prioritizing these classes of data, the WHO has established provisional policy approaches for data sharing, but it excludes or fails to recognize key emerging domains of data production and dissemination like qualitative and social science data, private sector/mobile GIS data, economic data, and ecological/vector control data.

E. Data Sharing During Public Health Emergencies: Histories and Precedents

Colonial provenance of data sharing during epidemics

Practices of data sharing in response to health emergencies long predate the 21st century. ‘In-network’ data sharing has existed for nearly as long as contemporary public hygiene and sanitation. In fact, it may be regarded as a constitutive feature of modern public health. For centuries, municipalities and countries have kept birth and death records, and since the latter half of 19th century, individual states have had systems for collecting and reporting epidemiological and demographic data. The first international institutions to coordinate international public health responses were the Office International d’Hygiène Publique, founded in Paris in 1907, and the Health Office of the League of Nations, established in Geneva in 1919. By the late 1920s, the League of Nations had established regular reporting for the prevalence and mortality of five major diseases.¹¹ Data sharing among the nation-state members of these organizations was principally concerned with communicating the immediacy of epidemic threat.

The official history of international coordination of disease control during epidemics dates from 1851-1891, when Mediterranean states convened ten international sanitary conferences to address the problem of epidemic cholera through quarantine and sanitary cordon, leading to widely ratified

³ International Health Regulations Articles 6-11

⁴ International Health Regulations Part I Article 1 “surveillance,” “personal data”

⁵ International Health Regulations, Part VIII Article 45

conventions.¹² Data sharing fits into this narrative through researchers based in European metropolitan medical and public health institutions, and in research institutions located in European colonies.¹³ Researchers developed personal networks for sharing findings, facilitated by mutual respect and trust⁶.¹⁴ There were no open repositories of biomedical data for researchers to consult, but this period (appx. 1880-1925) saw the launch of several journals to share research and observations regarding tropical medicine, public health, and hygiene and sanitation.

In colonial Africa, physicians and public health officials shared clinical and epidemiological data during epidemics. Such data sharing was extensive, important, and frequent. Through the early 20th century, researchers and clinicians from European imperial powers forged expert transnational networks that facilitated medical advances as well as colonial domination in African colonies.¹⁴ Through research on diseases such as trypanosomiasis (sleeping sickness), historical analysis has demonstrated that mass public health interventions worked simultaneously as a therapeutic agent, technique of governance, merchandise, and object of expertise, belief, and controversy; and they moved across multiple networks – biomedical, pharmaceutical, and imperial.^{15,16} Early trends in data production and data sharing have also persisted through today by neglecting to acknowledge the contributions of local public health workers and data aggregators.¹⁷ These “neglected actors” are important as producers of data, but are frequently overlooked as contributors to developing scientific knowledge, or as “key stakeholders” in data sharing networks.

Beginning in 1948, the World Health Organization of the United Nations, headquartered in Geneva, broadened data-sharing networks by creating authoritative consultation services that centralized clinical and epidemiological data collection and diffusion. Through its recruitment of health experts, the regular convening of expert committees that typically focused on individual disease threats, international conferences, and the establishment of regional offices (EURO, EMRO, AMRO/PAHO, AFRO, SEARO, and WPRO), the WHO extended networks of disease control experts from colonial North American and European centers to the rest of the world. In the postwar period, a proliferation of medical and public health journals diffused clinical and epidemiological information and helped to create personal networks of researchers that crossed national and imperial borders.

During the first two decades of the WHO’s existence, clinical and epidemiological reports often included anthropological observations, qualitative assessments, and information about the broader political and cultural environments in which disease control programs were carried out. These were considered integral to developing disease control programs that had realistic chances of success.¹⁸ Nevertheless, beginning in the mid-1960s, as part of an epistemological shift that swept the social sciences as well as the biomedical sciences, quantitative data came to dominate most fields of biomedicine. This shift was framed in the binaries of “scientific” versus “humanistic” and “rigorous” versus “non-rigorous.” Qualitative assessments and anthropological observations thereafter disappeared from the clinical and epidemiological reports.

Contemporary data sharing during epidemics

Data sharing in its current usage does not appear in scientific databases until the mid-1980’s, suggesting that our expectations of data sharing as a historical construct is very much informed by

⁶ In Egypt, for example, researchers from various national backgrounds intermingled and shared important discoveries such as the epidemiology of hookworm and schistosomiasis.²⁵³

a move to open science.¹⁹ In the last half-century, three parallel developments have emerged that are driving contemporary debates around data sharing during epidemics: the emergence of “open science” initiatives, increased global coordination in epidemic response, and new kinds of negotiations between national and international authorities during public health emergencies, as evidenced through the SARS case.

Open Science

First, we saw the establishment of “open science” initiatives from the 1980s-2000s to facilitate the sharing of molecular and DNA sequence data. This includes GenBank (1982), the Human Genome Project²⁰ (1990-2003), the Bermuda Principles (1996), and the Fort Lauderdale Agreement (2003). With these developments, the meaning of data sharing for health research began to shift to an open source model of public access to information. Prior to the Human Genome Project, data sharing for epidemics was regarded as a technical capacity available to public health research and response communities, for those who had a “need to know” in order to “respond.” The 1996 Bermuda Principles [Bermuda Accord] and the 2003 Fort Lauderdale agreement changed data sharing norms that had restricted the pre-publication release of genomic data. Defining a novel model of open data release, the Bermuda Accord declared that all DNA sequence data had to be released freely and publicly within 24 hours of generation; it also established rules for the rapid and public release of DNA sequence data. Since the development of the Human Genome Project, other platforms for genomic data sharing have been developed and deployed, including HapMap, dB Gap and the European Genotyping Archive.²¹

International coordination

Second, novel coordination capacities have been established to build both a system and a culture of international cooperation around epidemic response, with the World Health Organization at the center. These developments run parallel to other shifts in post-Cold War global governance that are (imperfectly, and with significant gaps) prioritizing international coordination, information sharing, and collective action over bilateral assistance.

Nowhere is this more evident than in the establishment of WHO collaborating centers, which are, by definition, the key data stakeholders in epidemic response. Of the 780+ WHO collaborating centers with designation dates listed in the WHO database, nearly half have been established in the last decade, and more than half have been established since the 2003 SARS epidemic. **However, the most prominent research centers featured in the two cases in this study include Public Health England, U.S. Centers for Disease Control, Institut Pasteur, and Institut National de la Santé et de la Recherche Médicale (INSERM). These have had WHO collaborating center designations since the early 1950s.** That kind of institutional history comes laden with the capacity to address and resolve PEARLES barriers through longstanding mechanisms for collaboration, negotiation, and de-confliction.

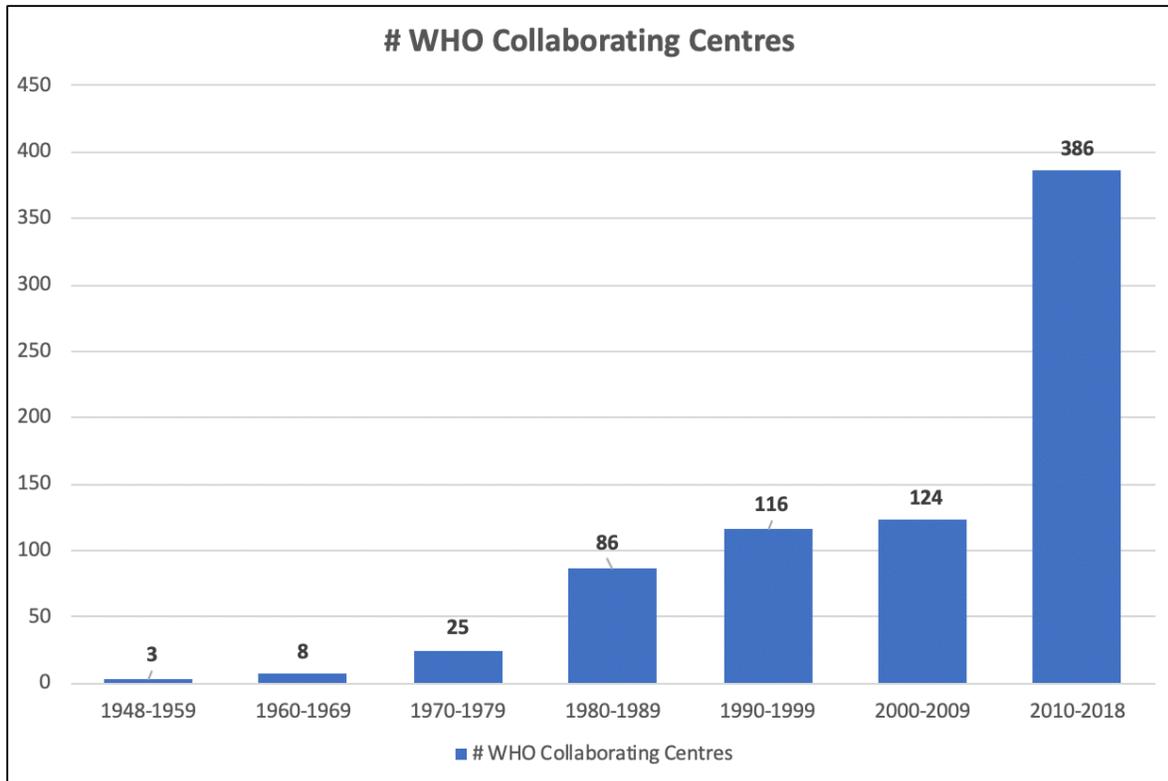


Figure 1: # of WHO Collaborating Centers by decade, approximately

Some of the oldest international coordination capacities have focused on influenza.²² For example, the WHO Global Influenza Surveillance Network (now the Global Influenza Surveillance and Response System) was created in 1947 to guide the annual composition of vaccines and to alert members to viral variants that might rapidly evolve and develop into a pandemic.²³ Relatively open data sharing agreements date back to the 1960s for characterization of type B virus and vaccine development; they continue today through mechanisms like FluNet (1995).^{22,24}

SARS

Post-9/11 global biosecurity concerns and pandemic preparedness activities created the conditions for a collision between the imperative to share data, national sovereignty, and international expectations for cooperation during epidemic response. Prior to SARS, the IHR required reporting of just five infectious diseases. SARS heightened realization that there was a need to extend the authority of the WHO to obtain data from member countries.^{11,25} SARS showed the importance of considering subnational and national ownership of data and authority over data sharing, a question that acquired enormous significance in the YFV and EVD epidemics. It also focuses attention on the national and international negotiation of perceptions around data credibility.^{6,26-28}

SARS (severe acute respiratory syndrome), which infected 7,761 people and caused approximately 800 deaths⁶ from 2002-2003, highlights the necessity for epidemic reporting and data sharing. It also demonstrates the impact that the state, particularly a strong centralized state, can have over preventing or facilitating a global public health emergency. In November 2002, a businessman living outside Guangzhou, Guangdong Province, China, near the Hong Kong border, was admitted to a hospital with what was then diagnosed as atypical pneumonia. It proved to be the SARS index

case.⁷ Public health authorities requested assistance from Beijing in January 2003, when the atypical pneumonia persisted, but the WHO did not receive notification of an outbreak until a month later, when a Chinese physician infected with this pathogen crossed into Hong Kong and transmitted it to other clients at a hotel. This led to further transmission in Taiwan, Vietnam, Singapore, and Toronto. As case numbers climbed, the Chinese Ministry of Health denied that Guangdong's atypical pneumonia cases were related to the cases in Hong Kong and beyond. After a whistleblower drew attention to the fact that there were far more cases in Beijing than reported, extensive negotiations between the Chinese government and the World Health Organization resulted in an invitation from China to the WHO to review information on the disease.

SARS was an emergent virus for which there was no clinical definition or diagnostic test. In response, the WHO worked with the Chinese government to reconcile the case definitions for atypical pneumonia and SARS; the WHO also organized 11 laboratories across nine countries to set up a SARS research network. Within weeks, this network identified the causal agent of SARS and developed a PCR test to detect genetic material of the SARS virus, although a negative PCR test could not exclude infection with the virus. The network shared SARS clinical samples in real time, including clinical samples, images of viruses obtained via electron microscope, sequences of genetic material, and viral isolates. A few weeks later, the outbreak was declared as contained using basic public health measures like source containment, epidemiological histories, case management, contact tracing, infection control at health care facilities, and quarantine.²⁹ There is still controversy over whether these measures were really what was responsible for containing the epidemic, or whether it 'burned out' on its own.

The SARS experience was and remains sensitive for the Chinese government and for Chinese scholars and authors.³⁰ Prior to SARS, China had established protocols for reporting any of 35 notifiable infectious diseases (including plague, cholera, tuberculosis, and HIV/AIDS) to district or county Centers for Disease Control and local health departments. Prior to SARS there was no system for monitoring and detecting emerging infections. Furthermore, Chinese health departments were not set up for collaboration, a situation that established barriers to communication about emerging infections.³¹ The SARS experience demonstrated to Chinese public health officials the need to strengthen and professionalize the Chinese disease surveillance system;^{25,31} the need for better international cooperation as a way of responding to pandemic outbreaks by adhering to IHR reporting requirements; the need to provide WHO with specimens for assessment; and the responsibilities of being members of the WHO and adhering to WHO regulations and recommendations.²⁵

H5N1, Indonesia

Avian flu caused a cluster of outbreaks from 2003-2007 and resulted in a flurry of debates about data sharing. In 2006, researchers working on avian flu decided to publish their sequences on GenBank, rather than to submit them to the WHO Surveillance Network.²² Calls to establish a platform for sharing data about various strains of influenza resulted in the establishment of GISAID.³²

⁷ Even this point seems disputed in some accounts. One indicated that GOARN was on alert in late November of this same year after one partner, the Canadian Global Public Health Intelligence Network (GPHIN), had collected media reports of an influenza outbreak in China.¹¹

After SARS, national governments became increasingly aware that their epidemiological data and biological samples had value during and after public health emergencies. In late 2006, Indonesia – a signatory to GISAID -- refused to share virus sequences with the WHO surveillance network. The Indonesian government argued that the sequences belonged to the nation-states where they were isolated. These sequences provided the basis for vaccine and therapeutic developments, but Indonesia argued that the originators of the viral sequences would derive no benefit from these patents. Although Indonesia was a signatory to GISAID and had agreed to share sequences through GISAID, it demanded that the benefits derived from H5N1 data and samples be returned to the population of Indonesia. By 2007, tensions mounted. In the end, approximately 20 WHO member states threatened to withhold viral strains from the WHO.

Indonesia was subjected to criticism for its refusal to share data with global researchers, but the move prompted the WHO to address the need to ensure that the benefits of research during epidemics return to local populations experiencing outbreaks. The WHO developed the Pandemic Influenza Preparedness Framework, a multi-sectoral agreement among its 194 member states and other stakeholders to facilitate virus-sharing for those flu viruses with pandemic potential, and to share benefits.³³

Post-Indonesia: A New Era of Nation-State Data Stakeholdership

“Data should be shared to be published. But since there is no such agreement, then each country considers its data its wealth: who has data has wealth.” (YFV-45)

After Indonesia, there has been a growing recognition among nation-states that during public health emergencies, epidemiological data, samples, and viral data have value to the international community. Governments such as Angola (YFV) and Sierra Leone (EVD) have restricted access to data and biological samples. Multiple countries have held access to public health data (Democratic Republic of Congo-YFV, Liberia-EVD) as subject to negotiations with response actors. Data sharing is increasingly seen by nation-states as a national asset and as a tool to wield in global health diplomacy during public health emergencies. Furthermore, by restricting access to data, governments with weak national infrastructures gain some ability to ensure that they exercise real authority over coordination and negotiations around epidemic response activities.

In response to Brazil’s Zika outbreak, the Wellcome Trust released a statement in February 2016 calling for Zika-related research data to be made available as rapidly and openly as possible. The statement was signed by 57 global health agency representatives.^{19,34,35} Furthermore, the *Bulletin of the World Health Organization* initiated a protocol requiring that submissions addressing the Zika virus epidemic include shared data (with a digital object identifier). Moreover, the *Bulletin of the WHO* committed to sharing publicly unpublished (and unpublishable) articles in a working paper repository.³⁶ Despite these efforts toward increased openness, rumbles of dissatisfaction from within the scientific community were heard when researchers who had openly shared genomic data saw their sequences published by unrelated scientific teams two weeks later, without attribution.³⁷

Over the past few decades, the rapid expansion of research capabilities outside of Europe, North America, and affiliate research networks and new south-south cooperation suggest a rapid de-centering of global health authority. Although China quickly reported the discovery of the H7N9 flu virus to the WHO and posted the full viral genome sequences of these cases to an international

database, it has been more reluctant to share biological samples. At this writing, China has not shared samples of the highly pathogenic H7N9 virus with the United States with the US.⁸ It has, however, shared samples with South Korea. This sharing pattern may be due to bureaucratic challenges involved in shipping the samples abroad, but it may also indicate how political considerations affect data and sample sharing.³⁸

The SARS and H5N1 outbreaks initiated and helped to consolidate global health cooperation between the United States and China. In 2005, both governments inaugurated a Collaborative Program on Emerging and Re-emerging Infectious Diseases, which spurred the establishment of a CDC China Center. That same year, both countries established the US-China Health Care Forum to address bilateral commercial, trade, and policy issues relating to health. In 2006, HHS and MOH further expanded their collaboration on biomedical research with a memorandum of understanding on research, technology, training, and personnel exchange.

F. Data Sharing: A Comparison of the Cases

Data sharing: Did it occur?

Yellow Fever Epidemic 2016

During the YFV epidemic, the Angolan state exerted considerable control over the types of data collected and institutions with which these data were shared. Sharing took place with a relatively few, historically close partners. In contrast to the EVD epidemic, the Angolan state made considerable efforts to formalize these sharing procedures and to clamp down on informal sharing, although in certain cases, authorities did appear to accept informal sharing. The increased formalization of data sharing procedures over the course of the epidemic led to complaints about Angolan restrictions on the circulation of data, and particularly its publication during and after the epidemic.

These restrictions on sharing limited the insights that could have been generated during the post-epidemic phase. Nevertheless, during the epidemic, key responders *did* receive the data that they needed in order to mount an effective response. Those actors and institutions truly needing the data during the epidemic received what they were seeking, albeit with certain delays.

West Africa Ebola Outbreak 2014-2016

The data sharing that took place at the peak of the West Africa Ebola epidemic was exceptional in its diversity, scope, and reach. There was extensive data sharing of all kinds of data – including never-before standardized data -- during the EVD outbreak. In order to enable this scale of data sharing, extraordinary steps were taken. Government officials signed on to unknown researchers' activities in order to allow data to be publicly circulated. Individuals within the U.N. system made independent determinations about who could be “read-in” on sensitive data in order to provide a novel analysis. The limits of existing data and research sharing arrangements were stretched to enable access to experts who would have otherwise lacked access to restricted data. And when all

⁸ This is despite the consolidation of a global health cooperation between the two countries in 2005, when both governments inaugurated a Collaborative Program on Emerging and Re-emerging Infectious Diseases, leading to the CDC China Center. 2005 also saw establishment of the US-China Health Care Forum to address bilateral commercial, trade, and policy issues relating to health. In 2006, HHS and MOH further expanded their collaboration on biomedical research with a memorandum of understanding on research, technology, training, and personnel exchange.

else failed, people shared data directly through emails, file transfers, and phone communications in order to expedite research and operational goals.

For each domain of research or response, a specific set of rules and judgements was applied to evaluate the context of data sharing. Many responders to the Ebola epidemic wore several “hats” – or multiple stakeholder perspectives simultaneously – clinician, researcher, technical advisor, scientist, health educator, government advisor, or ethics review expert. Each respondent, in effect, frequently represented multiple stakeholder roles, who had a varied set of intentions and demands from data, for data sharing, and for the structure of data transaction.

Frequently, respondents had intimate familiarity about the specific paradigms that should govern data sharing in each application. A real challenge, however, was to determine how to apply the right set of rules in real time when data were simultaneously epidemiological, clinical, molecular, and social. In doing so, response actors sifted through the details of their ethics, training, context analysis, and institutional and professional networks to mobilize informed judgements under the enormous pressure of an emergency situation. Some respondents built upon capacities from publicly available IT instruments or used crowd-sourcing inputs to build data itself. Others circulated de-identified epidemiological line lists within strictly defined elite response networks in accordance with routine practice in epidemic responses.

It is worth noting that because each participant had so much knowledge and expertise, and so many pre-existing relationships in each stakeholder role, participants were drawn to informalized, contextually-informed, processual approaches to resolve apparent conflicts. This “informalization” of data sharing frequently functioned as a kind of social lubricant that smoothed over impossible choices; and relegated the moral burden to trusted professional networks, institutions, or formal agreements. The necessity of this kind of informalization – especially for types of data that have low value to the international public health response community – reveals how researchers and practitioners reconcile concerns about data sharing with the immediacy of disease response.

In contrast, during the build-up to the epidemic, and its conclusion, there was considerably more formalization and less data sharing that took place. It would appear that when lead officials had the sense that they had the situation under control, and that epidemic response was transpiring in a “business as usual” way, the demand for and permissiveness around data sharing declined, and barriers to the sharing of data were re-erected.

G. PEARLES

The research literature on data sharing is replete with explanations for why people don’t share: professional “disincentives” for publication; the absence of mechanisms and standardized practices for sharing data; legal restrictions; ethical concerns about privacy; North-South inequalities; and lack of trust.^{7,39–42} Multiple studies have identified barriers and enablers of data sharing, and our preliminary review suggests that dozens of editorials and policy reports call for expanding access to epidemiologic and clinical data during epidemic emergencies.

In narrative accounts, PEARLES analyses were inextricably intertwined. Political facilitators were also simultaneously regulatory and ethical.

In both outbreaks, we found that across the PEARLES domains, the factors affecting data sharing could cut both ways – they could either be a help or a hindrance, depending on one’s role, status, context, and networks. For example - political pressures created by widespread media reporting

induced both researchers and responders to develop data sharing capabilities in the social sciences to address the sociocultural factors surrounding funerary practices, wild meat consumption, and health systems fragility in West Africa. Moreover, this can have durable effects beyond the life of any specific epidemic response. In nearly every post-2014 EVD intervention, some social science engagement has been prioritized by non-social sciences actors. They seem to have been effectively ‘trained’ that social science and community engagement are necessary...for Ebola, and for other novel outbreaks, like Zika. But not for YFV or other diseases.

Although data sharing is often thought of as a simple promotion of transparency in sharing epidemiologic or clinical data, recent research on “datafication”⁴³ in health research finds that data sharing is rarely neutral or egalitarian. Anthropologists have observed that the transformation of human experience into data, frequently rests upon unequal power relations. The complexity of these power relations become all the more challenging to disentangle when we consider the increasingly broad swath of data categories that are becoming relevant for epidemic preparedness and response.

Informal networks are frequently tapped to overcome such ambiguities. They are used to negotiate formal diplomatic, political, and public health agreements; navigate technical, social, and logistical barriers; and make sense of institutional incentives and disincentives. Between the research communities, epidemic response actors (“implementors”), and nation-states who are becoming more proprietary about health data, the resulting social space of conflicting messages, incentives, and disincentives to share data – or “the informalization of data sharing” - makes the establishment of minimum standards, international agreements, and formalization of data sharing practices particularly fraught.

The two case studies presented here offer contrasting narratives for how data is managed across epidemic response. The pivotal points of departure are: In the YFV case, data sharing for a known pathogen with a licensed intervention was negotiated through routinely deployed platforms, institutions, and institutional relationships with standing histories of collaboration and partnership, much of which carries deep social and political histories that cannot be easily overcome by policy. In contrast, in the EVD case, the “known pathogen” EVD emerged in an unanticipated location, rendering it an unknown and unfamiliar pathogen to key decision makers. The rapid surge of the epidemic in mid-2014, and the rise of Ebola as a global health security issue that received a PHEIC designation mobilized a set of response actions – including political direction at the highest levels – that was atypical for epidemic response coordination. Furthermore, in the absence of a licensed intervention, the extraordinary mobilization of research partnerships, humanitarian response actors, governmental coordination, and international funding mechanisms were mobilized to implement a three-country public health response.

Our efforts to apply PEARLES analyses to data sharing in each of these cases (see below) was complicated by the radically different institutional, temporal, funding, and historical dimensions of each of the cases. We came to believe that a PEARLES analysis disaggregates the “response ecologies” to such an extent that key differences between the two cases are masked rather than revealed.

For example, in the 2016 YFV epidemic, respondents saw data sharing as a feasible priority and an important public good but limited the value of sharing to the duration of epidemic response. Data sharing was so thoroughly restricted by national government prerogative, the closed environment that encircled epidemic response actors resulted in *a priori* inequalities in data

sharing. The barriers were multiple: lack of capacity; procedural problems, a lack of clarity in procedures for data sharing or, conversely, undue rigidity; economic repercussions; and personal and political relations that may conjugate with historical recollections and interpretations.

One respondent commented,

When you have a really powerful team and a weak [one]...you can't speak of sharing. This is an abuse of language. Either we share nothing, or give and others exploit, or keep back and nothing is done. But sharing, that means that each person has a capacity to do something...It is difficult for me to hear this word "sharing". It isn't sharing when it's a question of "I give" or "I keep". (YFV-05)

Figure 2: PEARLES Barriers to data sharing during the 2016 YFV epidemic

	Political	Economic	Administrative	Regulatory	Logistic	Ethical	Social
Clinical trials data							
Epidemiological data							
Genetic/phylogenetic data							
Vaccination coverage data							
Mobile/GIS data							
Entomological data							
Qualitative/Social science data							
Biological samples							
Routine health systems data							

In contrast, in the West Africa EVD case, there was a widespread view among many actors that data sharing was a necessary and important public good that needed to be facilitated using extraordinary measures, if necessary. This view contrasted sharply with the perspectives of routinely deployed response actors, like World Health Organization epidemiologists and U.S. Centers for Disease Control field epidemiologists, who were culturally habituated to data sharing practices in more typical, less sprawling institutional public health emergency response environments.

The future has to involve data sharing, and it has to involve it in a way that protects patient privacy, that provides benefits to the local individuals that are experiencing the outbreak, and to the local ministries and agencies that are responding, and to the global community that's figuring out how to respond. So, it's something that we need to have working, and it's something that we need to have working ethically. And it's a hard problem that's going to take a lot of people with diverse backgrounds thinking about it carefully and doing these kinds of analyses.” (EVD-15)

Figure 3: PEARLES Barriers to Data Sharing During the 2014-2016 EVD epidemic

	Political	Economic	Administrative	Regulatory	Logistic	Ethical	Social
Clinical trials data							
Epidemiological data							
Genetic/phylogenetic data							
Mobile/GIS data							
Private sector data							
Qualitative/Social science data							
Biological samples							
Routine health systems data							

The enormous scale of the West Africa Ebola response resulted in a clash between a lack of formalized systems for gathering data, and a hyper-demand for data analysis. The capacity to produce, analyze, and share data and findings was, to a large extent, mediated by the types of data themselves. Some categories of data (e.g. phylogenetic analyses) benefited from long-standing research presence in West Africa, well-organized networks of collaborating researchers, good relationships with national governments, and ready access to data sharing platforms. Other categories of data (e.g. qualitative research, anthropological research, and community engagement data) were disadvantaged by a lack of awareness, funding, pre-existing formal systems for researcher collaboration, and non-integration into national-level incident management systems.

In a direct comparison of the two cases (see Table 2), we find some surprising similarities and revealing differences. In both epidemics, data that is prioritized for epidemic response – in particular, epidemiological data and biological samples – have the most direct all-kind barriers to data sharing. This opens the possibility that increased prioritization of data sharing in targeted categories, combined with greater standardization of data sharing agreements and regulations in those categories, may create, not reduce, barriers. At the same time, because those data are prioritized, greater resources are available to ensure the high quality of the data, and to create capacities that allow users to overcome data sharing obstacles, like shared software platforms.

Table 2: Comparison of PEARLES barriers: YFV and EVD epidemics

		Political	Economic	Administrative	Regulatory	Logistical	Ethics	Social
Clinical trials	YFV	x	x		x		x	
	EVD	x	x	x	x		x	
Epidemiological	YFV	x	x	x	x	x	x	x
	EVD	x	x	x	x	x	x	x
Genetic/phylogenetic	YFV	x						x
	EVD		x	x				
Vaccination coverage data	YFV	x	x	x		x		
	EVD	n/a						
Routine health systems data	YFV							
	EVD			x		x		
Entomological data	YFV	x		x		x		x
	EVD	n/a						
Mobile/GIS	YFV	x						
	EVD		x	x	x	x		
Private sector data	YFV	n/a						
	EVD		x	x	x		x	
Qualitative/social science data	YFV	x						
	EVD	x	x			x	x	x
Biological samples	YFV	x	x	x	x	x	x	x
	EVD	x	x	x	x	x	x	x

For non-prioritized data, like qualitative/social science data, the table below disguises some revealing differences between the two cases. In the YFV case, there were almost no barriers to data sharing for qualitative/social science because no data was collected, save a single KAP study that was widely discredited due to methodological problems. In the EVD case for qualitative/social science data, nearly all barriers to data sharing pertained, save administrative and regulatory barriers. This is likely because there was – and continues to be – no administrative or regulatory recognition of the role that sharing qualitative social science data can play in informing an epidemic response.

H. Ethics

All epidemic response actors – healthcare workers, government, epidemiologists, researchers, community educators, vaccinators, data enumerators, contact tracers – have an ethics-based relationship to data before an epidemic ever occurs. By ethics, we refer to two significant aspects of experience informing epidemic response work: the formally defined ethics that pertain to specific domains of research and practice (medicine, biomedical research, public health ethics, governance/legal ethics, human rights)^{44–48}; and morals, or the individual subjective interpretation of ethics in the context of their specific professional and personal engagements with epidemic response.⁴⁹

Ethics about data are not, for the most part, negotiated during an epidemic. They are negotiated prior to epidemics, and they are implemented on a case-by-case basis based on situational judgement. Critical decisions about sharing data were made by individuals negotiating between formally defined ethics, informally ascribed ethics, and the demands of the situation. Furthermore, ethics were informed by the specific kinds of work done, and data required, in the labor surrounding the epidemic response. To cite just a few examples:

- Medical practitioners entered epidemic response environments with a pre-existing understanding of the ethics surrounding the management of clinical data. For clinicians, clinical data was a documentary process that involved a direct relationship between the patient, the clinician(s), and perhaps the patients' significant others. Specific pieces of that data, like biological samples or case fatality reports, might be called upon for public health response, but beyond that, additional data sharing veered into unknown and undefined terrains for medical ethics.
- Biomedical researchers entered into epidemic response environments with a pre-existing understanding of the ethics surrounding biomedical research. While patient protection and privacy were an acknowledged priority, there was a recognition that a strict adherence to using blood samples or associated data solely for the purpose of a designated intent defined in the moment could prevent future scientific discoveries or significant public health advances. Caught in a choice between respect for patient autonomy and the objective limitations of clinical practices for obtaining research consent in the middle of a high-mortality epidemic outbreak, some researchers devolved to their own humanitarian sentiments; while others chose to wait for slower, and potentially too-long delayed data sharing agreements.⁹

⁹ An alternative example would be anthropology, which does not yet have any ethics or norms for data collection, analysis, or dissemination during epidemic response.

- Government actors entered epidemic response scenarios with a clear ethics around national sovereignty, political accountability, national interest, and political alliances. Sovereignty is based on an ethical framework. Human rights are based on an ethical framework. Government actors do not and cannot suspend these ethical commitments to prioritize other ethical paradigms.

Clinical data, viral data, contact tracing data, qualitative data, survey data, economic data, GIS data – each data type has its own specific ethical complications. There is no one size-fits-all ethics policy that can address the specific ethical demands posed by the unique interpretation of reality that each type of data offers. Complicating the matter is the fact that many response actors – from Ministers of Health to laboratory technicians – have been each trained and inculcated in multiple frameworks of research ethics, public health ethics, medical ethics, and human rights ethics in the course of a single professional career. What data sharing ethics should a doctor/filovirus expert /epidemiologist invoke in an emerging response environment? Should a yellow fever epidemiologist prioritize partnership with the national government, or the sharing of granular vector data that might show disease spread beyond official pronouncements?

a) *Research Ethics*

In the YFV epidemic data sharing was perceived globally by actors as a kind of institutional or functional good: actors and institutions shared data to respond to an epidemic. For the most part, data was able to be shared sufficiently, for the purposes of response, under a rigid government policy that regulated the circulation of data in order to ensure that the host government remained at the center of the epidemic response. [Sovereignty is an ethic, too.] Where this moral obligation seemed to break down was in the post-epidemic phase, when lessons learned from the epidemic might have been published in scientific journals but were not. The ethical barriers were twofold. First, some types of data sharing would have compromised the privacy of individuals (cases). Second, data sharing did not take place because data stakeholders or data producers believed that sharing benefited researchers, rather than public health response activities. These concerns were never resolved.

In contrast, in the EVD epidemic, data sharing was regarded by many to be a moral imperative; a way of bringing attention to the plight of unnecessary suffering and death resulting from a failing epidemic response. Attitudes towards the ethics of sample and data sharing were almost completely divided: Was it necessary to share as much data as possible to stop people from dying? Or was it necessary, at all costs, to protect the privacy of African populations who were unable to give informed consent for research? Was humanitarian intent a fig leaf for covering less altruistic research purposes; or were restrictive data sharing expectations by default consolidating information in the hands of the already powerful?

During the EVD epidemic, open source data sharing, crowdsourcing, informal transfers of data, and unrestricted data sharing occurred at such a pace and velocity that many had concerns about breaches of confidentiality. At the same time, formal processes for managing data collection and data sharing were deeply conflicted. A key example would be the debates held in research institutions in Europe and the United States over the use of biological samples from patients that had not given informed consent because they arrived at ETUs unresponsive, died in care, or were unable to share any identifying information. The predisposition among ethics review boards in these situations was to deny use of the samples for research. Importantly, we never received any reports of actual breaches in confidentiality that had a negative direct impact on African local

populations. There were reports of abuses between researchers that resulted from data sharing (e.g. some researchers publishing on other researchers' data without attribution), but a fresh look needs to be given to whether ethics review board participants are managing the current anxiety around individual and community protections effectively for both public health and human rights.

b) *Social: It's a Matter of "Trust"*

Trust is a double-edged sword, a barrier and a facilitator, a signifier of deeper structural and relational complexities than the self-evident nature of the term allows. Trust in the literature on data sharing has been treated as a kind of sentiment, a professional regard, a prerequisite for sharing to take place.⁴¹ This understanding of trust does not fully capture the complexity of either the motivations or patterns of sharing we found in our case studies. Our findings suggest that "trust" is a signifier, a manifestation of underlying social, political, and sometimes historical relations that actors cultivate and share, and at times abrogate. In addition, "trust" is therefore not only the evidence that people point to in order to explain why they share (or not); they can also share data in order to cultivate trust.

From the colonial networks that shared public health data through to the modern day, trust is consolidated among privileged networks of individuals and institutions that share expertise and accord each other credibility. Sociological research reminds us of "the strength of weak ties," or the fact that high-value information can often be more widely transacted across thin, shallow, and sprawling relational networks than between dense, close, and insular networks.

"Trust" is often invoked by our informants as a motive for data sharing.⁴¹ "Trust" is the informal framework that individuals up and down the line of data production and analysis use to manage the risks associated with data sharing. To borrow from anthropologist Annette Weiner, data are a kind of inalienable object that creates risks of loss, destruction, misuse, or theft through lending and circulation. To control data loss, or the threat of data loss, individuals use all social means available to them to negotiate trusting relationships.

Trust is, above all, fungible and transferrable. Data stakeholders can assign and withdraw trust on the basis of historical relationships between institutions, personal relationships with colleagues or peers, or through formalized data sharing agreements between research institutions, governments, and international actors. This can involve borrowing credibility from the institution to the individual, as when a consultant for the United Nations is given unrestricted access to the de-identified EVD line list because it is presumed that she might be able to make appropriate use of it. It can involve extending credibility from an individual to a research team, as when a senior researcher provides unrestricted access to sensitive data to post-doctoral students with close or loose affiliations to the institution. It also can involve historical and institutional legacies of trust, for instance, between national laboratories that are currently or were once part of the Institut Pasteur network, as one African researcher observed,

The DRC, for us, these are really our friends. So, for us, we worked with them on projects before this (yellow fever) epidemic, so we're really close. Working in the DRC, it was as if we were at home. We have good relations, a mutual trust. There are no problems.... with the INRB personnel, it's a perfect collaboration. (YFV-07)

Trust can be motivated. During the EVD epidemic, thin relationships between peers that would have otherwise inhibited data sharing turned into trusting relationships, as peers recognized the

need to share resources to analyze data to raise the visibility of the epidemic. In the YFV epidemic, one researcher described his commitment to putting local data collectors at the center of the research process, in order to “[*build*] trust with the people who are generating the data, to give them the sense that first they need to trust us, they need to understand what’s going to happen with the data, they need to feel that they are part of the project. (YFV-02) “Trust” created with the data producer entailed a kind of buy-in, or acceptance of what he (the researcher) would do with the data, to include a commitment that the researcher would not misuse, misrepresent, or misinterpret the data, and would acknowledge the data collector in finished work.

Trust is also derived from shared language and history. In Angola during the YFV epidemic, social tensions between data producers and holders and those seeking to gain access to them were perceived to pose barriers to data sharing. But these social tensions were multiple. Some superficially involved linguistic barriers that resulted in communication problems, but they underpinned historical politics with roots in colonial and post-colonial relations.

Trust can serve as a premise for creating a more inclusive international scientific community; one that has standing relationships based on trust that can be mobilized quickly during an emergency.

On the other hand, trust can serve as a tool for exclusion. By invoking a lack of trust, key stakeholders with long-standing access to data can build walls around data access. Under the guise of trust – or the lack thereof - institutions hold the ability to hoard scientific resources and access to data; and set the rules for data access, use, and analysis. Despite rapid gains in recent years, the world of scientific research and data sharing during public health emergencies remains incredibly small; and continues to be consolidated in a limited number of key institutions.

Importantly, the lack of trust can extend to entire categories of data. Using a trust-based rationale, epidemic response capabilities can exclude unfamiliar and under-utilized sources of data. It can ignore and refuse to invest in the insights of scientific and implementation actors who bring new perspectives. And as the China narrative in the Ebola case suggests, it can sustain specific paradigms of epidemic response that may sustain global inequalities, a lack of access to international health and scientific resources, and the continued privileging of elites over non-European and non-American actors.

c) *Drawbacks of PEARLES analyses*

Importantly, a PEARLES analysis – while highly robust in capturing a wide range of barriers to data sharing – fails to integrate *scientific* barriers to data sharing in its framework. For example, in the YFV case study, historical research demonstrated that as YFV control efforts have evolved in the last century, vaccines emerged as a preferred form of public health containment over vector control, a previously used and effective method. Continued engagement with vector control could buttress challenges with coverage in mass vaccinations for children. But in the EVD case, the scientific barriers that impacted data sharing had much to do with the technical limitations of the context, the high prestige associated with scientific publication during this particular outbreak, concerns about the scientific ability of partners to conduct sophisticated or novel analyses (for example, molecular epidemiological analyses of EVD virus data), and a lack of clarity about which actors had privileged access to data in a fluid and chaotic environment.

A PEARLES analysis also struggles to consider the processes, meanings, and intentions behind the *informal* data sharing practices that occur during epidemics. In the absence of explicit agreements between national governments and ministries of health, the World Health Organization, formal WHO partners, and formal and informal allies in the research community,

researchers and practitioners make independent determinations based on their own situational analysis about which criteria to apply to inform their decisions about public, semi-private, and private data sharing. The practices of informal data sharing are further developed in the case studies, below.

I. Lessons learned: How could more data sharing have helped?

In both cases, more access to data, earlier access to data were perceived as necessary for improving the public health response to the epidemics. During the YFV epidemic, many respondents complained about delayed access to data. Respondents believed that the limitations placed on data sharing during the epidemic probably did not affect the course of the epidemic, but it may have slowed the response. From the debut of the EVD epidemic, the international research community was much more interested in procuring data that was being reported than in evaluating whether or not conditions existed for the creation of data itself. The primary challenge, for many months, was that there were no data, or that the data were unreliable. As a result, for respondents who worked in West Africa during the EVD epidemic, there was not a sense that *greater* availability of data could have enhanced the response. Rather, respondents emphasized that *earlier* availability of the data would have substantially improved the response and prevented its escalation. This, however, would have required a mass mobilization of resources in order to build out a primary system for data collection, which did not exist in any of the three most-affected countries at the time.

For Preparedness

- Primary capacity for data collection, data sharing, and data management needs to be developed. This includes pre-designed agreements to promote cross-border data sharing with neighboring and regional countries.
- National governments have the right to make determinations about the conduct of public health emergency response activities. Support should be given to national governments during “peacetime” to better enable key decision-makers to support effective research and response during public health emergencies.
- Consideration needs to be given for “peacetime” and post-epidemic data sharing in order to promote public health learning. Policies need to be developed to resolve issues of governance, access, regulation, and long-term data management.
- The ability of national governments to share data is impaired by the continued deployment of vertical data collection infrastructures that cannot communicate with existing public health information systems. Epidemic response and research capacities should be fully integrated into the permanent IT and operational infrastructure of national health information systems. This will resolve outstanding questions about the country’s ownership of built-for-purpose, temporary response data collection systems. This would support long-term policies for public health emergency data sharing, in coordination with national and international partners.
- Post-epidemic data sharing should be a norm.
- Informal data sharing practices are neither harmful nor helpful – they are neutral. They involve workarounds when existing approaches are failing to meet stakeholders needs and response and research aims.
- Data sharing abuses can happen. Policies around data sharing should consider what data sharing abuses are, and how to respond.
- Consideration can be given to how private sector data can be mobilized for epidemic response.

- In clinical trials, the data sharing and information demands of local populations needs to be considered in the development of target product profiles.
- National legislation should have provisions for sharing information with local populations during epidemics in order to ensure acceptability of research findings and developed products.

During Emergencies

- For all countries, explicit procedures for data sharing, with flexibility for informal sharing, should be integrated into national health strategies and WHO Emergency Response Framework.
- Often, there is no difference between research and response data. Trying to create artificial distinctions creates constraints on data sharing, data analysis, and short-term innovations that can advance public health response.
- In chaotic or challenging public health emergencies, research data may precede and build the infrastructure for response data.
- “Response data” can be defined more expansively to support innovation in methods, technologies, and strategies that can hasten the end of epidemics.
- Research data needs to be mapped into the primary architecture of public health emergency activities. Integration of research in a response architecture should be a component of the WHO Emergency Response Framework.
- Frequently, in disease outbreaks researchers are responders, and responders are researchers. Localized decisions around data sharing are made informally, based on context.
- The international community, when confronted with a known pathogen with a known therapeutic or vaccine, currently relies on its long history of public health response to control the outbreak.

J. Who is Responsible?

The World Health Assembly must recognize that there is a rapid “de-centering” of global health authority that is shifting authority, power, and resources away from traditional centers of power (Geneva, Atlanta, London, Paris) towards new centers of global health security and global health diplomacy (Beijing, Addis Ababa). Traditional centers of power are unlikely to be able to continue to set the agenda in the years to come without input from non-Western governments. A new multilateral front is needed for global health diplomacy in order to ensure that innovations in public health strategies, biotechnologies, research, and therapeutics do not become constrained by geopolitical relations motivated by non-public health or humanitarian factors. This is needed to ensure that global health diplomacy does not blind itself to important shifts in norms and procedures that may come with current shifts in global power.

The World Health Organization is the only institution with the legal, moral, and technical credibility and expertise to provide leadership on data sharing during public health emergencies. However, the WHO continues to have a conflicted relationship to data in the context of public health emergencies. As an anthropologist noted from the Ebola epidemic:

“At the beginning, in July [2014], it was kind of like, ‘If you weren’t doing something that was hands on, then you were unethical, or doing something that was not contributing helpfully at that moment... No one should be doing research. It’s unethical to be doing research. You’ve got to be doing stuff on the

response.’ Then, when it [the epidemic] was clearly getting so awful, and they wanted biomedical intervention stuff, the WHO said, ‘Actually, really it is ethical to do research in this context.’ [That] opened the door and changed the conversation about collecting data.” (E100-15)

These patterns persist. This model pre-determines conditions in which responders are conditioned to believe that unknown researchers as self-serving, except for “the good ones,” whose practicality or humanitarian intentions are known to key influencers. These assumptions need to be challenged on a case-by-case basis, and alternative rubrics and frameworks for making such decisions need to be developed.

K. Our Approach

Methodology

This study mobilized a multi-partner consortium of historians and anthropologists with country and topical expertise to research and analyze the aforementioned two case studies of data sharing during epidemic outbreaks. We used short-term, mid-term, and long-term historical timeframes to consider how recent epidemic outbreaks represent continuity of established practices or constituted a meaningful break from past experiences. Research was conducted with the ethical approval of Institut Pasteur (IRB2018-07).¹⁰

All members of the research team contributed to a comprehensive literature review of over 800 books, peer reviewed articles, working papers, online websites, and public statements on the histories of Ebola virus, yellow fever virus, data sharing during epidemic outbreaks, international coordination during epidemic outbreaks. This literature included milestone policy documents and publications on data sharing during public health emergencies, software, protocols, tools, and technical guidances for data sharing. The goal of the literature review was to identify key actors, themes, processes, capacities, networks, incentives, and policy issues around data sharing in global health emergencies.

Qualitative interviews were conducted with participants recruited using purposive and snowball sampling strategies.⁵⁰ In total, 133 interviews were conducted or reviewed for primary source information about data sharing during these two epidemics. We conducted 50 interviews with key individuals or groups of individuals to gain informants’ perspectives on data sharing during the two outbreaks (25 EVD, 25 YFV). For each of these interviews, respondents provided written informed consent for confidential participation and the recording of interviews. These were supplemented with 64 existing transcripts discussing data sharing from the Institut Pasteur/Ebola 100 project, 6 interviews with scientists and medical volunteers in China who participated in the Ebola response, and 13 publicly available interviews conducted as part of a CDC oral history project on the West Africa Ebola outbreak. We analyzed content using line-by-line inductive and deductive coding and revised our codes to account for larger data segments.

We qualitatively evaluated the degree of data sharing, the quality of data sharing, and the experiences of data sharing as reported by participants in each international response in order to

¹⁰ All investigators and study site staff complied with the requirements of the Data Protection Schedule provided by the Wellcome Trust in the contract, as well as relevant European Data Protection regulations with regards to the collection, storage, processing and disclosure of personal information.

identify the barriers or facilitators for data sharing. A mid-project meeting was held in Boston, Massachusetts on September 8, 2018. Interviews and report writing continued through November 2018, and a final draft was submitted to Wellcome Trust on November 26, 2018.

Study Limitations

In both case studies, there were several reasons for concern about bias from informants. In both the YFV and EVD cases, we were more likely to obtain interviews with individuals who were supportive of data sharing agendas; the YFV case was the only scenario for which we were able to procure strongly critical viewpoints. Research conducted in China was limited by the political sensitivity of the research, respondents' concerns about sharing personal views, and difficulty conducting virtual interviews and meetings. To compensate for this, we sent a field researcher to China to collect primary data on the EVD case with representatives of the Chinese Center for Disease Control; but those respondents were less willing to provide information about the YFV case.

For the YFV case study, we were unable to interview a fully representative range of stakeholders, including key informants from MSF, IFRC, the Cuba Cooperation, and several other prioritized bilateral aid organizations and NGOs, due in part to their current intensive engagement in the ongoing EVD emergency in the Democratic Republic of Congo. In lieu of these interviews, we depended upon publicly available publications, organizational communications, historical research, and peer-reviewed literature to approximate details around their engagement.

For the EVD case study, in contrast, we were confronted with an overwhelming output of studies, publications, scientific researchers, international responders, government actors, and local data stakeholders implicated in the response. We have been unable to decisively scale our findings due to the granularity of possible networks and outcomes that threatened to exceed the scope of this study. Furthermore, we noted that we were unable to obtain a good representation of the following kinds of data stakeholders: researchers and responders working in the Guinea-Conakry context [beyond Forecariah]; local data aggregators (fieldworkers, enumerators, etc.), national researchers (many of whom have moved on to new positions in-country or internationally).

A few notes: Interview quotes have been heavily edited for fluency. Details have been altered to protect respondent identities. Public health information about the epidemics that is a matter of the public record has not been assigned citations.

V. CASE STUDY: YELLOW FEVER EPIDEMIC 2016

A. Summary

Data sharing during the 2016 yellow fever epidemic in Angola was characterized by strong state control over which data were produced and with whom data were shared. Multiple actors were part of the response, and each had different degrees of distance from and responsibilities for producing data for the Angolan Ministry of Health. “The data belong to the state,” supported an approach that, over the course of the epidemic, imposed increasingly formal procedures on data sharing among collaborating partners. Our foregoing analysis shows that data sharing in the Democratic Republic of Congo occurred more fluidly among diverse actors and institutions, but comparatively smaller extent of the epidemic there yielded far less data produced -- with the exception of the mass vaccination campaign.

During the response, confronted with to a pathogen with a well-established prevention measure and a lengthy history, the Angolan state responders relied heavily on widely used YFV control measures and long-standing institutional relationships with the WHO, UNICEF, the U.S. Centers for Disease Control, the Cuba Cooperation, MSF, the European Center for Disease Control, and Institut Pasteur of Dakar. Taking into account the state’s long history of experience with these collaborators, these institutions were able to share data most easily with approved partners and the state. The response focused on specific kinds of data collection (clinical, epidemiological, vaccination) to improve clinical diagnosis of YFV and to support mass vaccination to control the epidemic. But this reliance on particular subsets of data meant that a more expansive approach to understanding the epidemic (ex. through the use of entomological and social science data) was not a priority when challenges arose, such as the need to use fractional dosing of YFV vaccine in response to a global stockpile shortage. Previous experiences with vector control and YFV control in the region, and for YFV more generally suggest that a more inclusive approach to types of useful data can enhance YFV epidemic responses.

After the response, post-epidemic data sharing and scientific publication has not been substantial. The principle barrier to publication is reported to be the Angolan government’s concern about attribution for data collection and analysis, and issues over authorship in peer-reviewed journals. This has prevented other countries that are vulnerable to yellow fever from learning from the 2016 epidemic.

B. Yellow Fever: A Historical Overview

Yellow fever, a viral hemorrhagic fever, is caused by arbovirus (genus *Flavivirus*) and is transmitted by the *Aedes aegypti* complex of mosquitoes. Although mass vaccination campaigns played a central role in controlling the 2016 YFV epidemic, the history of interventions to control yellow fever -- and the production and circulation of data among key actors -- was more variable. This historical overview highlights insights pertinent to data production and sharing and key actors in the 2016 epidemic.

A centuries-long experience with YFV has over time facilitated the emergence of specific institutional expertise in YFV research and the forging of some notable multinational institutional collaborations: The pattern of sending multinational teams from several different institutions that have been at the center of data collection and sharing in African YFV epidemics is a long-standing

one. In the 1970s and 1980s, the WHO appears to have organized these teams, with national health officials and local experts collecting and sharing data. How much national entities controlled these data is difficult to gauge from available evidence.

Mass reactive vaccination as a preferred prevention measure displaced an earlier focus on entomological research and vector control during YFV epidemics from the 1950s-80s. Data collection and sharing is clearly geared now towards reactive vaccination. The importance of vaccination has obscured the importance of other types of data, as well as the people on the ground collecting them. It has also diminished the need to collect and share data beyond what is seen to facilitate vaccine coverage and efficacy. The Yellow Fever Initiative (2005) seems to have given data sharing related to reactive vaccination greater impetus to prevent YFV outbreaks.

Key institutional actors, scientific research on YFV, patterns of data production and sharing, and shifting interventions are all inextricably intertwined in this history. Before the 20th century, efforts to control YFV epidemics depended on quarantine and disinfection, though such efforts were only partially successful. Early data sharing thus centered on reporting suspected cases in order to implement quarantine measures.⁵¹⁻⁵³

After the early 20th century discovery of YFV transmission by *Aedes aegypti* mosquitoes and successful vector control in Cuba and Panama, efforts to combat these epidemics shifted to vector control, most notably in Brazil under the initiative of the Rockefeller Foundation.^{54,55} Data sharing in epidemics incorporated entomological data alongside suspected and confirmed cases.⁵⁶⁻⁵⁹

The 1920s saw the creation of key YFV research institutions in Africa. Following the Rockefeller Foundation's initiation of YFV research in West Africa with the establishment of a research institute in Nigeria, the foundation collaborated with the British colonial government to create the Yellow Fever Research Institute in Entebbe, Uganda -- now the Uganda Virus Research Institute (UVRI).⁶⁰ IP-Dakar, founded in 1923, carried out YFV research and data collection.

These research institutions' efforts to isolate the etiological agent of YFV not only led to the discovery of the virus, but also international patterns of data and sample sharing and vaccine development. The Rockefeller Foundation sent virus samples from West Africa to its New York laboratories where in 1934, scientists used them to develop the highly effective 17D vaccine. At IP-Dakar, virus samples became the basis of another effective vaccine, the "Dakar scratch vaccine."⁶¹ In the following decades, IP-Dakar, the Rockefeller Foundation in Nigeria, and the Uganda Yellow Fever Research Institute collected and shared entomological, epidemiological, and eventually immunological data and blood samples within their institutional networks. They also shared findings with authorities in regions where YFV was endemic, and with international bodies to implement precautionary measures, so as to prevent the disease from spreading beyond endemic regions and especially to immune-naïve populations in Asia.^{62,63}

French colonial medical authorities began mass vaccination campaigns much earlier than their British counterparts, using the "Dakar scratch vaccine" developed at IP-Dakar in the 1930s. This work placed IP-Dakar at the center of yellow fever research, epidemic response, and vaccine production through the colonial and post-colonial period.^{61,64}

The Belgians also engaged in protective vaccination campaigns in the Belgian Congo. This work contributed to IP-Dakar's critical role in present-day DRC. So too did the fact that the contemporary Institut National de Recherche Biomedical (INRB) is a former node in the Institut Pasteur network until nationalized by Mobutu Sese Seko. These historical linkages help to explain

the longstanding institutional relationships that, along with shared language, appear to have facilitated data sharing in the 2016 epidemic.

Colonial YFV policy in Portuguese Africa is less well studied, limiting conclusions that can be drawn that relate colonial relations and practices to data sharing in the 2016 Angola epidemic. The first known YF outbreak in Angola dates back to 1860 or 1872, depending on the source. During the 20th century, multiple studies of yellow fever were carried out in 1934, 1952, and 1960. There appears to have been another scare in 1940s, which precipitated regular YFV vaccination (supplied by the Institut Pasteur of Dakar) among school children and people moving in or through Angola from 1949.⁶⁵ The private company Diamang integrated YF vaccination in its medical care for its resident populations of workers and their families' by 1949.⁶⁶

During Angola's late colonial period, a major yellow fever outbreak occurred in January 1971 in Luanda. Of note was that this epidemic coincided with an outbreak of chikungunya, in a striking parallel with the 2016 Angolan epidemic, which took place concurrently with a malaria epidemic. The 1971 epidemic, investigated by researchers at the National School of Hygiene and Tropical Medicine in Lisbon, was controlled in less than three months with prompt mass vaccination and intensive anti-mosquito measures (aerial spraying with ULV malathion).^{67,68} Official morbidity and mortality statistics (65 cases, 42 deaths) appear to have vastly underestimated the epidemic's impact: a sero-survey estimated that some 13% of the population had been infected with yellow fever.⁶⁹

The British reactive vaccination policy seems to have grown out of an apparent YF epidemic outbreak in western Uganda in 1941. The epidemic was discovered through immunological research among local populations and involved data sharing between the Rockefeller Foundation staff and colonial medical authorities. The resulting mass vaccination campaign reached 145,000 people in western Uganda and was seen as successful in containing the epidemic.⁷⁰ Thereafter the collection and sharing of data on YFV in British colonial territories appears to have centered on ensuring the success of reactive vaccination campaigns in the wake of epidemic outbreaks. This pattern of response continued after Independence. Although the Ugandan Institute was not highly involved in data sharing during the 2016 epidemic, it remains a key institution in YFV data collection and sharing in Africa.

From the late 1950s to the 1980s, greater emphasis was placed on collecting and sharing entomological data and knowledge about vector control techniques, water collection and storage practices, and human mobility that could facilitate transmission among different vectors. In response to the devastating 1965 West African YFV epidemic, a permanent surveillance system was established to share data in West Africa, involving a network of "sentinel hospitals," regional and national laboratories (including IP-Dakar), and two emergency epidemiological teams.⁷¹⁻⁷³ During this period, too, entomological research sought to identify likely sites for YFV emergence. Vector control appears to have played decisive roles in two other YFV epidemics, in the 1958 DRC (former Belgian Congo) outbreak, and in the 1971 Angola outbreak.⁶⁷ This recognition of the need to collect and share entomological data and to implement vector control is striking, given how little emphasis it received during the 2016 epidemic. By the 2016 outbreaks, YFV data collection and sharing emphasized vaccination as the central response. The wisdom of the more multi-pronged approaches appears to have been downgraded and eventually, lost.

Data sharing in the 2016 YFV outbreak appears to follow patterns established by the 1970s. During the 1978-79 outbreak in the Gambia, the WHO organized a multi-national team of experts from

the CDC-US, the British Medical Research Council, Institut Pasteur of Dakar, and the Virus Research Laboratory in Nigeria. Serological samples and clinical evidence were collected and the data analyzed and shared to assess: the scale of the epidemic (discovered to be far larger than reported cases indicated); the outbreak's origin and regions affected; and the coverage and seroconversion rates of the reactive vaccination campaign launched to contain the epidemic.^{74–76} Enhanced surveillance for yellow fever began in 2002, when a network of national laboratories was established to diagnose cases, and a system of case investigation put in place. Any “outbreak” (one or more confirmed cases) led to vaccination campaigns.⁷⁷

Finally, the risk of YFV transmission to Asia has been a long-standing preoccupation of both research and data sharing, one that was revived by the 2016 outbreak's expansion to China. The risk appears relatively lower in China itself, where the mosquito vector is a less effective transmitter of the virus.^{78–82} But other risks do exist: certain Asian strains of *A. aegypti* mosquitoes capable of transmitting YFV; low rates of vaccination; confusion over recognizing the virus because of serological cross-activity with Japanese encephalitis, typhoid fever, malaria, and viral hepatitis; high volumes of travelers, luggage, and cargo from China to Angola and back^{83–85}

C. Yellow Fever Epidemic in Angola and Democratic Republic of Congo (2016)

The 2016 outbreak that began in Angola and expanded to the Democratic Republic of Congo, and to a lesser extent to Kenya, and China, was the largest recorded yellow fever epidemic, following that of Nigeria in 1987. Although Angola had previously experienced major documented YFV outbreaks in 1971 and in 1860/1872,^{67,86} YFV outbreaks have been increasingly common throughout Africa and, to a lesser extent, Latin America since the 1980s. Other arbovirus outbreaks, including those of dengue, chikungunya, and Zika, are also on the increase, and have thus catalyzed the WHO in 2017 to develop a Global Vector Control Response.⁸⁷

It remains important to keep in mind that Angola's epidemic took place within a context of significant poverty and economic decline. According to the 2014 UNDP Human Development Report, Angola ranks 149th out of 187 countries; approximately 36% of its population lives below the poverty line and has limited access basic public services (water, sanitation, energy, health, education and housing). Dependent on its oil reserves, the country was experiencing a major decline in this sector because of declining oil prices.⁸⁸ Angola's initial YFV case was identified in early December 2015 in Viana, a municipality located 25 km from Luanda. The five first cases, occurring among Eritreans living in Viana, suffered from high fever and hemorrhaging.⁸⁹ On January 21, 2016, following confirmation of three cases and in concordance with the IHR (2005), the Angolan Ministério da Saude (Ministry of Health, hereafter known as MINSa) officially declared to the WHO through its National Focal Point that a yellow fever outbreak was under way.⁹⁰ By the end of February, weekly confirmed cases totaled over 80.⁹¹

In the following months, the Democratic Republic of Congo (DRC), China, and Kenya confirmed the presence of yellow fever among their populations, and these cases were linked to the Angolan outbreak.⁸⁰ Yellow fever expansion into the Democratic Republic of the Congo (DRC), first detected in March 2016, occurred through cross-border movements (laborers, people seeking work, and those visiting families). In April of the same year, the expansion of this epidemic into China came through unvaccinated migrant laborers who had been working in Angola. Kenya's two cases also came from Kenyan workers who had contracted the virus while working in Angola. In contrast to the EVD epidemic, the expansion of YFV into other countries did not provoke the

WHO to declare a PHEIC, most likely because outside of DRC, the outbreak did not provoke widespread transmission: cases in China and Kenya did not catalyze regional epidemics.⁹²

There remains, however, considerable uncertainty over total case numbers, although the 2016 epidemic likely represented the worst known YFV emergence in Angola in recent decades.⁹³ Sixteen out of 18 provinces, and 139 out of 166 municipalities (84%) in Angola were affected. Approximately 4347 suspected cases and 377 deaths occurred in Angola between 5 December 2015 and 10 October 2016, in addition to DRC's 2800 suspected cases and 78 confirmed cases of which 16 died. China and Kenya suffered 11 and two imported cases, respectively.⁹⁴

Mass vaccination was a crucial intervention mobilized to bring the epidemic under control in Africa, even though other interventions, notably vector control, have been effective in controlling YFV in the past. The widespread epidemic in Angola prompted mass vaccination – more than 18 million doses -- supported by UNICEF, Gavi, and the WHO. But this mass vaccination strategy depleted global supplies of yellow fever vaccine multiple times in 2016.^{95,96} The depleted global vaccine stock compelled the WHO to recommend and some responding institutions and organizations to administer fractional dosages of the vaccine to conserve the supply and to protect more people – a move that successfully contained the epidemic, although its consequences for long-term immunity among vaccinated populations are unknown. In Angola, national health authorities reported that they resisted fractional dosing, although debates over this strategy appear to have been heated.^{96,97}

China's role in this epidemic was multi-faceted. The country has a long history of relations with Angola and deploys over 250,000 workers there. It offered assistance to Angola when the YFV epidemic broke out in 2016. In January 2016, it was reported that China made USD 500,000 available to the government of Angola to respond to the YFV epidemic, part of an effort to strengthen relations between the two countries. In addition to this financial commitment, China also deployed a medical team to Luanda to offer free medical services to Angolans and to bring hospital equipment “in order to improve sanitary and health conditions in Angola.”⁹⁸ But its implication in this epidemic was considerably smaller than it was in the West African Ebola epidemic.

Moreover, detection of YFV among unvaccinated Chinese laborers who had been working in Angola shifted focus rapidly to case detection and prevention in China. Under its *Infectious Disease Prevention and Treatment Law*, the government implemented enhanced quarantine of Yellow Fever, requiring travelers from Angola to show proof of Yellow Fever vaccine upon entering the country or face quarantine upon entry.⁸⁴ Exit and entry ports implemented screening of travelers and products. The law also created a network of Centers for Disease Control and Prevention (CDC) at the national, provincial, prefectural and county levels to undertake “legally required vaccination, inspection and testing, and reporting work.”⁹⁹ Authorities also made TV news and social media broadcasts to inform the public and educate them about the risk, albeit low, of outbreak potential, but also sought to reduce potential panic. They tightened border health patrols at airports and seaports, especially for travelers arriving from Angola.⁸⁴

D. Data sharing during the Angola-DRC-China Yellow Fever epidemic

“Data” produced during the Angola-DRC-China YFV epidemic came in multiple forms, some of it created from biological samples (whole blood or pre-processed blood, for plasma is extracted,

permitting isolation of RNA and the virus).¹¹ Linked to these samples were line data collected on each individual. Social, political, and administrative dynamics informed data sharing at international, national, subnational, and local community levels.

In our initial analysis of publications and reports, our conclusion was that data sharing was relatively poor during this epidemic. Our interviews, however, somewhat altered that interpretation, although the divergent interpretations among different actors of data sharing during this epidemic remains striking.

For those actors who were within the Angolan Ministry of Health or part of a core group within the WHO's Incident Management System, data sharing did occur during the epidemic, and to a largely satisfactory degree, albeit with certain gaps and delays because of the challenges of responding to an epidemic of considerable amplitude. The WHO focal point for yellow fever, and to a lesser extent, responders from UNICEF, IP-Dakar, the US CDC, the Cuba Cooperation, and MSF who supported the response had comparatively greater access to different types of data produced during the epidemic. Neighboring countries, and particularly the DRC, also shared surveillance and other data. Other researchers brought in to assist the WHO with analyses for the response had less access to data, either through formal or informal channels. Finally, the ECDC team appears to have been shut out, and researchers external to the response had to make do with whatever data were made public by the WHO.

The normative version of sharing during this epidemic is best reflected in the recollections of a highly ranked official within Angola's MINSA:

A national commission was set up, and this national commission met always at 8am in the Ministry of Health. Then all the partners participated, and a report was presented with last week's data updated - clinical data, laboratory data, that is to say it was information shared by everyone, there was no confidentiality.

Yet this vision of state-centered, collaborative sharing is partial. First, our differently-positioned informants diverge considerably in their evaluations of the extent of data sharing. Hence, traces of data sharing are not always visible in oral testimonies or even publications related to this epidemic. No single informant or institution appeared to have a holistic view of what was shared and with whom – although certain claimed to. And second, just as the epidemic had its own temporalities, so too did data sharing, so that the functioning national commission with various partners around the table reflects particular periods within the epidemic and its response, but not for its entirety.

Below we address each type of data in turn, indicating to whom it circulated, how differently-positioned actors understood that sharing and its temporalities, and the effects on the public health response. There are several striking global insights that emerge from our analyses of diverse reports, publications, and interviews from the 2016 epidemic.

¹¹ In Angola, data production extended from the communal level to Luanda, and theoretically, results were reported back to the local level, although this reporting occurred with great difficulty. At the communal or provincial level, health workers collected data alongside sample collection for evaluation. In Luanda, all samples received an ID number, were checked and data on each case entered into Epi-info. Results were sent to the National Direction of Public Health, and questionable cases evaluated by a commission composed epidemiologists and technicians.

Response Coordination

Following official declarations of yellow fever outbreaks in Angola in January 2016 and in DRC in April 2016, the WHO activated the Incident Management Systems on the country level, the African Regional Office [AFRO] and Headquarters on April 22, 2016 to manage the response, bringing in expert contributions from WHO and its partners.⁹² The response rested on five pillars: surveillance and risk assessment; vaccination; case management; vector control and social mobilization and risk communication.^{100,101} The objectives of the IMS were to stop transmission in affected countries and to identify cases early and to manage them; to prevent YFV from spreading to other countries; and finally, to increase access to vaccination and improve the effectiveness of other preventive measures. In Angola, the primary emphasis was on vaccination and case management, and to a lesser extent, vector control and social sciences operational research. In DRC, where the outbreak was considerably smaller, response largely appears to have focused on surveillance, vaccination, case management, and to a lesser extent, vector control.

Although the epidemic was never declared a Public Health Event of International Concern (PHEIC), there was considerable fear of more widespread transmission, particularly because of intensive human mobility within central African countries and between the region and other parts of Africa and the world. In both Angola and DRC, an array of institutional, humanitarian and other international and bilateral actors participated in the IMS: the WHO international, regional, and country offices, GOARN networks, GAVI and UNICEF, MSF and IFRC, the US CDC and Cuba Cooperation, and Institut Pasteur-Dakar.⁹²

Early response coordination was hampered by a lack of personnel and infrastructural capacity within Angola, which made it difficult to produce the timely and reliable data needed to mount an effective response in the form of vaccination campaigns. The weaknesses in training and performance among Angola health personnel, within its health systems, and between the health sector and other programs were already well known. More than a year earlier, the weaknesses in Angola's health system had already been identified, including insufficient knowledge of vulnerable or at-risk populations; problems in management, standardization and sharing of health information; a lack of health professionals of access to health services. Some efforts had already begun to reorganize health services through provincial governors and municipal authorities.⁸⁸ Angola's surveillance system was weak and it initially had no laboratory capacity for detecting YFV through RT-PCR; it did not have sufficient personnel or capacity to collect reliable epidemiological data. Major constraints to technical cooperation between MINSA and the WHO were well known before the epidemic, including poor coordination between MINSA and other ministries, insufficient numbers of WHO experts, and inadequate coordination to support technical support missions.⁸⁸ During the early response, there were delays in providing entry visas for overseas partners, which also appear to have hampered the rapidity of the early response. The mass vaccination campaign in Angola, for instance, resulted from multiple coordination factors: a delay in the confirmation of early cases; a weak health infrastructure which was rapidly overwhelmed by an influx of cases; and insufficient vaccine stocks. Eventually, IMS support for the response in Angola coalesced in an Emergency Operations Center (EOC), a room repurposed from polio response, variously described as "next door" and "across the courtyard" from MINSA. The EOC held several actors from the WHO and its "core" partners – the US CDC, the Cuba Cooperation, MSF, and UNICEF. By this time, the Angolan state had asserted considerable control over data produced during the epidemic, setting up strict procedures for obtaining written permission on data

sharing. One MINSA official reported that following a visit from a WHO evaluation committee, the Angolan state imposed much stricter controls on all of its data:

Knowing the vulnerability of the situation, the magnitude of the situation initially caused us and the ministry to lose control of the data because there was pressure to share the data, WHO itself understood that the data should be shared. Only later, when the evaluation committee came, we were told that the data should not be shared, the data belong to the country. Because there was the CDC and MSF and the data were shared, readily, incoherently. So, we put our foot in it, we locked it, so the data would not be shared with anyone. (YFV-45)

“Core” actors clearly sensed this change in state practice, although they did continue to share data informally. Indeed, the EOC was set up explicitly to facilitate this type of sharing, along with an ease of access to MINSA. One WHO representative boasted,

I get everything. Sometimes, there might be some problems with people handing over data, but when that happens, I meet all of the directors, I meet with the Minister of Health, I am at the heart of everything, and nobody hides anything from me. (YFV-39)

But there were clearly limits to the flow of data around response coordination. WHO partners who were not part of this core group complained about their lack of access to data and to real authorities within the Angolan government. As one less favored actor complained of the Cuba Cooperation, for instance, “*I think you know the history of Cuba and Angola...I think it’s more a question of political relations that make the Cubans very strong in Angola. The Cuban team in charge of anti-vector malaria control didn’t even depend on the ministry of health, it answered directly to the President. Even internally, this posed a problem of coordination.*” (YFV-05)

The Cuba Cooperation did not, in fact, answer “directly to the President.” But this actor’s remarks are instructive in that they reflect a kind of hierarchy partners within the IMS: some were clearly more favored than others by the Angolan state.

Biological samples and clinical/diagnostic data

a) *Angola*

When the outbreak first occurred, Angola did not possess the laboratory diagnostic capacity to test blood samples for yellow fever. The Institut Pasteur of Dakar (Senegal) and the Zoonosis and Emerging Disease Laboratory of the National Institute for Communicable Diseases (NICD) (Johannesburg, South Africa) confirmed the initial cases.¹⁰²

Indeed, the very first blood samples went to the South African laboratory, Institut Pasteur of Dakar was also a WHO reference center, but received samples subsequently, although the timing of this receipt remains unclear. Just what the status of the NICD in South Africa was, and why it received samples first was unclear to many of our informants, although the WHO clearly indicates that the NICD has been a WHO Collaborating Centre for Reference and Research on Viral Hemorrhagic Fevers and Arboviruses since 2014.¹⁰³

That said, several informants appeared not to recognize this status, including a WHO official as well as multiple researchers from Africa and Europe (YFV-39, YFV-07, YFV-05, YFV-06).

Indeed, a high-ranking official in Angola contended that MINSA's sharing of samples with the South African laboratory diverged from an established, WHO-imposed constraint, and resulted from Angola's physical proximity and long-standing political and collaborative relations with South Africa and the NICD.¹² It allowed Angolan authorities to obtain a more rapid response to their suspicions that the first three cases were indeed yellow fever. At the time, he claimed,

We were not sure what was happening, and we have a good relationship with South Africa, we sent there for PCR. And they have a good molecular biology lab, because it was easier to send samples to South Africa. We have a direct flight that lasts 2 hours and 30 minutes, and the sample would not be badly handled. If we sent it to another country, that would take much longer. So, we sent to South Africa, and the first confirmatory diagnosis of Yellow Fever came from South Africa. (YF-44)

Following the declaration of a YFV epidemic, samples from suspected cases, first from Viana, and then from affected districts throughout the country, were sent for testing at the national laboratory, the Instituto Nacional de Saúde Pública (INSP). There, the samples underwent RT-PCR (Reverse Transcription Polymerase Chain Reaction) analysis and/or serological testing (IgM ELISA) to evaluate whether the patient indeed was infected with yellow fever. RT-PCR analysis provides a direct diagnosis, in that it detects the viral genome in the sample. It can only be conducted within a particular window of time in order to detect the virus within a patient. Serological testing provides indirect diagnosis, permitting the detection of Class M immunoglobulins. Technical support came from IP-D teams and from CDC to help the INSP to keep pace with diagnostic demands.

Once laboratory capacity was fully in place in Angola, that is, in early March 2016, the INSP performed all yellow fever testing. Bi-weekly case confirmation meetings addressed all positive test results for yellow fever, categorizing them as “confirmed” or “not confirmed”, depending on information in the epidemiological reporting form and the patient's vaccination history.

The samples themselves, evaluated through RT-PCR and/or serological analyses, provided the foundations for compiling diagnostic (and epidemiological) data.¹⁰⁴ Blood samples, coming from Angolan clinics and hospitals receiving suspected cases, were accompanied by information sheets with personal, clinical and epidemiological data about the patient.

The collection of clinical data was of particular importance to multiple actors, because YFV diagnosis poses certain challenges (its non-specific symptoms can be confused with other pathologies) and because there was no standardized clinical definition of a “case”. As a MINSA official observed, this epidemic

put great pressure internally and internationally on the importance of the differential diagnosis of febrile syndromes in our region, where malaria is the leading cause and death disease. That is to say, if I do not have the ability to make a good differential diagnosis between malaria among the other arboviral diseases like dengue and chikungunya, I will never reach a suspected yellow

¹² Perhaps predictably, one Dakar researcher contended that this very act delayed the implementation of a response.

fever with such speed. So, it is important that countries increase their ability to diagnose febrile syndromes differently. This not only because of Yellow Fever but in relation to other potentially epidemic diseases. At the height of Yellow Fever, Angola had a malaria epidemic outbreak and Zika cases confirmed. This was possible because we reinforced during the period of epidemic the differential diagnosis febrile syndromes. (YFV-44)

According to the WHO situation reports, Médécins sans Frontières and Medicos do Mundo worked with MINSA to support case management and to elaborate new yellow fever case management guidelines.¹⁰⁵

Line data that accompanied these samples into the national laboratory were highly detailed. One West African virologist working in the Angolan national laboratory indicated,

Each sample came with what we called an investigation sheet, which had the name, the patient's age, but also clinical information, when the illness began, etc., and what zone the patient lived. So, there was personal information, epidemiological information, clinical information that was connected to each sample.... (YFV-07)

As part of the support team for the INSP laboratory, this actor recalled that he compiled data each evening and then circulated them to a pre-set list, which included a data manager, the Angolan Ministry of Health, WHO yellow fever focal point and country representatives, Institut Pasteur of Dakar, and the CDC. Of the CDC, he said,

It was [the CDC], for example, when I sent the data, there was a team put into place at the level of the Ministry of Health. They were the ones who treated the information...the analysis was done at that level. I was making the database for the lab, I gave the results and I sent them along. So then, they were the ones exploiting the results. (YFV-07)

INSP and MINSA officials would receive this highly detailed data, and according to a high-ranking MINSA official, “Laboratory data were only shared with CDC and WHO. That is to say, [results of] samples, blood samples were only shared with CDC and WHO.” (YFV-44).

Overall, selective diagnostic and sample sharing did take place between the Angolan government, the WHO, and to a lesser extent, the US CDC, and MSF. A high-ranking MINSA official observed that sharing around “differential diagnosis of febrile syndromes” was especially important, both in Angola and internationally. Blockages occurred in reporting diagnostic results from the national laboratory to the provinces and districts. As one external participant observed,

That was the big issue with data sharing: the laboratory would report these results to us, but those results would never trickle down to the provinces or the districts, which was greatly frustrating to the physicians who had no results to report back to their patients. That was the big issue. And we asked multiple times and the response was, "we are a surveillance laboratory, we're not a diagnostic laboratory. The treatment for yellow fever will not change whether the person has yellow fever or not." And sometimes that would have facilitated some of the conversations we had with the province or district level officers if we were

able to report back. And those were the kinds of ad hoc information that we might be able to obtain from the laboratory. (YFV-37)

b) Democratic Republic of Congo

When the epidemic expanded to the Democratic Republic of Congo (DRC), the Institut National de la Recherche Biomédicale (INRB), the national laboratory, conducted the diagnostic testing, supported again by an IP-D team.

The DRC did provide data to the WHO, but insufficient detection and reporting capacities preventing its regular exchange. The dearth of data from the DRC seems less related to state reticence toward public data sharing, and more to insufficient capacity to collect and report.^{106–108} The Institut National de la Recherche Biomédicale (INRB) received most in-country samples and confirmed most cases. Sharing from the DRC, and particularly between the INRB and IPD was apparently easier. The INRB frequently exchanged samples with IP- Dakar¹⁰⁹ which in turn assisted the INRB to set up a mobile laboratory to expand testing capacities.¹¹⁰ According to one actor involved in these exchanges, “We have really good relations, a mutual trust”, which translated into daily exchanges of diagnostic data.

c) Kenya

In March 2016, two Kenyan workers infected with YFV in Luanda and returned to Kenya. Neither had received vaccination against yellow fever. The first died, and the second recovered. The Kenya Medical Research Institute (KEMRI) tested blood samples from these patients; RT-PCR were negative for both, but serology assays tested positive.¹¹¹

The initial cases within Uganda were confirmed by RT-PCR in early April 2016, and then subsequently, the Uganda Virus Research Institute sent blood samples to the CDC (Fort Collins) for confirmation.^{90,112} Although concurrent with the Angola YFV epidemic, these cases were deemed unrelated to the outbreak in Angola.

d) China

China’s 11 YFV cases were first detected in Angola, either as fever or as fully diagnosed cases, before they traveled to China. After arriving in China, all 11 patients were admitted to the hospital and rapidly received care. The first patient admitted to the hospital for treatment died shortly thereafter. One infectious disease physician responsible for the clinical and laboratory teams was interviewed briefly in the summer of 2018, and at greater length in December 2016. This doctor emphasized the team’s accomplishment in detecting and responding to the YFV cases within 44 hours and shared an unpublished manuscript detailing the timeline of the response to these 11 cases. Possibly China used this limited outbreak to demonstrate its new preparedness and capability of detecting and responding to an epidemic that posed a global threat. Following case detection, the Disease Outbreak News and Situation Reports concerning China publicly reported descriptions of the clinical symptoms of most of the reported cases.^{8,81,113–115}

e) Impact of sample and diagnostic/clinical data sharing

The impact of sample and diagnostic/clinical data sharing affected the epidemic and its control in three ways: it galvanized the creation of laboratory capacity for YFV diagnosis in Angola; it allowed identification of new outbreaks, and it assisted in Angola in the development of new differential diagnostics for febrile syndromes.

But data sharing had a mixed record during this epidemic. Delays in reporting diagnostic results were significant, particularly at the outset of the epidemic, and may have had important consequences for the spread of the epidemic. As one regional WHO official recalled,

I think the initial part of the outbreak, especially in Angola, the outbreak was really addressed very quickly. We did reactive vaccination, and that had a huge impact on the overall course of the epidemic. But there were delays in lab confirmation, because Angola didn't have capacity to do the laboratory confirmation, so there was a delay in notifying the WHO properly. So, the epidemic spread, beyond to DRC. (YFV-41)

Phylogenetic and genomic sequences

Sequencing of viruses did take place from blood or plasma samples of infected patients, to determine the relationship between the initial outbreak and prior ones, as well as to understand whether later outbreaks contemporaneous with the Angolan epidemic were related.¹⁰² One WHO official described what might be described as normative patterns of genetic sequence sharing: “we want to look at the genetics of the virus, where it comes from, and we will work with a collaborating center to know that.” (YFV-39)

MINSa shared its first samples with a team at the National Institute for Communicable Diseases (Johannesburg, South Africa), which subsequently produced one analysis of blood samples of three Angolan patients.¹¹⁶ IPD and IP produced another analysis of an Angolan patient co-infected with YFV and Japanese encephalitis (JEV); the Uganda Virus Research Institute (UVRI) conducted sequencing on samples from its outbreak to determine whether this outbreak was related to that in Angola.^{90,111,117} Sharing to identify linkages between outbreaks occurred with the DRC, Uganda, Kenya, and China.

A European-based biologist, however, obtained access to samples through more informal channels, by giving a professional talk in South Africa. He recalled that in 2016,

“We found out that the people generating data from Angola were in two groups: one group was in Dakar, the other group was in South Africa, in Jo'burg. So, we visited them [in Johannesburg], we gave a talk on the yellow fever experience in Angola. We started developing a tool for subtyping yellow fever where you can obtain a report on the genotype, on the position in terms of...the genoposition of that particular sequence...And it turned out the outbreak was related; it was the same genotype as the one circulating in Angola in 1988 (YFV-06).”

Oliver Pybus, posting on virological.org, a sequence sharing site, had this to say in June 2016:

Until last week, we (Nuno Faria and myself) thought there were no genetic sequences for the current outbreak of Yellow fever virus in Angola. However, over lunch at the Sanger Institute, George Gao (China CDC) mentioned that a recent traveler who had returned from Angola to China had been diagnosed with YFV and that the sequence had been placed on GenBank. We think this is accession number KX010994. The GenBank entry says it was an imported case but does not mention Angola, so we can't be 100% sure yet of its source. Thank you China CDC for publicly sharing data so quickly.¹¹⁸

These claims are of interest for two reasons – they highlight the dearth of sequences shared on virological.org or elsewhere a good six months into the epidemic, but also signal the Chinese CDC team sequencing, sharing on GenBank, and subsequently publishing the YF virus infecting four Chinese citizens repatriated from Angola.^{83,114,115,118,119} Phylogenetic analysis revealed that the viruses infecting these workers very closely related to Angola 71 strains.¹²⁰

Hence, limited sharing of sequencing data did occur at the outset and during the epidemic, but the sharing patterns reflected multiple stakes and considerations – long-standing political ties, performed openness. The NICD (South Africa) received samples and shared sequences in part because of its proximity (see previous section) to Angola, because of long-standing relations of training and trade between Angola and South Africa, but also because the NICD is a WHO Collaborating Centre for Reference and Research on Viral Hemorrhagic Fevers and Arboviruses. It could not have published those sequences without MINSAs accord. Institut Pasteur of Dakar received samples and shared sequences on the basis of its designation as a WHO reference center, although these sequences have never been published. We can only speculate that the Chinese CDC and government shared its sequence data, even prior to publication, perhaps to demonstrate an openness about what appeared to be a minimal threat of YFV expansion in China.

The impact of this genetic/genomic data sharing, even though it was limited, was that it helped identify where (and how) the epidemic expanded to new sites, as well as where other YFV outbreaks occurred independently. But further sharing and publication could potentially shed light on the dynamics of expanded transmission; although it is unlikely that data would have helped to contain the epidemic in real time, post-epidemic analyses might assist in predicting the processes and timing of future YFV outbreaks.

Epidemiological/surveillance data

Detailed data for every suspected case, including personal data, associated clinical, geographical and other information were produced on local district levels. These data were collected alongside biological samples from suspected cases. They were compiled on regional levels, suppressing personal data (although according to one researcher for WHO, these data sometimes slipped through) and providing information about suspected cases, confirmed cases, deaths, and locations. Data were then provided to MINSAs, the WHO Incident Management Team in Angola, WHO Country Offices in Angola and DRC. The WHO regional authority reported receiving data on

where the outbreak was taking place, which were the most affected provinces, where there were certain kinds of interventions.... confirmed cases, suspected cases, deaths, the districts affected, number of people vaccinated and overall vaccination coverage, diagnoses, vaccination coverage, number of stakeholders in the response, number of staffs deployed, etc. (YFV-41)

From this initial sharing with Angolan and certain CDC and WHO representatives (in Angola, Brazzaville and Geneva), diagnostic and epidemiological data were compiled into WHO Situation reports. WHO Situation Reports made case counts publicly available.⁸⁶ There also existed an “event site”, accessible to country officials who “gained access through a passcode. This information was not public.” (YFV-41) Epidemiological data sent to WHO headquarters was used to model different vaccination strategies.

Sharing data also took place between country authorities, specifically between Angola and DRC, which has a century-long history of data sharing during epidemic outbreaks, between Angola and

Namibia, and Angola and South Africa. Surveillance data in particular were shared between health ministries, and between CDC offices in Angola and DRC.

Other agencies or NGOs also received epidemiological data. The European Centre for Disease Control, which sent a mission to provide epidemiological and policy support, did receive some highly aggregated data (ECDC).¹²¹ MSF received epidemiological data for its vaccination campaigns.

Views of how easily epidemiological data were shared depended substantially on who evaluated the sharing. Although one WHO official insisted on the relative ease of obtaining data, another official, responsible for developing the Situation Reports, found it more challenging to gain access to the full epidemiological databases in Angola than in DRC. In Angola, he said, he needed MINSA to clear his request at a high level, but in DRC, access to this type of data was “simpler” (YFV-40). Certain WHO reports support this claim. Angola refused to share non-aggregated epidemiological data and to provide access to raw data and national databases.¹²¹ As a result, WHO publications and updates appeared erratically throughout the outbreak, and many reports are still not publicly available on the WHO website.

For a US CDC representative, it was not always easy to obtain the data needed, but this difficulty had less to do with a lack of sharing and more to do with MINSA’s workload:

We might have difficulty collecting a certain type of data, but just because of the nature of the response...the timeliness and all of these things, or just the fact that we were swamped with other elements of the response. But I never had any issues obtaining information from other partners. From the Ministry of Health sometimes it was a bit difficult to obtain details, but I think it was more because the person we were asking was overwhelmed and didn't get to our request as quickly as we would have liked.

Overall, however, with respect to epidemiological data sharing, this same responder concluded

we were quite good. The incident manager was actually my day-to-day boss at CDC, so we worked well together, but he instituted the SitRep right away, once a week. He did not cave to the pressure of WHO, who wanted daily SitReps. (YFV-37)

That said, other researchers, differently positioned within epidemiological data sharing pathways, were less enthusiastic in their evaluations of sharing during this epidemic. One European research working with WHO-headquarters, indicated that the relative dearth of sharing had much to do with Angolan reticence to do so:

The fact that the epidemic wasn't declared a public health emergency of international concern meant that the epidemiological data still belonged to the country. That's the biggest difference with Ebola.... The WHO sent us the data, telling us that the work that we did would remain confidential. We produced for them a lot of reports for internal use, for epidemiological analysis. (YFV-35)

An ECDC epidemiologist on mission also experienced some difficulties obtaining epidemiological data, but attributed it not to Angolan control, but because of capacity problems:

Yes, sometimes from the Ministry of Health it'd happen that they'd say yes, but we never got it. I remember that we needed some data on some cases, some contacts, and sometimes it wasn't easy to get. And it can be data that hasn't really been collected or gathered, so it's one of these things that you think is there but it's not, and sometimes it's because of...it was not shared but it was not necessarily because people don't want to share, it's because of data not reaching the lab in proper time, or things like that. Or they don't know how to send the data. (YFV-28)

It does appear that MINSA was vigilant in its control over epidemiological data (and samples), and that this control reportedly tightened between June and August of 2016. After one US CDC informant's arrival in Angola, a conflict erupted after CDC-Atlanta had received samples and data that had not received written authorization for exportation from Angola, although they had acquired verbal authorization from MINSA personnel, but not necessarily the appropriate personnel. This employee had to reconstruct the chain of events and suggested that MINSA had not been explicit about the procedures necessary for sample or data sharing. The employee recounted seeking to reassure MINSA, and then "*follow to the letter procedures set in place for data sharing,*" so that no data would leave the country without appropriate written MINSA authorization, and from the appropriate people (YFV-37). That said, a high-ranking authority within MINSA itself appeared more equivocal about sharing. On one hand, he averred,

There is no formal agreement or contract for data sharing, it was all on the basis of mutual trust." Just a few moments later, he insisted that informal data sharing did not occur, that "All data sharing activities were either planned or under the national disease control committee or under the subcommittees. (YFV-44)

Angolan public health officials had quite distinct perceptions of those with whom they shared or refused to share. Whereas they professed close relations with the CDC, MSF, and the Cuba Cooperation, organizations that had a "right" to these data. They expressed impatience for the ECDC, whom they found "inexperienced" and the WHO, whom they found entirely too vertical in their approach (YFV-44; YFV-45).

We have less insight into epidemiological data sharing in the DRC epidemic, but most accounts from responders in different positions (WHO, US CDC, Institut Pasteur of Dakar, external researchers) attest to more open sharing with DRC health authorities than with Angolans. One European researcher who worked on the response through the WHO observed that

From what I recall, the relations between the WHO and the DRC were always much better than those between the WHO and Angola, especially for data sharing and even for the management of the epidemic. (YFV-35)

It should be noted that these are all *retrospective* evaluations of epidemiological data sharing, pronounced more than two years after the epidemic itself. Reports written during the epidemic asserted that uneven and slow epidemiological data sharing among different key stakeholders contributed to delayed response in Angola and DRC.^{122,123} (One letter, however, contends that the delays were not significant).¹²⁴ Interpreting these disparities between retrospective and contemporaneous evaluations is not easy. Retrospective evaluations may underplay the importance of non-sharing on delays because responders ultimately controlled the epidemic. On the other hand, reports produced contemporaneously with the epidemic may overstate the significance of

insufficient sharing and delays, since writers may not have been able to assess the import (or lack thereof) of unshared or delayed data.

Any assessment of the impact of epidemiological data sharing must take into account these mixed evaluations of the degree of sharing. Although epidemiological data was used to model different vaccination strategies, publicly available data were more aggregated than what was collected, and initially, the data appeared to many users to be neither robust nor rapidly produced. The availability of reliable, granular data in real time could potentially have affected the rapidity with which vaccination campaigns were undertaken. Moreover, it is possible that greater access to more granular epidemiological data might allow for better insight into future epidemics in Angola and central Africa.

Vector data

The Cuba Cooperation has had a lengthy history in conducting vector control for malaria in Angola.¹²¹ Even prior to the December 2015 outbreak, the Cuba Cooperation was conducting assessments of arbovirus vectors in Angola as well as residual spraying of specific provinces. During the epidemic, it indicated to MINSA and the Emergency Operations Center which provinces appeared to be at greatest risk and documented its efforts at indoor spraying to control insect vectors.¹²⁵ There were complaints, however, that the entomological data collected were thin and unreliable. Although the Cuba Cooperation had experience with entomological research and control of malaria vectors, it did not have experience with *A. aegypti* vectors transmitting yellow fever.

In January 2016, an entomology team led by Institut Pasteur of Dakar followed and conducted a second assessment, reportedly in an effort to reinforce prior entomological field research conducted by the Cuba Cooperation. That work, pursued through the WHO, involved training of onsite entomologists as well as multidisciplinary collaborations with Angolan epidemiologists. In DRC, entomologist André Yebakima from Martinique conducted an evaluation of mosquito vectors in DRC for MSF and identified vector control strategies for *A. aegypti*, including wearing protective clothing, filling in receptacles or puddles with stagnant water or various kinds of chemical or biological pesticides.¹²⁶

Data production and sharing on vectors and vector control did occur, albeit to a limited extent, between the Cuba Cooperation, MINSA, Institut Pasteur of Dakar, the WHO, MSF and the US CDC. Moreover, the extent to which Angola and DRC benefited from vector studies and interventions remains uncertain, if only because we have to rely on claims of their efficacy, rather than data supporting these claims.¹²¹ Angolans clearly contended that vector control efforts worked. According to medical epidemiologist Rosa Moreira, such interventions included

a mass distribution of larvicide and a social mobilization campaign to explain to people how to use it. We also did indoor and outdoor spraying with insecticides. Initially we faced resistance: some people kept the larvicide at home and did not use it. So, we asked community leaders to help us persuade people to join the campaign. As a result of these vector control measures, the mosquito density level fell substantially.⁸⁹

In Angola, the Cuba Cooperation had been doing some documentation of mosquito vectors and vector control for arboviruses for at least a year prior to the initial outbreak, but these data are quite limited. During the epidemic, the Cuba Cooperation had close relations with MINSA and the core

responding groups (MSF, CDC, WHO), according to several sources. But not everyone found working with the Cuba Cooperation easy. As one actor from an LMIC observed,

In the context of these epidemics, what is really sensitive, it is precisely this notion of data and there is a circuit of information, as they say. Me, when I collect, I may have data that I can't exploit without the authorization of the country, but equally without the accord of the WHO. ...The country is the proprietor of the data. And these data, they weren't for scientific publication because there weren't enough for an excellent scientific article. But even so, it's also because quite simply these were data that could serve a purpose.... When you talk about data sharing, for us, everything was transparent, we gave to the Ministers, we showed our results. The Cuban team never wanted to share with us for multiple reasons. That is to say, they were there in Angola. (YFV-07)

Indeed, a sampling of the entomological data that was shared from the Cuba Cooperation revealed reports with minimal detail of the locations of vector control, just prior to the outbreak.

The impact of vector data sharing, as already noted, remains uncertain, at the very least because responders raised questions about the quality of the data. Although vector data was clearly collected and shared among limited partners, this type of collection took a back seat to other types of data collection and has done so for decades. The long-term neglect of vectors and entomological data collections seems to us a substantial oversight, the consequences of overwhelming emphasis in the response placed on vaccination. Deep understanding of mosquito vectors and of their control has achieved significant successes in the historical control of yellow fever and other vector-borne diseases, and its contemporary relative neglect has put an undue burden on vaccination as the primary intervention to prevent transmission.

Vaccination data

MINSAs began vaccination campaigns in late January 2016, producing data on numbers of people vaccinated, number of doses, rerouting of excess doses, and waste management of vaccines.⁹⁰ The Democratic Republic of Congo began vaccination shortly after confirmation of its first cases. Both countries received support from the WHO, Gavi, UNICEF, International Federation of the Red Cross, and MSF.¹²⁷ In keeping with other assessments signaling delays in data production that led to delays in mass vaccination, a WHO official observed

I think the initial part of the outbreak, especially in Angola, the outbreak was really addressed very quickly. We did reactive vaccination, and that had a huge impact on the overall course of the epidemic. But there were delays in lab confirmation, because Angola didn't have capacity to do the laboratory confirmation, so there was a delay in notifying the WHO properly. So, the epidemic spread, beyond to DRC. (YFV-41)

Mass vaccination campaigns put a considerable strain on global yellow fever vaccine supplies, raising questions about whether to engage in fractional dosing – that is to extend the vaccine stock by injecting children and adults with a fraction of the normal vaccine dose in order to achieve some (unknown) duration of immunological protection and thus to prevent further transmission. Debates about whether to engage in fractional dosing centered on vaccine supplies, but also questions about the evidence used to support the practice, and of course, on politics.

Angolan officials were quite adamant about not doing fractional dosing. According to Rosa Moreira, medical epidemiologist in MINSA, Angolan refusal to use fractional dosing stemmed from the country's insistence on providing its citizens with lifelong immunity to yellow fever with the full vaccine.⁸⁹ In an interview with another MINSA official, the president, he said, had funds readily available to purchase 18 million doses of yellow fever vaccine, a choice that seems in part to have been a point of national pride.

Angola was under great pressure to reduce the concentration of the vaccine, that we should reduce by half.... During the epidemic, Angola did not accept this advice. Angola insisted that it would not use half the dose, because there was no scientific evidence to prove that half the dose would actually produce antibodies for 1 year, 2 years or 10 years or a lifetime. DRC agreed to vaccinate its population with half the dose.... Of course, the DRC will have to do the follow-up of these people, and that in 1 year, or should already assess if they still had antibodies to the disease. (YFV-44)

The fractional dosing question had indeed been evaluated by the WHO Strategic Advisory Group of Experts on Immunization (SAGE) by mid-2016,⁸ but it is true that the duration of protection was not established. The DRC, however, eventually did opt for fractional dosing, although several months after mass vaccination began. Why Angola did not engage in fractional dosing and the DRC did is not entirely clear, but it appears that politics, available global vaccine stocks, and timing played an important role here. Angola's outbreak occurred earlier, and it – and, for a time, the DRC – were able to rely on existing stocks, although reports reveal that global stocks were exhausted multiple times during the first several months of 2016.⁹⁵ The Democratic Republic of Congo, however, undertook a pre-emptive mass vaccination campaign in Kinshasa in August 2016, seeking to vaccinate some 7.6 million people in 10 days. Global stocks, however, had been depleted, and thus the DRC's campaign employed a fractional dose of the 17DD vaccine (produced by the Brazilian vaccine manufacturer, Bio-Manguinhos) at one fifth (0.1 ml) of the standard dose. Nonpregnant adults and children aged 2 and older received this vaccination.¹²⁸

Angola and DRC shared their vaccine-related data with UNICEF, MSF, the WHO, and reportedly GAVI, and subsequently these data were shared with biomedical researchers and the public, especially through the weekly publication of the Angolan Incident Management System report.¹²⁹ The Chinese government also deployed personnel to Angola to vaccinate Chinese workers living there.¹³⁰ (One study estimated that none of the 259,000 Chinese who travel to Angola received yellow fever vaccination.^{85,130})

At times, it appears that the quality (timeliness, accuracy) of shared vaccination data suffered because of a dearth of accurate complementary data, including epidemiological. Delays and inaccuracies in vaccination data and census data hampered the production of estimate vaccination coverage. Eventually, their broader public availability allowed the scientific community to examine the effectiveness of the vaccination response during the 2016 outbreak, but these were largely insights that had no real impact on the control of the epidemic.¹³¹

The impact of vaccination data sharing was that it contributed to critical discussions concerning the benefits and limits¹³² of reactive vaccination campaigns to control yellow fever outbreaks.^{8,116} It also contributed to the WHO SAGE Working Group investigation of the effectiveness of fractional dosing for yellow fever vaccines, to remedy a possible shortage of yellow fever vaccines in outbreak settings.^{96,128,133,134}

Social sciences and social mobilization data

Social sciences and social mobilization data were primarily collected to strengthen case detection, to improve vaccination coverage, and to a lesser extent, encourage environmental sanitation and bed net use.¹³⁵ UNICEF also supported the Incident Management Team by conducting Social Mobilization and Risk Communications activities. The social mobilization campaign, particularly focused on vaccination was considerable, involved traditional authorities, local authorities, media, churches, schools and businesses. This mass social mobilization is one significant factor that made it possible for the response to vaccinate 18 million people in Angola. That we have no data documenting this intervention is deeply regrettable, denying future responders the opportunity to learn from this mass effort.

So far as social sciences investigation goes, there were none – no studies of the local impact of deaths, of stigmatization, of the uses of “traditional” medicines to treat or prevent the diseases. There were no studies of local rumors around the disease or its response, of the impact of the epidemic on local health staff or health structures, or of the processes, gaps or consequences of mass vaccination across the country within a highly compressed period of time. This absence of social sciences investigation remains a major missed opportunity to learn from this epidemic.

The sole social investigation from this response was a Knowledge, Attitudes and Practices (KAP) rapid assessment among 302 men in April 2016, conducted by the US CDC, in collaboration with the Angolan MINSA and WHO.¹³⁶ Its purpose was to study Angolan men’s yellow fever vaccination coverage. The social science data generated and shared for this KAP study of attitudes and practices around yellow fever vaccination occurred under the scrutiny of MINSA and a formal data sharing agreement was concluded through the intervention of the national ethics committee.

Among its findings, the study concluded that a third of the men questioned did not receive YF vaccination for a variety of reasons (lack of knowledge about where to obtain; lack of time because vaccination sessions occurred during working hours; believed the vaccine to be dangerous; did not want to wait to be vaccinated). There have been, however, multiple questions raised about the quality of this study: that it was conducted only in Luanda, that it took place towards the end of the epidemic, and that it focused exclusively on men and not on women. This limited its potential for contributing to any effective response. Moreover, at least one of its findings – that men did not receive vaccination because sessions occurred during working hours – has prompted substantial questioning of the robustness of the data themselves: in a population with very high unemployment rates, why would vaccination sessions during working hours pose a barrier to vaccination?

Late in the epidemic, an epidemiologist working on a modelling analysis suggested that there was indeed a need for on-the-ground, social sciences data:

Another thing that would be very helpful is to have more information, even if it's anecdotal, from people on the ground. We didn't really have insights from people who have seen the outbreak, who have seen what's going on, to give us more information that we could work into our model. What that really looks like, in terms of data, is difficult to say, but it's just having someone on the phone once a week to tell us what's going on could have been helpful. Really understanding the particular sites that people go to, why do they go to at these intervals, what are their family structures within the country. (YFV-04)

So, what was the impact of social sciences data sharing? Broadly speaking, the major problem with social sciences and social mobilization data sharing is that there simply was not enough of it. That there were reportedly only two KAP studies produced, few traces of sharing of community mobilization data, and apparently little integration of social sciences with epidemiological or modelling analysis appears to have been a lost opportunity, and one that could have assisted the response in important ways.

Clinical trial data

To our knowledge, the clinical trial for fractional dosing of YFV vaccine in Democratic Republic of Congo was the sole clinical trial conducted during this epidemic. The effectiveness of fractional dosing was of critical importance, again because of the depletion of global stocks of yellow fever vaccine. Multiple investigations had already been conducted on fractional dosing, but following a WHO review of cohort studies of various strategies to conserve doses, the trial was conducted in a large-scale campaign in the DRC in August 2016.¹³⁷ Funded by USAID and the US CDC, the study, published in the *New England Journal of Medicine*, evaluated immunological response among 716 people (non-pregnant adults, children aged two and older) vaccinated over 10 days with a fractional dose of the 17DD vaccine (Bio-Manguinhos) at one-fifth of the standard dose.¹²⁸

GIS data

In conjunction with its vaccination activities in Kinshasa (DRC), MSF collected and used GIS data to strengthen vaccination coverage.¹³⁸ This approach was part of a MSF Geographic Information System Strategy 2016–2019 to deploy a GIS specialist during an outbreak and to evaluate to what extent GIS helped MSF do its work. The conclusion was that GIS was "a very important enabler" but not "critical" in helping MSF to carry out its work. The Missing Maps initiative, created by MSF and supported by IFRC and OpenStreetMap, added building outlines to digital maps of health zones where vaccination would take place. Geographical images were developed to track YFV vaccine coverage and vector control activities.

MSF released “non-sensitive data sets” to the DRC Central Health Zone Office (Bureau Central de la Zone de Santé, BCZ) and made them publicly available by uploading them OpenStreetMap (OSM).

E. Post-epidemic data sharing

One major concern about data sharing has focused on its afterlife – what was collected but never published. Post-epidemic data sharing appears to have been the focus of considerable commentary for our interviewees, but also raises the question of whether more sharing would make a difference for future epidemics.

At one end of the spectrum was a WHO official, clearly convinced that data sharing was the focus of complaints from researchers who wanted only to publish high impact results. Data sharing, he averred, had no effect on the course of the 2016 YFV epidemic, nor was it especially necessary over the longer term. “*Sharing,*” he opined, “*global analyses, these are the concerns of academics. For the response to the epidemic itself, countries have no real interest in hiding their data. But if it’s to publish, that’s something different.*” (YFV-39)

Yet it would seem that this informant had a highly restrictive understanding of response, delineating it sharply from research and denying the possibility that research could contribute to present and future responses. Researchers, however, including those integrated into the response

through the WHO or informal networks, were considerably less enthusiastic about the record of data sharing during this epidemic. Several researchers brought in to conduct analyses to support the response largely concurred that data sharing *during* the epidemic was not optimal, and *afterwards*, even less so. On two occasions, when we informed two different informants (both researchers) that we were working on data sharing during the 2016 YFV epidemic, they both laughed, “*You won’t have much to talk about.*” Still another argued,

There was very little data sharing available for the yellow fever outbreak in Angola. I think, for Brazil, in comparison...Brazil is so big and there's so many different research groups with so much funding.” (YFV-06; also YFV-01, YFV-04, YFV-35)

Two other researchers (one from an LMIC and another from Europe) involved in two YFV publications generated after the epidemic. Both had dour evaluations of sharing and publication. For one of these researchers, the problems resulted from Angolan reticence:

There was a publication that the WHO was preparing through the ministry of health. They sent it to me, and I gave my inputs. But I have never seen the paper come out. So, I think that people were talking on the level of the ministry, and they didn’t want to give any information. For this blockage, I don’t know. Maybe it was on the level of the ministry, or, I don’t know. But this I do know: even for the paper on Japanese Encephalitis that we wanted to link to yellow fever, when it was sent, there was a reticence on the part of the ministry, which said, no...There was a total blackout. They didn’t want to publish it. So, it was really thanks to the WHO that we published it, because they said we should. So afterwards, the Angolans said that we had to add their names, and we accepted and sent the paper along to the journal. (YFV-07; also YFV-01)

For this researcher, then, it was only with WHO pressure – presumably because of the public health implications of a Japanese encephalitis-YFV coinfection – that MINSA relented and allowed publication.¹¹⁷ Another researcher attributed the lack of publication to the workload of certain LMIC researchers who have shuttled from one epidemic emergency to the next, without a moment to tackle the analytical and writing process (YFV-01). For a third researcher, however, the lack of access to granular epidemiological or vaccination data had more to do with how the data are collected, and not a reticence to share.

One of the big limitations...is that we had to rely on only the epidemic curve for Luanda, and then for the entire country. So we didn’t have epidemic curves with numbers of cases for each of the different districts, so it would have been beneficial for us to have access to case counts per district... then one very, very important thing that we also didn’t have access to was vaccination information. So we did not have estimates of, first, the underlying immunity, so knowing how many people have been vaccinated, what that process was.... I think this information is often not registered in a way that is directly shareable to outside researchers...(YFV-04)

Would access to that data have made a difference? One researcher was skeptical, “*For that particular outbreak in DRC and Angola,*” he noted, “*I think we were too late, and I think that the analysis will only hopefully show relevance for future outbreaks.*”^fHe was thus convinced that the

insights generated from this study could assist in developing control strategies in future YFV epidemics.

That said, we would argue that publication is not simply to further the careers of academic researchers: the point is also to intervene, to propose the optimal use of scarce resources in order to curtail transmission and to bring outbreaks to an end. By not enabling this kind of post-epidemic publication, it does seem that we are denied an opportunity to learn lessons from the 2016 events.

F. Key barriers and facilitators to data sharing

Below we address key barriers and facilitators to data sharing during the YFV epidemic. What follows is a loose PEARLES analysis, because we find considerable overlaps and interactions between these factors and data sharing. Moreover, in certain cases, historical politics could underpin multiple barriers.

Figure 4: Facilitators and Barriers of Data Sharing during the 2016 YFV Epidemic

Facilitators of data sharing in the YFV Epidemic	Barriers to data sharing in the YFV Epidemic
IHR/WHO policy on data sharing during epidemic emergencies	State sovereignty and insistence on its ‘ownership’ of data
Logistical arrangements through the Incident Management System that facilitated informal and formal sharing	Insufficient technical capacity and standardization to produce or collect data and to share results
State concerns to protect industries (oil, diamond) from economic fallout in the event of an uncontrolled epidemic	Insufficient number of personnel to produce data
State concerns about political relations with neighboring countries	Health systems overwhelmed by the response and thus unable to respond to requests to compile and share
Historical political relations between actors and institutions	Insufficient training of personnel for producing data
Sociolinguistic relations between actors, institutions, organizations and networks	Insufficient funding
Moral sense that data sharing could help to control epidemic	Procedural restrictions
State interest in securing additional support from international partners	Procedural lack of clarity around data sharing
	Social tensions between responders
	Lack of interest in particular kinds of data and in providing documentation of the response
	Angola’s political image in the press, with its citizens, and with its medical personnel
	Lack of power to compel sharing back to local levels
	Threat of economic repercussions on oil, gas, and diamond industries due to the epidemic
	Fear/resentment over credit for data production and analysis
	Unduly rigid distinctions between “response” and “research”, and the assumption that “research” could not contribute to “response”

a) *Political and social barriers and facilitators*

“Sharing usually boils down to politics,” one of our informants observed. During the YFV epidemic, *political considerations* both impeded and facilitated data sharing with institutions, other entities, and populations.

We have observed that the Angolan state imposed significant restrictions on data sharing during and after the epidemic, and officials staunchly defended their prerogative to not share data. As one high ranking official put it,

There are various policy guidelines. If politicians decide that we cannot share data, that there is state secret information, then there is data that cannot [be] shared, information of state secrets or country policy information. If we are guided not to share data for as long as we have, we do not share. (YFV-45)

At times, these politics involved the country’s *political image* with its own people, with state employees, and also with other countries. Another MINSA official, for instance, contended that whereas information about an epidemic needed to be shared with international institutions, “politicians interpret this [declaration of an epidemic] as a sign of incompetence, of the country’s political incapacity to solve the problem.” Indeed, sharing information with media outlets (“either our great ally or our main enemy”) and a broader public posed danger. Communications with media outlets during the epidemic, according to Angolans, were largely appropriately handled, although some lay populations resorted to locally-used herbal remedies to treat jaundice, which resulted in liver damage and some mortality. These concerns about communications with media and lay publics are pertinent to data sharing, since buy-in from lay populations are essential to an effective response. For their part, medical personnel, too, also mistrusted “who is making affirmations that an epidemic is happening, that they have no competence to do so, or are questioning the competence of [Angolan] medical personnel.”

These concerns about political image may have something to do with the paltry number of publications that came directly from this epidemic, in stark contrast with Ebola or Zika epidemics. Angola remains the proprietor of all data collected during this epidemic, and whereas they were willing – or strongly encouraged, depending on who one speaks to – to share during the epidemic, there have been very few publications in its aftermath. Angola may be concerned about its global image, and thus reticent to release these data.

Another researcher suggested that Angola’s strict control over data and publication resulted from strained relations with the WHO, resentment of other researchers publishing high-impact articles without involving Angolans who had labored to collect the data in the first place.

At the time, it seems to me that the Angolan health minister had his eyes on a position in WHO-AFRO that he didn’t get, so relations were very strained. Well, I wasn’t privy to these discussions, so I don’t know if it’s the truth or not. At any rate, I know that we tried to push them, to say, “Here, let’s do an epidemiological paper.” And we were told...we had to have the official accord of Angola, we had to bring in people from there...we had dealt only with the WHO, which was kind of painful, and apparently it was a diplomatically very complicated situation. (YFV-35)

Other times, these barriers might involve political and social tensions that have roots in colonial and post-colonial relations, although it remains exceptionally difficult to parse “political” from “social” factors. One researcher, framing the dearth of sharing between researchers and institutions as “*social, historical,*” suggested

I think it's more difficult to see French-speaking groups sharing data with English or Portuguese-speaking institutes in Africa. I think there's an interesting – still -- separation between them, but that's my personal perspective on that. I feel that there is a community of researchers that communicate in the same language, but not that much with people from different languages. (YFV-06)

Linguistic barriers themselves could pose communication problems, but they also underpinned diverse experiences and a lack of familiarity that sharing a language could facilitate. A European researcher indicated, ‘*historically, it was about [people from Europe] coming and saying, “ah yeah, you are going to work for me,” and there's that feeling, a sort of a neo-colonial...’* (YFV-02). Although this perception might appear simplistic, what is important is that the researcher invoked it, either convinced that researchers from LMICs perceived him as “neo-colonial” or perhaps to score political points with the interviewer. It is clear that this point illustrates a significant overlap with social barriers to sharing.

Some social tensions, perhaps with political undercurrents, did exist between different teams. The ECDC, for instance, came under considerable fire by Angolan public health officials, for having sent young, inexperienced personnel who were simply using the epidemic as an opportunity for experience. Although such tensions may have been the consequence of youth, inexperience (and perhaps perceived arrogance), but they may also have resulted from the fact that these youthful responders were European. We learned of tensions simmering between Angolan and Senegalese teams, since our interviews hint obliquely at clashes; observers suggested that these tensions centered around resentment of Senegalese teams “rescuing” their Angolan counterparts, and perceptions of arrogance. Other interviewees observed partners who were critical of Angolan personnel for lacking rigor and motivation, and they thus attributed insufficient sharing to tensions around work practices. Just how these social tensions played out on a daily basis are difficult to detect, as are their resolution. Whereas certain responders attributed the lack of sharing to local incapacity, potential sharers of data (in MINSA, for instance) deliberately withheld, delayed, or apportioned it piecemeal. Certain external responders, frustrated their inability to obtain data, responded by limiting the time that they spent in Angola.

Political considerations and social ties between MINSA and certain core responders within the IMS were also important facilitators of data sharing. Shared experiences of prior outbreak responses and material support forged this “trust”, which was both a prerequisite for sharing, and an act that simultaneously cultivated and reinforced the trust to extract certain kinds of material support. MINSA officials clearly indicated that there were certain “privileged” partners in its data sharing: UNICEF, the US CDC, the Cuba Cooperation, and MSF. All of these partners shared recent and/or long-term experiences in tackling health problems and outbreaks in Angola.

- **The US CDC** had been working in Angola for many years. Prior to the YFV outbreak, it was already “an integral part” of the INSP, providing training, some equipment, and reagents, and receiving epidemiological data on various pathogens, including malaria. The MINSA official recalled, “*in 2005, when we had the Marburg epidemic, our great collaboration was with CDC Atlanta to diagnose cases.*” (YFV-44) For its part, the

American CDC lead insisted that anyone deployed to Angola had to speak Spanish well, and that some facility in Portuguese was a highly prized asset. This capacity reflected more than simply transcending linguistic barriers: any anthropologically-inclined field researcher will attest to the importance of language as a way of sharing a particular way of interpreting and engaging with the world.

- **The Cuba Cooperation** has had an even longer history in Angola. Angolan interactions with Cuba began in the 1960s, and during the Angolan war for independence (1975-1991), some 400 000 Cuban soldiers and 50 000 Cuban civilians contributed to Angolan struggles— what Christine Hatzky has called “a clear indication of the historic significance of this South-South relationship.”^{139,140} These contributions have continued since the war in other domains, most notably in health and teaching.¹⁴¹ The Cuba Cooperation was deeply involved in a YFV epidemic response in 1986, including epidemiological surveillance, environmental sanitation, vector control and vaccination. In the 2016 outbreak, the Cuban Cooperation focused on vector control, because it already constituted “*the main partner of the Angolan execution of the anti-vectoral fight in the country.*” Recognition of this decades-long history, as well as subsequent shared experiences of working on outbreaks and health concerns sustained trust and data sharing. One of our informants within MINSa, for instance, had first worked with the Cuban Cooperation on a small YFV outbreak in 1986.
- **Médécins sans Frontières (MSF-Spain)** received data because they were a “privileged partner”, offering crucial logistical and technical support, particularly for the response pillar of vaccination in DRC and clinical care in Angola. Interestingly, data sharing with MSF (and likely other “core partners”) occurred not just because they were core, but because the sharing of data could cultivate increased trust, potentially allowing the further flows of support. One MINSa official recalled of MSF, “We decided to share the information to give our partners more confidence. And on the other hand, [we did so] to get more logistical support...mainly in the field of vaccines – and technical support.”

Finally, political relations and proximity with other countries (DRC, Republic of Congo, Zambia, Namibia), as well as air connections to South Africa and Portugal appears to have facilitated some data sharing between Angola and these countries.” (YFV-44)

b) *Economic facilitators and barriers*

We have considerably less insight into the economic facilitators and barriers to data sharing. Fear of economic repercussions seemed to operate as either a catalyst or a brake to sharing. The economic stakes of an epidemic were clear enough: Angola remains highly dependent on foreign capital to exploit some of its valued resources, including oil, gas, and diamonds. The country also has a sizeable number of Chinese laborers. Extensive communication about an epidemic seems to have put the brakes on sharing information widely. One WHO representative speculated, “They [the Angolans] worry that the epidemic, or information about the epidemic, will have an impact on the economy, on tourism. So, we are in a position of trying to get them to give us the data,” but this factor could just as easily cut the other way, in that suppressing data about an epidemic could exacerbate more disease transmission, aggravate the severity of an epidemic, and potentially compel neighboring countries to take action, such as increased checks or even border closures. Hence, countries neighboring Angola, particularly DRC, Republic of Congo, Namibia, and

Zambia, did receive some data because, as one MINSA official observed, “not passing on this information immediately is a risk for the spread of the disease.”

c) *Administrative barriers*

Administrative factors also served as barriers. We have not been able to identify administrative factors that facilitated data sharing during this epidemic.

The lack of trained personnel translated into significant delays and non-sharing in multiple ways, particularly for response coordination, clinical, epidemiological and vaccination data. Although Angola has extensive experience with vector-borne disease and had certain teams investigating arbovirus transmission, its emergency response teams had been largely geared towards other pathogens, notably polio eradication. Reorganizing its Emergency Operations to tackle the largest outbreak for nearly 30 years took time, more labor, and training oriented to responding to a pathogen whose mode of transmission differed from that of polio, and for which response needed to occur much more rapidly to prevent further spread of the disease. High population mobility (especially among migrant worker populations) and the wide geographical distribution of YFV cases, particularly in remote areas underserved by medical structures, increased demands on existing personnel. Hence, it took time to put into place the Incident Management Team in Angola. Moreover, a profound death of trained personnel (in addition to logistical problems, see below) significantly delayed early reporting of clinical results, and may have resulted in the rapid spread of the epidemic into DRC.

Rapid staff turnover and what appears to have been a reluctance to share databases and non-aggregated information⁹² was seen to hamper timely data sharing. And some underscored the capacity problem in terms of inadequate training. As one responder from an LMIC emphasized,

Our mission should have been limited to orienting people, helping them to implement a protocol, and supporting the country with its strategies, etc. Unfortunately, because these are countries that don't have expertise, we were obliged [to do more] With the local team, we had to create a collaboration with [other] teams that were in the field, understand a bit about where the index cases were, their mobility, where they came from...and all of the other localities through which that index case had moved. (YFV-05)

These personnel challenges translated into the interventions and integration of broader networks of responders who were only able to undertake their activities piecemeal. One MINSA official alluded to these difficulties, contending that effective response required reinforcement of epidemiological and entomological surveillance, of laboratory capacity, and of care facilities. The surveillance system, for instance, did not have the capacity to detect systematically all cases or to collect necessary epidemiological data. This is certainly the case more generally in central Africa: DRC, too, faced problems with irregular and inaccurate surveillance and epidemiological data collection, contributing to significant delays in reporting to WHO.⁹² Both internal and external responders signaled surveillance problems at the DRC-Angola border, which tends to have very high cross-border mobility coupled with a dearth of surveillance and health posts. (YFV-44, YFV 37)

Procedures for data sharing posed barriers to sharing, either because they were not always clear to those involved in sharing or because the pathways were perceived as too rigid. This barrier involved not only procedural issues, but also legal restrictions. In this sense, there are genuine

disparities between the categorical claims by various officials about what is supposed to happen and what actually happens with sharing. The normative claim, repeated by multiple informants, is that “data belongs to the country producing it” and one has to ask permission in order to share. In addition, “countries have to share, in accordance with the International Health Regulations.” And yet in practice, sharing never seemed to be so straightforward. The example of the US CDC is instructive here, in which CDC representatives in Angola shared samples and some slides with data with CDC Atlanta, but without the written authorization of MINSA. “The Ministry of Health when I arrived was not very clear on the procedures for data sharing and sample sharing,” explained one CDC representative.

The difficulty was that these changes came quite suddenly. So, we were presented with new protocols from one day to the next, and we had to rearrange. So that was probably just poor communication, maybe on our part. But there was a bit of difficulty understanding exactly what the procedures were to request data sharing and sample sharing. But in the end, we had a number of conversations and we understood the reasoning behind it and the requirements and we were able to present these requests and have them satisfied. (YFV-37)

In the end, the US CDC and MINSA resolved the lack of clarity through open discussion to specify the rules more clearly, and then strict adherence to these newly articulated procedures.¹³

For others, it was less a question of clarity than the rigidity of data and sample sharing procedures. MINSA personnel in particular complained that WHO procedures for declaring an epidemic, shaped by pre-determined channels for sharing samples and data with its reference laboratories, were too rigid. The high-ranking official, for instance, justified sending samples to South Africa on the grounds that

it is not justified that I, in order to declare an epidemic, have to have the approval of WHO. And the Dakar laboratory makes a diagnosis that is not DNA identification, it is a diagnosis of immunoglobulin. But from a scientific point of view, [the diagnosis] has more credibility when I can do DNA extraction and identify it, that is to look for antibodies.... Between the time that South Africa confirmed the diagnosis with a molecular biological test until the moment the WHO confirmed that it was Yellow Fever, we had a delay of three weeks. And in an epidemic of Ebola, Marburg or Yellow Fever, if it takes 3 weeks to officially declare an epidemic, that immediately complicates the transmission of the disease.... I think WHO has to modernize and have to be less bureaucratic and more proactive in responding to these situations. (YFV-44)

In this case, MINSA characterized what it perceived as WHO rigidity through *bricolage*: the identification of what appeared to be an alternative to produce a more rapid response.

d) *Regulatory*

Both the IHR and the WHO Policy Statement on data sharing require certain kinds of data sharing in the event of a WHO declared epidemic. Differently positioned actors in the YFV response often

¹³ Although various responders, including CDC, seem to have been unaware of it, we found that Angola had on the books a law from 2011 governing data, but it may not have been applied prior to this epidemic.

invoked the IHR in underscoring their responsibility to share data and claimed that state actors in particular were morally compelled to share.

Yet how these responsibilities played out were considerably messier than this mandate to share in epidemic emergencies would suggest. MINSA officials, for instance, invoked “rights” that certain partners had to data produced, blurring distinctions between regulatory frameworks that mandated sharing and the political relations that facilitated official and more informal sharing. As one MINSA official noted,

...the situation was that everyone wanted data, but we did not give data. Apart from the ones, as I said, those who had “the right” to data because they worked with us, were the WHO and the CDC. The others might have data, but not in official form. We did not share data with everyone. But when the country made a decision that it could not share data, then we no longer shared with [them]... (YFV-45)

e) *Logistical barriers and facilitators*

Logistical arrangements were important for both impeding and facilitating data production and sharing during these epidemics.

Insufficient technical capacity and funding posed a problem for data production and sharing. This was particularly the case with laboratory capacity, and the ability to diagnose YFV. As one responder noted, “*there were delays in lab confirmation, because Angola didn’t have capacity to do the laboratory confirmation, so there was a delay in notifying the WHO properly. So, the epidemic spread, beyond to DRC.*” (YFV-41)

Technical problems here translated at times into “improper”, unstandardized, or insufficient data collection. These problems were related to the administrative problem listed above -- a dearth of personnel with insufficient training, who had to produce data under conditions where they lacked standardized data collection tools (YFV-04, YFV-05, YFV-07, YFV-28, YFV-41, YFV-44). As the WHO representative working in Angola and DRC observed, “*some data that we wanted just was not collected...So data that should have been collected wasn’t.*”(YFV-41) Others were concerned about data accuracy, perhaps due to “*faulty reporting or poor data entry protocols*” (YFV-28; YFV-37) When external agencies referred to MINSA as “overwhelmed” and not always capable of responding to requests for data in a timely fashion, it might be concluded that MINSA personnel had other priorities and tasks other than to compile and report data.

Sometimes lack of data resulted from the gaps between the needs of response and those of research and publication. The data production line and the needs of the response were not necessarily aligned with what would be needed for a scientific publication. One researcher noted that

“We deal with situations where it is about containing the outbreak tomorrow, and it’s not about someone sitting down to put a .cvs file together, to put it all in an electronic repository...for people to be able to access such information. It is a bit of disconnect in what we think is important in the moment, and what needs to be achieved on the ground.” (YFV-04)

Logistical barriers were related to a lack of funding. One researcher who had underscored the dearth of data sharing framed it as insufficient funding to support data production activities in Angola:

And so, there's so much more funding in Brazil compared to Angola for research unfortunately and I think that Angola has the capacity, it has the research, it has the groups, but it needs more funding for research. (YFV-06)

These barriers were addressed in multiple ways. Various organizations (MSF, IFRC, Cuban Cooperation) and institutions (UNICEF, WHO, CDC, ECDC) provided technical and other assistance to bolster data production and reporting. This lack of equipment was remedied by bringing in external teams to train local personnel and equipment donations, some of it after the epidemic. In other cases, demanders of data repeated their requests, approached hierarchical superiors in MINSA, waited, or did without.

A logistical facilitator came in the form of the **emergency operations center**, established within the framework of the IMS to house key actors from UNICEF, the US CDC, MSF, the Cuba Cooperation, and the WHO, permitting formal and informal exchanges of data and analyses. As one US CDC occupant of the Emergency Operations Center observed,

All of us responders at the national level were working out of the same room. And that's a standard procedure for emergency response; this was the emergency operations center. And within that context obviously information sharing was constant and encouraged; this EOC was exclusively for partners. (YFV-37)

In addition, the IMS facilitated capacity building among Angolan scientists and technicians. At the outset of the outbreak, in the INSP (Angola's national laboratory), Institut Pasteur-Dakar virologists worked alongside Angolan scientific staff to set up diagnostic capacities and had an established procedure for compiling and reporting results to key response partners. Once established, these logistical arrangements facilitated data sharing each evening, with pre-set list of recipients who would receive daily reports. Of concern is that the reports, including personal data of individual cases, were reportedly sent without encryption – posing a genuine risk to the confidentiality of cases. It is worth noting that although the spatial and digital logistics assisted with data, but it could also exclude other actors who were not part of the central response and could not gain access, or only limited access to data.

f) Publication and credit barriers

Broader commentaries and studies of data sharing have amply observed that publication and credit concerns pose a barrier to data sharing. These concerns had to do with receiving acknowledgement for having generated data, particularly for publications. The Angola-DRC-China YFV epidemic has been marked by a dearth of publications emerging from this experience, with the consequence that it remains exceptionally difficult to draw any lessons learned. Most of our informants attribute this lack of publication to the restrictions on data imposed by the Angolan state. But for their part, the Angolans interviewed were all deeply displeased at publications that had taken place without Angolan state authorization, or in which they received no credit. One informant went so far as to suggest that data were leaked for publishing purposes. A WHO official noted that one particular publication raised the hackles of Angolan officials, because “*It's a case of Northern institutions taking credit without even acknowledging the country where the data was collected. The publication didn't even acknowledge those countries*”. (YFV-41)

Several other responders and researchers recognized that the situation was unjust. One researcher acknowledged that those on the ground work hard to develop surveillance systems but are reticent to hand over data for publication without recognition.

And often it's people who spend often years in the field, like, doing very hard work to set up the surveillance system, to interact with local governments to generate this data, and so the idea that they did all this work for common good and now they're going to send it in the platform where people are going to be able to use it to sometimes to publish without their name associated, like it's simply not going to happen. (YFV-02)

This point was repeated by multiple researchers, who appeared acutely aware of these imbalances. “*This is a big, big, big problem,*” an African researcher noted. “If you’re going to publish data from a country, me, I think it is imperative to have the country involved [in the publication].” (YFV-07) Another African researcher concurred

I think we have to put everyone at ease, and in the context of epidemics, have perhaps precise ideas about data sharing but also about authorship, in a way that allows let’s say to give to members of local teams more comfortable places in publications. Even though we know that the institutions deployed...don’t participate in the writing work, or the analysis, nothing would ever come out if it weren’t for them. Sometimes we see publications in where there isn’t a single Angolan scientist...that’s concerning. (YFV-05)

One problem impeding this recognition was that the names of those people who have labored to produce data are not visible to their users. Several indicated that it was *easy to forget the people who collected that data on the ground,*” because they had no visibility on those who had actually done the work to produce it.

Finally, the publication of data seems to have been hampered because certain key people were either overwhelmed by other responsibilities (for instance, engaged in other outbreaks), incapable of bringing publications to fruition, or deeply worried about losing control of the publication outcome and particularly authorship. (YFV-01)

g) *Ethical barriers and facilitators*

Ethics, the broadest sense of the term, underlay motivations for sharing and withholding data. For external responders, a genuine sense of moral obligation facilitated data sharing. In the YFV epidemic, data sharing was perceived globally by actors as a kind of moral good: actors and institutions shared data to respond to an epidemic. But what “response” was, and how it was related to or distinguished from research, remained unresolved. For one WHO official, data sharing was only for the purposes of bringing the epidemic under control:

We share data with countries to protect them from outbreaks. This is part of the International Health Regulations. So, we share with everybody, sometimes through the passcode site. If it is a question of data specific to a country, normally we would seek permission from country. If there were boundary issues, if there is an epidemic that is threatening surrounding countries, if we know that we have data that we want to share, if there is an interest in the IHR, I would do

*so even if the country refused. If it was going to protect the world, I would share.
We are bound by that. (YFV-41)*

For various researchers involved in the epidemic, however, where this moral obligation seemed to break down was in the post-epidemic phase, when papers would have been published but were not.

But political sovereignty, is also an ethic, and it seemed to mediate against data sharing in the context of Angola. “*Everyone wanted data, but we did not give data,*” one official declared. “*When the country made a decision that it could not share data, then we no longer shared with [them].*” (YFV-45) Angolan officials seemed to perceive epidemic management – and the data produced during this epidemic – not just as a public health and political action, but as intimately linked to their moral claims of sovereign control over data and the labor of its employees.

VI. CASE STUDY: WEST AFRICA EBOLAVIRUS EPIDEMIC 2014-2016

A. Summary

The Ebola outbreak of 2014-2016 in West Africa constituted a seminal event in the history of international health responses to epidemics. A large number of international actors responded to the Ebola epidemic, bringing in medical personnel and equipment in an effort to treat the sick and slow the transmission of the virus. The logistical challenges were daunting. So were the barriers to effective data-sharing. For many reasons, the sharing of epidemiological, viral, diagnostic, clinical, genomic, and anthropological data across an array of different platforms was partial and thus sub-optimal.

This case study explores the historical context in which the Ebola epidemic in West Africa emerged and advances a narrative of how the epidemic unfolded in Liberia, Sierra Leone, and Guinea. The imperative for data-sharing during the epidemic was a function of the size of the outbreak. In the aftermath of the 2014-2016 epidemic, there was a perceived need for sharing clinical data on Ebola virus disease to help in diagnosis¹⁴² and in the epidemiological and molecular domains.¹⁴³ There has been little effort to integrate community engagement data into epidemiological modeling¹⁴⁴ although it appears that these data is important to accurate forecasting and the allocation of resources.

It is essential to recall that the West Africa Ebola epidemic was long. Officially, the first cases of an undiagnosed haemorrhagic fever were reported around December 24, 2013, and the final suspected cases were confirmed as cleared in 2016. According to an UNMEER framing, the epidemic could therefore be divided into four timeframes, which roughly align with four response phases. (See Figure 6) These phases align roughly well with changing trends in data sharing activities because data sharing was aligned with epidemic response coordination itself.

Figure 5: Data sharing during the EVD epidemic by response phase

Response phase	Epidemic trends	Data sharing
Pre-epidemic: Dec '13-Jun '14	Cases are rising, the scope of the epidemic remains undefined	There's a great deal of uncertainty about the disease and the response. Primary data is needed and difficult to access. Data sharing is unsystematic and is focused on internal core of response actors. There are early efforts to publicly share viral sequencing data, and basic data collection capabilities are being mobilized.
Phase 1 Jul '14-Dec '14	Number of cases surges. Mortality is high. The capacity of the response to manage the epidemic is recognized as failing, There is a massive mobilization of governments and international actors.	Targeted questions are emerging about how to respond to the epidemic. Funding is released, and mechanisms are established to coordinate the sharing of information. There is a surge in data collection capacities. Most data sharing emphasizes improving the response and profiling the disease and transmission. The focus is on sharing operational information, virologic and diagnostic test results, contact tracing, and epidemiological data.

Phase 2 Jan '15-Aug '15	Epidemic responders' activities are stabilizing, funding to support activities is clearly understood. Epidemic response capacities have been organized	In-depth research activities are launched. KAPs are mobilized and brought to scale. Clinical trials for therapeutics and vaccines come online.
Phase 3 Sep '15-end	All countries have surveillance capacities in place. Efforts are towards identifying and isolating last cases.	Data sharing for response activities declines. Data sharing for research activities continues, but under highly structured relationships or agreements.

It is also essential to acknowledge that, unlike the yellow fever case above, the Ebola epidemic involved a high-visibility response environment where learning was able to be prioritized. Early failures during the response outbreak meant that key actors at the most senior levels of government and the WHO were forced to acknowledge that the usual epidemic response playbook was failing, and new thinking and learning was required. This necessitated data sharing. There were so many uncertainties about Ebola virus disease, prevention, control, treatment, and basic research questions that data sharing was a necessary practice.

B. Ebolavirus disease: A Historical Overview

Ebolavirus disease is a known pathogen which had no known vaccine or therapeutic intervention prior to late 2015/early 2016.¹⁴ Ebolavirus disease, formerly known as Ebola hemorrhagic fever, causes an acute viral hemorrhagic disease of both human and non-human primate populations. Since its discovery in 1976 during two simultaneous outbreaks – in Nzara, South Sudan and in Yambuku, Democratic Republic of Congo, most outbreaks have occurred in remote villages in Central Africa, near tropical rainforests. At-risk populations for Ebola are believed to number 22 million people across Central and West Africa.¹⁴⁵

Ebolavirus takes its name from the Ebola River, near the Yambuku village in DRC. EVD was initially discovered by a team of researchers at the Institut of Tropical Medicine at Antwerp, led by Peter Piot and Guido van der Groen.¹⁴⁶ Since then, and prior to the West Africa outbreak, major outbreaks occurred in five African countries: Democratic Republic of Congo, Sudan, Gabon, Uganda, and Republic of Congo (a map of human EBV outbreaks is available in multiple publications.^{147–151} Within the genus Ebolavirus, five species have been identified: Zaire/Ebola [EBOV], Bundibugyo [BDBV], Sudan [SUDV], Reston [RESTV], and Taï Forest [TAFV].

The first recorded outbreak of the haemorrhagic fever known as Ebola virus disease (EVD) occurred in Sudan in 1976, and this was followed shortly thereafter by an outbreak in Zaire (now Democratic Republic of Congo). Over the thirty-year period 1976-2013, the CDC catalogued a total of 35 outbreaks of EVD in tropical Africa; most were short-lived.¹⁵ This thirty-year period includes a fourteen-year period (1980-1993) with no recorded outbreaks. However, the list of outbreaks may be incomplete. Isolated cases may have occurred without being reported, and several epidemiological sero-surveys reported high prevalence of Ebola antibodies in communities

¹⁴ Vaccines and therapeutics have both been identified and are being deployed and studied in clinical trials in the 2018 EVD outbreaks in Democratic Republic of the Congo.

¹⁵ Epidemiologists searched for the index cases, but in many outbreaks the human index case could not be identified. This was true of all the outbreaks occurring from 1976 to 1979, the outbreaks of Mekouka (Gabon) in 1995, Booué (Gabon) in 1996, Kikwit (Democratic Republic of Congo) in 1995, and all the outbreaks of E. Sudan in Sudan (1976, 1979, and 2004) and Uganda (2000).

in the absence of reports of Ebola outbreaks,^{152–156} but these findings may also be indicative of immunosuppression.

Three viral types – Zaire, Bundibugyo, and Sudan – account for most of Africa’s large outbreaks. Meta-analyses indicate that Ebola Zaire virus has a CFR (case fatality rate) ranging from 69-88% and a mean incubation rate of 1-21 days; Ebola Sudan virus has a CFR of 53-69%, a mean incubation rate of 1-16 days, and Ebola Bundibugyo has a CFR of 34-42% and a mean incubation rate of 2-20 days.¹⁵⁷ ¹⁶ To date, there is little evidence of substantial genetic mutation within epidemics.¹⁵⁸

EVD is a zoonotic disease; the disease is transmitted from infected animals to human beings through physical contact with blood or other bodily fluids or organs. This zoonotic infection can take place through hunting, scavenging, and butchering practices, but other modes of transmission are possible: attacks by infected animals, consumption of fruits or other foods partially consumed by infected animals, and aerosolized transmission in laboratory settings.^{159,160} The EVD reservoir remains “a mystery”, although bats are suspected.^{161,162} Multiple mammals, including nonhuman primates, have served as amplifiers of the pathogen.^{151,162–167}

Following zoonotic transmission to a human being, human-to-human transmission occurs through direct contact (via mucous membranes or skin breaks) with blood or other bodily fluids or organs of infected people. The virus persists in the placenta, amniotic fluid, in fetuses of women infected during pregnancy, and in breastmilk, posing considerable challenges in providing supportive care to pregnant, laboring, and post-partum women.¹⁶⁸ EVD can be sexually transmitted; the virus can remain in human semen for three months to a year, although long-term survivor studies are currently under way to improve these estimates.^{169–172} It may also persist in bodily fluids during convalescence¹⁷³ and in immune-privileged sites, including the inside of the eye and the central nervous system.¹⁷⁴ Patients are believed to be non-infectious while they are asymptomatic. Contact with fomites (notably materials contaminated with infected bodily fluids) can also transmit the virus.¹⁶⁴ Healthcare workers, non-healthcare workers in healthcare settings, and home-based caregivers are thus at particular risk for transmission.^{175–177}

Clinical diagnosis of EVD has proved difficult. EVD symptoms are highly non-specific and may be confused with other pathologies, although the case definition emphasizes hemorrhagic symptoms.¹⁶⁴ The symptoms of EVD are similar to those of some other diseases. There is also the problem of co-infection with partial diagnosis.¹⁴⁸

Most diagnostics used RT-PCR assays that detected the virus in plasma or serum.¹⁷⁸ T-PCR, however, was slow, requiring continuous cold-chains, long processing times, high-risk sample collection. Additionally, it was expensive, which made it ill-suited for a pandemic response. Throughout the epidemic, multi-day delays in sample transportation and processing contributed to difficulties with case identification and contact tracing, and often left suspected cases in the same physical units as confirmed cases, leading to a risk of iatrogenic infection as people waited for their results. The international community deployed approximately 40 mobile field laboratories,

¹⁶ Further details regarding mean reproduction numbers, serial interval distribution (time intervals between symptom onset in a secondary case infected by an index case), generation time distribution (time intervals between infection of an index case and infection of a secondary case infected by an index case), and relative risk for contracting EVD.

eventually decreasing response time in communicating with healthcare facilities and individuals about test results.^{179–182}

There is no known clinical treatment for EVD. Clinical teams rely on multiple supportive care interventions. In low-resource settings, clinical support has included the aggressive provision of fluids by volume, electrolyte management, oral and intravenous nutrition, and medications to address co-infections like malaria and typhoid, and medications to control fever, gastrointestinal distress, pain, anxiety, and psychological responses.^{183,184} This contrasts with high-resource settings in the United States and Europe, where which aggressive treatment, intensive surveillance, experimental protocols and medications, and intravenous fluid replacement is the norm.¹⁸⁵ Multiple therapeutic measures were evaluated during clinical trials, but most were limited by severe context limitations and restrictions on interventions.¹⁸⁶ As a result, mortality outcomes in developed countries are significantly better than those in African countries. Almost 100% mortality is reported among pregnant and laboring women, fetuses, and newborns.^{187,188}

In the four decades since EVD's discovery, MSF has established itself as a leading NGO with the clinical response capability to manage EVD outbreaks. Their response centered on the construction of Ebola Treatment Units (ETUs), or the adaptation of existing facilities into ETUs; providing supportive care, contact tracing, enhanced infection prevention and control methods, and quarantine. Public health responses have historically emphasized the distribution of protective equipment to health care workers and family members caring for Ebola sufferers, the use of barrier nursing techniques, the distribution of health education material, active and passive case finding, and the burying of the dead in plastic bags by a trained team teams of volunteers who wore gloves and protective clothing.

From the discovery of Ebolavirus disease in 1976 through every EVD outbreak preceding the West Africa Ebola outbreak, data sharing was characterized by a “business as usual model” that allowed external actors to manage data collection, data extraction, and the collection and export of biological samples from outbreak sites. Given that previous outbreaks tended to be small and were rapidly contained, there was little demand for epidemiological and clinical data; in fact, much of the filovirus research community was directly involved in previous EVD response efforts. The U.S. Centers for Disease Control, Gabon's Centre International de la Recherche Médicale de Franceville (CIRMF), Institut Pasteur, and Democratic Republic of the Congo's Institut National de Recherche Biomédicale (INRB) led field and laboratory diagnostics; national clinics and hospital and NGOs like Médecins Sans Frontiers drew blood during clinical work; and excess biological material was sent to Paris or Atlanta for further research. As one respondent remarked, “They did research on it, and then other researchers would say, “hey, Atlanta, could you spare some specimen?” and they would say yes or no, according to their own algorithm. As time went by, the folks in Winnipeg joined in, and then basically in 2007, because all the European labs got excluded, they said, “well, if that's how the game's played, we're going to create our own mobile lab and send that to the field”, and so EMLAB showed up for the first time during the West African outbreak, because nobody was good about sharing specimens.”

As recently as 2012, scientists at U.S. Army Medical Research Institute of Infectious Diseases (USAMRIID) working on filoviruses were able to informally submit requests to epidemic responders to procure and ship biological samples from the sites of outbreaks. This prompted medical NGOs to begin to consider the need for a physical biobank for EVD specimens based at a biosafety level 4 (BSL-4) laboratory, or an alternative biobanking mechanism that would evaluate the merits of requests for biological samples and put into place a fair distribution mechanism. Pre-

2014 discussions about a biobank became mired down by a lack of consensus about governance mechanisms. Some remarked that key stakeholders were “happy with the status quo.”

C. West Africa Ebola epidemic (2014-2016)

The 2014-2016 EVD epidemic in West Africa was remarkably different from earlier outbreaks in its duration, spatial extent, number of cases, number of deaths, and the nature of the international response. It appeared to be the first EVD outbreak that affected human populations in West Africa. (This may be in question: One retrospective analysis determined that 8.6% of blood samples taken in 2006-2008 from suspected Lassa fever cases in Sierra Leone that tested positive for antibodies for Ebola antigens.¹⁸⁹) The outbreak infected 28,616 cases, and caused 11,310 deaths, with estimated case fatality ratios of 48-90% and an estimated R_0 was 1.3-2.7.^{190,191} The epicenter of the outbreak was the countries of Liberia, Guinea, and Sierra Leone.^{192,193}

The West African EVD outbreak was caused by the Zaire type of Ebolavirus. Initial reports of a hemorrhagic fever outbreak occurred on December 24, 2013; official laboratory confirmations of EVD were provided by Institut Pasteur-Dakar and the Lyon-based laboratory of INSERM and Institut Pasteur in March 2014. The West African outbreak index case occurred in Meliandou, Guinea, reportedly when a child came into contact with excreta or other bodily fluids of fruit bats, a suspected reservoir of EVD.¹⁶⁶ The index case spread the virus to a family member, who later infected a traditional healer, eventually leading to more widespread transmission in southern Guinea and the capital Conakry.

Within two months, the epidemic crossed land borders to Sierra Leone and Liberia. Scattered cases occurred elsewhere in West Africa—in Senegal (1 case), Mali (8 cases). An outbreak in Nigeria led to concerns of global transmission. The epidemic spread into highly populated urban settings and across national borders, and infected individuals in the United States, Spain, and the United Kingdom.

Although previous Ebola outbreaks in other parts of sub-Saharan Africa were rapidly contained, early efforts to stop the virus were unsuccessful. MSF mobilized early in the Guinea outbreak to lead a response; and the outbreak appeared to be declining in April-May 2014. Soon, however, the outbreak had spilled over Guinea’s southern borders into Sierra Leone and Liberia. With unanticipated population density, cross-border interchange, and human mobility between these three countries, the outbreak rapidly spread to major population centers in Liberia and Sierra Leone. NGOs active in the region sought to mount a response to EVD but were unprepared to do so. Early efforts by NGOs and public health care facilities resulted in widespread mortality among healthcare workers, including some of the leading filovirus doctors and researchers in the region in a matter of months. NGOs scaled back activities in order to recalibrate, re-assess the situation, and provide additional training, resources, and staff; while healthcare workers based in government hospitals and clinics walked out of facilities that lacked basic infection prevention and control capabilities EVD testing capacities, and adequate systems for triage and patient care.

The declaration of a Public Health Emergency of International Concern (PHEIC) under the International Health Regulations was made on August 8, 2014 amidst escalating crises in Sierra Leone, Guinea, and Liberia. Shortly thereafter, the United Nations Security Council announced the establishment of a U.N. Mission for Emergency Ebola Response (UNMEER) to coordinate efforts to contain the epidemic. Leading political figures in every major country in the world committed funding, resources, and political support to the Ebola response. Awkward efforts were made to marry the functions of functioning national government’s directions of the epidemic

response with a WHO-lead technical response with a quasi-humanitarian cluster system mobilization of hundreds of local and international NGOs.

Most observers agree that the WHO failed to respond adequately, early, and was overly sensitive to political considerations. Early and effective decision-making among all response partners seemed to function poorly at all levels.¹⁹⁴ At the forefront of international response was the WHO and MSF, who provided technical information and guidance to other response actors, but were incapable of mobilizing needed coordination and resources to stem the epidemic. Once a massive international response was mobilized, responders struggled to negotiate between national health systems, global health response systems, and humanitarian response systems in the context of Liberia, Guinea, and Sierra Leone, countries ranking near the bottom of the Human Development Index. Public health intervention models focused on increased contact tracing, improved access to PPE for healthcare personnel, and planning for the use of pharmaceutical interventions in hospitalized patients.^{195–198} Innumerable individuals characterized the West Africa environment as “chaos.”

Complicating matters was the fact that initially, few efforts to address or model the impact of behavioral, community-based, or psychosocial interventions occurred. While governments and international responders dealt with confusion, delay, a lack of local capacity to produce data and find cases, and limited epidemic response infrastructure, local populations were dealing with escalating mortality, a lack of information, failing reporting systems, and dehumanizing encounters around EVD ranging from failing to provide information about deceased family members to indecent management of human remains. Local populations experienced widespread panic, fear, and aversion to government and international intervention slowed response activities. They feared that international teams were introducing, not preventing Ebola and thus resisted international actors. Community engagement strategies lacked coordination in all three countries; and frequently prioritized risk communication and behavior change messaging programs over more labor-intensive community engagement approaches.^{199–202} Social scientists mounted an aggressive international engagement strategy to encourage epidemic response actors to seriously consider the sociocultural, customary, economic, and political factors impacting local populations’ interactions with the Ebola response campaign.²⁰³

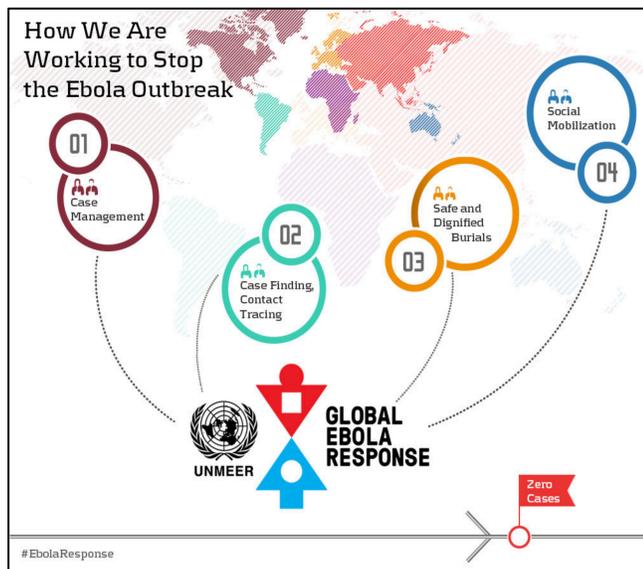
Clinical identification of Ebola cases was complicated by a range of factors. These included a low level of skilled healthcare workers with prior experience identifying Ebola in clinical contexts, EVD’s similar case presentation to other diseases (e.g. malaria, pneumonia, yellow fever), and a clinical case definition that healthcare workers did not fully trust.²⁰⁴ At the onset of the West Africa Ebola outbreak, there was limited laboratory capacity for the diagnosis of Ebola in the most-affected countries. The Institut Pasteur-Dakar and a Lyon-based laboratory linking IP-Paris and the European Mobile Laboratory, and CDC ran labs in Guinea; the Kenema Government Hospital Viral Hemorrhagic Fever Laboratory operated in Sierra Leone; and the Liberia Institute of Biomedical Research provided research capacity in Liberia. Eventually a 40-country consortium fielded emergency mobile and fixed laboratory capabilities.

Eventually, across the entirety of the response, an administrative architecture was established for each of the three countries for overseeing key response functions. The vertical administrative structure of the Incident Management Systems involved six technical working groups/pillars—case management, contact tracing, safe burials, surveillance, laboratory, and social mobilization—and clearly defined the lines of authority and accountability within the system.¹ While facilitating

intra-pillar coordination, this response architecture would become a barrier to data sharing between working group/pillars (see Figure 7):

- **In Guinea**, where the first outbreak occurred, MSF partnered with local and international research institutions to identify the virus and mobilize a strategy to isolate suspected cases in Ebola treatment centers and to implement safe burials. The Guinea government’s reluctance to acknowledge the outbreak delayed the WHO’s ability to appeal for international support to combat the epidemic. For its part, the WHO was slow to articulate an international appeal because of widespread perceptions that the outbreak would be rapidly contained, and reluctance to contradict the Guinea government. Experts did not anticipate that the Ebola response would encounter widespread popular resistance and opposition, nor did they anticipate the hypermobility of local populations moving across West Africa’s borders. As a result, prior to March-May 2015, there was inadequate surveillance and data collection; a lack of investment in shoring up IPC capacities in healthcare systems, and a lack of community engagement efforts to induce the support and buy-in of local populations.
- **In Liberia**, an insufficiently funded response, an undue focus on zoonotic transmission rather than human-to-human transmission, and a lack of health systems capacity resulted in the rapid escalation of the epidemic as it moved aggressively from Liberia’s northern border to its capital, Monrovia, where over 50% of the population resided. The spread of Ebola to major population centers in Nigeria and to Texas (USA) via air travel mobilized international attention to the growing crisis in West Africa,¹⁷ and by September 2014 the Liberian government was leading a robust response to the outbreak. From then on, the Ebola response focused on prevention and community engagement (led by a tightly coordinated consortium of international and local NGOs) and on targeting a RITE (Rapid Isolation and Treatment of Ebola) strategy for remote populations to prevent further spread to major population centers.²⁰⁵

Figure 6: UNMEER EVD Response Pillars



- **In Sierra Leone**, the government-led Ebola response could not coordinate appropriate actions to end the epidemic, disburse funds appropriately, or shore up healthcare worker capacity in highly affected areas, including Kenema. By September 2014, the National and District Ebola Response Coordination (NERC, DERC) system was established to lead the

¹⁷ Models mapping the potential spread of Ebola to international population centers stirred international mobilization.²⁵⁴

epidemic response under the intensive direction of the U.K. government and foreign actors. The response worked on a district-by-district basis to respond to EVD outbreaks as they occurred.

Across the three most-affected countries, the effects of the EVD epidemic were similar. Cross-border transmission associated with local population movement sustained continued reinfection of local populations, drawing out the epidemic. Widespread transmission among healthcare workers, in healthcare facilities, through super-spreader events associated with traditional healers and funerary practices resulted in widespread mortality across Liberian, Sierra Leonean, and Guinean populations. The rapid escalation of the epidemic and high mortality among healthcare workers resulted in the partial collapse of local health systems by June 2014, leading to increased overall morbidity and mortality in all three countries.^{206,207} In all three countries, one major response priority was to introduce and to train health workers at all levels in infection prevention and control (IPC) procedures.²⁰⁸

Today, the cause of the original EVD cases in West Africa remains unknown, although an index case has been identified. However, the scale of the West African outbreak was caused by systemic factors: a lack of familiarity with EVD in the region; weak and post-conflict health systems a lack of disease surveillance capacities; intensive population mobility; persistent, widespread transmission in urban areas; unclear organization of epidemic response.²⁰⁹⁻²¹¹ Geospatial analyses also suggest that the spatial distribution of rural populations may have contributed to multiple factors that increased vulnerability, including weak health systems, food insecurity, and sensitivity to the impacts of ecological shifts.^{212,213}

D. China's Response to Ebola in West Africa

In contrast to the 2016 YFV outbreak, The People's Republic of China (PRC)'s engagement with the EVD outbreak was a first effort to engage in global health diplomacy as part of its One Belt, One Road Initiative.¹⁸ Beyond taking domestic precautions to protect its national population (enhanced screening capacity at points of entry, designated hospitals for EVD cases, IPC training for hospital personnel), China provided instrumental support in West Africa for the EVD response after the declaration of the PHEIC totaling a commitment of USD \$125 million.

China is not a stranger to the field of African foreign assistance. Since 1963, the Government of China deployed medical missions to Africa, beginning with a mission to Angola. During this epidemic, the effort was coordinated through the relatively new Chinese CDC, which first deployed a public health team of nine prominent Chinese epidemiologists, virologists, and lab scientists (three to each most-affected country), followed by 850 medical personnel. By 2016, China had sent 1,200 laboratory scientists, epidemiologists, and public health peer educators, and had built ETUs in Sierra Leone and Liberia.

By all accounts, Chinese field teams operated independently, but integrated effectively with local data sharing and coordination capabilities. After initial consultations with MSF and WHO, they

¹⁸ With this initiative, China is working on a scale that rivals the Marshall Plan to expand its soft power and to create economic ties with countries in Southeast, Central, and South Asia, Europe, and Africa. Between 2000 and 2012, China committed a total of USD 3 billion to 255 projects on health, population, and water sanitation in Africa. The country constructed hospitals and malaria control centers in Africa, invested in medical equipment, provided anti-malarial treatment, and trained health care workers.

distributed PPE to local health workers, and set up a laboratory, a medical facility, and a peer education infrastructure. Lacking knowledge of Ebola, they educated themselves from local American CDC teams, and rapidly built an ad hoc surveillance system, just as WHO and CDC field epidemiologists were doing. Senior officials remarked on the reluctance of West African governments to release data due to fears about the economic impacts of a public declaration of an Ebola outbreak.

After first setting up mobile laboratories, China built a state-of-the-art BSL3 laboratory in Freetown, Sierra Leone, called the Sierra Leone-China Friendship Biological Safety Laboratory.²¹⁴ It operated from November 2014-February 2015, and tested 7,000 samples. Today, the lab has been designated as a National Lab for Hemorrhagic Fever, and a National Training Center for Biosafety. Chinese scientists also carried out one of the first clinical trials for an adenovirus-vectored Ebola vaccine in cooperation with partners from Sierra Leone and isolated three monoclonal antibodies against the Ebola virus identified in West Africa in 2014.²¹⁵⁻²¹⁷

Chinese responders were regular participants in DERC coordination meetings. From the Chinese respondents' perspectives, stakeholders came to the meetings with Excel spreadsheets that were provided by the Sierra Leonean MOHS. Chinese teams shared laboratory results. Several Chinese informants, however, had the impression that there was little true coordination or collaboration.

There was a sense among some non-Chinese interviewees that Chinese laboratories bypassed some of the regulatory and administrative hurdles to removing samples and data from Sierra Leone, but one American commented, "I'm thinking of their behavior during the West African outbreak and it doesn't seem that much different than behavior from Europeans." (EVD-18)

E. Data Sharing during the West Africa Ebola Epidemic

Response Coordination

A crucial aspect of information sharing – which bordered on data sharing – was the exchange of information that occurred within the context of epidemic coordination. EOCs, each with a different name, were established in each country to facilitate the Incident Management System, which lead coordination between the government, NGOs, WHO, and other response actors. Meetings were held nearly daily to facilitate information sharing about all aspects of the outbreak, from clinic overcrowding to contact tracing to laboratory capacity or community engagement. The information shared through response coordination was often seen as purely operational; but the information exchanged was based on a complex calculation of response needs, individual interest, NGO mandates, and national government demands.

Ebola was known to the international community and had a four-decade history of research, scientific investigation, and response. As the epidemic escalated, pre-existing relationships that were regularly mobilized during prior epidemic responses brought together “the usual suspects” in filovirus research and Ebola response in the World Health Organization, academic research institutions, medical NGOs, and governments. The international leadership of the Ebola response involved people who were known to each other, who had worked together before, and were able to presume a certain set of common understandings about epidemic response priorities. Within these semi-formal networks based on recognition of participants' relevance and credibility, information, communications, and data were shared widely and constantly through in-person meetings, phone calls, and email communications.

At the national level, however, data sharing was cast in a very different light. In principle, each government affected by EVD was responsible for its own response; the WHO, NGOs, international donors, and bilateral arrangements were focused on supporting each country's official response plan. In practice, however, the first 6-9 months of the epidemic was impractically led by under-resourced government offices with close to zero epidemiological surveillance capacities in all three of the most affected countries. They were supported by insufficiently empowered WHO personnel who could do little more than provide technical guidance and aggregate data for international publication in WHO SitReps. As the epidemic worsened, our respondents described a daily press scrum in which Ministers of Health were mobbed by an international press that demanded information about epidemic hot spots, case counts, and news of international aid waste, fraud, and abuse. International scientists besieged Ministries of Health demanding the original epidemiological data; accusing governments of poor analysis, miscalculating data, or misrepresenting the scale of the epidemic. In Ebola, the epidemic occurred before the crisis, and the crisis co-emerged with a public demand for data and transparency in all aspects of Ebola response. This is evident in the next two examples, which details response coordination and data control in two of the three most-affected countries, Sierra Leone and Liberia.¹⁹

By October 2014, mechanisms for coordination had been established in Sierra Leone and Liberia, each adhering to different sets of tacit or explicit agreements around the sharing of data. In Liberia, the Ministry of Health was both the affirmed and the actual authority behind the Incident Management System (the IMS). As the lead convener of IMS meetings in a capital that had rapidly slowed a surging crisis, the Ministry of Health was able to ensure an inclusive coordination body of NGOs that disseminated information widely to its partners—but largely excluded the leaders of local Liberian communities. Over the next 18 months, those partners worked to install a national system of disease surveillance and response in each of Liberia's 15 counties.

In Sierra Leone, the United Kingdom had assumed effective leadership of the National Ebola Response Centre (NERC), the national-level entity representing the actions of District Ebola Response Centres (DERC). Each DERC was comprised of Sierra Leonean district medical officers, district health technicians, and representatives of numerous international and local NGOs. Each DERC individually developed systems for data collection, data sharing, data reporting, and data analysis; they were responsible for sharing a limited number of reports to their superiors at the national level but were otherwise left to their own devices to manage the flow of data and information as they saw fit for the custom-built purposes of the response. This could amount to intricate district-specific SitReps circulated daily, or it could amount to the widespread circulation of a single Microsoft Excel spreadsheet for the aggregation of all EVD epidemiological [line] data. As time passed, the Sierra Leone government appeared to some to be a titular figurehead in the EVD response (others – especially laboratory workers, described the Ministry as the owner of the data and the first recipient throughout the response), but rumors and evidence of unauthorized removal of EVD biological samples from Sierra Leone prompted the government to shut down all exports of biological specimens for several months, and to severely curtail international export thereafter.

A crucial gap in governmental coordination was inter-governmental coordination around border areas. When confronted with the lack of data sharing and cooperating between governments, local

¹⁹ We have insufficient data on data sharing and coordination in Guinea to draw conclusions.

and international actors took it upon themselves to liaise directly through informal mechanisms (cell phones, email) with actors in neighboring districts or across nearby bordered to share information about case counts, suspected movements of potentially infected individuals, or other public health activities (community outreach, IPC trainings, etc.) This often involved bypassing formal structures that required the solicitation of permission to share data outside of one's institution; but at the same time, we heard no reports that anyone was penalized for engaging in this kind of informal data sharing. It appeared to be a routine practice justified by the exigencies of the emergency.

For individuals working in this context, data sharing depended on one's positionality. Being an acknowledged expert in this environment could be a heady experience, placing one at the center of multiple flows of data and information. The informal networks and relationships that emerged from previous epidemic response activities did help manage the sheer chaos of the epidemic and supported the decision-making activities of multilateral institutions. A senior medical NGO worker commented on his own role²⁰:

I'm one of a handful of people that have been around long enough that much of the institutional knowledge is locked up in our heads. Our time is often best used supporting other people rather than doing things directly, because that takes us out of service as a resource to other people. When people say, "What were you doing during the Ebola outbreak?", I'll say, 'Going to meetings and answering email... I spent a lot of time in Geneva at various WHO meetings, 'How should we be providing care?' 'What kind of PPE should we be wearing?' 'How are we going to make use of experimental therapies?' 'How should we be setting up clinical research?' All of these multilateral, decisional bodies, providing the [NGO] input into those things. (EVD-34)

In contrast, for those closer to the periphery of the response, like a director for a small NGO working in Liberia, the response environment made it difficult to obtain even the most basic information or share vitally needed contextual details. Crucially, this NGO was seeking to share information about local health-seeking behaviors that were driving suspected cases to pharmacists and to "black baggers," rather than clinics and ETUs. The director had hoped that they could inform response activities, but she was unable to penetrate the inner circle of policy and decision-making.

For MSF it's very easy – they go to top level ministry officials... but for smaller NGOs, we spent a lot of time trying to coordinate with the government making sure that we were trying to do what the ministry decides. We had to just accept whatever MSF wanted to do because it was coming from the central level, we were working with lower levels of the ministry, and it made it very hard. (E100-83)

²⁰ For elites involved with coordination, there is a taken-for-granted quality to their narratives that suggest a comfort with the privilege of being at the center of information creation, sharing, and decision making. They were used to having access to all the information they needed that was then available. They were often unaware of how little information was available to people outside of the inner circles. They were also often unaware of what kinds of information external actors felt like the inner circles needed to have access to, but remained unaware of, like community engagement and social mobilization data.

For people trying to collect, analyze, and disseminate novel types of data, like anthropological data, it could be difficult to find an opening at all. One anthropologist described an ambiguous and disorganized attitude towards anthropological research, which largely involved talking to people at risk of EVD infection, rather than mapping those already infected. Importantly, this researcher noted that no time, funding, few human resources, and no attention was accorded to the analysis of over 800 household surveys and 50 focus groups. She was simply expected to share “intelligence.”

Clinical Trials Data

When the Ebola epidemic began to escalate, there was an expectation that biomedical research would rapidly end the epidemic by finding a therapeutic or a vaccine. The reality ended up being substantially more complex, and WHO, the research community, and the medical humanitarian response community collaborated to develop clinical profiles of EVD, test therapeutic interventions like ZMAPP, and study the most likely vaccine candidates in clinical trials.

During the Ebola outbreak, a massive global investment in bringing an Ebola vaccine to fruition resulted in intensive deliberations. The WHO led a series of international meetings that included stakeholders like private-sector (pharmaceuticals, bilateral donors and regulators (CIHR, U.S. FDA, NIH), private philanthropies, research institutions (IP), MSF (involved in research implementation). There was a lack of public transparency around these meetings, leading observers worldwide and local populations in West Africa to worry about the deals being struck behind closed doors. Data sharing during clinical trials was addressed during these deliberations, and a tense balance was struck between withholding proprietary data and releasing the effective results of clinical trials as soon as possible to inform the response.

Three concurrent trials to test possible vaccine candidates were administered during the EVD outbreak. Results from the rVSV-ZEBOV trial conducted in Guinea proved effective at preventing the spread of EVD.²¹⁹ Clinical trials for ZMAPP and the EVD vaccines were implemented through what some called “an unholy partnership” between research institutions, pharmaceutical companies, and frontline healthcare NGOs. Clinical trials data were therefore technically proprietary data, and individuals who worked on the clinical trials were bound by non-disclosure agreements that prohibited data sharing. At the same time, there was an expectation that the pharmaceutical companies and researchers would expedite the release of top-line findings to the WHO and national governments. These non-disclosure agreements were reputed to have a chilling effect on the sharing of information about clinical trials.

A WHO consultation on Data and Results Sharing During Public Health Emergencies was held in 2015²²⁰, but the issues surrounding data sharing were raised repeatedly over the preceding year. Published pronouncements called for the widespread sharing of clinical trials data as soon as it was available, in accordance with the terms of the study research protocols. There was no ambiguity about the fact that completed clinical trials would share their data with the international scientific community. The race to publication, and secrecy and concealment of data beforehand is well-documented, but exhibited in this account:

In clinical trials and in research in general, people were going to share the results of their research through publication in a journal. Well, you can imagine all the problems there, that people don't share their data... The time to publication is what it is even in an outbreak, and people don't want to screw up

their chances of getting something published, and so they keep their cards close to their chest. That causes problems. (EVD-34)

In one incident, a foreign research entity partnered with an international medical NGO to submit a research protocol to the Guinea ethical review board but attempted to claim all ownership of the research data for their institution (without the partner or the Guinea government). In Guinea, this was taken as a kind of disrespect for the function of the national ethics review board, and a disregard for their right to ensure the ethical conduct of outbreak-related research. He went on to say that such behavior indicated that the actors in question were solely focused on protecting themselves and their institutions and were less concerned with “thinking about the sick, protecting them, to do research that is worthy and acceptable.” (E100-148IP)

Secrecy about clinical trials research findings raised alarm and frustration among local populations, and among the healthcare workers involved in trying to deal directly with the disease. One healthcare worker described her frustration with the secrecy of a clinical trial in an epidemic hotspot:

“If a clinical trial shows that something doesn't work, the problem is, people are like, ‘Should we keep giving it? What do we do with this stuff? Does it work or not?’ ‘I can't tell you.’ ‘Does that mean we give it, or does it mean we don't give it?’ ‘I can't tell you.’ ‘You're not stupid, right?’” (EVD-34)

However, respondents involved in research in West Africa raised concerns about the lack of data sharing with local communities during the rVSV-ZEBOV trial in Guinea. Participants were directly implicated in the trials and were also at most risk of infection due to the proximity of the EVD epidemic. In interviews dating back to 2015, one scientist acknowledged the methodological concerns that justified prohibiting information sharing with local populations, especially biasing results through the too-early release of data from clinical trials.

If we keep the results until the end of the study... it posed a problem for the ethical committees which did not understand that the vaccine's results are not [known]. To avoid biasing the protocol, they had to wait almost until the end of the study to [debrief]. This created suspicion because we know that people are vaccinated according to the Ring vaccination strategy, but we do not know the results in terms of the immunology, or in terms of patient follow-up etc. ... (E100-153IP)

However, the same scientist raised fundamental concerns about the ethics of denying data to local populations on the basis of technically-informed decisions. He contended that the protocol was drafted in such a way that that basic human demands for information were not considered or acknowledged.

For some Guineans, it posed a number of problems. They said “tell us at least if it works a little. What is the situation?” But the protocol did not allow that... Our research is a little too focused on the technical side of the solution; it should be organized to take into account ...the social aspect implied by medical countermeasures. (E100-153IP)

To redress this issue, the researcher proposed that consideration of local populations' information demands needed to be taken into account long before the clinical trial. He suggested, in fact, that

data sharing with local populations needed to be integrated into the development of the target product profile, a common framework for detailing the parameters for a proposed therapeutic, vaccine, or diagnostic test developed in close collaboration with regulators (usually in foreign countries). Due to the technical sequence for developing a clinical trial protocol, population-based needs for data sharing and information need to be integrated into the target product profile or by legislated into law in order to ensure that it is taken into consideration. Once a clinical trials protocol is approved, there is almost no flexibility for deviation.

[However powerful a vaccine may be] if the population rejects it, it is useless. The reasons they will accept it or not should be reflected and should be taken into account in the target product profile. This product must be given according to such law this is what that means. Same thing for the diagnosis, same thing for the therapies. A number of therapies in a number of populations may have a consonance that does not fit with reality. (E100-153IP)

Epidemiological Data

WHO and US CDC field epidemiologists, as well as international epidemiologists deployed from the Chinese CDC, Cuban Cooperation, Public Health England, ECDC built data collection systems from the ground up in all three most-affected countries. They did so by combining data from Ebola call-in numbers, community-based investigations, clinic and hospital reports, and contact-tracing lists. Data was aggregated into Excel spreadsheets updated daily and shared via email. Through November 2014, the sensitivity of epidemiological investigation was known widely to be missing the mark in terms of capturing the true number of cases in all three countries (according to CDC estimates, close to a 30% underestimate). However, by the end of the epidemic in 2016, the spreadsheet included more than 100 column variables, and cases were identified and captured within a matter of hours.

In interviews with WHO's district-level coordinators in Liberia, Guinea, and Sierra Leone, respondents described similar experiences of being sent to rural districts with no support, staff, or sufficient transportation and resources, and working almost entirely with district, county, or prefecture-level officials to coordinate Ebola response and share information. On a daily basis, they were expected to submit daily reports with requested epidemiological data. Local WHO and sub-national response actors were often developing data management strategies – including basic design, distribution, and use of Microsoft Excel spreadsheets- while the epidemic was surging. (EVD-2, EVD-11)

SitReps, or situation reports, were the dominant ‘technology’ used to share public-facing epidemiological data with the public. One WHO field officer described the district-specific SitReps that she developed with the District Emergency Response Center (DERC-comprised of Sierra Leone district health workers and the district medical officer) to help lead district-level coordination. This helped set up a strong cross-border surveillance system between Sierra Leone and Guinea, including 50 unofficial entry points.

When I arrived, there was no SitRep. [All the other organizations contributed to it]. There was no way of reporting information. The only thing that people could do was transmit the line list to the national level. But by the time I left we had a weekly SitRep, quite complete. We were able to look at past trends. We were able to predict future trends, predict which areas we wanted to visit and

prioritize, and we were able to send a team, even before there were any cases, confirmed cases.... (EVD-11)

...We were able to identify which areas were reporting too few deaths, just on a regular basis, which was an indicator for secret burials. And we were able to forward teams to those places as well, and this was all information that we captured, and we were able to report in our SitReps. (EVD-11)

Of all the data in the district-level data that was collected in district, county, and prefecture-level SitReps, just a fraction was reported out in the WHO SitReps circulated to the international community. These internationally distributed WHO SitReps, however, took on a life of their own. From their debut during the epidemic, WHO SitReps reported suspected cases, confirmed cases, case fatalities, and contextual information about the status of the WHO Ebola response. A WHO official based in Liberia circulated these documents as portable document files (PDFs) to the international community, in order to ensure that data was not accidentally altered or edited in anyway. This kind of formatting, however, prevented international researchers, policy makers, government actors, or NGO workers from using the data in an analytical capacity. A leading open source advocate who established a GitHub to circulate WHO data into machine-readable formats that could be analyzed. She described how those data were made accessible to the international community:

When Ebola first started to be recognized as a serious crisis—probably in June—we decided to pivot our attention, and as part of our activities we had planned to produce recurring models for the Department of Defense. In order to construct those models, I started looking for data. At the time the situation reports from Liberia and Sierra Leone were the best available data, but they were all only available in PDF form. I spent many, many hours—transferring that data into spreadsheets [CSV files]. As I was doing so, I realized that if I needed [machine-readable] data probably a lot of other people would too.

So, I began posting the digitized situation reports on GitHub and I continued doing that through December. The situation reports were daily and sometimes I would only update them every other day or so, but they were quite timely. And in addition to digitizing them, I standardized them a little bit. At the height of the outbreak the repository was receiving about 2000 views a day. I heard from every major NGO and the White House that they used my data. In November—if memory serves—the WHO started doing something similar by releasing machine-readable updates on their website. (EVD-13)

Key lessons emerge from this GitHub narrative. First, basic machine-formatted data can make the critical difference between data's ability to be consumed passively, or data actually being "shared." Second, this informant indicated that senior officials – the U.S. White House, the U.S. Department of Defense – were using GitHub, as well as response actors looking for any kind of granularity in the WHO data. They did not have access to the non-anonymized line data in the West Africa region. This suggests that networks of "core" access to sensitive data might have been elite, but they didn't include all people or agencies in positions of power. Third, the author of the GitHub database was uncertain how to manage issues of citation and attribution for this dataset.

The two central databases that constituted most of the epidemiological data during the West Africa Ebola outbreak included the U.S.CDC-designed EPI INFO Viral Hemorrhagic Fever application (a.k.a. VHF database²¹)²²¹ and national “line lists” – non-anonymized epidemiological databases. Reports from informants indicate that the flow of information around these lists was as chaotic as the response itself. NGO workers, for example, with little understanding of the data and no awareness of the sensitivity of the information would receive the line lists in their inboxes from a friend or colleague; while the director of an NGO might use the then, redacted data provided in the GitHub described above to determine where to send a plane full of supplies. Moreover, neither system was adapted to integrate with Liberia, Guinea, and Sierra Leone’s effectively unusable health information systems²².

Genomic analyses

Genomic data was derived from the blood samples and swabs collected from suspected cases, both living and dead. After PCR analysis was conducted on the samples at laboratories across the region to confirm the presence or absence of the virus, it was possible to isolate the virus and export them for genomic analysis. Subsequently, the data from a collection of samples was sent on to specialists to analyze phylogenetic data for epidemiological insights.

At the time of the West Africa Ebola outbreak happened, the role of genetic sequencing and molecular epidemiology was not fully defined for Ebola outbreaks. While the potential long-term contributions to new product development for vaccines, therapeutics, and diagnostics was evident, it was unclear what, if anything, genetic and phylogenetic research could contribute to an ongoing public health emergency.

Several interviewees were connected directly or indirectly to a well-established international network of researchers (including the Broad Institute, Tulane University, Public Health England) that publicly shared the first viral sequences of the EVD virus through GenBank. One scientist recalls the scramble to deal with data sharing issues around this:

There was a there was a window of time that before the sequences went on GenBank, which is kind of considered a Wild West, different groups had taken and put onto their institutional website just a file of the raw data, which is basically sequence, collection date, and location, and attached a waiver to it effectively saying ‘We’re sharing this data because it’s a public health emergency. You can’t publish on it. You can look at it. You can do stuff with it. It can help you with your understanding of the epidemic, but you may not publish on it.’ (EVD-18)

The crux of their data sharing activities begins with the Lassa Fever laboratory in Kenema, Sierra Leone run by Tulane University, which was repurposed as an EVD diagnostic laboratory soon

²¹ Challenges arose with the VHF database, according to respondents. Although it was designed specifically for VHF response, and included robust contact tracing and case management capabilities, Initially, it was designed for single user data entry. Given the size of the epidemic, and the number of response actors and ETUs, the CDC adapted the app to enable SQL server support by August 2014 to allow for multiple user data entry.

²² In Liberia, some of these database capacities were not able to be used during the peak of the epidemic due to the large scale of the outbreak and the high demand placed on the VHF application that the platform could not support. By December 2014, the Liberia MoH switched to DHIS2 software – an increasingly widely adopted national health information systems web platform- which had been specifically adapted to the needs of the Liberian health system.

after EVD was confirmed in Guinea. The Lassa Fever laboratory had existed for several decades before the EVD outbreak. There was a dense, long-standing international network of scientific research institutions that had worked with Lassa fever data from the laboratory, a strong working relationship with the Sierra Leone government, and long-term, intense friendships and partnerships with Sierra Leonean scientists and laboratory technicians based in Kenema. Because of these relationships, researchers from Tulane were able to procure and export virus samples early during the response, send them to the Broad Institute at Harvard University for analysis, and share the virus sequence through GenBank within a few days of sequencing.²³

As with other actors who decided to make data or analyses publicly available before receiving credit or attribution through publications,

the reasons, in retrospect, were quite simple. It was just this really frantic emergency of a situation. We were really interested in some relatively narrow genetic questions, but we recognized that there's this whole field of filovirus research and we recognized that this data would be extremely useful across multiple sectors. So, we felt that we had to get it out there as soon as possible. (EVD-21)

This relatively rosy narrative of data sharing is complicated by the observations of uninvolved actors, who reported,

I was not directly involved with Tulane, nor part of the very ugly war that went on between Tulane and Metabiota about controlling data that came out of the laboratory in Kenema, about who was discovering what, and what the response was. (EVD-32)

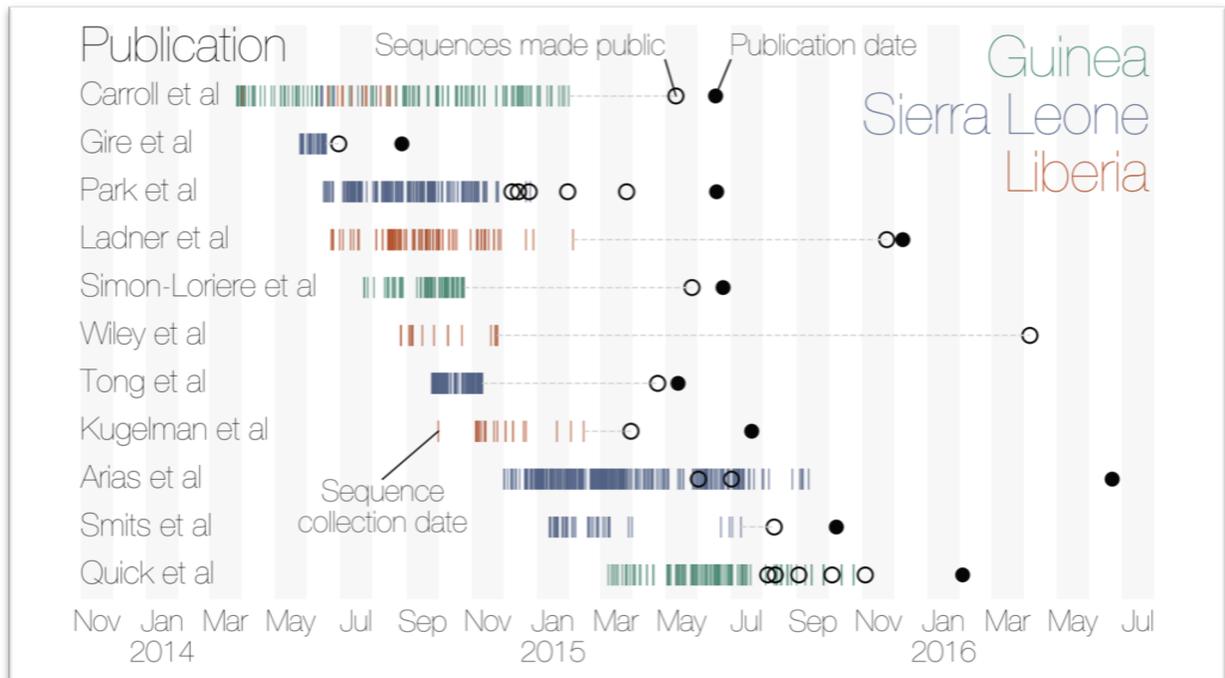
These researchers bring a particular disposition towards “the democratization of sequencing” (EVD-21) to bear on their approach to data sharing, and some attest that publication norms are shifting from “first to publish the article” to “first to publish the sequence.”

After this initial “data dump,” there was a delay of several months before updated sequence information was shared through GenBank. Continuous sequencing was being done by the Broad Institute, USAMRIID, and Institut Pasteur. Respondents disagree about why the delay occurred. Some believed that it simply took a lot of time to ship the samples in a difficult regulatory environment, obtain a sufficient number of samples, process them, clean the data, and analyze the data. Others believe that the data were withheld for publication.

Genetic research was highly fragmented, “No single group was in West Africa for the duration of the epidemic. And I think only one sequence parses for more than one country. People [who were] looking at their own data without the context of other people's data got a very limited picture of what's going on (EVD-31).” Figure 8 suggests that most held on to their sequences nearly until publication.

²³ The timeline: “So we received sample shipments on June 4th and June 23rd of 2014. And we did multiple sequencing runs at the Broad Institute on those samples and we got the first approval from the Ministry of Health in Sierra Leone allowing us to publish the viral sequences on June 18th, and then on July 3rd we released the first batch of sequences to GenBank database. And then our second batch of sequences we made available on July 25th.” (EVD-21)

Figure 7: Personal communication, Data compiled by Andrew Rambaut. Visualization by Gytis Dudas



Stakeholders with access to genomic data on Ebola needed to collaborate with one of just a few leading global experts on phylogenetic analysis – Trevor Bedford and Andrew Rambaut. According to several accounts, at certain times during the response, Andrew Rambaut was the only person on the world who had access to all of the known sequencing data for the West Africa Ebola epidemic. His role was specific and remarkable:

Andrew was very hooked into WHO. It's all a tight little network. Immediately when Ebola started, Andrew was working on it very squarely. Gytis was Andrew's PhD student and did a lot of these analyses, where data that wasn't getting shared publicly was getting shared directly to Andrew and they were then doing these private analyses and sending back the results rather than in a public way. Just like directly to the people that were there generating the data. Andrew ...was like Switzerland... he knew what was going on but had promised different groups he wouldn't share their data beyond what they had asked. It's really impressive how small of a network it really is. (EVD-18)

Scientists working on sequencing data do believe that their work impacted their response in the short term. They argue that genomic epidemiological analyses underscored social dimension of the outbreak and elaborated or redefined early models of transmission driving the response. It confirmed that transmission was mainly human-to-human, and efforts focused on wild meat transmission were unhelpful. They were able to provide some information about the origins and duration of the virus, and its likelihood of mutation, which helped to resolve some highly publicized international anxiety about the virus mutating in aggressive or unpredictable ways. It demonstrated that transmission did not follow random patterns; rather, it took place in socially determined clusters,²²² so that an entire household could be decimated, but other households in close proximity remained unaffected. These analyses showed that particular mobilities between

Liberia, Guinea, and Sierra Leone contributed to a lower likelihood of introductions to non-affected neighboring countries they also demonstrated that transmission included widespread, unassociated patterns, clusters, and durations.¹⁵⁸

Clinical data

Clinics were data collection points for epidemiological purposes and outbreak control; and targeted data were collected and supplied to the Ministries of Health. Patient data rolled over to epidemiological purposes and outbreak control. Most medical NGOs entered data into a standard case reporting form used with the Epi Info VHF app (designed by U.S. CDC); results were submitted to the Ministries of Health.

Throughout the duration of the epidemic, there was never a coordinated mechanism to standardize, host, and analyze clinical data from across the many ETUs and hospitals managing EVD cases. The barriers were not technical - a wide range of novel approaches to patient data documentation were deployed to accommodate the challenges of the clinical environment. The issue instead seemed to have to do with how clinicians defined the ethics around sharing patient data. When clinicians were using a clinical framework to define their ethical decisions, they tended to err on the side of patient confidentiality. When clinicians were engaged in clinical research with the intent of improving patient outcomes across the epidemic, they tended to wear the hat of “researcher” and consider data sharing from that perspective. When clinicians wore the mantle of “implementing partner” and “government partner” their decisions about data sharing tended to follow yet another set of logical considerations. The challenge for clinicians and patients and researchers and epidemic responders was that many of these actors were all of these roles at the same time; they were informed by a multiplicity of ethical frameworks and options for making decisions; and there were no clear super-ceding logics or discourses that lead to a natural preference for one over the other.

- **Clinicians as Researchers:** A researcher/clinician from Public Health England who worked in Sierra Leone felt that it was necessary to aggregate clinical data, clinical outcomes and patients’ experiences in order to identify bottlenecks, delays, and other issues affecting clinical care. (E100-119IP) Working with Connaught Hospital, Public Health England, the Sierra Leone ethics board, and the Ministry of Health, this researcher/clinician was involved in a number of research activities to determine presenting case symptoms, rapid diagnostic test accuracy, and – later – clinical trials. This researcher noted that data sharing and publication was compromised in Sierra Leone by ‘rogue actors’ who were seen to be introducing experiments into clinics and removing samples from the country without authorization and “poisoned the research environment.”²⁴

We [could not finish the research because we] were held up for a long time by ethics from the Government, and there was a moratorium on people publishing anything; international researchers, because of some very bad practice from a variety of agencies and organizations without asking the Government; in a really uncontrolled, unrandomized and unscientific manner. And there were lots of feelings of theft of samples, like who owns the data, was it the National

²⁴ The particular scandal in question was the use of amiodarone at Lakka center in Freetown – a drug for hypertension- that had been tested without the authorization of the Sierra Leone government.²⁵⁵

Government, the Chinese, the British, the South Africans, the Americans? We had a good working relationship with the Government and we always wanted to do things completely in agreement and in partnership with them. That was six months, it was very difficult to get ethical approval. (E100-119IP)

- **Clinicians as doctors:** MSF was widely acknowledged as a “sharer” of clinical protocols and practices with response partners; and as a generous partner who provided support and advice for healthcare worker training, ETU construction, and management. But it was reputed to retain clinical information internally and refused to share findings. MSF participants in this study argued that the basic ethical principles governing the sharing of patient data conformed to routine clinical norms for patient privacy. An MSF official indicated that in some ETUs, decisions regarding the sharing of patient information (suspected, probable cases) were made using the same criteria as one would ordinarily apply in any emergency room – Was the person seeking the information a family member? Was it a response actor or public health official who required case numbers in order to make decisions about epidemic response activities? (EVD-32) Reports from local healthcare workers confirmed that routine data collection continued, with the normal collection of patient data for clinical management, and the routinized reporting of health facility statistics. Within MSF, data management practices for confidential patient information did not materially change during the Ebola outbreak, according to reports from clinicians, midwives, and healthcare workers.
- **Clinicians as implementing partners:** During the outbreak, clinics, hospitals, and ETUs utilized patient data to inform research questions about Ebola that had direct implications for patient care. High priority questions, for example, included the development of a revised clinical definition for EVD cases,²⁵ research on candidate therapeutics, and EVD natural history research. These research demands placed clinicians in compromising situations for obtaining patient consent during and after the outbreak. There were all kinds of reasons why patients who arrived at ETUs might not be able to provide consent for research. They may have arrived in advanced stages of the disease, or they might rapidly worsen during their stay, become unconscious, experience delirium, or die. Patients were often unable to provide basic information about themselves, like their names, ages, or homes of origin; and medical NGO workers did not anticipate requesting human subjects research consent for the long-term reuse of biological specimens or clinical data. Once the samples made their way to the laboratory, lab technicians worked on diagnosis using self-designed lab intake forms. They tried to get patient data from drivers carrying samples and ran diagnostic tests through the night. By 7:00AM the next morning, lab technicians were under pressure to convey the laboratory results to the Ministry of Health and the clinical teams before a daily 10:00AM press conference in Freetown. (E100-110IP)
- **Clinicians as mediators:** Healthcare workers came to believe that they played a distinct role in data collection and data sharing as mediators between the patients, the biological

²⁵ Early characterizations of Ebola cases emphasized late-onset symptoms (red eyes, hemorrhagic bleeding) over early onset and widely reported symptoms (fever, vomiting, diarrhea). The nonspecific symptoms of EVD may have contributed to false negatives, premature releases, and large clusters of healthcare worker infections.²⁵⁶

samples and an unknown final number of laboratories set up in West Africa to process EVD tests. The ensuing chaos created by the rapid influx of mobile and stationary laboratories was unsettling.

In the beginning, it was just the MLAB in Guinea. Once things took off in Liberia, CDC and NIH Rocky Mountain lab showed up in Monrovia, along with USAMRIID's lab. They were in with the Liberian National Lab, so a lot of American players in Liberia, and then as things got hot in [inaudible] in, the Public Health England. Then the Chinese were there, and I don't know who the hell was there. At some point, everybody was there, anybody with a ... big enough Ziploc bag pretty much ran their own labs.... I mean at the end, it was just ridiculous. There were like dozens of labs processing thousands of specimens, the vast majority of which were all negative because it was towards the end of the outbreak and anybody who coughed got a blood specimen taken and was determined to be negative. (EVD-34)

MSF, for example, came to believe that the organization held a special responsibility to engage with the process for sharing biological samples that were procured during clinical work. Clinicians sometimes were unsettled by how blind they were to the end destination of the blood samples. As one MSF respondent remarked,

"We have a moral obligation to see that these specimens are handled appropriately with the right consent ...but we can't really enforce that. The host countries can, it looks like they're catching on. "[We] should be at the table to be the advocate for the patients; we are involved because we're the conduits. We draw the blood from these people and hand it off, [and] hey, we never ask our patients if it's okay with them that their blood is used in this way and even though it's whoever doing it, we are the conduits and we have to actually be transparent with them." (EVD-34)

Biological Samples

Existing laboratory capacities in the region were poorly equipped to manage an epidemic at this scale; but rapid declines in the cost of diagnostic technologies that could be brought to the field changed the domain of the possible for EVD diagnostics at a scale that had been previously unimaginable for West Africa. Under pressure to expedite a resolution to the backlog of diagnostic tests, the WHO supported a globally expedited effort to innovate novel tests for EVD that could address issues with electricity supply, the need for rapid diagnostics for viral detection, low-skilled or restricted laboratory workforces, difficult transportation environments, and the possible transmission via blood through the use of a needle for blood sample collection. In September 2014, the WHO introduced an emergency procedure under its prequalification program for rapid assessment of Ebola diagnostics for UN procurement.²²³ On 12 December 2014, diagnostic experts and companies joined the WHO and the nongovernmental organizations FIND and MSF to expedite development, production, and testing of adapted and rapid Ebola tests.

As international demand for EVD samples grew, Guinea, Liberia, and Sierra Leone came to recognize that the samples were their property by default. Regulatory barriers impeded the shipment of samples from West Africa to Europe and the United States, leaving researchers in the U.S. and Europe pleading for access to EVD samples.²²⁴ Plausible rumors circulated that Russian

and Chinese laboratory teams were removing biological samples without approval or consent to be sent back home for research. (When asked how Chinese researchers obtained the material needed to isolate an Ebola antibody, one person commented “*It helps to be on the ground.*”)

During the West Africa Ebola outbreak, African governments became aware that biological samples and epidemiological data were scarce national resources that could be leveraged to develop national health research capacities. One respondent characterized African governments’ consolidation of authority over EVD data and biological samples:

The West Africans became aware during the West African outbreak that hey, these specimens are in fact ours and maybe we shouldn't be just signing any piece of paper saying anybody can run off with them to do as they please, and so they started clamping down. Sierra Leone got very tight with specimen sharing during the West Africa outbreak. Guinea was pretty wide open, Liberia somewhere in the middle. But they're now sort of very much involved with, hey, how do we want this biobanking thing to proceed. Many of them are saying, hey, this is an opportunity for infrastructure development and we're going to build our own biobanks and so forth (EVD-21)

Abayomi et al. documented,

The Ebola outbreak brought a rush of international institutions aiming to assist in stopping the outbreak, and in the middle of the devastating outbreak, the Government had difficulty monitoring and keeping track of all of the actors and their actions. This was made even more complicated by the absence of any national biosafety/biosecurity legal or regulatory framework to guide the process of sample safety and security or the ethics of sample sharing. This lack of existing legal and regulatory infrastructure, combined with the number of actors operating in the country as part of the outbreak response, and the chaos of the outbreak itself, resulted in a situation in which it became and remains impossible to track what happened to all of the biomedical samples of Ebola.²²⁵

The chaotic environment and lack of coordination was acknowledged by many respondents. Logistical and transportation deficits prevented the secure movement of highly infectious biological specimens²⁶ across borders. In Liberia, every ETU managed their samples their own way: qualitative accounts from one USAID evaluation revealed that U.S. military closing an ETU destroyed EVD biological samples that had been set aside for research, following to operational orders.

The following account from a clinician gives a sense of the “Wild West” described by several respondents.

Well, effectively, once it's in the hands of the lab, we don't have possession of it anymore. We would, of course, be nosy and so for example, in Guinea, where we were working with the European mobile lab, we would ask them, hey, what

²⁶ Within the region, transfer of samples could be insecure, as well. In Guinea, news reports detailed a taxi heist that resulted in thieves unknowingly making off with blood samples that were being sent to a laboratory for EVD testing.²⁶

are you doing with those specimens and they would say, we are shipping them back to Europe to do research on them. Here's the piece of paper signed by the Guinean Ministry of Health that authorizes us to do that. We'll be like, well, it looks legit. It's rather broad and I can't believe they signed that, but you know, you've got a green light. In Monrovia at some point, all the specimens ended up on a plane and went off to Atlanta. Well, I shouldn't say they all went off to Atlanta. Many of them went off to Montana, but again, with authorization. Sierra Leone, an awful lot of stuff did not get out of that country. For example, we did a study where we were trying to look at infectivity of recovered viral material in the environment of an ETU so just one swab of the environment, and then they did PCR on it. Yes, there's RNA signal here, there's already signal there. Is any of that infectious? I don't know. We got to take it home to do viral culture. Sierra Leone said, that stuff's not leaving the country. It's like we swabbed the cement, you know, it doesn't matter, that's not going anywhere, and it went nowhere. (E100-113IP)

Guinea seemed to have little regulatory authority over the movement of biological samples. In Sierra Leone, by contrast, tensions between the government and researchers ran high over fears of researchers stealing biological specimens. As noted earlier, rumors and evidence of unauthorized removal of EVD biological samples from Sierra Leone prompted the government to shut down all exports of biological specimens for several months, and to severely curtail international export thereafter. An American doctor described her perception of the attitudes of Sierra Leone government officials:

"I need to know...because you are as a foreigner, what are you going to do with our samples? Where do you want to take, are you going to take them? Before January 2015... Nobody knew exactly what was going to happen and nobody trusted anyone; the local authorities didn't trust the foreigners and the foreigners didn't trust the local authorities."

For African researchers, the accounts of the politics surrounding sample sharing suggested that foreign researchers were poorly prioritizing their research studies. One researcher suggested that research on biological specimens took precedence over more important issues of transmission, ecosystems, reservoirs, and diagnostics.

I think that's where the countries have to win. Ebola is Ebola. Whether in Liberia or elsewhere, traditional Ebola strategies are known. The biggest specificities are the questions we ask ourselves. And these questions that we ask ourselves will be solved by research. It's just saying what are our concerns today regardless of the color of the speaker, their power. What is the problem today that concerns us? The transmission routes of the epidemic, sexual transmission, the ecosystem, or the reservoir. Dig deeper into this and work together. Not much has been done in this way, unfortunately. Only the samples were transported outside.... Unfortunately, I am in a position in which I cannot direct the vision of research. Those who are in the leadership do not see things the same way as me. I would not have managed the samples as they managed it. (E100-132IP)

A senior laboratory scientist involved with EVD testing in Guinea related this extensive critique:

Sample sharing has gone through several stages. At the very beginning, the problem did not arise because there were very few laboratories present. All the laboratories, until the end of the first week of April, all the samples came to our laboratory. There was a second laboratory which was in Guinée Forestière...responsible for Guinée Forestière and surrounding areas, including Liberia. Things were clear...The more the epidemic progressed, the more difficult it was to share the samples and the information.

As the epidemic unfolded, the different laboratories had different research projects. Given the scale of the epidemic, the stakes were so high, and the institutions so important that there was a pretty fierce competition, and the lack of coordination was not helping. It was like the Wild West with regards to who did what.

There was a little coordination of the laboratories. There was a little exchange of information-for example, whether to release a patient who had been sick - but very little exchange of data since obviously, most laboratories and people who worked there worked with institutions for whom coordination and cooperation were not the easiest. (E100-153IP)

Figure 8: Sharing data about diagnostic thresholds

During the West Africa Ebola epidemic, issues around data sharing ran up against limited information regarding diagnostic thresholds. In our research, we identified three specific cases in which a lack of granularity around quantitative PCR results caused difficulty for epidemiologists and clinicians.

- A U.S. Centers for Disease Control epidemiologist complained that PCR results from Public Health England only indicated if cases were positive or negative. This prevented field epidemiologists from being able to determine what a “positive” status meant for the possibility of future transmission. (EVD-5)
- A doctor from a medical NGO observed that requested data about quantitative PCR results were not released by Institut Pasteur Dakar or the Guinean National Laboratory. Instead, results were returned as positive, negative, or positive with +++. Later, a published article appeared in a PLoS journal with the quantitative thresholds. The medical NGO felt that those data would have been valuable for providing stratification for clinical trials and profiling historical control groups. (EVD-34)
- Speaking at an international technical meeting about filoviruses, an Ebola expert from a medical NGO observed that during the West Africa outbreak, there was an extraordinary surge of innovation in the private sector production of rapid EVD diagnostics; many were tested in West African ETUs. For clinicians, these diagnostics were difficult to use because the thresholds for reporting positive and negative status were not always transparent or consistent between devices. (participant observation)

According to WHO-originated articles, during the EVD epidemic, investigators proposed obtaining biological samples in 13/24 clinical trials protocols and proposed retaining unused samples for future use in 8/24 protocols. In the absence of a biobanking system for managing EVD samples, and considering the scale of the emergency, the WHO-Ethics Review Committee “Information on sample and data ownership, data sharing policy, processes for determining future use of samples was frequently insufficient.”⁴⁵ Specifically, a lack of information on rules and procedures for sample ownership, and how results would be shared with participants and their communities impeded review processes.

GIS Data

If governmental agencies can't figure out how to gather and share the kinds of data that we need for outbreak response, then private sector startups or NGOs are going to figure out how to do it. And they're not going to have to share and they're going to have very different interests when it comes to sharing. (EVD-15)

Infectious disease cartography was implemented in several ways during the Ebola outbreak, and nearly all efforts depended on open-source shared data. New hobby sites were set up like Ebola

GeoNode, through which a U.S. government official posted Ebola-related maps. Efforts to use geolocation to assess the velocity of spread of Ebola drew upon publicly shared data provided by the WHO²²⁶ and national census data. Mapping zoonotic niches was based on primary data collected from public literature on previous epidemics, GenBank, Google Maps, and NASA's Modis Satellites^{151,227}.

MSF-CH crowdsourced volunteers through OpenStreetMap and the Humanitarian OpenStreetMapTeam (HOT) to manually digitize Guekedou-area village and urban locations.²²⁸ Researchers' GIS datasets were shared with the public on a number of open-source platforms including figshare,²²⁹ Humanitarian Data Exchange, and others. MSF also recruited locals in Tonkolili District, Sierra Leone, to build local maps using self-owned Android smartphones installed with open-source survey software (OpenDataKit) and open-source navigation software (OpenStreetMap).²³⁰

While impressive, researchers working on these problems believe that de-identified private sector-owned GIS data from call detail records (CDR) could better inform epidemiological insights into population movements and flows.²³¹ This was done previously during the Nepal Earthquake humanitarian response. In our interviews, a leading advocate for sharing GIS data for epidemic response bemoaned the failure to use digital surveillance as in fighting the Ebola outbreak. He argued that private companies were dragging their feet in sharing GIS data, and believed that there was no privacy issue involved, *"It is population-level movement flows. It's not individual phone calls... We could model flows across the continent and work out not just for Ebola, but for any kind of infectious disease that can be transmitted."* (E100-124IP)

Critics have argued that the seductive idea of big data to fight epidemics misses key limitations of both modelling assumptions and technological resources as they are used in lived contexts.²³² But for those unswayed by these arguments, the barriers to private sector data use are substantial, and largely hinged on the legal requirement for private sector partners to prioritize individual privacy concerns; the ethics of using private sector data for unapproved purposes, and difficulties establishing the contractual foundations for data sharing. Leading advocates of private sector data applications for epidemic response contend that data sharing may not be a viable goal; instead, establishing open or semi-open analytical que try capacities to ask question of private sector data may be the way to go. Both of these issues are further complicated by the EU General Data Protection Regulation, country-level variations in regulatory concerns, and political factors like ministry-level political appointee turnover. (EVD-39)

Data sharing within the social mobilization pillar

The social mobilization pillar was led by the Ministries of Health and UNICEF in Guinea, Sierra Leone, and Liberia. From a coordination perspective, it was the main entry point for the conduct and use of social sciences data during the Ebola epidemic. Initially, social science insights were initially solicited to explain practices that seemed exotic or unusual, like wild meat consumption and West African funerary practices or practices that functioned as barriers to response activities, like community resistance. Sociocultural complications that impacted the response environment received substantial media attention and placed a broader and more diverse assemblage of social scientists into dialogue with the response than had been seen in any previous epidemic, with the exception of HIV/AIDS. By early 2015, however, social science was increasingly engaged in a wider range of topics (see Figure 10), including issues that could inform epidemiological challenges.²³³

One actor involved in the social mobilization pillar characterized information sharing in the social mobilization pillar thus:

Figure 9: EVD-related research demands from social scientists

- Transmission in rural areas
- Rumors about EVD
- Local characterizations of EVD
- Transmission patterns within social networks
- Funerary practices
- Explaining cultural norms
- Engagement with religious and community leaders
- Vulnerable populations (women, children, the elderly)
- Social responses to isolation and quarantine
- Basic needs during quarantine
- Community engagement
- Survivor experiences
- Psychosocial reactions to EVD
- Vaccine hesitancy
- Attitudes towards clinical trials
- Avoidance of healthcare facilities
- Wild meat consumption
- Community reticence or resistance
- Attitudes towards hospitalization
- Hiding patients from contact tracers
- Burial practices
- Popular attitudes towards EVD commemoration
- Community resistance to spraying
- Social responses to personal protective equipment
- Traditional healers
- Local funerary experts
- Impact of EVD on local economies
- Local perceptions of NGO activities

Data sharing was not really formalized until later, in the state of the outbreak. Initially it was mainly through exchange of emails, through sharing of information verbally or in meetings, so it was that kind...where risk communication and community engagement is concerned. It wasn't done in a systematic manner until the pillar organized itself and set up different sub-working groups to work on the response, particularly in the area of social mobilization. There was a group looking at monitoring and evaluation, there was a group looking at information, data repository, messages, etc. (YFV-21)

In this section, we address anthropological data sharing, Knowledge-Attitudes-Practices surveys and focus groups, and community engagement data, each of which has a unique history of informing epidemic response.

The quantity of potential data capture in Liberia alone would have been impressive. With over 120 local and international NGO partners working just in the social mobilization pillar in Liberia, it might have

been possible to gain granular insights by layering community-level data on epidemiological or health systems data. However, throughout the response, in all affected countries, social science data, community engagement data, and social mobilization data was siloed and compartmentalized. The existing data were available for response use, but never integrated into the other response pillars.

The parameters set around the intended use of social science data had an important impact on how quickly, completely, and fulsomely data could be shared. Despite the enormous expansion of the scope of social science research demands during the epidemic, funding, logistical support, and institutional support did not keep pace. At least one estimate (developed by author SA) has suggested that the total expenditure on social science research (not including community

engagement activities) amounted to less than .05% of the total funds expended on the West Africa response.

a) *Anthropological Data*

Anthropological “data” has two dimensions: (a) the raw historical, observational, interview, focus group, or survey data collected by anthropologists to inform their ethnographic research; (b) the analysis of that data and its transformation into ethnographic narratives and theoretical insights. For anthropologists, the ethnographic analysis is a primary extension of the researcher’s involvement in the data collection process itself, ethnographic analyses, theoretical critiques, and primary accounts are all recognized within the discipline as having the status of “data,” or primary origin.

Qualitative research poses particular problems for data sharing. Social science data is intrinsically focused on social, cultural, political, and economic factors and therefore poses risks to informants. As a result, there are mandates to share data with one’s informants, but there is no precedent for sharing, borrowing, or handing over data to an uninvolved party. In fact, the idea of sharing qualitative data is ethically suspicious²³⁴⁻²³⁶ and there has been no effort to invest in building consensus around sharing qualitative data and findings for health emergencies.

These tensions directly informed the unexpected role that anthropologists came to play during the West Africa Ebola Outbreak. At a scale unprecedented outside of HIV/AIDS, anthropologists were integrated into epidemic response activities on global and local levels. After it became apparent that conventional response activities were failing to contain community-based transmission, select individuals were recruited to help response actors navigate complex – and sometimes hostile – local environments. Sharing constituted the provision of primary information and analysis to response actors in order to gain better intelligence about the local response environments.²³⁷

At first, during the period of Ebola’s escalation in West Africa, a limited number of anthropologists were invited to contribute insights to key decision-makers and to intervene in incidences of community-based resistance or reticence to response activities (ex. burials, transportation to ETUs.) Frequently, these practices of information-sharing were bidirectional. Anthropologists provided information about the governance of the response to local communities desperate for information about the epidemic, and local response actors shared politically sensitive information about compliance and non-compliance with response activities. They launched the SHS Ebola Network²⁷ to facilitate information and data sharing among interested researchers in order to generate cross-national and regional comparisons, but with funding difficulties, funding delays, and a lack of access to the field the value of the website was not fully realized.

By mid-2014, the London School of Hygiene and Tropical Medicine received funding to establish the Ebola Response Anthropology Platform (ERAP), a coalition of UK and Sierra Leone-based researchers who were sought to inform the DFID response to the EVD epidemic.²³⁸ ERAP launched a website for the dissemination of anthropological writings about Ebola, and created an open-access space for the distribution of pre-prints, white papers, published short-form articles, and peer-reviewed publications that had never existed before.

Despite these advances, engaging anthropologists remained a countercultural activity in epidemic response; and integrating anthropological information into response practice was a murky process

²⁷ Réseau Ouest-Africain de Sciences Humaines et Sociales sur Ebola

at best. In August of 2014, a growing recognition of “super-spreader events” associated with burial practices led UNMEER to bring an anthropologist into its operations. In a New York Times Op-Ed, Anthony Banbury wrote

Too often, the only way to speed things up is to break the rules. That’s what I did in Accra when I hired an anthropologist as an independent contractor. She turned out to be worth her weight in gold. Unsafe burial practices were responsible for about half of new Ebola cases in some areas. We had to understand these traditions before we could persuade people to change them. As far as I know, no United Nations mission had ever had an anthropologist on staff before; shortly after I left the mission, she was let go.²³⁹

A dozen interviews show that the placement of an anthropologist within the Ebola response mattered. Proximity to key decision makers was as important as facilitation of community information. This resulted in three novel innovations for qualitative data sharing. First, when anthropologists were physically, politically, and strategically situated close to key response actors they could access priority response questions and solicit rapid feedback from the social science community. Second, the anthropologist – in partnership with the global network of West Africa and medical anthropological experts with information to provide the response – devised a mechanism of processing the community’s responses into syntheses called “briefs.” The briefs were co-authored with a third network – the American Anthropological Association’s Emergency Ebola Anthropology Initiative, which shared real-time requests for information, connected researchers seeking partnerships, and facilitated requests for data analysis through basic listserv and discussion board platforms.²⁸ Lastly, through these briefs, the anthropologist was able to situate herself as an information pass-through for a community of previously disregarded regional and area experts. These reports were then disseminated through the UNMEER network to key response actors and were stored for public access through the ERAP platform.

All of these events occurred between July-October 2014. In September 2014, as multiple anthropologists were mobilizing to build webpages and online resources to respond to the epidemic, a small group of anthropologists met in Europe and agreed that anthropologists should avoid unnecessary duplication of work, share information and insights, and work in a coordinated manner to influence the West Africa Ebola response.¹⁴⁴ These agreements were informally made and informally disseminated but were accepted by most as a necessary precondition for collective action in an underfunded, under-prioritized response environment.

Social scientists working in West Africa also worked through pre-existing informal relationships with researchers to disseminate their own reports and articles, and sought help processing enormous quantities of data for which they had no analytics funding, time, resources, or staff. These activities were discouraged by the World Health Organization, and national government representatives gave last minute approval to sanction the transfer of data and the establishment of research collaborations.²⁴⁰⁻²⁴² At key moments, this kind of data sharing impacted the response; for example, the transfer of focus group and field notes data from a field-based anthropologist was rapidly analyzed for insights about the public attitude towards cremation by a team in the United States, and findings were reverted through the UNMEER anthropologist to the President of Liberia

²⁸ Supported by Wenner-Gren Foundation, George Washington University, and the International Development Research Centre

and informed the change in Liberia's policy of Ebola-related cremations. These data were never published.

Interviews suggest that the informalization of information sharing and data transfers were highly sought by anthropologists early in the response in order to gain a foothold in impacting the course of the epidemic. Within six months, however, the vagaries around credit, attribution, access to decision-makers, and a perceived inequitable distribution of funding support and resources resulted in data "sharers" feeling exploited and used. While a collectivist approach to the development of the briefs lifted the burden of research and publication from the shoulders of a few senior anthropologists, as one respondent commented

It was not for the purpose of publishing. It was clearly for the purpose of selling expertise and frankly, it was too complicated. It was maybe the extreme of data sharing. It was like with journalists in the heat of the epidemic – there were moments on the telephone when communications became difficult because one sensed that they wanted information and were less interested in analysis. Eventually, I only worked with those who [worked correctly] and with whom I had a high regard. But frankly, there was an impression of predation, somehow [with UNMEER]. (EVD-37)

Anthropologists involved in writing "briefs" for response actors, in contrast, criticized peers for shielding their data within organizations, taking too long to publish findings, and an excessive preoccupation with privacy. One responder complained that the anthropologists, in turn, were more focused on developing a 150-page report that would come online in six months' time, rather than have information to share during daily IMS briefings. (E100-58)

Efforts to establish coordination mechanisms for the sharing of qualitative data locally in Liberia, Guinea, and Sierra Leone were initiated but were unsuccessful. On a country-by-country basis, internal differences between social scientists undermined efforts to develop collaborative information-sharing meetings and coordination mechanisms²⁹.

The hierarchy of the response caused friction between anthropologists trying to share information and pressures discouraging data sharing. In Liberia, tensions emerged around the perception that anthropologists needed to relate information about what they had seen in the field that day, or in the last few days; and anthropologists were reticent to make specific generalizations on the basis of a limited period or limited sites of data collection. One observer reported,

²⁹ In Guinea and Senegal, respondents identified at least four teams that were operating in the field and refusing to collaborate with each other due to ideological, political, or social differences. Data were instead shared informally between anthropologists and response actors, and across anthropological networks. In Liberia, early efforts to convene anthropological working groups were weakened by the refusal of U.S. CDC anthropologists to participate, accusations by some participants that the group was being driven by external agendas, and participants' lack of autonomy and control over their research agendas and data. Major research institutions (Harvard University, Johns Hopkins University) conducted research and established direct relationships with the Ministry of Health and response actors and were able to bypass other social scientists working in the field. In Sierra Leone, local efforts to bring together social science researchers were rapidly abandoned due to scheduling limitations, social scientists' geographic dispersion across the country, and a lack of clarity around the mission of the group.

The Ministry of Health expected from us that they would get intelligence, or at least a snapshot picture of any critical concerns or feedback from the community based on the day's interaction, because they were visiting different communities. Anthropologists were reluctant to share that information because they felt that they were working under research protocol, and they had to maintain confidentiality, and they felt that that information could provide some bias. But from the response side, the rest of the WHO team and the Ministry of Health felt that that information could feed a lot into the community concerns, and we could be addressing those concerns on a day-to-day basis. Even though they were coming from specific communities, some of the concerns could be brought in and be taken into consideration more seriously in adapting a response. (YFV-21)

Two social scientists suggested that their African colleagues could be subject to retaliation from government actors or the Ministry of Health for sharing sensitive political or social findings. Foreign anthropologists reported conflict and “really violent reactions” from response actors when they sought to publish reports about their experiences and observations within the Ebola epidemic (EVD-37). Some said that major organizations involved in the response created barriers to sharing anthropological insights from the field; while others reported difficulty accessing non-social science data. Key barriers included excessive oversight, difficulties moving between field and management offices, bureaucratic rigidity, and excessive emphasis on approvals of changes to protocols from senior officials far removed from the field. (EVD-36, EVD-37) This is indicative of the lack of seniority that social scientists held on field-based response teams. At least two respondents reported that MSF and the Red Cross quashed some parts of anthropological reports, or prevented publication of such reports, out of concern that they reflected poorly upon the organizations themselves.

b) *KAP Studies*

KAP studies are a widely utilized survey approach during epidemics that are targeted to individuals, households, or communities using in-person and mobile data collection techniques. The goal of KAP studies is to uncover what populations know about the disease, how they feel about the disease and the response environment, and what they are doing to prevent the spread of the disease or respond to the disease. These studies are regularly well-funded, have large population samples, and are routinely conducted, but have come under widespread critique for a thin approach to knowledge and behavior, a lack of engagement with contextual and structural factors. Nevertheless, they are a frequent part of the public health arsenal for epidemic response, and were widely administered during the Ebola outbreak. ^{243–246}

Most KAP studies came online very late in the response; long after information about sociocultural contexts, behaviors, practices, and public information about the disease was needed. (Respondents also suggested that delays were caused by donors, who were slow to approve projects and disburse funds. (E100-49)) By the time that KAP studies were conducted, the populations of Liberia, Guinea, and Sierra Leone ranked among the most expert publics in the world at understanding and addressing Ebola. The lateness of the KAPs resulted in a lack of targeting, precision, and specificity in addressing local populations' actual informational demands. Most KAP study results-unsurprisingly-found that after a year of exposure to Ebola, “communities actually have a very high level of knowledge... I think the messaging could've evolved much more fluidly or agile. It could have been a lot more nuanced like messaging from the beginning”. (E100-58)

The mostly widely known and cited study – the National Knowledge Attitudes and Practices (KAP) Study on Ebola - was conducted in Liberia during a two-week period in December 2014²⁴⁷, well after the epidemic had largely been contained. The experience of developing the Liberia KAP study was an object lesson for an “open-science” approach in social science research for epidemic response. By the time that most funding had been released for Liberia KAP studies in the second week of November 2014, at least six separate organizations were designing KAP surveys to target thousands of Liberians. After an uproar over the lateness of the study and the need for cooperation, a single KAP study was co-designed, with the intention that either the data or the analysis would be shared widely with response actors and researchers.

One of the things that I personally experienced as one the respondents, or one of the teams in there, was that there were a lot of institutions who were competing amongst one another, rather than working as a collective, so that raised quite a bit of tension in terms of getting some kind of studies out. Everybody was doing some form of data collection, but the information wasn't really shared on a real time basis; either because they were concerned thought the government would not approve it if it was released, as a formal research, or either because they had to wait and get approval; there were various reasons, and all of them had different reasons for it. (YFV-21)

In Sierra Leone, four KAP studies were conducted by NGOs: August 2014, October 2014, December 2014, and June 2015.²⁴⁸ Respondents indicated that the data were made available to principles involved in the response, but there was no interest in the findings of the studies outside of the social mobilization pillar. Social mobilization data was not regarded as relevant to clinical work, contact tracing, or any of the other key functions of the response. (EVD-35). This response indicates the lack of engagement with KAP and community engagement data; and it also points to the widespread ‘chaotic’ informal communication about population perspectives:

I feel like I kept hearing that UNICEF had done a KAP and had information in the abstract about what people were thinking, why there was resistance happening, and what people's reactions were. I didn't have any reasons to - that wasn't my function, so I didn't look into what information was out there. I feel like the program coordinators knew what people were saying and they knew what was happening and I, so feel like they were pretty keyed in to I guess what their counterparts were telling them. (E100-39)

In contrast, senior researchers involved with Sierra Leone's KAP study observed a lack of interest in KAP-related research. KAP in this narrative appears to emerge as an unfunded, locally-driven mandate to understand what was happening with local populations.

FOCUS 1000 saw the need to do a KAP survey... in March 2014. We had some challenges getting support. At first, we had some interest from various partners. But then as time went on, once Ebola hit Sierra Leone, we were pretty much told that folks had been overtaken by events. The idea was to focus on what we can do now, you know, and research was not seen as a priority at that time. I mean, as you can imagine, it was very frustrating for a lot of people like us. When I went back in July, Sierra Leone had cases already. We said, 'You know what, we're just going to start, and others will join us along the way. We have the

capacity to do it.’ ... And so that we can add science to communication as opposed to just guessing and working in the dark. Cause that’s what we saw, you know? We saw that the messages were not grounded in any evidence. (E100-63)

Guinea conducted a small, Conakry-based EVD KAP survey of healthcare workers in August 2014, and researchers conducted another small study in three prefectures between December and January 2015²⁴³, but neither mobilized a large-scale population-based sociocultural and behavioral response until approximately April 2015. The only large-scale KAP study to be conducted in Guinea was conducted in August 2015, over a year and a half after the start of the outbreak.^{249,250} This study was widely disseminated through publications and contained valuable information about attitudes towards Ebola vaccination, cross-border issues, and perceptions of the Ebola response but its lateness limited its utility.

In a review of UNICEF’s Communications for Development (C4D) lessons learned, UNICEF staff contend that KAP studies were “critical to improving decision making and program strategy.” Additionally, they noted that technological “innovations in open-source platforms for mobile phones, such as Rapid Pro and U-report, as well as mobile messaging (SMS) were deployed across all 3 affected countries to gather real-time community insights and attract underrepresented groups such as young people. These technologies enabled greater responsiveness to rumors that required rapid redress to prevent undermining the response.”¹⁹⁹

Soon, KAP study objectives were integrated into community engagement strategies. They were optimized for open-source data collection platforms using GIS data, mobile phone technology, and field-adapted tablets for data collection; and data were shared to open source platforms (in Liberia), or semi-closed coordination systems (e.g. UNICEF and SMAC in Sierra Leone). This kind of information was not gathered or analyzed during most of Guinea’s Ebola outbreak timeframe.

The comments of one informant suggest that KAP studies alone were delayed due to their status as a research activity; it may be that by shifting over KAP-related data collection and data sharing to operational research, data was able to be collected more frequently, and disseminated more widely across practitioner networks.

c) Community Engagement Data

Community engagement entailed the deployment of a range of communication strategies to convey information to local populations about Ebola transmission, prevention, response activities, reporting, and isolation and quarantine. Data associated with community engagement is frequently program data, but it often includes qualitative information about community activities, plans, local perceptions and rumors, and psychosocial issues that arise in the context of communications and outreach activities.

A vast quantity of community engagement data was collected by international and local NGOs. The potential impact of these data has never been fully realized, nor have data sharing frameworks, platforms, or agreements to advance the use of community engagement data. Epidemiologists and modelers have observed that the observed data from community engagement has not been adapted to replace the assumptions used by modelers in understanding and forecasting outbreak trends.²⁵¹

In Sierra Leone, for example, the SMAC consortium (comprised of Restless Development, GOAL, Focus 1000 local NGO and BBC Media Action) possessed data on community engagement and circulated weekly reports based on their findings within the social mobilization pillar. Consortium

members shared data with each other, consolidated their findings from key variables, like attitudes to burials, safe burials, or cases reporting within 24 hours of symptoms, and circulated reports to DFID and the National Ebola Response Centre (NERC).

longitudinal data [was] collected by pairs of mobilizers...across 10,000 communities; they collected data on where they went, how many people attended, who attended...what did they discuss, did they develop an action plan, what were the steps in that action plan, how was the community going to protect itself against Ebola, what were the main concerns, what were the main rumors,, were burials happening...We're looking at 40,000 surveys, and tens and tens of thousands of data points. ... We think [it is] one of the most comprehensive data sets of any epidemic response looking at community engagement.

In Liberia, data sharing was facilitated by the Ebola Community Action Platform (ECAP), funded by USAID and administered by Mercy Corps and IRC. Data collection using mobile phones, the ECAP Dashboard, the MELS system, and Dey Sey¹ were conducted routinely to identify changing baselines in KAP-related issues. All results from KAP phone surveys, community engagement data collection efforts, and monitoring and evaluation surveys was uploaded to the ECAP Dashboard – an open-access platform for the dissemination of community engagement data. However, in Liberia, as in Sierra Leone and Guinea, this open-source data sharing platform was not integrated into core Incident Management System data systems. Data was widely available and accessible to all actors involved with community engagement, but it was not seen as a priority data area that needed to be captured and synthesized for overall epidemic response activities.

There was no parallel for these community engagement or data sharing activities in Guinea.

Community engagement-based respondents are quick to note that while they experienced challenges around the use and integration of community engagement data, they were able to access as much non-social science data as they needed, as implementing partners. By several reports, there was a loosely restricted flow of information from the core of the response to the implementation actors, presumably on the basis of a loosely applied “need-to-know” criterion.

F. Post-Ebola Data Sharing

By the end of the response, credit for these efforts – and investments in future capacities - flowed disproportionately to those actors with powerful institutional connections and funding, while the efforts of others disappeared. By the end of the response, sub-groups of researchers with close proximity to major donors, government offices, and response actors ensured that it got credited for the work done by the entirety of the social science community. Particularly excluded from recognition was the work of individuals who worked within organizations to raise the visibility of data sharing, and the work of the less formalized, less-funded, or entirely unfunded organizers and partners.

In some ways, though, the end of the epidemic is just the beginning of the long-term process of dealing with the challenges of sharing data and biological specimens from the Ebola epidemic. The long-term afterlife of epidemic information and material continues to be fodder for working through and negotiating data sharing principles and practices.

People make a good case, sometimes you just got to put it in the freezer, because the interesting study will not become clear for another 10 years. It's an investment on the future. (EVD-34)

By the end of the epidemic, one WHO staff person informed us, attitudes towards data sharing at WHO

has changed a lot. It has definitely generated a lot of discussion on how we can better share data; we're discussing a lot more about open access, we're discussing about the timeliness, and we're discussing involvement and engagement of a wider cascade of partners—not just the teams that are responding on the ground, but at different levels—who can provide support from different aspects, in different ways, for example remotely. I think it has changed a lot, and the fact that it has generated a lot of discussion.... there is a lot of hope that we will have more robust data sharing mechanisms. (YFV-21)

The epidemic also garnered support for collaborative African-based research and surveillance capacities, such as the Africa Centres for Disease Control and Prevention and five Regional Collaborating Centres in Egypt, Nigeria, Gabon, Zambia, and Kenya, and the African Public Health Network with collaborating National Public Health Institutes in members states.²⁵² Non-governmental organizations such as the African Field Epidemiology Network and the African Society for Laboratory Medicine have been prioritized for support and engagement.²⁵² All of these capacities should lead to greater data sharing capabilities across the African continent, and mark the end of “business as usual” in some respects.

China’s Freetown BSL-3 laboratory led to collaborations between the Chinese CDC, the U.S.CDC, WHO, and Sierra Leone’s MOHS in running viral persistence studies to study the persistence of Ebola in bodily fluids.

Data custodianship has become a crucial issue in regulating access to data and biological specimens from the West Africa Ebola epidemic. All epidemiological data – including the VHF database, the epidemiological line data - is the property of the governments of Guinea, Liberia, and Sierra Leone. In theory, those governments have the authority to make decisions about who has access to data. In practice, however, these decisions are being distributed across stakeholders in a haphazard manner. Two examples may help elucidate this:

- 1) The Sierra Leone Epidemiological Database (SLED), while technically the property of Sierra Leone, has been handed over into the custodianship of the U.S. Centers for Disease Control. The CDC took the SLED database, which includes data from 30-35 partners – and has been working to consolidate the all of the available datasets on behalf of the government of Sierra Leone and develop mechanisms and processes for ensuring that data is shared, but in a way that protects individual privacy and confidentiality. The data is currently housed at the Research Data Center, a section of the U.S. Census Bureau. To date, just five research studies have been invited to submit proposals for the use of the data, and research proposals have been going through serial review processes at the CDC. One respondent indicated that their team’s proposal had gone through 25 iterations in order to meet the CDC’s demands, which is independent of the wishes of the government of Sierra Leone. As this respondent notes, there are “generous” and “ungenerous” explanations for this kind of custodianship and review

process, but access has been facilitated by involvement with a high-ranking public health donor organization. (EVD-35)

- 2) MSF is funding and leading a consortium of partners to try to develop a biobank and a data sharing platform to disseminate EVD data and biological samples. Partners include Oxford University, Wellcome Trust, the Infectious Diseases Data Observatory to support the Ebola Data Initiative, and the project is working actively to engage WHO and African leaders. One participant notes, “We were really pushing to have a new committee with a maximum of African representatives to enable their capacity to control and direct the research in a good way.” To date, however, the project is confronting major challenges that need to be resolved. Substantial uncertainties regarding ethics, data protection, national and regional ownership, who has the right to request access, who has the right to give access, and permanently unresolvable challenges around patient consent³⁰. Like the US CDC, the secretariat of the initiative is also confronting enormous challenges with the storage, cleaning, and curation of data, data transfer agreements, terms of references, etc. (EVD-40) (Notably, the reference laboratories that MSF is working with are also from Sierra Leone.) There is no plan for sustainability of the platform at this time, and real questions about the viability of the plan.

Considerable concern has been dedicated to the lack of global governance over the management of infectious disease biological specimens after an epidemic. Writing about Sierra Leone, Abayomi et al. documented,

“There is as yet no agreed protocol for closing the international labs stood up during the outbreak, handing over the samples or cataloguing their data. As labs continue to close, they either export the positive samples, or transfer them to other facilities with a closing date further out in time. Often these transferred samples are found without proper monitoring, files, data or chain of custody records in secluded areas of the secondary or even tertiary labs. Every time they are moved, the chance is increased that sample and data can be separated in an irreconcilable manner, or that samples may be lost...In Sierra Leone, regulating the export of samples is the domain of the Pharmacy Board... It is still developing capacity to deal with small amounts of research-based requests for export of biomedical samples.”²²⁵

According to our MSF respondents, the WHO needs to take a stronger lead in training countries to protect themselves, protect their samples, and develop national laboratory capacities; and countries need to have clear leadership roles in post-epidemic data sharing. (EVD-40) notes that WHO was supposed to be leading an initiative to create guidelines for material transfer agreements that are specific to the referring country and the referring situation, but “after 2 years, there is nothing – we can find something about it on the web, but the research itself is disappearing.” He does note that countries are making strides to develop their own capacities – Institut Pasteur de Côte d’Ivoire has just finished a biobank. Many respondents suspect that key data stakeholders are comfortable with the current system, with all its ambiguities, informal sharing, and peer-to-peer data sharing agreements.

³⁰ Ex. lack of patient approval for the long-term use of their data; the impossibility of obtaining patient consent due to a loss of contact with patients, death, or a lack of adequate identifiers; governance issues; mandate.

In contrast to high-demand databases, datasets like that collected by SMAC are not being widely shared because few data stakeholders seek to gain access to them.

NGOs, once they've taken what they need out of the community engagement data, it usually sits on the shelf. And so, it's only [NGO] that appreciates the data that they have. It sits on a hard drive but there is no formal mechanism for sharing it. DFID also theoretically co-own it, as does the government of Sierra Leone. During the early stages of this project I went to DFID, to the government of Sierra Leone and to all partners to say you own this, "What do you want to do in terms of how we share it?" And they all said, we don't care, effectively. (EVD-35)

For sequencing data, the democratization of sequencing has been rapidly facilitated by international investments like ACEGID to localize technical capacity for processing genetic data for infectious diseases in Africa. One scientist remarked that

there are still a lot of key things that remain missing—really integrating the data and the analysis tools, and also being able to really link what we can link about the genetics of the pathogen with the clinical data together in real time, in an integrated network. That's the holy grail that a lot of the field is moving towards. And I think that's a key thing for the future. (EVD-21)

G. Key barriers and facilitators to data sharing

PEARLES factors have positive and negative impacts on data sharing. Rather than acting as “facilitators” or “barriers,” PEARLES factors more typically aligned with “opportunities” or “threats” throughout the Ebola implementation period (see Figure 11). Greater detail can be found in the case studies, but a brief overview of PEARLES factors is provided here for review. These are broad generalizations and should not be taken as a definitive summary of this very complex and diverse case.

Figure 10: Facilitators and Barriers of Data Sharing during the 2014-2016 EVD Epidemic

Facilitators for data sharing in the EVD Epidemic	Barriers to data sharing in the EVD Epidemic
Climate of “emergency” encouraged sharing, including breaking norms and rules	Institutional pressure to gain consolidated access to data
Chaotic response environment made data sharing agreements difficult to produce or enforce	Epidemic response “elites” discouraged inclusion of other data stakeholders throughout the long build-up to the epidemic
Novel computing technologies allowed for low-cost, widespread mass communications, dissemination, and collaboration of data	High costs (technical, human, resource, training) needed to effectively sequence data and conduct an epidemiological analysis
Costs of certain kinds of research (molecular, GIS) had dropped substantially	Privacy of individual health data
Small, specialized research communities with consensus around key actors in the network	Political sensitivity of geographically marked data
Norms within the network that support data sharing (with or without future publications)	Competition for publication
	The lack of discipline-specific ethics and norms around data sharing

<p>Existing research institutions or relationships based in affected areas</p> <p>Strong personal relationships with national governments that precede the public health emergency</p> <p>Strong personal relationships with locals based on continuous efforts to nationalize research and share credit.</p> <p>Popular open-source web-based platforms for crowd-sourcing data and analysis, editing data</p> <p>Informal networks based on “trust,” pre-existing social relationships, recognition of expertise, or institutional affiliation</p> <p>Donor mandate to direct resources to data sharing, epidemic response</p> <p>High visibility in the media, resulting in widespread expectations of transparency and accountability at the peak of the responses</p> <p>A culture of curiosity and learning for the purposes of research and response activities</p>	<p>The lack of technical platforms or training for data sharing</p> <p>A lack of interest in specific types of data</p> <p>Legal and regulatory barriers (e.g. private sector/telecoms data)</p> <p>Lack of standardization of data formats, test formats, survey formats, etc.</p> <p>Restricted entry to data portals</p> <p>Data loss due to failure to maintain/archive data portals post-epidemic</p> <p>Lack of “trust”</p> <p>Lack of power (e.g. local community leaders)</p> <p>Non-inclusion of data sharing provisions in target product profiles, resulting in overlooking data sharing in development of research protocols</p> <p>Lack of a funder mandate to utilize response funds for data management and data sharing</p> <p>Non-disclosure agreements in clinical trials</p> <p>Lack of trans-national coordination (coordination between the three most affected countries) meant that non-comparable data was collected, according to different data agreements with each national government</p> <p>Lack of standardization of data</p> <p>Perceptions among response leadership that the situation was “under control” at both the beginning and the end of the epidemic</p> <p>Private sector concerns about legal and regulatory risk if data is shared</p>
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

a) *Political Factors*

Clinical trials data sharing was impacted by political considerations. Due to the severity of the crisis, there was an enormous degree of international visibility for the EVD clinical trials. Political considerations impacted researchers’ research protocols including the timeframe for reporting data and mechanisms for sharing data with local communities. Additionally, national governments sought to ensure that local populations would derive benefits from clinical trials, which required transparency between researchers and government actors.

Clinical data sharing was impacted in that healthcare workers found themselves on the front lines of mediating between an enormous political demand for cooperation with requests for epidemiological information and laboratory samples, and healthcare ethics of patient privacy.

Epidemiological data sharing was impacted by political considerations. The international and national publics were demanding an enormous degree of transparency about the dynamics of the epidemic from the WHO and the national governments.

Genetic sequences data sharing was impacted by political considerations. Researchers who shared sequencing data during the epidemic are known advocates for the democratization of sequencing; and are situated in a network of institutions that are committed to building national research capacities in sub-Saharan Africa.

Biological samples sharing was impacted by political considerations. High income countries imposed barriers on the transport of biological samples due to concerns about infectious disease spread. Countries that had funded research on biological samples in the most-affected countries had pre-existing institutional relationships that enabled barriers to be overcome. National governments also escalated restrictions on the export of biological samples during the outbreak, as public concerns grew that international researchers were stealing African populations' biological property.

GIS/private sector data

Social mobilization pillar data sharing was impacted by political considerations. There was a mass mobilization of social mobilization data collection and data sharing capacities. These measures were taken to respond to population-based rumors that the government was spreading Ebola, that the government was colluding with the international community to test Ebola on local populations, and that the government was receiving financial benefits from clinical trials.

b) *Legal*

Clinical data sharing and Social mobilization pillar data sharing were not impacted by legal considerations. Clinical data was shared using customary practices among healthcare workers, for social mobilization pillar data there is no legal framework, beyond the mandate to obtain ethics review board approval, that imposes limitations or privileges social mobilization data sharing.

Epidemiological data sharing, genetic sequence data sharing, and biological samples data sharing was impacted by legal considerations. Epidemiological line data was widely regarded as the property of the government; users of epidemiological line data regarded themselves as stewards of the government's data. Formal data sharing agreements were established between the WHO and WHO collaborating centers that imposed strict legal restrictions on the use and sharing of epidemiological data. The sharing of biological samples was subjected to unclear and evolving laws around the movement of biological samples in and out of the country.

Clinical trials data sharing and GIS/private sector data sharing were both impacted by concerns about adherence to privacy regulations EU and the United States.

Genetic sequences data sharing was not impacted by legal considerations. Because it was possible to share information about EVD's genetic sequences without providing identifying information about individuals, EVD sequences could be shared freely via open access platforms.

c) *Economic*

Epidemiological data sharing was impacted by economic considerations. At first, all three governments were reluctant to release data suggesting that the EVD epidemic was happening. Later, epidemiological data was regarded as a government asset in Sierra Leone and Liberia that could be leveraged against future commitments of investment to strengthen the health system. It remains unclear what has happened to the epidemiological line data in Guinea.

Clinical data sharing was not impacted by economic considerations.

Clinical trials data sharing was substantially motivated by economic considerations. Data collected through the clinical trials were the property of for-profit pharmaceutical corporations that had committed to scaling development of therapeutics and vaccines. Participants in clinical trials were bound by non-disclosure agreements, which restricted their ability to share information about the clinical trials. However, these economic considerations were couched in the context of a mandate to partner with national governments and the World Health Organization to ensure benefit sharing with local populations and the national government,

Social mobilization pillar data sharing was impacted by economic considerations. There was *Insufficient* funding to collect, centralize, manage, and share social mobilization data throughout the epidemic and afterwards. There continues to be a lack of recognition that social science needs to be a priority-funded activity. However, with the exception of the HIV/AIDS epidemic, few epidemics have seen as great an investment in social mobilization a single epidemic outbreak as occurred during the EVD outbreak.

Biological sample sharing and Genetic sequences data sharing was impacted by economic considerations. Researchers who were dependent on publications for career advancement and research funding withheld sequencing data until publication in order to ensure that they received credit and attribution for their work.

d) *Administrative*

Clinical data sharing was impacted by administrative considerations. Healthcare workers were seen as most responsible for procuring patient consent for use of their information. However, once clinicians handed over information or samples to laboratories and EVD response teams, they had no further influence on the chain of data stakeholdership, and little influence over how data or samples were used or shared.

Genetic sequences data sharing was impacted by administrative considerations.

Social mobilization pillar data sharing was impacted by administrative considerations. There was no pre-existing administrative architecture for building data collection or data sharing platforms for social mobilization, KAP, or anthropological data. There also was no administrative capacity to manage information flows beyond the pillar system. Numerous actors built administrative capacities for sharing data from the ground up in West Africa and globally, only to see them become defunct when the epidemic ended.

e) *Regulatory*

Clinical data sharing was not impacted by economic considerations.

Genetic sequences data sharing was impacted by regulatory considerations. Several international agreements have pre-positioned the public sharing of genetic sequencing data as a public good during epidemics.

Social mobilization pillar data sharing was not impacted by regulatory considerations. There were no regulatory barriers to sharing social mobilization pillar data. However, there were also no regulatory facilitators for sharing social mobilization data beyond the social mobilization pillar.

f) *Logistical*

Clinical data sharing was impacted by logistical considerations. Healthcare workers described how difficult it was just to generate data within the ETU context; and some were able to list the defects of various platforms designed to facilitate the digitization of data and data sharing.

Genetic sequences data sharing was impacted by logistical considerations. Initially a lack of laboratory capacity substantially impacted researchers' ability to generate enough data to develop robust conclusions about the molecular epidemiology of the virus. Once the data was obtained, there were multiple platforms through which data could be shared, and analyses could be circulated.

Social mobilization pillar data sharing was impacted by logistical considerations. There is no standing infrastructure for the consolidation, maintenance, and sharing of data for social mobilization. Temporary capacities were established by a range of actors, but most became defunct or were archived in websites after the epidemic ended. Additionally, social mobilization data was not integrated into overall response data analysis and data sharing. It is unclear why – it may be because there are technical and logistical barriers that are preventing integrated data sharing and analysis.

g) *Ethics*

Clinical data sharing, epidemiological data sharing, biological samples data sharing, and genetic sequences data sharing were all impacted by ethical considerations (narrowly defined as human subject's research regulations).

Social mobilization pillar data sharing was impacted by ethical considerations. Independent researchers and NGOs were concerned that sensitive information about local communities could be revealed if data were shared, and that local populations could be subjected to political reprisals. On the other hand, data sharing in the social mobilization pillar in each country was seen as a path to transparency, accountability, and effectiveness in the EVD response.

h) *Social*

Clinical data sharing was impacted by social considerations. Healthcare workers described taking extraordinary efforts to share data with local populations concerned about patients. Healthcare workers also describe a somewhat informal system of information sharing between the ETUs and local EVD response actors.

Epidemiological data sharing was strongly impacted by social considerations. De-identified line list data was freely shared across socio-professional networks that were loosely informed by the social attribute of trust.

GIS data was impacted by social considerations. Organizations like MSF was able to leverage crowd-sourcing platforms to populate GIS data to support case identification and contact tracing. However, *private sector data (mobile data)* was not impacted by social considerations.

Social mobilization pillar data sharing was impacted by social considerations. For months during the epidemic, social mobilization data was transmitted via informal and semi-informal networks that were mobilized for the purpose of engaging with the Ebola response. These networks drew heavily on the personal credibility of the individuals involved in coordination; and on informal mechanisms of data sharing. It was not until much later in the epidemic that anthropological, public health and social mobilization data was streamlined. At that point, access to social mobilization data became much more restricted.

VII. WORKS CITED

- 1 Health Communication Capacity Collaborative (HC3). Social Mobilization Lessons Learned: The Ebola Response in Liberia. Baltimore, MD, 2017 www.healthcommcapacity.org (accessed Oct 12, 2018).
- 2 Whitty CJM, Mundel T, Farrar J, Heymann DL, Davies SC, Walport MJ. Providing incentives to share data early in health emergencies: the role of journal editors. *Lancet* 2015; **386**: 1797–8.
- 3 Whitty CJM. The contribution of biological, mathematical, clinical, engineering and social sciences to combatting the West African Ebola epidemic. *Philos Trans R Soc Lond B Biol Sci* 2017; **372**: 20160293.
- 4 Yozwiak NL, Schaffner SF, Sabeti PC. Data sharing: Make outbreak research open access. *Nature* 2015; **518**: 477–9.
- 5 Christopher Dye, Kidist Bartolomeos, Vasee Moorthy, Marie Paule Kieny. Data sharing in public health emergencies: a call to researchers. *Bull World Health Organ* 2016; : 1.
- 6 Mason KA. The correct secret: Discretion and hypertransparency in Chinese biosecurity. *Focaal* 2016; **2016**: 45–58.
- 7 Bezuidenhout L. To share or not to share...incentivizing data sharing in life science communities. *Dev World Bioeth* 2018; : 1–7.
- 8 Calisher CH, Woodall JP. Yellow Fever-More a Policy and Planning Problem than a Biological One. *Emerg Infect Dis* 2016; **22**: 1859–60.
- 9 Cori A, Donnelly CA, Dorigatti I, *et al.* Key data for outbreak evaluation: Building on the ebola experience. *Philos Trans R Soc B Biol Sci* 2017; **372**. DOI:10.1098/rstb.2016.0371.
- 10 World Health Organization (WHO). An R&D Blueprint for Action to Prevent Epidemics: Plan of Action. Geneva, Switzerland, 2016.
- 11 Castillo-Salgado C. Trends and Directions of Global Public Health Surveillance. *Epidemiol Rev* 2010; **32**: 93–109.
- 12 Harrison M. Contagion : how commerce has spread disease. Yale University Press, 2012 <https://yalebooks.yale.edu/book/9780300123579/contagion> (accessed July 23, 2018).
- 13 Tilley H. Africa as a living laboratory : empire, development, and the problem of scientific knowledge, 1870-1950. University of Chicago Press, 2011.
- 14 Neill DJ. Networks in Tropical Medicine : Internationalism, Colonialism, and the Rise of a Medical Specialty, 1890-1930. Stanford University Press, 2012.
- 15 Lachenal G. The Lomidine files : the untold story of a medical disaster in colonial Africa. 2017.
- 16 Lachenal G. Le médicament qui devait sauver l’Afrique : un scandale pharmaceutique aux colonies. La Découverte, 2014 http://www.editionsladecouverte.fr/catalogue/index-Le_medicament_qui_devait_sauver_l_Afrique-9782359250879.html (accessed July 23, 2018).
- 17 Lachenal G, Owona Ntsama J, Ze Bekolo D, Kombang Ekodogo T, Manton J. Neglected

- Actors in Neglected Tropical Diseases Research: Historical Perspectives on Health Workers and Contemporary Buruli Ulcer Research in Ayos, Cameroon. *PLoS Negl Trop Dis* 2016; **10**: e0004488.
- 18 Webb Jr JL. The long struggle against malaria in tropical Africa. Cambridge: Cambridge University Press, 2014 <http://admin.cambridge.org/academic/subjects/history/african-history/long-struggle-against-malaria-tropical-africa> (accessed July 23, 2018).
 - 19 Chretien J-P, Rivers CM, Johansson MA. Make Data Sharing Routine to Prepare for Public Health Emergencies. *PLOS Med* 2016; **13**: e1002109.
 - 20 Simon Tripp. Economic Impact of the Human Genome Project. 2011 <https://www.battelle.org/docs/default-source/misc/battelle-2011-misc-economic-impact-human-genome-project.pdf> (accessed July 29, 2018).
 - 21 Kaye J, Heeney C, Hawkins N, de Vries J, Boddington P. Data sharing in genomics--reshaping scientific practice. *Nat Rev Genet* 2009; **10**: 331–5.
 - 22 Cassier M. Flu epidemics, knowledge sharing and intellectual property. In: Giles-Vernick T, Craddock S, eds. *Influenza and Public Health: Learning from Past Pandemics*. Earthscan, 2010: 221–40.
 - 23 Heymann DL, Rodier G. Global Surveillance, National Surveillance, and SARS. *Emerg Infect Dis* 2004; **10**: 173–5.
 - 24 Galambos L, Sewell JE. *Networks of Innovation: Vaccine Development at Merck, Sharpe and Dohme, and Mulford, 1895-1995*. Cambridge University Press, 1995.
 - 25 Mackey TK, Liang BA. Lessons from SARS and H1N1/A: Employing a WHO–WTO forum to promote optimal economic-public health pandemic response. *J Public Health Policy* 2012; **33**: 119–30.
 - 26 Kleinman A, Watson JL. *SARS in China : prelude to pandemic?* Stanford University Press, 2006.
 - 27 Mason KA. *Infectious change : reinventing Chinese public health after an epidemic*. Stanford: Stanford University Press, 2016.
 - 28 Langat P, Pisartchik D, Silva D, *et al*. Is There a Duty to Share ? Ethics of Sharing Research Data in the Context of Public Health Emergencies. *Public Health Ethics* 2011; **4**: 4–12.
 - 29 Weinstein RA. Planning for Epidemics — The Lessons of SARS. *N Engl J Med* 2004; **350**: 2332–4.
 - 30 Zhong NS, Zheng BJ, Li YM, *et al*. Epidemiology and cause of severe acute respiratory syndrome (SARS) in Guangdong, People’s Republic of China, in February, 2003. *Lancet (London, England)* 2003; **362**: 1353–8.
 - 31 Feng D, de Vlas SJ, Fang L-Q, *et al*. The SARS epidemic in mainland China: bringing together all epidemiological data. *Trop Med Int Heal* 2009; **14**: 4–13.
 - 32 Bogner P, Capua I, Lipman DJ, Cox NJ, others. A global initiative on sharing avian flu data. *Nat* 2006 4427106 2006; published online Aug 30.
 - 33 World Health Organization (WHO). *Pandemic influenza preparedness framework for the sharing of influenza viruses and access to vaccines and other benefits*. Geneva, Switzerland,

- 2011
http://apps.who.int/iris/bitstream/handle/10665/44796/9789241503082_eng.pdf;jsessionid=33BD232F320DAE7CBE0A863F6B0F2342?sequence=1 (accessed July 20, 2018).
- 34 Delaunay S, Kahn P, Tatay M, Liu J. Knowledge sharing during public health emergencies: from global call to effective implementation. *Bull World Health Organ* 2016; **94**: 236–236A.
- 35 Public Health Surveillance: A Call to Share Data | IANPHI. 2016
<http://www.ianphi.org/news/2016/datasharing1.html>.
- 36 Christopher Dye, Kidist Bartolomeos, Vasee Moorthy, Marie Paule Kieny. Data sharing in public health emergencies: a call to researchers. *Bull World Health Organ* 2016; : 1.
- 37 Callaway E. Zika-microcephaly paper sparks data-sharing confusion. *Nature* 2016.
- 38 Bollyky T, Fidler DP. The Decline in Virus Sample Sharing is not just about China. 2018.
- 39 Serwadda D, Ndebele P, Grabowski MK, Bajunirwe F, Wanyenze RK. Open data sharing and the Global South-Who benefits? *Science* 2018; **359**: 642–3.
- 40 Tindana P, Molyneux S, Bull S, Parker M. ‘It is an entrustment’ : Broad consent for genomic research and biobanks in Sub-Saharan Africa. *Dev World Bioeth* 2017; published online Oct 23. DOI:10.1111/dewb.12178.
- 41 Jao I, Kombe F, Mwalukore S, *et al.* Research Stakeholders’ Views on Benefits and Challenges for Public Health Research Data Sharing in Kenya: The Importance of Trust and Social Relations. *PLoS One* 2015; **10**: e0135545.
- 42 Boulton G. Science as an Open Enterprise Report:www.royalsociety.org. Edinburgh, 2013
https://openaccess.sdum.uminho.pt/wp-content/uploads/2013/02/1_GeoffreyBoulton_OpenAIREworkshopUMinho.pdf (accessed Feb 24, 2018).
- 43 Ruckenstein M, Schüll ND. The Datafication of Health. *Annu Rev Anthropol* 2017; **46**: 261–78.
- 44 Presidential Commission for the Study of Bioethical Issues. Ethics and Ebola: Public Health Planning and Response. *Ethics and Ebola* 2015; : 90.
- 45 Alirol E, Kuesel AC, Guraiib MM, de la Fuente-Núñez V, Saxena A, Gomes MF. Ethics review of studies during public health emergencies - the experience of the WHO ethics review committee during the Ebola virus disease epidemic. *BMC Med Ethics* 2017; **18**: 43.
- 46 Ethics and Best Practices in Sharing Individual-level Research Data - Global Health Bioethics, Research Ethics; Review. <https://bioethicsresearchreview.tghn.org/research-data-sharing/> (accessed June 18, 2018).
- 47 Crowcroft NS, Ca) NC, Rosella LC, Pakes BN. The ethics of sharing preliminary research findings during public health emergencies: a case study from the 2009 influenza pandemic. *Euro Surveill* 2014; **19**. www.eurosurveillance.org;pii=20831. (accessed July 17, 2018).
- 48 Bull S, Roberts N, Parker M. Views of Ethical Best Practices in Sharing Individual-Level Data From Medical and Public Health Research. *J Empir Res Hum Res Ethics* 2015; **10**: 225–38.

- 49 Abramowitz S, Panter-Brick C. Medical Humanitarianism. 2015 DOI:9780812291698.
- 50 Benoot C, Hannes K, Bilsen J. The use of purposeful sampling in a qualitative evidence synthesis: A worked example on sexual adjustment to a cancer trajectory. *BMC Med Res Methodol* 2016; **16**. DOI:10.1186/s12874-016-0114-6.
- 51 Harrison M. Contagion: How Commerce Has Spread Disease. New Haven, CT: Yale University Press, 2012.
- 52 Willoughby UE. Yellow fever, race, and ecology in nineteenth-century New Orleans. Baton Rouge: Louisiana State University Press, 2017.
- 53 Kotar SL, Gessler JE. Yellow fever: a worldwide history. Jefferson, North Carolina: McFarland & Company, Inc., Publishers, 2017.
- 54 Stepan N. Eradication: Ridding the World of Diseases Forever? Cornell University Press.
- 55 Webb JLA. *Aedes aegypti* suppression in the Americas: historical perspectives. *Lancet (London, England)* 2016. DOI:10.1016/S0140-6736(16)31225-9.
- 56 Packard RMCN-R. P 2016. A history of global health: interventions into the lives of other peoples. Baltimore: Johns Hopkins University Press, 2016.
- 57 Espinosa M. The Threat from Havana: Southern Public Health, Yellow Fever, and the U.S. Intervention in the Cuban Struggle for Independence, 1878-1898. *J South Hist* 2006; **72**: 541–68.
- 58 Humphreys M. Yellow fever and the South. Rutgers University Press.
- 59 Delaporte F. The History of Yellow Fever: An Essay on the Birth of Tropical Medicine. Cambridge, Mass: MIT Press, 1991.
- 60 Vaughan M. A Research Enclave in 1940s Nigeria : The Rockefeller Foundation Yellow Fever Research Institute at Yaba , Lagos , A Research Enclave in 1940s Nigeria : The Rockefeller Foundation Yellow Fever Research Institute at Yaba , Lagos ,. *Bull Hist Med* 2018; **92**: 172–205.
- 61 Echenberg M. “For Their Own Good”: The Pasteur Institute of Dakar and the Quest for an Anti-Yellow Fever Vaccine in French Colonial Africa, 1924-1960,. In: Bado J-P, ed. *Les Conquêtes De La Médecine Moderne En Afrique*. Paris, France: Karthala, 2006: 53–69.
- 62 Bell H. The International Construction of Yellow Fever. In: *Frontiers of Medicine in the Anglo-Egyptian Sudan, 1899-1940*. Oxford University Press, 1999: 163–97.
- 63 Strode GK ed. Yellow Fever. New York, NY: McGraw-Hill Book Company, Inc., 1951.
- 64 Durieux, Mass YF Vaccination French Africa. .
- 65 Cambournac F. Yellow fever in Angola and the islands of São Tomé and Príncipe. *Bull World Health Organ* 1954; **11**: 504–7.
- 66 Varanda J. “A bem da nação”: medical science in a Diamond company in twentieth-century colonial Angola’. 2007.
- 67 Pinto MR, Filipe AR. Arbovirus studies in Luanda, Angola. 1. Virological and serological studies during a yellow fever epidemic. *Bull World Health Organ* 1973; **49**: 31–5.

- 68 Pinto MR, Filipe AR. The yellow fever epidemic in Luanda in 1971. *Bull Soc Pathol Exot Filiales*; **64**: 708–10.
- 69 Monath TP. Yellow fever: Victor, Victoria? Conqueror, conquest? Epidemics and research in the last forty years and prospects for the future. *Am J Trop Med Hyg* 1991; **45**: 1–43.
- 70 Yellow Fever Research Institute, Entebbe, Uganda, Report of Studies, 1939-1946. 1939.
- 71 Robin Y, World Health Organization (WHO). Emergency Teams for Yellow Fever in Africa-Dakar. In: Meeting of Directors of WHO Reference Centres for Arboviruses, Chlamydiae, and Rickettsiae. Geneva, Switzerland, 1974. http://apps.who.int/iris/bitstream/handle/10665/77645/VIR_RC_74.26_Arbo_eng.pdf?sequence=1&isAllowed=y (accessed July 20, 2018).
- 72 World Health Organization (WHO). Present problems of yellow fever in Africa: Report by the Director-General. Geneva, Switzerland, 1970 http://apps.who.int/iris/bitstream/handle/10665/144988/WHA23_PB-14_eng.pdf?sequence=1&isAllowed=y (accessed July 20, 2018).
- 73 Vainio J, Cutts F. Yellow Fever. Geneva, Switzerland, 1998 <http://www.who.ch/gpv-documents/> (accessed July 20, 2018).
- 74 Germain M, Samba EM, Salaun J-J, *et al.* Yellow Fever in the Gambia, 1978–1979: Epidemiologic Aspects with Observations on the Occurrence of Orungo Virus Infections *. *Am J Trop Med Hyg* 1980; **29**: 912–28.
- 75 De Cock KM, Nasidi A, Enriquez J, *et al.* EPIDEMIC YELLOW FEVER IN EASTERN NIGERIA, 1986. *Lancet* 1988; **331**: 630–3.
- 76 Nasidi A, Monath TP, DeCock K, *et al.* Urban yellow fever epidemic in western Nigeria, 1987. *Trans R Soc Trop Med Hyg* 1989; **83**: 401–6.
- 77 Monath TP, Vasconcelos PFC. Yellow fever. *J Clin Virol* 2015; **64**: 160–73.
- 78 Regional Office for Africa (WHO). WHO | Yellow Fever Outbreak Weekly Situation Report, Incident Management Team, Angola - 27 June 2016. 2016 https://www.afro.who.int/sites/default/files/2017-06/angola.yf_sitrep.v3.w25.27june.2016.final_.pdf (accessed July 10, 2018).
- 79 Regional Office for Africa (WHO). WHO | Yellow Fever Outbreak Weekly Situation Report, Incident Management Team, Angola - 4 July 2016. 2016 https://www.afro.who.int/sites/default/files/2017-06/angola.yf_sitrep.v1.w26.01july.2016_3.pdf (accessed July 10, 2018).
- 80 World Health Organization (WHO). WHO | Yellow fever situation reports. WHO. 2018. <http://www.who.int/emergencies/yellow-fever/situation-reports/archive/en/> (accessed July 13, 2018).
- 81 World Health Organization (WHO). WHO | Yellow Fever – China, Disease Outbreak News – 22 April 2016. WHO. 2016. <http://www.who.int/csr/don/22-april-2016-yellow-fever-china/en/> (accessed July 17, 2018).
- 82 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 5 August 2016. 2016 <http://www.who.int/mediacentre/factsheets/fs100/en/> (accessed July 10, 2018).

- 83 Chen Z, Liu L, Lv Y, *et al.* A fatal yellow fever virus infection in China: description and lessons. *Emerg Microbes Infect* 2016; **5**: e69–e69.
- 84 Chen J, Lu H. Yellow fever in China is still an imported disease. *Biosci Trends* 2016; **10**: 158–62.
- 85 Wasserman S, Tambyah PA, Lim PL. Yellow fever cases in Asia: primed for an epidemic. *Int J Infect Dis* 2016; **48**: 98–103.
- 86 Kraemer MUG, Faria NR, Reiner RC, *et al.* Spread of yellow fever virus outbreak in Angola and the Democratic Republic of the Congo 2015–16: a modelling study. *Lancet Infect Dis* 2017; **17**: 330–8.
- 87 WHO. Global Vector Control Response, 2017-2030. 2017 <http://apps.who.int/iris/bitstream/handle/10665/259205/9789241512978-eng.pdf;jsessionid=4C351A4DABD90C5CDC929BF36873A085?sequence=1> (accessed Nov 18, 2018).
- 88 WHO. Who country cooperation strategy: Liberia. Brazzaville, 2011 DOI:10.1109/ICIP.2007.4379119.
- 89 Soares AA. Reining in Angola’s yellow fever outbreak. *Bull World Health Organ* 2016; **94**: 716–7.
- 90 World Health Organization (WHO). WHO | Yellow fever outbreak - Timeline. WHO. 2016. <http://www.who.int/emergencies/yellow-fever/mediacentre/timeline/en/> (accessed July 10, 2018).
- 91 European Centre for Disease Prevention and Control. Assessing the yellow fever outbreak in Angola – European Medical Corps mission undertaken in the framework of the European Union Civil Protection Mechanism, 10–20 May 2016. Stockholm, 2016 <https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/yellow-fever-angola-joint-ecdc-mission-report-2016.pdf> (accessed Feb 24, 2018).
- 92 WHO Health Emergencies Programme. WHO Progress Report on the yellow fever response. 2016 http://www.who.int/about/who_reform/emergency-capacities/oversight-committee/Yellow-Fever-Health-Emergency-Progress-Report-20Oct2016.pdf (accessed July 10, 2018).
- 93 World Health Organization (WHO). Situation Report: Yellow Fever. 28 October 2016. 2016.
- 94 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 28 October 2016. 2016 <http://www.who.int/mediacentre/factsheets/fs100/en/> (accessed July 10, 2018).
- 95 UNICEF Supply Division. Yellow Fever Vaccine: Current Supply Outlook. 2016 https://www.unicef.org/supply/files/YF_number_3_Supply_Update.pdf (accessed July 10, 2018).
- 96 Wu JT, Peak CM, Leung GM, Lipsitch M. Fractional dosing of yellow fever vaccine to extend supply: a modelling study. *Lancet* 2016; **388**: 2904–11.
- 97 Boyd AT, Dombaxe D, Moreira R, *et al.* Notes from the Field: Investigation of Patients Testing Positive for Yellow Fever Viral RNA After Vaccination During a Mass Yellow

- Fever Vaccination Campaign — Angola, 2016. *MMWR. Morb. Mortal. Wkly. Rep.* 2017; **66**: 282–3.
- 98 China to the rescue as yellow fever hits Angola | CAJ News Africa. <http://cajnewsafrica.com/2016/02/29/china-to-the-rescue-as-yellow-fever-hits-angola/> (accessed Oct 14, 2018).
 - 99 Mason KA. Becoming modern after SARS. Battling the H1N1 pandemic and the politics of backwardness in China’s Pearl River Delta. *Behemoth A J Civilis* 2010; : 8–35.
 - 100 World Health Organization (WHO). WHO | Yellow fever situation report - Angola - 4 July 2016. WHO. 2016. <http://www.who.int/emergencies/yellow-fever/situation-reports/04-july-2016/en/> (accessed July 10, 2018).
 - 101 Regional Office for Africa (WHO). WHO Health Emergencies Programme in the African Region. 2016 [https://reliefweb.int/sites/reliefweb.int/files/resources/WHO Annual Report 2016.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/WHO%20Annual%20Report%202016.pdf) (accessed July 12, 2018).
 - 102 World Health Organization (WHO). WHO | Yellow Fever – Angola, Disease Outbreak News – 12 February 2016. WHO. 2016. <http://www.who.int/csr/don/12-february-2016-yellow-fever-angola/en/> (accessed July 10, 2018).
 - 103 WHO. WHOCC - WHO Collaborating Centres. http://apps.who.int/whocc/List.aspx?institution_full_name=centers+for+disease+control& (accessed Aug 3, 2018).
 - 104 Domingo C, Charrel RN, Schmidt-Chanasit J, Zeller H, Reusken C. Yellow fever in the diagnostics laboratory. *Emerg Microbes Infect* 2018; **7**: 129.
 - 105 World Health Organization (WHO). WHO | Yellow fever situation report - Angola - 24 July 2016. WHO. 2016. <http://www.who.int/emergencies/yellow-fever/situation-reports/24-july-2016/en/> (accessed July 10, 2018).
 - 106 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 8 July 2016. 2016 <http://www.afro.who.int/en/yellow-fever/sitreps/item/8782-situation-report-yellow-fever-outbreak-in-angola-4-july-2016.html> (accessed July 10, 2018).
 - 107 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 15 July 2016. 2016 <http://www.who.int/mediacentre/news/statements/2016/yellow-fever-vaccine/en/> (accessed July 10, 2018).
 - 108 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 21 July 2016. 2016 <http://apps.who.int/iris/bitstream/handle/10665/246242/yellowfeversitrep-21Jul16-eng.pdf?sequence=1> (accessed July 10, 2018).
 - 109 World Health Organization (WHO). WHO | Yellow Fever – Democratic Republic of Congo, Disease Outbreak News – 11 April 2016. WHO. 2016. <http://www.who.int/csr/don/11-april-2016-yellow-fever-drc/en/> (accessed July 17, 2018).
 - 110 World Health Organization (WHO). WHO | Yellow Fever – Democratic Republic of Congo, Disease Outbreak News – 2 June 2016. WHO. 2016. <http://www.who.int/csr/don/02-june-2016-yellow-fever-drc/en/> (accessed July 10, 2018).
 - 111 World Health Organization (WHO). WHO | Yellow Fever – Kenya, Disease Outbreak News

- 6 April 2016. WHO. 2016. <http://www.who.int/csr/don/6-april-2016-yellow-fever-kenya/en/> (accessed July 17, 2018).
- 112 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 5 May 2016. 2016
http://apps.who.int/iris/bitstream/handle/10665/205947/yellowsitreps_5May2016_eng.pdf?sequence=1 (accessed July 10, 2018).
- 113 World Health Organization (WHO). WHO | Yellow Fever – China, Disease Outbreak News – 29 March 2016. WHO. 2016. <http://www.who.int/csr/don/29-march-2016-yellow-fever-china/en/> (accessed July 10, 2018).
- 114 World Health Organization (WHO). WHO | Yellow Fever – China, Disease Outbreak News – 6 April 2016. WHO. 2016. <http://www.who.int/csr/don/6-april-2016-yellow-fever-china/en/> (accessed July 17, 2018).
- 115 Song R, Guan S, Lee SS, *et al.* Late or Lack of Vaccination Linked to Importation of Yellow Fever from Angola to China. *Emerg Infect Dis* 2018; **24**: 1383–6.
- 116 Grobbelaar AA, Weyer J, Moolla N, Van Vuren PJ, Moises F, Paweska JT. Resurgence of yellow fever in Angola, 2015–2016. *Emerg. Infect. Dis.* 2016. DOI:10.3201/eid2210.160818.
- 117 Simon-Lorriere E, Faye O, Prot M, *et al.* Autochthonous Japanese Encephalitis with Yellow Fever Coinfection in Africa. *N Engl J Med* 2017; **376**: 1483–5.
- 118 Pybus O. Yellow fever virus in Angola - Yellow fever virus - Virological. 2016. <http://virological.org/t/yellow-fever-virus-in-angola/184/3> (accessed July 13, 2018).
- 119 Chen Z, Liu L, Lv Y, *et al.* A fatal yellow fever virus infection in China: description and lessons. *Emerg Microbes Infect* 2016; **5**: e69–e69.
- 120 Cui S, Pan Y, Lyu Y, *et al.* Detection of yellow fever virus genomes from four imported cases in China. *Int J Infect Dis* 2017; **60**: 93–5.
- 121 European Center for Disease Control. Assessing the yellow fever outbreak in Angola – European Medical Corps mission undertaken in the framework of the European Union Civil Protection Mechanism, 10–20 May 2016. 2016; : 10–1.
- 122 Regional Office for Africa (WHO). WHO | Yellow Fever Outbreak Weekly Situation Report, Incident Management Team, Angola - 5 August 2016. 2016
https://www.afro.who.int/sites/default/files/2017-06/angola.yf_sitreps.v1.w31.5august.2016.pdf (accessed July 10, 2018).
- 123 Regional Office for Africa (WHO). WHO | Yellow Fever Outbreak Weekly Situation Report, Incident Management Team, Angola - 6 June 2016. 2016
https://www.afro.who.int/sites/default/files/2017-06/angola_yf_sitreps_6june_2016.pdf (accessed July 10, 2018).
- 124 Rossetto EV, Luna EJ de A. Reporting delay during the yellow fever outbreak, Angola, 2016. *Rev. Inst. Med. Trop. Sao Paulo.* 2016. DOI:10.1590/S1678-9946201658091.
- 125 Angola Thanks Cuba for Support and Cooperation - ACN. 2016. <http://www.cubanews.acn.cu/economy/5505-angola-thanks-cuba-for-support-and->

- cooperation&c=8014877823109663841&mkt=en-us (accessed July 25, 2018).
- 126 Médecins Sans Frontières. Hunting down mosquitoes to combat yellow fever | Médecins Sans Frontières (MSF) International. 2016. <https://www.msf.org/hunting-down-mosquitoes-combat-yellow-fever> (accessed July 31, 2018).
 - 127 Médecins Sans Frontières. Angola & DRC: MSF teams help curb yellow fever | Médecins Sans Frontières (MSF) International. 2016. <https://www.msf.org/angola-drc-msf-teams-help-curb-yellow-fever> (accessed July 31, 2018).
 - 128 Ahuka-Mundeke S, Casey RM, Harris JB, *et al.* Immunogenicity of Fractional-Dose Vaccine during a Yellow Fever Outbreak — Preliminary Report. *N Engl J Med* 2018; : NEJMoa1710430.
 - 129 World Health Organization (WHO). WHO | Situation Report - Yellow Fever - 30 June 2016. 2016 <http://www.afro.who.int/en/yellow-fever/sitreps/item/8747-situation-report-yellow-fever-outbreak-in-angola-20-june-2016.html> (accessed July 10, 2018).
 - 130 Wilder-Smith A, Massad E. Estimating the number of unvaccinated Chinese workers against yellow fever in Angola. *BMC Infect Dis* 2018; **18**.
 - 131 Wilder-Smith A. Yellow fever vaccination: estimating coverage. *Lancet Infect. Dis.* 2017; **17**: 1109–11.
 - 132 Wilder-smith A, Monath TP. Responding to the threat of urban yellow fever outbreaks. *Lancet Infect. Dis.* 2017; **17**: 248–50.
 - 133 Monath TP, Woodall JP, Gubler DJ, *et al.* Yellow fever vaccine supply: a possible solution. *Lancet* 2016; **387**: 1599–600.
 - 134 Zhao S, Stone L, Gao D, He D. Modelling the large-scale yellow fever outbreak in Luanda, Angola, and the impact of vaccination. *PLoS Negl Trop Dis* 2018; **12**: e0006158.
 - 135 IFRC. Emergency appeal | Angola : Epidemic (Yellow Fever). ; : 1–9.
 - 136 Marlow MA, Pambasange MAC de F, Francisco C, *et al.* *Notes from the Field* : Knowledge, Attitudes, and Practices Regarding Yellow Fever Vaccination Among Men During an Outbreak — Luanda, Angola, 2016. *MMWR Morb Mortal Wkly Rep* 2017; **66**: 117–8.
 - 137 Jean K, Donnelly CA, Ferguson NM, Garske T. A Meta-Analysis of Serological Response Associated with Yellow Fever Vaccination. *Am J Trop Med Hyg* 2016; **95**: 1435–9.
 - 138 Lüge T, MSF GIS Unit. GIS support for the 2016 MSF yellow fever vaccination campaign in Kinshasa. Lausanne, 2017 https://reliefweb.int/sites/reliefweb.int/files/resources/GIS_Support_Yellow_Fever_2017_MSF_EN.pdf (accessed Aug 3, 2018).
 - 139 Hatzky C. Cubans in Angola : South-South cooperation and transfer of knowledge, 1976-1991, The Univer. 2012.
 - 140 Gleijeses P. *Visions of Freedom: Havana, Washington, Pretoria, and the Struggle for Southern Africa, 1976-1991.* Chapel Hill: University of North Carolina Press, 2013.
 - 141 Kirk JM. *Healthcare without Borders: Understanding Cuban Medical Internationalism.* Gainesville: University Press of Florida, 2015.
 - 142 Maxmen A. Massive Ebola data site planned to combat outbreaks. *Nature* 2017; **549**: 15–

- 15.
- 143 Modjarrad K, Moorthy VS, Millett P, Gsell P-S, Roth C, Kieny M-P. Developing Global Norms for Sharing Data and Results during Public Health Emergencies. *PLoS Med* 2016; **13**: e1001935.
- 144 Abramowitz S. Epidemics (Especially Ebola). *Annu Rev Anthropol* 2017; **46**: 421–45.
- 145 Pigott DM, Golding N, Mylne A, *et al.* Mapping the zoonotic niche of Ebola virus disease in Africa. *Elife* 2014; **3**: e04395.
- 146 Groen G van der, Swanepoel M. On the trail of Ebola : my life as a virus hunter. 2016.
- 147 Georges-Courbot MC, Sanchez A, Lu CY, *et al.* Isolation and Phylogenetic Characterization of Ebola Viruses Causing Different Outbreaks in Gabon. *Emerg Infect Dis* 1997; **3**: 59–62.
- 148 Georges A, Leroy EM, Renaut AA, *et al.* Ebola Hemorrhagic Fever Outbreaks in Gabon, 1994–1997: Epidemiologic and Health Control Issues. *J Infect Dis* 1999. DOI:10.1086/514290.
- 149 Mylne A, Brady OJ, Huang Z, *et al.* A comprehensive database of the geographic spread of past human Ebola outbreaks. *Sci Data* 2014; **1**: 140042.
- 150 Pigott DM, Milllear AI, Earl L, *et al.* Updates to the zoonotic niche map of Ebola virus disease in Africa. *Elife* 2016; **5**. DOI:10.7554/eLife.16412.
- 151 Pigott DM, Golding N, Mylne A, *et al.* Mapping the zoonotic niche of Ebola virus disease in Africa. *Elife* 2014; **3**: e04395.
- 152 MacNeil A, Reed Z, Rollin PE. Serologic Cross-Reactivity of Human IgM and IgG Antibodies to Five Species of Ebola Virus. *PLoS Negl Trop Dis* 2011; **5**: e1175.
- 153 Gonzalez JP, Nakoune E, Slenczka W, Vidal P, Morvan JM. Ebola and Marburg virus antibody prevalence in selected populations of the Central African Republic. *Microbes Infect* 2000; **2**: 39–44.
- 154 Busico KM, Marshall KL, Ksiazek TG, *et al.* Prevalence of IgG Antibodies to Ebola Virus in Individuals during an Ebola Outbreak, Democratic Republic of the Congo, 1995. *J. Infect. Dis.* ; **179**. DOI:10.2307/30117610.
- 155 Becquart P, Wauquier N, Mahlaköiv T, *et al.* High Prevalence of Both Humoral and Cellular Immunity to Zaire ebolavirus among Rural Populations in Gabon. *PLoS One* 2010; **5**: e9126.
- 156 Muyembe-Tamfum JJ, Mulangu S, Masumu J, Kayembe JM, Kemp A, Paweska JT. Ebola virus outbreaks in Africa: Past and present. *Onderstepoort J Vet Res* 2012. DOI:10.4102/ojvr.v79i2.451.
- 157 Van Kerkhove MD, Bento AI, Mills HL, Ferguson NM, Donnelly CA. A review of epidemiological parameters from Ebola outbreaks to inform early public health decision-making. *Sci Data* 2015; **2**: 150019.
- 158 Dudas G, Carvalho LM, Bedford T, *et al.* Virus genomes reveal factors that spread and sustained the Ebola epidemic. *Nature* 2017; **544**: 309–15.

- 159 Narat V, Alcayna-Stevens L, Rupp S, Giles-Vernick T. Rethinking Human–Nonhuman Primate Contact and Pathogenic Disease Spillover. *Ecohealth* 2017; **14**: 840–50.
- 160 Johnson E, Jaax N, White J, Jahrling P. Lethal experimental infections of rhesus monkeys by aerosolized Ebola virus. *Int J Exp Pathol* 1995; **76**: 227–36.
- 161 Leroy EM. [The Emergence of Ebola virus in humans: a long process not yet fully understood]. *Bull Acad Natl Med* 2015; **199**: 651-69; discussion 669-71.
- 162 Feldmann H, Wahl-Jensen V, Jones SM, Ströher U. Ebola virus ecology: A continuing mystery. *Trends Microbiol.* 2004; **12**: 433–7.
- 163 Narat V, Alcayna-Stevens L, Rupp S, Giles-Vernick T. Rethinking Human–Nonhuman Primate Contact and Pathogenic Disease Spillover. *Ecohealth* 2017; **14**. DOI:10.1007/s10393-017-1283-4.
- 164 U.S. Centers for Disease Control. Ebola virus disease. 2018. <http://www.who.int/news-room/fact-sheets/detail/ebola-virus-disease> (accessed Aug 12, 2018).
- 165 Pourrut X, Kumulungui B, Wittmann T, *et al.* The natural history of Ebola virus in Africa. *Microbes Infect.* 2005. DOI:10.1016/j.micinf.2005.04.006.
- 166 Mari Saez A, Weiss S, Nowak K, *et al.* Investigating the zoonotic origin of the West African Ebola epidemic. *EMBO Mol Med* 2015; **7**: 17–23.
- 167 Osterholm MT, Moore KA, Kelley NS, *et al.* Transmission of Ebola viruses: what we know and what we do not know. *MBio* 2015; **6**: e00137.
- 168 Caluwaerts S, Fautsch T, Lagrou D, *et al.* Dilemmas in Managing Pregnant Women With Ebola: 2 Case Reports. *Clin Infect Dis* 2016; **62**: 903–5.
- 169 Christie A, Davies-Wayne GJ, Cordier-Lassalle T, *et al.* Possible sexual transmission of Ebola virus - Liberia, 2015. *MMWR Morb Mortal Wkly Rep* 2015; **64**: 479–81.
- 170 Mate SE, Kugelman JR, Nyenswah TG, *et al.* Molecular Evidence of Sexual Transmission of Ebola Virus. *N Engl J Med* 2015; **373**: 2448–54.
- 171 Thorson A, Formenty P, Lofthouse C, Broutet N. Systematic review of the literature on viral persistence and sexual transmission from recovered Ebola survivors: evidence and recommendations. *BMJ Open* 2016; **6**: e008859.
- 172 Uyeki TM, Erickson BR, Brown S, *et al.* Ebola Virus Persistence in Semen of Male Survivors. *Clin Infect Dis* 2016; **62**: 1552–5.
- 173 Chughtai AA, Barnes M, Macintyre CR. Persistence of Ebola virus in various body fluids during convalescence: evidence and implications for disease transmission and control. *Epidemiol Infect* 2016; **144**: 1652–60.
- 174 Wong G, Qiu X, Bi Y, *et al.* More Challenges From Ebola: Infection of the Central Nervous System. *J Infect Dis* 2016; **214**: S294–6.
- 175 Senga M, Pringle K, Ramsay A, *et al.* Factors Underlying Ebola Virus Infection Among Health Workers, Kenema, Sierra Leone, 2014-2015. *Clin Infect Dis* 2016; **63**: 454–9.
- 176 Kilmarx PH, Clarke KR, Dietz PM, *et al.* Ebola virus disease in health care workers--Sierra Leone, 2014. *MMWR Morb Mortal Wkly Rep* 2014; **63**: 1168–71.

- 177 Evans DK, Goldstein M, Popova A. Health-care worker mortality and the legacy of the Ebola epidemic. *Lancet Glob Heal* 2015; **3**: e439-40.
- 178 Leroy EM, Baize S, Lu CY, *et al.* Diagnosis of Ebola haemorrhagic fever by RT-PCR in an epidemic setting. *J Med Virol* 2000; **60**: 463–7.
- 179 Simon-Loriere E, Faye O, Faye O, *et al.* Distinct lineages of Ebola virus in Guinea during the 2014 West African epidemic. *Nature* 2015; **524**: 102–4.
- 180 Tong YG, Shi WF, Liu D, *et al.* Genetic diversity and evolutionary dynamics of Ebola virus in Sierra Leone. *Nature* 2015; **524**: 93–6.
- 181 Gire SK, Goba A, Andersen KG, *et al.* Genomic surveillance elucidates Ebola virus origin and transmission during the 2014 outbreak. *Science (80-)* 2014; **345**: 1369–72.
- 182 Rambaut A, Dudas G, de Carvalho LM, *et al.* Comment on ‘Mutation rate and genotype variation of Ebola virus from Mali case sequences’. *Science (80-)* 2016; **353**: 658.
- 183 Agua-Agum J, Ariyaratnam A, Blake IM, *et al.* Ebola virus disease among children in West Africa. *N Engl J Med* 2015; **372**: 1274–7.
- 184 Dixon MG, Schafer IJ. Ebola viral disease outbreak--West Africa, 2014. *MMWR Morb Mortal Wkly Rep* 2014; **63**: 548–51.
- 185 Uyeki TM, Mehta AK, Davey Jr. RT, *et al.* Clinical Management of Ebola Virus Disease in the United States and Europe. *N Engl J Med* 2016; **374**: 636–46.
- 186 Liu G, Wong G, Su S, *et al.* Clinical Evaluation of Ebola Virus Disease Therapeutics. *Trends Mol Med* 2017; **23**: 820–30.
- 187 Bebell LM, Oduyebo T, Riley LE. Ebola virus disease and pregnancy: A review of the current knowledge of Ebola virus pathogenesis, maternal, and neonatal outcomes. *Birth defects Res* 2017; **109**: 353–62.
- 188 Henwood PC, Bebell LM, Roshania R, *et al.* Ebola Virus Disease and Pregnancy: A Retrospective Cohort Study of Patients Managed at 5 Ebola Treatment Units in West Africa. *Clin Infect Dis* 2017; **65**: 292–9.
- 189 Schoepp RJ, Rossi CA, Khan SH, Goba A, Fair JN. Undiagnosed acute viral febrile illnesses, Sierra Leone. *Emerg Infect Dis* 2014. DOI:10.3201/eid2007.131265.
- 190 Towers S, Patterson-Lomba O, Castillo-Chavez C. Temporal variations in the effective reproduction number of the 2014 west Africa ebola outbreak. *PLoS Curr* 2014; **6**. DOI:10.1371/currents.outbreaks.9e4c4294ec8ce1adad283172b16bc908.
- 191 Nishiura H, Chowell G. Early transmission dynamics of Ebola virus disease (EVD), West Africa, March to August 2014. *Euro Surveill* 2014; **19**.
- 192 Althaus CL, Low N, Musa EO, Shuaib F, Gsteiger S. Ebola virus disease outbreak in Nigeria: Transmission dynamics and rapid control. *Epidemics* 2015; **11**: 80–4.
- 193 Shuaib F, Gunnala R, Musa EO, *et al.* Ebola Virus Disease Outbreak - Nigeria, July-September 2014. *MMWR Morb Mortal Wkly Rep* 2014; **63**: 867–72.
- 194 Van Kerkhove MD, Bento AI, Mills HL, Ferguson NM, Donnelly CA. A review of epidemiological parameters from Ebola outbreaks to inform early public health decision-

- making. *Sci Data* 2015; **2**: 150019.
- 195 Rivers CM, Lofgren ET, Marathe M, Eubank S, Lewis BL. Modeling the impact of interventions on an epidemic of Ebola in Sierra Leone and Liberia. *arXiv Preprint arXiv14094607* 2014.
- 196 Fang LQ, Yang Y, Jiang JF, *et al.* Transmission dynamics of Ebola virus disease and intervention effectiveness in Sierra Leone. *Proc Natl Acad Sci U S A* 2016; **113**: 4488–93.
- 197 Guo Z, Xiao D, Li D, *et al.* Predicting and Evaluating the Epidemic Trend of Ebola Virus Disease in the 2014-2015 Outbreak and the Effects of Intervention Measures. *PLoS One* 2016; **11**: e0152438.
- 198 Ajelli M, Parlamento S, Bome D, *et al.* The 2014 Ebola virus disease outbreak in Pujehun, Sierra Leone: epidemiology and impact of interventions. *BMC Med* 2015; **13**: 1–8.
- 199 Gillespie AM, Obregon R, El Asawi R, *et al.* Social Mobilization and Community Engagement Central to the Ebola Response in West Africa: Lessons for Future Public Health Emergencies. *Glob Heal Sci Pract* 2016; **4**: 626–46.
- 200 Nabarro D. Including Communities in Public Health Action: Harnessing Best Practices. *J Health Commun* 2017; **22**: 1.
- 201 Winters M, Jalloh MF, Sengh P, *et al.* Risk Communication and Ebola-Specific Knowledge and Behavior during 2014–15 Outbreak, Sierra Leone. *Emerg Infect Dis* 2018. DOI:10.3201/eid2402.171028.
- 202 Bedson J. Communities are the Real Heroes Doing Social Mobilisation Differently: Lessons and Recommendations from the Ebola Outbreak. *Ebola Response Anthropol Platf* accessed April 2015; **3**: 2016.
- 203 Abramowitz S. Epidemics (Especially Ebola). *Annu Rev Anthropol* 2017; **46**: 421–45.
- 204 Zachariah R, Harries AD. The WHO clinical case definition for suspected cases of Ebola virus disease arriving at Ebola holding units: reason to worry? *Lancet Infect Dis* 2015; **15**: 989–90.
- 205 Kateh F, Nagbe T, Kieta A, *et al.* Rapid response to Ebola outbreaks in remote areas - Liberia, July-November 2014. *MMWR Morb Mortal Wkly Rep* 2015; **64**: 188–92.
- 206 Parpia AS, Ndeffo-Mbah ML, Wenzel NS, Galvani AP. Effects of Response to 2014-2015 Ebola Outbreak on Deaths from Malaria, HIV/AIDS, and Tuberculosis, West Africa. *Emerg Infect Dis* 2016; **22**: 433–41.
- 207 McLean KE, Abramowitz SA, Ball JD, *et al.* Community-based reports of morbidity, mortality, and health-seeking behaviours in four Monrovia communities during the West African Ebola epidemic. *Glob Public Health* 2016. DOI:10.1080/17441692.2016.1208262.
- 208 Hansch S, Sadaphal S, Leigh J, *et al.* Evaluation of the USAID/OFDA Ebola Virus Disease Outbreak Response in West Africa 2014-2016. Vienna, VA, 2014 https://pdf.usaid.gov/pdf_docs/PA00SSC3.pdf (accessed April 24, 2018).
- 209 Piot P. Ebola's perfect storm. *Science (80-)* 2014; **345**: 1221.
- 210 Piot P, Muyembe J-J, Edmunds WJ. Ebola in west Africa: from disease outbreak to humanitarian crisis. *Lancet Infect Dis* 2014; **14**: 1034–5.

- 211 Walsh S, Johnson O. Getting to Zero : A Doctor and a Diplomat on the Ebola Frontline. .
- 212 Stanturf JA, Goodrick SL, Warren Jr. ML, Charnley S, Stegall CM. Social Vulnerability and Ebola Virus Disease in Rural Liberia. *PLoS One* 2015; **10**: e0137208.
- 213 Bausch DG, Schwarz L. Outbreak of ebola virus disease in Guinea: where ecology meets economy. *PLOS Negl Trop Dis* 2014; **8**: e3056.
- 214 Liu WJ. On the ground in Western Africa: from the outbreak to the elapse of Ebola. *Protein Cell* 2016; **7**: 621–3.
- 215 Zhu F-C, Wurie AH, Hou L-H, *et al.* Safety and immunogenicity of a recombinant adenovirus type-5 vector-based Ebola vaccine in healthy adults in Sierra Leone: a single-centre, randomised, double-blind, placebo-controlled, phase 2 trial. *Lancet (London, England)* 2017; **389**: 621–8.
- 216 Han M, Gui J, Gao G, Liu W. China in Action: National Strategies to Combat against emerging infectious diseases. *Life Sci* 2017; **60**: 1383–5.
- 217 Zhang Q, Gui M, Niu X, *et al.* Potent neutralizing monoclonal antibodies against Ebola virus infection. *Sci Rep* 2016; **6**: 1–15.
- 218 Fink S. A Chinese Ebola Drug Raises Hopes, and Rancor. *New York Times*. 2015; published online June 11.
- 219 Henao-Restrepo AM, Camacho A, Longini IM, *et al.* Efficacy and effectiveness of an rVSV-vectored vaccine in preventing Ebola virus disease: final results from the Guinea ring vaccination, open-label, cluster-randomised trial (Ebola Ça Suffit!). *Lancet* 2016.
- 220 Goldacre B, Harrison S, Mahtani KR, Heneghan C. WHO consultation on Data and Results Sharing During Public Health Emergencies. Background Briefing. Sep 2015 Centre for Evidence-Based Medicine Background Briefing: WHO Consultation on Data and Results Sharing During Public Health Emergencies Background Briefing for WHO consultation on Data and Results Sharing During Public Health Emergencies. 2015. http://www.who.int/medicines/ebola-treatment/background_briefing_on_data_results_sharing_during_phes.pdf (accessed July 24, 2018).
- 221 Schafer IJ, Knudsen E, McNamara LA, Agnihotri S, Rollin PE, Islam A. The Epi Info Viral Hemorrhagic Fever (VHF) Application: A Resource for Outbreak Data Management and Contact Tracing in the 2014–2016 West Africa Ebola Epidemic. *J Infect Dis* 2016; **214**: S122–36.
- 222 Scarpino S V, Iamarino A, Wells C, *et al.* Epidemiological and viral genomic sequence analysis of the 2014 ebola outbreak reveals clustered transmission. *Clin Infect Dis* 2015; **60**: 1079–82.
- 223 World Health Organization (WHO). WHO | Diagnostics. *WHO* 2017. http://www.who.int/medicines/ebola-treatment/emp_ebola_diagnostics/en/ (accessed Aug 12, 2018).
- 224 Steenhuisen J. U.S. Ebola researchers plead for access to virus samples | Reuters. Reuters. 2014. <https://www.reuters.com/article/us-health-ebola-usa-research-exclusive-idUSKBN0IP1DZ20141105> (accessed Oct 14, 2018).

- 225 Abayomi A, Katz R, Spence S, Conton B, Gevao SM. Managing dangerous pathogens: challenges in the wake of the recent West African Ebola outbreak. *Sci Policy* 2016; **1**: 51–7.
- 226 Zinszer K, Morrison K, Anema A, Majumder MS, Brownstein JS. The velocity of Ebola spread in parts of west Africa. *Lancet Infect Dis* 2015; **15**: 1005–7.
- 227 Pigott DM, Milllear AI, Earl L, *et al.* Updates to the zoonotic niche map of Ebola virus disease in Africa. *Elife* 2016; **5**. DOI:10.7554/eLife.16412.
- 228 Lessard-Fontaine A, Soupart M, de Laborderie S. Supporting Ebola Combat with Satellite Images: The MSF Perspective. *GI_Forum* 2015. DOI:10.1553/giscience2015s445.
- 229 Mylne A, Brady OJ, Huang Z, *et al.* A comprehensive database of the geographic spread of past human Ebola outbreaks. *Sci Data* 2014; **1**: 140042.
- 230 Nic Lochlainn LM, Gayton I, Theocharopoulos G, *et al.* Improving mapping for Ebola response through mobilising a local community with self-owned smartphones: Tonkolili District, Sierra Leone, January 2015. *PLoS One* 2018; **13**: e0189959.
- 231 Ayeni F, Misra S, Omoregbe N. Using big data technology to contain current and future occurrence of Ebola Viral Disease and other epidemic diseases in West Africa. In: Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics). 2015. DOI:10.1007/978-3-319-20469-7_13.
- 232 Erikson SL. Cell phones as an anticipatory technology: Behind the hype of big data for ebola detection and containment. Halle, 2018 www.spp1448.de (accessed Oct 14, 2018).
- 233 Abramowitz SA, Hipgrave DB, Witchard A, Heymann DL. Lessons from the West Africa Ebola Epidemic: A Systematic Review of Epidemiological and Social and Behavioral Science Research Priorities. *J Infect Dis* 2018; published online June 23. DOI:10.1093/infdis/jiy387.
- 234 Tsai AC, Kohrt BA, Matthews LT, *et al.* Promises and pitfalls of data sharing in qualitative research. *Soc Sci Med* 2016; **169**: 191–8.
- 235 Chenhall R, Senior K, Belton S. Negotiating human research ethics: Case notes from anthropologists in the field (Respond to this article at <http://www.therai.org.uk/at/debate>). *Anthropol Today* 2011; **27**: 13–7.
- 236 Mauthner NS, Parry O. Qualitative data preservation and sharing in the social sciences: On whose philosophical terms? *Aust J Soc Issues* 2009; **44**: 291–307.
- 237 Abramowitz SA, Bardosh KL, Leach M, Hewlett B, Nichter M, Nguyen V-K. Social science intelligence in the global Ebola response. *Lancet* 2015; **385**. DOI:10.1016/S0140-6736(15)60119-2.
- 238 Martineau F, Wilkinson A, Parker M. Epistemologies of Ebola: reflections on the experience of the Ebola Response Anthropology Platform. *Anthropol Q* 2016.
- 239 Banbury A. I Love the U.N., but it is failing. *New York Times*. 2016; : S45.
- 240 Abramowitz S, McKune SL, Fallah M, Monger J, Tehoungue K, Omidian PA. The Opposite of Denial: Social Learning at the Onset of the Ebola Emergency in Liberia. *J Health Commun* 2017; **22**. DOI:10.1080/10810730.2016.1209599.

- 241 McLean KE, Abramowitz SA, Ball JD, *et al.* Community-based reports of morbidity, mortality, and health-seeking behaviours in four Monrovia communities during the West African Ebola epidemic. *Glob Public Heal* 2016; : 1–17.
- 242 Abramowitz SAA, McLean KEE, McKune SLL, *et al.* Community-Centered Responses to Ebola in Urban Liberia: The View from Below (vol 9, e0003706, 2015). *PLoS Negl Trop Dis* 2015; **9**: e0003706.
- 243 Buli BG, Mayigane LN, Oketta JF, *et al.* Misconceptions about Ebola seriously affect the prevention efforts: KAP related to Ebola prevention and treatment in Kouroussa Prefecture, Guinea. *Pan Afr Med J* 2015; **22 Suppl 1**: 11.
- 244 1000 F, Prevention C for DC and, UNICEF. Follow-up Study on Public Knowledge, Attitudes, and Practices Relating to Ebola Virus Disease (EVD) Prevention and Medical Care in Sierra Leone - KAP-2 Final Report - December 2014. 2014.
- 245 Kobayashi M, Beer KD, Bjork A, *et al.* Community Knowledge, Attitudes, and Practices Regarding Ebola Virus Disease - Five Counties, Liberia, September-October, 2014. *MMWR Morb Mortal Wkly Rep* 2015; **64**: 714–8.
- 246 Iliyasu G, Ogoina D, Otu AA, *et al.* A Multi-Site Knowledge Attitude and Practice Survey of Ebola Virus Disease in Nigeria. *PLoS One* 2015; **10**: e0135955.
- 247 Health Communication Capacity Collaborative, Government of Liberia Ministry of Health. National Knowledge, Attitudes, and Practices (KAP) Survey on Ebola Virus Disease in Liberia. Baltimore: Johns Hopkins Center for Communication Programs, 2017 https://healthcommcapacity.org/wp-content/uploads/2017/07/Liberia_KAP-II_Report_Final-May-2017_HC3.pdf (accessed Oct 14, 2018).
- 248 Pedi D, Gillespie A, Bedson J, *et al.* The Development of Standard Operating Procedures for Social Mobilization and Community Engagement in Sierra Leone During the West Africa Ebola Outbreak of 2014–2015. *J Health Commun* 2017; **22**: 39–50.
- 249 Jalloh MF, Robinson SJ, Corker J, *et al.* Knowledge, Attitudes, and Practices Related to Ebola Virus Disease at the End of a National Epidemic - Guinea, August 2015. *MMWR Morb Mortal Wkly Rep* 2017; **66**: 1109–15.
- 250 Jalloh MF, Bunnell R, Robinson S, *et al.* Assessments of Ebola knowledge, attitudes and practices in Forécariah, Guinea and Kambia, Sierra Leone, July-August 2015. *Philos Trans R Soc Lond B Biol Sci* 2017; **372**: 20160304.
- 251 Bill & Melinda Gates Foundation. Modeling and Measuring Community Engagement in Health Emergencies Convening : Summary Report. 2017.
- 252 Nkengasong JN, Maiyegun O, Moeti M. Establishing the Africa Centres for Disease Control and Prevention: responding to Africa’s health threats. *Lancet Glob Heal* 2017; **5**: e246–7.
- 253 Farley J. *Bilharzia: a history of imperial tropical medicine*. Cambridge: Cambridge University Press, 2012 <http://admin.cambridge.org/academic/subjects/history/history-medicine/bilharzia-history-imperial-tropical-medicine> (accessed July 23, 2018).
- 254 Bogoch II, Creatore MI, Cetron MS, *et al.* Assessment of the potential for international dissemination of Ebola virus via commercial air travel during the 2014 west African outbreak. *Lancet* 2015; **385**: 29–35.

- 255 Untested Ebola drug given to patients in Sierra Leone causes UK walkout. *Guard*. 2014; published online Dec 22. DOI:10.1038/emi.2014.88.
- 256 Senga M, Pringle K, Ramsay A, *et al*. Factors Underlying Ebola Virus Infection Among Health Workers, Kenema, Sierra Leone, 2014–2015. *Clin Infect Dis* 2016; **63**: 454–9.