



# Data Sharing during the West Africa Ebola Public Health Emergency: Case Study Report November 2018

## 1. Introduction

### a. Background to the 2013-15 outbreak:

On December 6, 2013, Emile Ouamouno, a 2-year-old from Meliandou, a small village in the Guinea *forestière*, died after four days of suffering from vomiting, fever, and black stool.<sup>1</sup> The cause of his infection is unknown, although he is now widely considered to be the index case for the outbreak of Ebola hemorrhagic fever now Ebola Virus Disease (EVD). Within a month, the child's sister, mother, and grandmother died after experiencing similar symptoms.<sup>3</sup> The funeral for the latter was attended by a midwife who passed the disease to relatives in another village, and to a health care worker treating her.<sup>4</sup> That health care worker was treated at a hospital in Macenta, about 80 kilometers (50 miles) east. A doctor who treated her contracted Ebola. The doctor then passed it to his brothers in Kissidougou, 133 kilometers (83 miles) away.<sup>4</sup>

Although the outbreak of EVD originated in Guinea, between December 2013 and March 2014, it spread more rapidly in the eastern regions of Sierra Leone and then in North Central Liberia, followed by Nzérékoré in Guinea.<sup>5</sup> Between December 2013 and April 10, 2016, a total of 28,616 suspected, probable, and confirmed cases of Ebola virus disease (EVD) were reported.<sup>5</sup> A total of 11,310 deaths were attributed to the outbreak.<sup>5</sup> The largest numbers of cases and deaths occurred in Guinea, Liberia, and Sierra Leone, but 36 cases were reported from Italy, Mali, Nigeria, Senegal, Spain, the United Kingdom, and the United States.<sup>6</sup> After reaching a peak of 950 confirmed cases per week in September 2014, the incidence dropped precipitously toward the end of that year.<sup>5</sup>

Epidemiological investigations have revealed that primary human infections with the Ebola virus are associated with the handling of infected chimpanzees, gorillas, fruit bats, monkeys, forest antelope and porcupines.<sup>2</sup> Human-to-human transmission of Ebola occurs through close and direct physical contact with infected bodily fluids, the most infectious being blood, feces and vomit.<sup>7</sup> Funeral practices in the region that involved touching and washing dead bodies as well as the unsanitary conditions in many healthcare facilities magnified the risks of human-to-human transmission in the infection, treatment, and death cycles.<sup>7</sup> The 2013-15 outbreak was the 24th known outbreak of Ebola and by far the most severe.<sup>8</sup> A new outbreak occurred in the Democratic Republic of Congo in May, 2017 and then the following year on April 4, 2018.<sup>9</sup> For the latter outbreak, a total of 38 laboratory confirmed and 15 probable cases (deaths for which it was not possible to collect laboratory specimens for testing) have been reported. Of these 53 cases, 29 died, giving a case fatality ratio of 54.7%. On August 1, 2018, a new outbreak occurred in North Kivu province, DRC, on the other side of the country



from the April outbreak. With a case fatality rate of around 55%,<sup>9</sup> and treatments or vaccines licensed only in China and Russia (several candidates are now being considered by EMA and FDA), Ebola remains a biomedical research priority.<sup>10</sup>

There is much that remains unknown about Ebola. Even after nearly 30 outbreaks, scientists still do not know what explains the pathogenicity of the virus or the exact route of zoonotic transmission, even for the 2013-15 outbreak.<sup>11</sup> Fruit bats appear to be the “most likely source of animal-to-human transmission”,<sup>9</sup> although their exact role in the transmission cycle is still unclear. Ebola vaccines are licensed only in China and Russia based on limited clinical data, although licensure dossiers are pending before FDA and EMA and those experimental vaccines were authorized for emergency use for 2017 and 2018 outbreaks in the DRC.<sup>12</sup> Given the major knowledge gaps associated with Ebola, global collaboration and data sharing continue to be vital to understanding and controlling this recurrent infectious disease.

b. Data-sharing during the Ebola outbreak:

The failure to provide or share timely relevant data has been cited as one of the key impediments to mounting an effective response to the Ebola outbreak.<sup>12,13</sup> Although the outbreak was eventually contained, data sharing and communication breakdowns contributed to a significant delay in acknowledgment about the outbreak’s severity and corresponding response.<sup>7</sup> Data sharing barriers were particularly high between medical and scientific researchers and between researchers and responders. Data sharing is important during public health emergencies “to help identify the causative agents; investigate and predict disease spread; define diagnostic criteria; and evaluate treatments and methods to contain further spread.”<sup>14</sup> Experiences with influenza, MERS-CoV, and Zika as well as Ebola have all demonstrated that limitations on data sharing and data accessibility remain significant barriers to global epidemic preparedness and response.<sup>15</sup>

When NGOs, particularly Médecins Sans Frontières (MSF) on the ground in Guinea, called the Ebola outbreak “unprecedented”, the global health community and the World Health Organization doubted the claim in some measure because of incongruous methods of data collection and forms of data sharing. Because WHO maintained significant activities in Guinea, Liberia, and Sierra Leone and cases reported in Guinea and Liberia between April and May technically declined,<sup>16</sup> WHO believed that “that the virus dynamics were not unlike those of past outbreaks, nor was the outbreak unprecedented.”<sup>7</sup> But the perceived decline in cases was itself a result of inadequate data sharing between health ministries, health workers on the ground, and WHO. In addition to problems sharing data on the disease as cases exploded, especially in Sierra Leone, hospitals and health ministries refused to share lists for purposes of contact tracing and containment.<sup>7</sup> The three most affected countries did not share data with each other, but relied upon WHO to act as liaison.

In their statement following a meeting on data sharing during public health emergencies, focusing on Ebola, WHO noted several issues with data sharing during the outbreak: perception that pre-publication disclosure of key results may prejudice journal publication; inconsistent public disclosure of genome sequence data related to emerging pathogens;



delays introduced by data use agreements for evaluation of interventions before or during public health emergencies; delays introduced by clinical trial agreements for evaluation of interventions before or during public health emergencies; non-disclosure of epidemiologic data related to potential public health emergencies; non-disclosure of clinical trial data related to research and development in the context of public health emergencies; capacity development in resource-poor settings to support research and product development for emerging pathogens; ethical considerations focusing on research and product development prior to and during public health emergencies; and lack of awareness about pre-publication data and results sharing mechanisms.<sup>17</sup> The perceived inadequacies of data sharing by biomedical firms and the countries in which they were located raised continuing issues of equity and commitment to response.<sup>18</sup>

As a viral hemorrhagic pathogen first discovered in 1976, and with a history of relatively efficacious containment, but typically afflicting countries without developed healthcare infrastructure, the outbreak of Ebola is an important case study for data sharing practices during public health emergencies in low resource settings. The research response in the early days of the outbreak involved the identification of the pathogen (it was thought in early 2014 to possibly be influenza, Lassa fever, malaria, or typhoid among others), whether it was spreading through a vector or through human-to-human transmission, epidemiological investigations and the development of rapid diagnostics. Before the Ebola outbreak, there was little demographic information about the region so even data about populated villages and their location had to be collected and shared.<sup>19</sup>

Later stages of the research response are ongoing and involve investigations into viral pathogenesis, the animal reservoir species and spillover factors, transmission dynamics, the efficacy of known antiviral drugs and the development and testing of vaccines by stringent regulatory authorities. An effective research response requires the sharing of many types of data, ranging from surveillance and epidemiological information, risk assessments, healthcare facility and emergency management information, observational and experimental studies, clinical trials, viral and patient genomic data. Garnering insights into the data sharing practices relating to the research response to Ebola therefore necessitates engaging a wide range of stakeholders, including community leaders, clinicians, infectious disease specialists, public health authorities, government officials and vaccine developers. Such engagement provides the broadest possible picture of formal and informal data sharing practices through bilateral and multilateral arrangements, between multiple stakeholders at the local, national and international levels.

The data sharing practices associated with the Ebola research response was plagued by many of the same problems encountered during other public health emergencies. Legal and ethical problems associated with patient privacy and informed consent, lack of professional norms around data sharing, uncertainty about which parties are responsible for sharing certain data and who should bear the associated costs of data curation and maintenance, intellectual property considerations of commercial parties, pressure to publish in scientific journals before data is released to the public, technical barriers associated with appropriately disseminating and securing the data, as well as concerns about data reliability and suitability.



There were also data sharing issues that were specific to the response to Ebola because the development of therapeutics and vaccines depended upon idiosyncratic relationships between military funders, public research laboratories, small entrepreneurial biomedical firms, and large pharmaceutical firms with networks and capabilities to work with governmental or military partners.

c. Background to this Report:

This report was commissioned by the Wellcome Trust to analyse the data sharing practices of multiple stakeholders during the response to the West Africa Ebola outbreak. This case study of data sharing for a public health emergency caused by a known pathogen without a licensed intervention will be used to better understand the barriers and enablers to data sharing and how these inform the research response to such outbreaks.

The report team conducted 26 semi-structured interviews ranging between 11 and 67 minutes in duration. Two interviewees preferred to respond to written questions provided via email. Most of the interviewees were identified from media coverage of the Ebola outbreak and applicable scientific literature including scholars and researchers contributing to a volume edited by one of the case study authors. Additional interviewees were identified during the interview process. Interviewees were from Belgium, Canada, France, Germany, Guinea, Liberia, Nigeria, Sierra Leone, Switzerland, the United Kingdom, and United States of America, representing a wide range of stakeholders including public health officials, government representatives, virologists, members of the World Health Organization, hospital-based researchers, public health researchers, and representatives from Médecins Sans Frontières (MSF). Before the interviews took place, interviewees were sent a list of the question categories to be covered in the interviews. Consent was sought from the interviewees and their responses and quotes are de-identified in this report. In some instances, the observations of interviewees have been augmented with reports from the news media and scientific literature.<sup>1</sup>

As per the terms of the project, this report focuses on issues of data sharing in the research response to Ebola, that is epidemiological, surveillance (clinical, laboratory), emergency response, health facility data, pathogen genome data, research data including surveys, qualitative and quantitative data from social science and humanities research, observational studies, clinical trials of diagnostics, therapeutics and preventives, quality controlled interim results, final research results, ancillary research results, 'negative' and inconclusive results. 'Stakeholders' are defined as those involved with the research and public health response to outbreaks, including clinical and public health researchers (including virologists, epidemiologists, geneticists, and epidemiologists among others), social science scholars, clinicians, funders, politicians, modellers, non-governmental organisations and humanitarian organisations, and public health bodies.

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<sup>1</sup> This study was approved as exempt by Georgetown University's Institutional Review Board.



The key themes identified in these interviews have been grouped in this report to cover the barriers to data sharing during the Ebola outbreak (what did not work well during the outbreak), the enablers of effective data sharing (what worked well), and the opportunities for improvement for future public health emergencies (what was learned from the Ebola outbreak).



## 2. Barriers to data sharing during the Ebola outbreak:

Some of the most commonly raised barriers to data sharing were related to 1) the relatively undeveloped state of health infrastructure in the three most affected countries; 2) the fractured sources of relevant data; 3) the lack of coordination and clear roles for data generating sources including non-governmental organizational and governmental responders; 4) the development of diagnostics, therapeutics, and vaccines through multiple layers of public-private partnerships; 5) incentives for private sector researchers that penalized or prohibited sharing; 6) incentives for public sector researchers that penalized or prohibited sharing; 7) ethical and legal constraints related to patient confidentiality and informed consent; and 8) community-level barriers to data sharing.

### a. Standardized and Uniformity in Data Collection and Sharing

Before the Ebola outbreak, Guinea, Liberia, and Sierra Leone had suffered from devastating civil wars or internal conflict, which leveled a corresponding effect on the countries' health system infrastructure.<sup>51</sup> Under WHO assessments, their health infrastructures were among the weakest in the world.<sup>52</sup> These weak infrastructures led to two related problems in the context of data sharing. First, the provision of healthcare and the surveillance and reporting roles often undertaken by public authorities were fractured among dozens of non-governmental organizations, many of which paid higher salaries or offered employment on more favorable terms than state-administered entities of the healthcare system. These organizations maintained non-uniform systems for collecting, centralizing, analyzing and transferring data. Second, when EVD cases emerged in remote areas of the most affected countries, data about illnesses and deaths was confused with other common causes of morbidity and mortality that occurred at high rates in all three countries.

#### i. Epidemiological Data

Diagnosing and treating an infectious disease with epidemic or pandemic potential involves individual-level data, exposure data, and population-level data.<sup>19</sup> These data are used to create line-lists and projection models.<sup>2</sup> Population-level statistics such as demographics and geographic information are then used to predict the future spread of the disease. From December 2013 until March 2014, the lack of uniformity in collecting data and the lack of standardization in reporting it explains discrepancies in the initial assessments by NGOs on the ground, particularly MSF, WHO and the Governments of Guinea, Liberia, and Sierra Leone.<sup>21</sup>

In March 2014, WHO activities in the three most affected countries were extensive and cases in Guinea between April and May had declined under the metrics then used.<sup>53</sup> Although WHO released official case definitions of confirmed, probable and suspected Ebola cases, different

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<sup>2</sup> Line-lists are tables that list each infected patient and contain demographic details such as age, race, potential exposures and transmissions, etc. Line-lists are used to determine how diseases are spread among populations, as well as contact tracing and control efforts.



countries adopted different testing strategies, thereby limiting the opportunity for inter-country comparison. The Government of Sierra Leone used only laboratory confirmed cases in its preliminary response analyses.<sup>54</sup> In Guinea, deceased individuals were not tested for Ebola, meaning these individuals were never classified as confirmed cases, unlike in Liberia and Sierra Leone. In Liberia, “ministries (including port, airport, finance, health and environment) local governments, clinicians, nongovernmental organizations, suppliers, and donors” all collected data related to identifying cases and taking immediate action, but there was “no information sharing” because there was no centralized authority or resource to do so.<sup>54</sup> Even within data collected, inconsistencies limited usefulness. Dates recorded on a case document might have referred ambiguously to when data was collected, submitted, or edited.

Some NGOs providing health services in Guinea and Sierra Leone worked under agreements that authorized the sharing of relevant data only with official health authorities and, in some cases, only with specific administrators.<sup>55</sup> Requests by other NGOs, especially for contact lists, were rejected pretextually or actually on this basis.<sup>7</sup> For instance, one district-level Ebola response centre (DERC) in Sierra Leone found it problematic that NGOs engaged in contact tracing spontaneously but in coordination with their role of providing supplies to families in quarantine. The NGOs took it upon themselves to start taking temperatures, recording travel and contact histories. There was already a contact-tracing team from the DERC visiting them over several days to monitor symptoms and gather information on exposure to risk. There were several other organizations visiting or doing similar activities, undermining the role of the centralized, official authority.

Inconsistent and haphazardly collected and transmitted data bottlenecked at the hospital, ministry, and international levels. Data quoted by Sierra Leone’s Ministry of Health and Sanitation, for example, were inconsistent with WHO’s which was in turn inconsistent with determinations made by responders reporting from the field. MSF, interpreting data based on the geographic dispersion of cases confirmed through methods other than laboratory confirmation and identification of family networks crossing Guinea, Liberia, and Sierra Leone, determined that cases were spreading in the latter well before May 26, when the first case was officially confirmed.<sup>7</sup> The result was data that justified both action and inaction by relevant stakeholders, with other political and economic pressures favoring the latter from March until July 2014.

In Sierra Leone, the Ministry of Health and Sanitation shared data infrequently and sometimes not at all with its own National Ebola Response Centre (NERC) (which integrated UK DFID, UN, and other international stakeholders), but they would share it with WHO. NERC received summary data, but not detailed data relevant to its activities. WHO would publish its data according to its own criteria which affected the credibility of data issued by the NERC, which in turn had to request data from UK DFID and other aid or public health agencies.

The delay had material, significant effect. According to one study, if resources committed in September and delivered in October had done so one month earlier, 12,500 cases could have been prevented.<sup>62</sup>



Sharing of epidemiological and contact list data in Sierra Leone is contrasted with its sharing in Nigeria. There, Nigeria's Port Health Services obtained records of an Ebola-infected patient's travel, contact lists were compiled by public authorities, and 18,000 visits were made by local health workers to those contacts to ensure that the infection wasn't spreading and that those who needed treatment received it. All data was collected at the direction of, and processed through, an emergency Ebola centre.

### *ii. Operational Data*

Operational research requires the collection of accurate, harmonized, and routine data. Across Ebola treatment centres, even just within those run by a single organization like MSF, information was not collected, recorded, and shared through standardized methods. This discrepancy led to difficulties when trying to amalgamate and analyse patient data. Additionally, clinical interventions, such as the use of intravenous fluids, were not recorded systematically across Ebola treatment centres. This lack of records proved to be a lost opportunity because retrospectively assessing what effect interventions and others had on patient outcomes was not possible.<sup>76</sup>

### *iii. Clinical and Genetic Data*

The fractured state of health services provision in Guinea, Liberia, and Sierra Leone resulted in makeshift facilities those seeking treatment visited, limits on the control and use of diagnostics and blood sampling in those facilities, and the transfer of "thousands" of samples out of the countries (evidence suggests less control and therefore more transfer from Guinea and Sierra Leone), research upon which has gone largely unshared.<sup>24</sup>

Before more rapid Ebola diagnostics were developed, several methods for detecting infection and/or disease with Ebola virus had been developed that were amenable for use in clinical laboratory settings.<sup>22</sup> Those fell into three basic categories: (i) serologic tests that detect host antibodies generated against the virus, (ii) antigen tests that detect viral proteins, and (iii) molecular tests that detect viral RNA sequences.<sup>23</sup> The latter method also allowed genetic data to be used to trace genetic mutations so as to track the virus's spread, as well as to determine whether it was sustained by human-to-human transmission or by contact with bats or some other carrier.<sup>24</sup> Genetic data also suggested new probable routes of infection and, importantly, revealed where and how fast mutations were occurring.

In addition to identifying the source and spread of Ebola, this information is crucial to designing effective diagnostics, vaccines and antibody-based therapies.<sup>25</sup> Genome data sets are large and complex, and the best way to understand these complex sequences is to share data "as widely and as quickly as possible."<sup>26</sup> Although researchers in some cases quickly uploaded genetic sequence analyses to platforms like GenBank, there was no standardized way to share or disseminate the data.<sup>25</sup> Just as importantly, of the thousands of samples transferred for purposes of genetic sequencing, few and for many months zero, Ebola virus





sequences were made publicly available.<sup>25</sup> The result of uncontrolled collection and transfer of human and non-human biological samples has been the corresponding distrust fomented by the governments of Guinea and Sierra Leone especially. Access to biological samples is now significantly more regulated by those governments, which have imposed stronger limitations on access and sharing, and more elaborate notifications as to the subject and use of samples studied on or from Guinean or Sierra Leonean territory. Stakeholders from international charities, WHO, aid agencies, and biomedical researchers all confirmed that *legal* acquisition of samples for research through normal *regulatory* channels is now a major impediment to necessary research.

#### b. Community-Level Barriers to Data Sharing

The collection of epidemiological and surveillance data described above informed the emergency response which aimed in significant measure at medical outreach and behavior changes at the community level.<sup>7</sup> Community engagement involves interaction between emergency response workers and members of the affected communities.<sup>37</sup> Community engagement gives researchers an opportunity to surveil the community and learn behaviors and customs and it helps the community be better prepared for future public health emergencies.<sup>38</sup>

Community engagement may describe a wide range of activities including “information delivery, consultation, collaboration in decision-making, empowering action in informal groups or formal partnerships[,] and in health care delivery and promotion.”<sup>39,40</sup> Traditional community engagement efforts involve community partnerships and community meetings, but community engagement has recently expanded to efforts with digital technologies and social media.<sup>41</sup>

After the outbreak was declared a public health emergency, researchers were met with barriers to a surveillance system implementation at the community level.<sup>42</sup> One reason for these barriers was the lack of community context and communication in regard to the proposed systems.<sup>43</sup> One of the largest obstacles researchers met when dealing with West African communities was the misinformation spread about Ebola.<sup>40</sup> In a survey conducted by the CDC, community members in Guinea and Sierra Leone hesitated to share relevant information because of the interruptions to customary practices around burial that would ensue.<sup>3</sup> Community burial customs led to a still-unknown number of “secret burials” in Guinea, Liberia, and Sierra Leone.<sup>44</sup> In Guinea, mishandling of Ebola information resulted in regular violent resistance to surveillance and contact tracing activities.

Emergency response workers assumed a level of homogeneity and hierarchy that hindered data collection and sharing. In the three most affected countries, there were sub-groups within communities as well as overlapping community identities. In one incident in the Guinea *forestière*, emergency response workers assumed village chiefs would be the most effective liaisons for communication and collection of information.<sup>43</sup> Later investigation revealed distrust of those chiefs as well as the identity of leaders with more legitimacy in the community.<sup>44</sup>



Similar barriers were encountered in Sierra Leone:

One international epidemiologist in Sierra Leone said that he achieved more by paying community members to inform on sick people than he did by using the official system, which entailed fines for hiding patients or failing to report someone who was ill. He offered 150,000 leones for information and access to a family or community member, and another 100,000 leones if the person tested positive for Ebola.<sup>57</sup>

### c. Patient confidentiality and informed consent

Where Ebola treatment centres were established (in both rural areas as well as in and around larger cities) and in the context of formalized healthcare facilities like hospitals, the treatment of Ebola patients involved the limitations that patient confidentiality and informed consent pose for biomedical and clinical researchers. In the case of Ebola, these matters became even more relevant given that individual treatment and the public health response were intertwined - sequencing of the Ebola virus strain enabled researchers to trace the outbreak's origin and pattern of transmission.<sup>56</sup> Because people exposed to Ebola showed phenotypic variability in susceptibility to infection and disease severity, human genetic variation likely contributed to individual immunity and infectivity.<sup>33</sup>

Genomic research would not be possible without the collection and sharing of human genomic data.<sup>33</sup> In the three most affected countries, genomic data was in some cases collected and labeled with a patient's identifiable information (name, age, sex, etc.).<sup>33</sup> Data could then be theoretically de-identified, but all mechanisms for protecting sensitive health data were rudimentary (e.g. locked file cabinets) or non-existent. MSF for example, which holds significant data collected and analysed during the outbreak, limits access to data related to sensitive data, contacts or MoUs signed by MSF or the custodian with third parties and by the scope of formal consent.

The sensitivity of data collected from patients posed a dilemma for researchers: obtain informed consent and respect confidentiality according to ethical guidelines or facilitate data sharing for purposes of response.<sup>28</sup> Concern over the confidentiality of data about individuals was the single most consistently cited barrier to data sharing.<sup>14</sup> These concerns led many researchers to hesitate or refuse to sharing data that might compromise patient confidentiality.<sup>29</sup> In the Ebola context, researchers saw firsthand the discrimination faced by both infected persons and survivors, as well as their families.<sup>28</sup> The Liberian Ministry of Health, for example, mandated that no names be released and no bodies photographed.

Informed consent procedures posed similar delays and dilemmas for data sharing.<sup>14</sup> Indeed, some early genomic analyses admitted that informed consent had not been obtained.<sup>58</sup> There were widespread ambiguities as to whether patients had to consent to secondary or other downstream uses of their data.<sup>14</sup> Repeat consent delayed further research and exposed patients to additional risk of stigmatization.<sup>14</sup> Many patients were incapacitated and/or were minors whose parents had died and guardianship became a complex matter of family, village,



or tribal affiliation. All of these unresolved issues contributed toward hesitation and refusal to share data during the Ebola outbreak.<sup>34</sup>

#### d. Speed versus accuracy

Politically and scientifically, there is a frequent dilemma between the speed with which action should be taken if a serious infectious disease is identified and the delay that accompanies additional testing or testing using more effective technologies to ensure that data is accurate. In Sierra Leone, the first confirmed case of Ebola was tested “several times” because the laboratory researchers understood the consequences for the patient who presented, the research underway at that laboratory, and the government of Sierra Leone, which would face inevitable panic by its population, adverse investment and trade consequences abroad, and the necessity to mobilize its weak health infrastructure toward a single threat. The previous 8 largest outbreaks of Ebola took on average two months to be recognized and confirmed.<sup>59</sup>

Solutions to the speed-versus-accuracy dilemma include platforms that allow preliminary posting of analyses and results, like arXiv.org and bioRxiv.org, where researchers can freely post findings that have not been peer reviewed. But the lack of peer review on such sites can leave readers uncertain about quality while exposing researchers to the prospect that major peer-reviewed journals will reject the work as no longer novel, discussed below in 2.e. and 2.f. For example, only 16 Ebola related results were posted to bioRxiv.org before January 1, 2016, and only 7 of those dealt with the sharing of data relevant to the public health response. It is not clear the extent to which concerns about accuracy played a role in the delay in data sharing relative to intellectual property and scientific attribution discussed below.

#### e. Intellectual property and ownership of data

Even in the course of the Ebola outbreak, data was largely regarded as proprietary even if a large number of stakeholders invoked a “moral imperative” for free and open data sharing due to its importance for the response. Intellectual property includes both rights in diagnostics, therapeutics and vaccines that result from research as well as data ownership and original author accreditation.<sup>14</sup> Researchers undertaking genetic sequencing work specifically did not share readily, and, according to one interviewee, would only share with Andrew Rambaut at the University of Edinburgh for purposes of reviewing their raw data, analysis, and conclusions.

##### i. Attribution

As a general matter in the infectious disease context, researchers are reluctant to share data to prevent other researchers from using their work without attribution.<sup>35</sup> Measuring delay in data sharing due to concerns about intellectual property rights or academic attribution is difficult given confounding variables and proffered reasons. One company-based researcher on the ground in Sierra Leone stated that relevant laboratory data could not be shared because he worked under an agreement that required that data could only be shared with a specific administrator at the hospital where the research was done. A second researcher



based at a government public health authority stated that he had “encountered” refusal to share data based on attribution but could not formulate a method by which it could be measured in the Ebola context. It was acknowledged that those generating data are often unable or unwilling to quickly transfer information beyond their research groups or collaborating networks because they either lack the technical capacity or harbour concerns that the data would be analysed and published without due recognition.<sup>61</sup>

Researchers also cited the misuse of data as a reason not to share data.<sup>21</sup> Misuse or misinterpretation of data can lead to the original researcher being discredited, which leads to hesitation when deciding to share data.

### *ii. Commercial Value*

In August 2014, an advisory panel convened by the director general of the World Health Organization determined that using Ebola products not yet tested on humans was ethical given the nature of the emergency. WHO thereafter coordinated research and development efforts with MSF having a significant voice in clinical protocols given the necessity of using MSF facilities. In 2015, trials for the experimental treatments favipiravir and convalescent plasma took place in Guinea, as did trials for brincidofovir in Liberia. The trial for rVSV-EBOV vaccine started in Guinea in March 2015.

Biomedical firms, largely working from research funded by Canadian and U.S. militaries, accelerated the development of the aforementioned therapeutics and vaccines. These firms included Chimerix, Jansen, NewLink Genetics (NewLink), Novavax, Merck, GlaxoSmithKline (GSK), Profectus BioSciences, Inc. (Profectus), Mapp Biopharmaceutical (Mapp), and others.<sup>47</sup> These firms worked in partnership with ministries of health, WHO, the U.S. National Institute for Allergy and Infectious Diseases, and the Norwegian Institute of Public Health.

Evidence on data sharing in light of intellectual property concerns was mixed. A retrospective assessment by WHO authors noted that “trials of two Ebola vaccine candidates (ChAd3-ZEBOV and rVSV-ZEBOV) benefited greatly from an open collaboration between investigators and institutions in Africa, Europe, and North America. These teams, coordinated by the WHO, were able to generate and exchange critical data for the development of urgently needed novel vaccines along faster timelines than have ever before been achieved.”

But a story published by *ScienceInsider*, a news website of the journal *Science*, argued that the theory that NewLinks, the licensee of the most promising vaccine candidate, “dragg[ed] its feet because it was “worried about losing control over the development of the vaccine.”<sup>47</sup> NewLink received at least \$50 million and future post-licensing royalties to collaborate with Merck to further develop and commercialize their vaccine.<sup>47</sup>

Protection of data and trade secrets is necessary for intellectual property and related commercial claims that might be later asserted.<sup>47</sup> Researchers on data sharing between firms especially noted that there were insufficient incentives and infrastructure to do so.<sup>48</sup>



This problem was particularly applicable for “negative” and inconclusive results. For example, Tekmira Pharmaceuticals developed a promising potential treatment for Ebola, TKM-Ebola-Guinea.<sup>50</sup> When the treatment did not show efficacy in Sierra Leone, Tekmira halted enrollment in clinical trials. The company stated that it was “not likely to demonstrate an overall therapeutic benefit.”<sup>50</sup> Tekmira stated that “the data were being analysed and would be made available later.”<sup>50</sup> Similarly, Chimerix of Durham, North Carolina, would not publicly reveal why it withdrew support for a trial of brincidofovir in late January after four patients had been treated.<sup>18</sup> The experimental drug ZMapp was given to a handful of patients before supplies ran out in August 2014. Detailed information on the patients’ reactions to the drug was not released, owing to fears that this would prevent researchers from publishing on the cases.<sup>18</sup> At least two interviewees attributed the failure to share negative or inconclusive data about therapeutics to the potential market for those drugs – because they were developed with several disease targets in mind, not even primarily Ebola – negative results about Ebola trials could adversely affect investor interest or regulatory approvals for other diseases for which they might be effective.

Although there have been ethnographic criticisms of data gathered through mobile phone applications, it is largely understood to represent a promising way to communication information, contact trace, and coordinate response. Cell phone data including GPS locations are not part of an official record, but could communicate routes, patterns, and other relevant data. The ownership of cell phone data was ambiguous and a subject of significant dispute: was that data owned by the government, by the cell phone companies, or users; how do we share data that is not specifically obtained in response to a form generated as solicited messages to users? West African telecommunications companies—Orange, Safaricom, Digicel, and others—had in the past shared call record data for public health programs, but telecommunications firms, the United Nations and the Sierra Leonean government could not agree on terms by which that data would be shared.<sup>68</sup>

#### j. The publishing imperative

One of the fundamental dilemmas for researchers with primarily academic affiliations is in the incentive structure for tenure, promotion, pay, and status. Release of preliminary data may not only subject the researcher to later criticism if the data is erroneous or flawed, but also may jeopardize his or her opportunity to publish the data in peer review journals that satisfy tenure and promotion criteria.<sup>21</sup> Delays and barriers to data sharing of relevant Ebola information included the time taken by authors to prepare, write and submit their papers; desire to first submit results to high profile journals; time taken by journals to review and make decisions about publication; and time taken to complete the publication process.

These delays applied to all data related to the research response including epidemiological, surveillance, emergency response, health facility data, pathogen genome data, research data including surveys, observational studies, clinical trials of diagnostics, therapeutics and preventives, quality controlled interim results, final research results, and inconclusive results. Measurement of this delay has been far more robust for clinical trial data. As of November



14, 2017, ClinicalTrials.gov had listed 35 completed Ebola trials. None had posted a summary of its results onto the database, even though 30 trials had passed the one-year disclosure deadline set by the WHO. For clinical trials related to Ebola, the median publication lag-time (from the end of the study) was 338 days (range 157–621), the median submission lag-time (from study end to submission to the journal where it was eventually published) was 297 days (116–450), and the median review lag-time (from submission to publication) was 178 days (137–193).<sup>64</sup>

Currently, there are few mainstream efforts to address these barriers during public health emergencies. Publishing research takes time, and the peer review process is often not expedited during public health emergencies. The earliest published genomic analyses of the Ebola outbreak, crucial for determining where it originated and how it was transmitted, did not appear until August, 2014. This is a long-standing problem. During the 2003 SARS outbreak, an estimated 22% of research studies relating to SARS were submitted to journals, and only 7% were published.<sup>27</sup>

As with intellectual property barriers, negative results, which are often as helpful as positive results, generally go unpublished because of these structures.<sup>21</sup> Where negative or inconclusive results may be useful, the publishing imperative results in similar delays. Detailed information on the patients' reactions to the drug ZMapp was not released; the stated reason was the adverse effect on the study authors publishing the cases.<sup>18</sup> Physicians in the field employed treatments such as blood plasma, based on the positive results from a minitrial of just eight patients in 1999. Trials set up during the outbreak indicated that this treatment was ineffective, but their results were not immediately made public. "Negative results made public earlier may have diminished pursuit of this [plasma treatment] in a more timely way."<sup>20</sup>

#### k. The lack of data sharing or governance agreements

The structure of data sharing was mediated through entities employed by major funders: the Bill & Melinda Gates Foundation, CDC, CDC Foundation, DFID, the Paul Allen Foundation, the UK government, and USAID among the most significant. These entities operated under agreements that limited or prohibited data sharing, required open data sharing, specified avenues for data sharing, or left the matter of data sharing ambiguous and unpredictable. Entities hired to collect, analyse, or work with discrete forms of data generally did not share that data outside contractual obligations or financial incentives to do so. "Without agreement about the mutually beneficial roles, responsibilities, and legitimate contributions of clinicians, scientists, and public health authorities, parties end up either encroaching on one another or not communicating."<sup>14</sup> These practices are reflected in the retrospective reports entities drafted for donors and others, emphasizing number of geographic locations in which there was a presence, number of volunteers trained, and number of staff hired. One report listed 78 partners and 36 sub-grantees.<sup>69</sup>

Some funders like the Bill and Melinda Gates Foundation and UK DFID made data sharing and data accessibility explicit requirements, although the commitment is broadly to openness



after publication. One agreement between the CDC and a logistics support entity depended upon the program officer who had rotated into the field (every four weeks) with each program officer in turn making different decisions on data sharing. Entities or persons collecting and/or analyzing data would claim that specific agreements under which they worked prohibited data sharing except to specific persons or ministries.

With respect to clinical trial data collected following WHO's August 11, 2014 declaration on emergency uses of products not yet tested in humans, the coordination between WHO, NIAID, MSF, ministries of health in Guinea, Liberia, and Sierra Leone, the Norwegian Research Council, IRDC Canada, donors, and universities minimized data sharing barriers. This coordination was attributed to agreements that clearly defined roles, transparent and agreed-upon categories of data needed for the trials to show evidence of safety and efficacy, and adequate resources to enroll volunteers, conduct trials, and gather information.

Despite the relatively smooth sharing of data during clinical trials, third parties have complained that the data supporting arguably the most important trial in Guinea have never been made completely available. Trials were also delayed because of disagreements over logistics and ethics. For example, after MSF and researchers at the University of Oxford organized trials of the drug brincidofovir that did not include placebo groups, the US Food and Drug Administration pushed for randomized trials that would include untreated controls. The brincidofovir trial eventually went forward without a control group. Requirements for gathering evidence sufficient for FDA approval contemplated paper-based records that, in Sierra Leone, were logistically difficult or impossible.

## I. Political pressures

### i. *Geopolitical and International Organizational Pressures*

Political pressures created both bottlenecks for relevant data as well as incentives to hide or obfuscate data. Between March and July of 2014, the Governments of Guinea and Sierra Leone sought to decrease the perception that there was a crisis, resulting in artificial suppression of the spread of the disease.<sup>7</sup> A retrospective study by Chatham House noted that "several interviewees stated that WHO was not playing an independent role, and that no one in authority wanted to admit to [Sierra Leone] President Koroma how bad the situation was."<sup>65</sup> The health minister played down the severity of the outbreak and the ministry's ability to cope with it.<sup>65</sup> British participants in the response said that by late July they had decided that information coming out of the Sierra Leone Ministry of Health and Sanitation had to be ignored.<sup>65</sup> This sentiment was confirmed by other logistics, humanitarian, and aid representatives.

Separate retrospective studies have catalogued the accusations made between March and July 2014 against MSF, that it was stirring a panic in order to raise donations.<sup>7</sup> In a report by the WHO Ebola Interim Assessment Panel in January 2015, it acknowledged that "problems with information flow and decision-making within WHO and difficult negotiations with countries" explained much of the failure to respond as robustly as it should have, and those



problems and negotiations involved desires primarily by Guinea and Sierra Leone to control or delay the messaging about a health emergency.<sup>66</sup> Ministries overseeing both the economy and finance in Sierra Leone were concerned about what closing the borders would mean to the post-conflict improvements in Sierra Leone's economic outlook, which in early 2014 were significant and promising.<sup>68</sup>

ii. *Domestic Political Pressures*

Similarly, domestic political pressures affected data sharing as national responders worked around internal political divisions and international responders met political resistance they did not understand.

WHO had recruited all 25 members of the district council, but didn't realize they were in an intra-political conflict within the [Sierra Leone] APC [All People's Congress]. This dated back to a point where the district councils were divested of development budget administration, particularly the health budget. In order to punish the APC party, and in particular the president, all 25 members of the district council, in their capacity [as] having been recruited by WHO to be contact tracing supervisors, would simply drag their feet . . . They would see everything happening and they would do nothing to effect positive outcomes in contact tracing. These kinds of things were really railing against us and it took a bit of time to understand this.<sup>65</sup>

This was especially true of the relationship between Sierra Leone's Ministry of Health and the National Ebola Response Centre, which – though nominally partners – often acted as rivals. In one incident in the Guinea *forestière*, emergency response workers assumed village chiefs would be the most effective liaisons for communication and collection of information.<sup>43</sup> Later investigation revealed distrust of those chiefs based on old colonial affiliations as well as the identity of leaders with more legitimacy in the community.<sup>44</sup>





### 3. Enablers to data sharing during the Ebola outbreak:

Over the course of the outbreak, ad hoc and rapidly assembled data sharing enabling forums, committees, digital platforms, shared email accounts, mobile applications, and decision-making hierarchies developed to address the barriers identified above. Responders developed community interventions that lowered barriers to community members sharing information about new cases, secret burials, and recent contacts. Informal networks developed between governmental, for-profit and charitable actors that facilitated the creation of rapid diagnostics and promising vaccine candidates.

#### a. Standardized data collection and sharing forms

Most interviewees agree that the data sharing problems around epidemiological and surveillance data were never fully addressed. In Liberia, field reports from general community health volunteers were often incomplete or very late because of transporting paper copies and the illegibility of completed or semi-completed forms. Shared calendars, listservs, and common platforms emerged, but were underused.<sup>69</sup>

A national alert system with a single, national toll-free phone number, 117, was introduced in Sierra Leone in August 2014 to facilitate prompt identification, investigation, isolation and testing of potential Ebola cases and deaths.<sup>67</sup> During this period, the government maintained a policy of mandatory reporting and Ebola testing for all deaths. The 117 system remained an integral response component during the enhanced surveillance period from the official end of the Ebola epidemic in Sierra Leone in November 2015 until June 2016.<sup>67</sup>

Although the 117 system became the primary mechanism for reporting deaths to the Sierra Leone District Ebola Response Centres and to District Health Management Teams after the DERCs were wound down in December 2015, according to one interviewee, the U.S. Centres for Disease Control Prevention and the World Health Organization rejected the system “out of principle” because incorporating information from the system might require integration of the data in formats incongruous with those they had put in place to assess probable or unlikely cases, build line lists, and inform WHO situation reports.

In Liberia, cell phones were similarly deployed with a “Monitoring, Evaluation, and Learning System” (MELS) that measured knowledge and uptake of behaviors and attitudes. The data could be analysed according to county and district level data. The use of personal digital assistants (i.e., small, mobile, handheld device that can store and retrieve information) has the potential to avert the problem of missed data collection in future outbreaks.<sup>76</sup>

Because data was shared through portable document formats (PDFs), Microsoft PowerPoint presentations, and Excel spreadsheets, especially for line lists, responders in Liberia developed a shared Gmail account. Username and password information to the email account was shared, facilitating information relevant to the response.



## b. Community Engagement Mechanisms

A number of community engagement mechanisms enabled more rapid data sharing of relevant information. Social media sites created forums where communities could share news, updates, and call for assistance.<sup>41</sup> Social media platforms were utilized to track disease progression and gauge community knowledge about infectious diseases.

Analyzing social media websites such as Facebook and Twitter gave researchers useful information about community demographics, disease spread, and state of Ebola treatment centre facilities.<sup>41</sup> Twitter specifically conveyed accurate information about the disease; one retrospective analysis suggested that most information on social media came from mainstream news agencies, which generally report information from public health agencies.<sup>72</sup> Social media platforms also provided channels for *misinformation*. Anecdotal evidence suggests that Twitter might have played a role in Nigeria's efforts to control Ebola at the outset of the 2014 Ebola outbreak, but the World Health Organization (WHO) noted rumors circulating on social media claiming that certain products or practices could prevent or cure Ebola virus disease.<sup>70</sup> One study of English-language tweets found that 55% of those messages from Guinea, Liberia, and Nigeria during September 1–7, 2014, using the terms "Ebola" and "prevention" or "cure" contained at least some medical misinformation. Yet this is consistent with past experience; one analysis estimated misinformation at only 2%, consistent with similar analyses for H1N1.<sup>72</sup> Rural communities without access to digital platforms did not similarly benefit.

Community engagement to facilitate data sharing was implemented during the West Africa Ebola outbreak.<sup>37</sup> While community engagement was in some ways successful, it revealed the need for ongoing community engagement to be fully prepared for future outbreaks.<sup>38</sup> One implementation of community engagement was five-step social mobilization project conducted by Community Engagement and Accountability (CEA), a Red cross affiliate.<sup>38</sup> CEA worked to inform communities about Ebola, and used surveys to track changes in knowledge, behaviors and attitudes.<sup>38</sup> Retrospective analyses do suggest that as a result of community engagement efforts, knowledge regarding Ebola and Ebola transmission rose significantly from the beginning to the end of the campaign, although the effect on behaviors showed an uncertain relationship.<sup>38</sup>

Public information campaigns were the main source of community engagement during the West Africa Ebola outbreak. The sources of information were varied, ranging from radio and television, to church services and community meetings.<sup>3</sup> Researchers also relied on word-of-mouth among the members of the community to help spread information about Ebola.<sup>37</sup> Community artists and musicians also helped raise awareness of Ebola.<sup>37</sup> The Sierra Leone Refugee All Stars recorded a song about Ebola, and Liberian hip-hop artist Shadow released *Ebola in Town*, an informative song describing tips for Ebola prevention.<sup>46</sup> A radio talk show was developed for six community radio stations including health messages related to causes, management, and prevention of EVD.<sup>69</sup> Radio was found to be "the most important method of transmitting messages" to remote locations in Liberia in a short period of time.<sup>69</sup>



c. Fast tracking of Ebola related publications by some scientific journals

Over the course of the outbreak, high impact journals adopted expedited review processes for relevant data including the *New England Journal of Medicine*, *BMJ*, and the *Lancet*.<sup>73,74,75</sup> The World Health Organization has recommended that more journals streamline publishing and expedite the peer review process during public health emergencies.<sup>14</sup>

d. Data Sharing Platforms

Relatedly, data sharing platforms emerged, although they went largely unused or became “data dumpsters.” During the Ebola outbreak, researchers unaffiliated with official response efforts translated surveillance reports into machine-readable formats and shared them in public repositories.<sup>77</sup> Some teams assisting the response rapidly deposited Ebola virus genetic sequences into public databases like Genbank.<sup>24</sup> These efforts appeared to work in some specific contexts—80% of peer-reviewed epidemiological modeling studies published during the outbreak used only open data – but not in others, like clinical trial data for therapeutics including convalescent plasma.<sup>13</sup>

On July 15, 2014, the United Nations Office for the Coordination of Humanitarian Affairs (OCHA) announced the development of the Humanitarian Data Exchange (HDX). HDX was intended as “a new data sharing platform that encompasses the best standards in data collection, offering access to useful and accurate data.”<sup>80</sup> HDX allows users to track and follow specific data sets, create curated organization data hubs, and share data across previously siloed organizations working to improve humanitarian efforts around the world. At its launch, HDX held around 1,600 files, covering a range of regions and humanitarian concerns.

By late 2014, the original 1,600 files on the platform were significantly increased in number, mostly with the addition of regional data – from Sierra Leone, Guinea and Liberia – drawn from WHO. WHO fed data into the platform on the number of Ebola cases and fatalities, the locations of cases, the amount of money being spent on the crisis, as well as information on Ebola Treatment Centres (ETCs – e.g., how many were open at the time, how many were eventually planned to be opened, and their locations).

The result of a collaboration with the Red Cross, World Bank, Global Facility for Disaster Reduction and Recovery (GFDRR), UNMEER and the US Humanitarian Information Unit (HIU), Ebola GeoNode is an open source geospatial platform that lets users build maps and conduct geospatial analysis on Ebola’s impacts in West Africa. Ebola GeoNode is primarily “an open data platform” designed with the intent “to make as much [data] as you can, open.”<sup>80</sup>

Other platforms include(d) EbolaClinicalTrials.org and Ebola Virus Disease Data Sharing Platform Initiative.

e. Informal networks for data sharing



The formation of informal networks of researchers, responders, and decision-makers (aid, national, and international) facilitated data sharing. “Digital humanitarians” applied big data analytics to humanitarian relief via, for example, participatory mapping, crowdsourcing translation, and real time social media communications.<sup>68</sup> Although interviewees largely regarded organizational meetings held between May and August of 2014 as forums where participants struggled to voice concerns and little follow up action took place, they also had the effect of putting national-level researchers in contact with CDC, USAID, CIDA, DFID, WHO and non-governmental organizations. Those Guinean, Liberian, and Sierra Leonean researchers formed a core of trained personnel who worked with international partners.

CDC staff members gathered additional data through professional contacts, media reports, and international authorities.<sup>18</sup> CDC’s established relationships with these and other external partners provided a platform through which scientific knowledge and tools could be shared during the response. However, even with these relationships, the creation of policies such as data-sharing agreements took an extended period of time, sometimes much longer than anticipated.<sup>18</sup> Similar data sharing occurred through agencies and NGOs between May and August 2014, although by that time, many NGOs had evacuated their staffs from the countries, leaving the response to a smaller number of organizations (therefore facilitated response) but also losing the knowledge held by those NGOs.

#### f. Updated reporting systems

In Liberia, the health response was more immediate and transparent. The Ministry of Health and Social Welfare was organized so that a National Technical Management Coordinator aggregated epidemiological, surveillance, mental health, contact tracing, case management and laboratory data.<sup>69</sup> If the national coordinator was not available, then data bottlenecked, a problem that was resolved by the appointment of an incident manager and a deputy incident manager that coordinated with large external entities like CDC.<sup>69</sup> Liberia also reached out specifically to the U.S. National Institute for Allergy and Infectious Diseases for assistance with the research response. Even with active outreach, however, it took NIAID a month to send a response letter detailing requirements for cooperation. In Sierra Leone, information management reportedly improved after the National Ebola Response Centre launched the Situation Room Academy, a training camp on mapping, mobile data collection and advanced Microsoft Excel. More than 600 people across 20 ministries subsequently received skills training to manage data and direct it to the correct decision-maker.

Territorial-based bureaucracies facilitated data-sharing in Liberia and Sierra Leone specifically. After the NERC was formed, it established 14 district level response centres (DERCs) which called or emailed to the NERC once per day with information on the response. The data included the number of safe beds available, how many calls each had received every day to investigate a case, and how many people had died, in order to provide a safe burial. The NERC leadership then received twice-daily briefings focused on identifying and operationalizing key action points based on the day’s information, typically included officials from the government, UNMEER and other UN agencies, and governmental and nongovernmental aid agencies. In part, this was because the priority reporting chain for



agencies was to their own agency. Also, they were collecting data, but not necessarily the data needed for the response. The NERC convened a meeting of all agencies that were collecting data, and as a result trimmed back the key performance indicators from 160 to 41. By the end of January 2015 it had succeeded in harmonizing data collection sufficiently for a more effective response.

#### 4. Opportunities for improving data sharing in future outbreaks of known infectious diseases:

The enablers described above also provide opportunities for improving data sharing in future outbreaks involving a known pathogen without a licensed intervention, although the vaccine developed over the course of the Ebola outbreak is being used in subsequent outbreaks in the Democratic Republic of Congo. Indeed, subsequent outbreaks in DRC have shown how some data sharing enablers have been used and expanded, facilitating a quick and robust response.

These opportunities include template agreements with pre-negotiated terms (parties, confidentiality, intellectual property rights, attribution); data sharing linked to reciprocally beneficial intellectual property agreements that promote both sample and data sharing; regulatory frameworks that are consistent, clear, and versatile with respect to protecting patient confidentiality, informed consent, and facilitating exchange with researchers; formal data sharing platforms and other forms of curation, synthesis and dissemination; and, new publishing models such as pre-print servers and post-publication peer review. Academic reward structures could be modified to reflect the value of data sharing.

##### a. National-led Response Informed by International Health Regulations and Accompanying WHO Support

The failure of the international community and national-level actors to follow the International Health Regulations including capacity building support from the former and failure to report by the latter has been a significant source of blame for the outbreak's course. With respect to data sharing specifically, WHO did not assess the significance of threat nor take action under the IHR in a timely way and the governments of Guinea and Sierra Leone specifically distorted relevant information about the number of cases and the degree of the threat. Even when those barriers eroded, there was significant delay in establishing rational decision-making hierarchies in all three countries. There was little and sometimes no capacity to contact trace, assess geographic spread of the disease, and correspondingly tailor the response.

By contrast, in 2017, the DRC's Ministry of Health informed WHO in May about undiagnosed illness and deaths including haemorrhagic symptoms in Likati Health Zone, Bas Uele Province in the north of the Democratic Republic of the Congo (DRC), bordering Central African Republic. The DRC has a larger healthworkforce and more laboratory



capacity especially for Ebola detection and it was able within two days to confirm Ebola virus subtype Zaire at the Institut National de Recherche Biomédicale (INRB) in Kinshasa. Even before laboratory confirmation, on 10 May 2017, a multidisciplinary team led by the MoH and supported by WHO and partners was deployed to the field and reached the affected area by 13 May 2017 to conduct an in depth field investigation. The DRC activated its national committee against viral haemorrhagic fever and met daily to coordinate the response. All contacts were identified immediately and monitored with support from WHO. The possibility of introducing an Ebola ring vaccination through a “compassionate use” regulatory pathway was approved. The outbreak was declared over on July 2, 2017, when the last patient had tested negative for Ebola a second time.

Similarly, in Guinea, Liberia, and Sierra Leone, national level laboratories and preparedness plans have persisted. Sierra Leone closed the NERC and distributed its personnel and authorities throughout the Ministry of Health and Sanitation. This decision met concern from the public as NERC was viewed as relatively free from the political influences within MOHS. In Liberia, county-level health teams are prepared to detect, report, and respond to probable cases of Ebola and has since responded to outbreaks in 2015 and 2017 that were rapidly contained. In Guinea, the Ministry of Health undertook a comprehensive audit, devolved some functions to the district health level, ministry created a strategic communications unit composed of a spokesperson, a media relations attaché, and a regional and district communication officer. It also developed an intranet site for internal communications. In February 2018, it was able to dispel rumors of an outbreak of Lassa fever. Because the ministry had revamped its website, trained communication staff, and created a monthly newsletter and Facebook page, the ministry was able to more effectively disseminate accurate information.

In Sierra Leone, the 2016 National Civil Registration Act established a new authority in Sierra Leone that registers citizens and residents and records vital events, including births and deaths. As of March 2017, Sierra Leone has in place an electronic reporting system for Integrated Disease Surveillance and Response (IDSR) with weekly data from >95% of health facilities for all IDSR priority diseases.<sup>67</sup> Provided sufficient political will, funding and continuous social mobilisation and community engagement to increase usage, the 117 system could become a model for toll-free, phone-based death reporting tool that could be used in other low-income and middle income countries.<sup>67</sup>

#### b. Open Data Platforms and Databases

In addition to national initiatives that create rational hierarchies for data collection, management, analysis, and distribution, the digital platforms for open data sharing offer an opportunity to facilitate information about index cases, contact tracing, health facility data, trials involving unlicensed therapies, and response coordination.<sup>21</sup> These opportunities are overlapping and mutually supporting. One of the barriers to data sharing using these platforms over the course of the Ebola outbreak was the non-standardized methods for data collection and sharing; this barrier may be addressed through the training of local healthworkers versed in standardized methods of data recording, editing, and analysis.<sup>13</sup>



Guinea, Liberia, and Sierra Leone lacked the resources for serological surveys and accurate census data in the past.<sup>19</sup>

Significant problems with the operation of HDX and Ebola GeoNode were the initial collection of data by real human beings who entered incomplete, inaccurate, or altogether false data. That data in turn was sent to WHO for validation, so that information that was supposed to be available in “real-time” actually reflected a two-month or more delay because of this validation process.

Standardization of databases is important to ensure that data are accurate and not repeated within the database.<sup>36</sup> Standardization requires commitment to procedure and training to ensure procedure is followed properly.<sup>14</sup> Forms and barcodes should be standardized throughout the database, and data should be cleaned to ensure no data is repeated in the database.<sup>19</sup> Maintaining databases can be costly, and there must be consistent capital to maintain these databases.<sup>14</sup> Control of databases should be distributed among stakeholder so that transparency and trust are secure.<sup>36</sup>

To address these shortcomings, Médecins Sans Frontières (MSF), in collaboration with the World Health Organization (WHO), has called upon stakeholders to establish a coordinated network of Ebola biobanks. Additionally, MSF has joined Oxford University’s Infectious Diseases Data Observatory to establish a data-sharing platform for existing and future clinical, biological and epidemiological data, with the aim of making this information accessible to stakeholders and researchers with relevant scientific questions.

Data sharing through biobank is an established practice in many health research fields, from the Global Burden of Disease collaboration to surveillance and response to influenza, drug-resistant malaria and severe acute respiratory syndrome (SARS). Biobanks are well-established resources for disease research, for example on human immunodeficiency virus (HIV), malaria, and rare diseases.

c. Means to identify preliminary data as opposed to confirmed data:

The use of channels for posting preliminary results for use by others has increased unevenly over disciplines relevant to response. Epidemiologists and modelers, for example, have made more significant use of these platforms than have geneticists. Over the Ebola outbreak, 80% of epidemiological studies used data from an open source, while genetic sequencing data was largely hoarded by researchers.

d. The need for standardized data sharing protocols:

“Researchers working on outbreaks — from Ebola to West Nile virus — must agree on standards and practices that promote and reward cooperation. If these protocols are endorsed internationally, the global research community will be able to share crucial information immediately wherever and whenever an outbreak occurs.”<sup>24</sup>



A minimum standard – what information should be included for reporting cases etc. and identifying what is desirable information. A number of organizations including the Royal Institute of International Affairs, the Wellcome Trust, and the World Economic Forum have begun to develop template forms that parties may use for surveillance data sharing, data management plans, sharing benefits, and managing intellectual property rights.

e. The current academic reward system should be restructured:

There was overwhelming consensus among stakeholders that research data are generally considered proprietary, with potentially lucrative benefits that researchers hesitate to freely share. WHO has suggested that researchers treat data sharing as a free trade market, where one researcher must exchange intellectual property for another researcher's intellectual property.<sup>14</sup> Data licensing and transfer negotiations, however, are costly in terms of both time and financial and other resources. This regime further portends adverse effects on researchers from low- and middle-income countries, who lack the resources of researchers in high-income countries.

The International Committee of Journal Committee Editors committed to a position that pre-publication of research results during public health emergencies would not affect publication decisions, but all stakeholders interviewed about that question argued that it had made no difference in the perceptions of researchers that they would be so penalized.

The most frequently proposed approach was the creation of an award system for data sharing that would both reward evidence of sharing by researchers and conversely penalize them, mainly through funding mechanisms, upon a showing that they had not shared when under an obligation to do so.

f. Capacity building initiatives in LMICs:

Researchers were significantly dependent upon staff hired from the three most affected countries. These staff either did not have the knowledge and training to make data sharing effective even when it was proposed and, at higher levels, the importance or relevance of data being shared. "Public health authorities increasingly complement notifications with laboratory data, although in practice, this practice is often limited to high-income countries because it requires considerable laboratory capacity and advanced information technology infrastructure."<sup>31</sup> The Ebola outbreak showed the need for additional investments in health infrastructure and workforce to report data accurately and efficiently.

At a more general level, data sharing improvements should not distract from data accuracy, which would have been significantly improved with investments in health infrastructure. Contact tracing was far more effective when done by healthworkers and volunteers than through cell phone data, for example. NGOs filled much of the healthcare gap in the three most affected countries, but that made coordination and collection of data difficult during





the emergency. Rural regions, like the area where Ebola first emerged, have the lowest levels of both health care practitioners and facilities.<sup>68</sup>

g. Data sharing arrangements made before public health emergencies:

For some relationships, particularly those involving large private sector and for-profit actors, template agreements on data ownership, conditions of subsequent and secondary uses, and distribution of rights may facilitate data sharing. Similarly, it appears that agreements between public health or aid agencies and contractors may be informed by pre-existing terms so that program officers will have guidance when data sharing questions are posed from contractors.

Agreements with national, public funders may also require data sharing and enhance coordination. For example, trials of two Ebola vaccine candidates (ChAd3-ZEBOV and rVSV-ZEBOV) benefited greatly from an open collaboration between investigators and institutions in Africa, Europe, and North America. These teams, coordinated by the WHO, were able to generate and exchange critical data for the development of urgently needed, novel vaccines along faster timelines than have ever before been achieved.<sup>61</sup>

The consensus solution in the secondary literature, confirmed by interviewees, was to enhance data management capacity and analytic expertise in under-resourced settings and to establish data transfer agreement templates now in order to set conditions in the future for the proper use of data and assignment of credit.<sup>61</sup>

## 5. Conclusions:

In the context of the Ebola outbreak, where there was a known pathogen without a licensed intervention, data sharing was important not only to the initial response including treatment of those infected and tracing their contact with others, it was also critical to the research response involving diagnostics, therapeutics, and vaccines. Epidemiological and surveillance data sharing was impeded by the unwillingness or inability of contact tracing organizations to do so because of contractual or funding interests. Once the data *was* shared, it was widely distributed on open platforms although its underlying accuracy was problematic because data entry was not standardized.

Health facility data sharing similarly suffered in the early days of the epidemic because health facilities were being spontaneously constructed. After the dedication of a centralized response authority and a specific means to communicate that information (e.g. 117 in Sierra Leone), that data became more widely and effectively shared.

Pathogen genome data was not widely shared. Indeed, it appears that thousands of samples sent out of Guinea and Sierra Leone remain unaccounted for, potentially subject to study, while few results were released. Genomic sequencing data bottlenecked with one or two



academic authorities who researchers trusted to verify results as part of the scientific process, but ultimately for publication, not for response.

For research on biomedical interventions, data sharing was at its most robust when it was centrally coordinated and funded, for example, by the National Institute for Allergy and Infectious Diseases, the Wellcome Trust, Canadian Institute for Health Research, the World Health Organization, and similar large charitable and governmental stakeholders. This data sharing was less robust for negative or inconclusive results, which were either not released or delayed.

In general, community engagement during the West Africa Ebola outbreak involved meetings with community leaders and public information campaigns. While many of these efforts were successful, the implementation of each exposed the need for preventative, ongoing community engagement to prepare for future outbreaks.

Finally, political pressures negatively affected data sharing by creating an incentive for the Guinea and Sierra Leone governments specifically to view skeptically data pointing to a severe public health emergency, data which was in turn made questionable by the lack of health infrastructure available to gather and report it in a standardized way. Once the extent of the emergency became clear and decision-making infrastructure was put in place at the national level, data sharing became more robust.

Each of these data sharing barriers may be addressed, at least partially and in some cases wholly, through planning and targeted investments. For some barriers, enablers emerged over the course of the Ebola public health emergency that may serve as models for future efforts at data generation, collection, sharing and analysis. For others, focused policy measures and monetary investments will be necessary to fill in gaps and remedy weaknesses, especially where centralized public health infrastructure is underdeveloped.



## Bibliography:

1. Roberts, M. First Ebola boy likely infected by playing in bat tree. *BBC*, Dec. 30, 2014. <https://www.bbc.com/news/health-30632453>. Accessed July 24, 2018.
2. World Health Organization. Ebola Virus Disease. Feb. 12, 2018. <http://www.who.int/news-room/fact-sheets/detail/ebola-virus-disease>. Accessed July 24, 2018.
3. 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. *Phil. Trans. R. Soc. B.* 2017;372:20160304. doi:10.1098/rstb.2016.0304.
4. Yan H. and Smith, E. Ebola: Who was patient zero? *CNN*, Jan. 21, 2015. <https://www.cnn.com/2014/10/28/health/ebola-patient-zero/index.html>. Accessed July 24, 2018.
5. WHO Ebola Response Team. After Ebola in West Africa - Unpredictable Risks, Preventable Epidemics. *N Engl J Med* 2016; 375:587-596 DOI: 10.1056/NEJMSr1513109.
6. Ansumana R, Jacobsen KH, Sahr F, et al. Ebola in Freetown area, Sierra Leone — a case study of 581 patients. *N Engl J Med* 2015;372:587-588.
7. Medecins Sans Frontieres. Pushed to the limit and beyond: a year into the largest ever Ebola outbreak. 2015. <https://www.doctorswithoutborders.org/sites/usa/files/msf143061.pdf>. Accessed July 24, 2018.
8. Corum J. A History of Ebola in 24 Outbreaks. *New York Times*. Dec. 29, 2014. <https://www.nytimes.com/interactive/2014/12/30/science/history-of-ebola-in-24-outbreaks.html> Accessed July 24, 2018.
9. World Health Organization. Ebola Virus Disease: Democratic Republic of Congo External Situation Report 15. [http://apps.who.int/iris/bitstream/handle/10665/273088/SITREP\\_EVD\\_DRC\\_20180712-eng.pdf?ua=1](http://apps.who.int/iris/bitstream/handle/10665/273088/SITREP_EVD_DRC_20180712-eng.pdf?ua=1). Accessed July 24, 2018.
10. Restrepo, A. et. al. Efficacy and effectiveness of an rVSV-vectored vaccine expressing Ebola surface glycoprotein: interim results from the Guinea ring vaccination cluster-randomised trial. *Lancet*. July 31, 2015 [http://dx.doi.org/10.1016/S0140-6736\(15\)61117-5](http://dx.doi.org/10.1016/S0140-6736(15)61117-5).
11. Lever, R. and Whitty, C. Ebola virus disease: emergence, outbreak, and future directions. *British Medical Bulletin*, Volume 117, Issue 1, 1 March 2016, Pages 95–106, <https://doi.org/10.1093/bmb/ldw005108>.
12. Sane J, Edelstein M. *Overcoming Barriers to Data Sharing in Public Health: A Global Perspective.*; 2015.
13. Chretien JP, Rivers CM, Johansson MA. Make data sharing routine to prepare for public health emergencies. *PLoS Med*. 2016;13(8):e1002109. doi:10.1371/journal.pmed.1002109.
14. Goldacre B, Harrison S, Mahtani KR, et al. WHO consultation on data and results sharing during public health emergencies. Centre for Evidence-Based Medicine. 2015. [http://www.who.int/medicines/ebola-treatment/background\\_briefing\\_on\\_data\\_results\\_sharing\\_during\\_phes.pdf](http://www.who.int/medicines/ebola-treatment/background_briefing_on_data_results_sharing_during_phes.pdf).



15. Bruckner, T. Where's the Data? Missing Trial Results Undermine Pandemic Preparedness, *Devex* (Nov. 14, 2017), <https://www.devex.com/news/opinion-where-s-the-data-missing-trial-results-undermine-pandemic-preparedness-91162>. Accessed July 24, 2018.
16. Hein, W. Response to the West African Ebola Outbreak (2014-16): A Failure of Global Health Governance? in *The Governance of Disease Outbreaks International Health Law: Lessons from the Ebola Crisis and Beyond*. Vierck, Leonie, Villareal, Pedro and Weilert, A. Katerina Eds, Nomos. 2017.
17. World Health Organization. Statement arising from a WHO Consultation held on 1-2 September 2015. [http://www.who.int/medicines/ebola-treatment/blueprint\\_phe\\_data-share-results/en/](http://www.who.int/medicines/ebola-treatment/blueprint_phe_data-share-results/en/). Accessed July 24, 2018.
18. Hayden E. Ebola teaches tough lessons about rapid research. *Nature*. May 27, 2015. <https://www.nature.com/news/ebola-teaches-tough-lessons-about-rapid-research-1.17623>. Accessed July 24, 2018.
19. Cori A, Donnelly CA, Dorigatti I, et al. Key data for outbreak evaluation: building on the Ebola experience. *Phil. Trans. R. Soc. B*. 2016;372:20160371. <http://dx.doi.org/10.1098/rstb.2016.0371>.
20. Mupapa K, Massamba M, Kibadi K, Kuvula K, Bwaka A, Kipasa M, Colebunders R, & Muyembe-Tamfum JJ, Treatment of Ebola Hemorrhagic Fever with Blood Transfusions from Convalescent Patients: International Scientific and Technical Committee, *J. Infect. Dis.*; 179 SUPPL. 1 (Feb. 1999), <https://www.ncbi.nlm.nih.gov/pubmed/9988160>.
21. Brack M, Castillo T. Data sharing for public health emergencies: key lessons from other sectors. Chatham House. 2015. [https://www.chathamhouse.org/sites/files/chathamhouse/field/field\\_document/20150417DataSharingPublicHealthLessonsBrackCastillo.pdf](https://www.chathamhouse.org/sites/files/chathamhouse/field/field_document/20150417DataSharingPublicHealthLessonsBrackCastillo.pdf). Accessed July 25, 2018.
22. World Health Organization. First Diagnostic Test for Ebola Accepted by WHO. [http://www.who.int/medicines/news/1st\\_diagnostic\\_test\\_ebola/en/](http://www.who.int/medicines/news/1st_diagnostic_test_ebola/en/). Accessed July 25, 2018.
23. Broadhurst M. et. al. Diagnosis of Ebola Virus Disease: Past, Present, and Future. *Clin. Microbiol. Rev.* October 2016 vol. 29 no. 4 773-7931 October 2016. doi: 10.1128/CMR.00003-16
24. Yozwiak NL, Schaffner SF, Sabeti PC. Data sharing: Make outbreak research open access. *Nature*. 2015;518:477-479. doi:10.1038/518477a.
25. Lewis, T. How Do Doctors Test for Ebola?, *LiveScience*. Oct. 3, 2014). <https://www.livescience.com/48141-how-doctors-test-for-ebola.html>. Accessed July 25, 2018.
26. Marian, A. Sequencing Your Genome: What Does it Mean?, *Methodist Debakey Cardiovascular Journal* (Jan. 2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4051326/>.
27. Merson, L. et al., Trust, Respect, and Reciprocity Informing Culturally Appropriate Data-sharing Practice in Vietnam, *Journal of Empirical Research on Human Research Ethics* 10, NO. 3 (July 1, 2015), doi: 10.1177/1556264615592387.
28. Geller G, Dvoskin R, Thio C.L, Duggal P, Lewis M.H, Bailey T.C, Sutherland A, Salmon D.A, Kahn J.P. Genomics and infectious disease: a call to identify the ethical, legal, and



- social implications for public health and clinical practice. *Genome Medicine*. 2014;6:11. doi: 10.1186/s13073-014-0106-2
29. Bull, S. et al., Best Practices for Ethical Sharing of Individual-Level Health Research Data From Low- and Middle-Income Settings, *Journal of Empirical Research on Human Research Ethics* 10, NO. 3 (July 1, 2015), doi: 10.1177/1556264615594606
  30. Gardy J, Loman NJ, Rambaut A. Real-time digital pathogen surveillance - the time is now. *Genome Biol.* 2015;16(1):15-17. doi:10.1186/s13059-015-0726-x.
  31. Edelstein M, Lee LM, Herten-Crabb A, Heymann DL, Harper DR. Strengthening Global Public Health Surveillance through Data and Benefit Sharing. *Emerg Infect Dis.* 2018;24(7):1324-1330. doi:10.3201/eid2407.151830.
  32. Milne-Price S, Miazgowicz KL, Munster VJ. The emergence of the Middle East Respiratory Syndrome coronavirus. *Pathog Dis.* 2014;71(2):119-134. doi:10.1111/2049-632X.12166
  33. Privacy in ethics and Ebola: public health planning and response. Presidential Commission for the Study of Bioethical Issues. 2016. <https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/5%20Privacy%20-%20Ethics%20and%20Ebola%209.30.16.pdf>. Accessed July 25, 2018
  34. Emmett KJ, Lee A, Khiabani H, et al. High-resolution genomic surveillance of 2014 Ebolavirus using shared subclonal variants. *PLOS Currents Outbreaks.* 2015;1. <http://currents.plos.org/outbreaks/article/obk-14-0092-high-resolution-genomic-surveillance-of-2014-ebolavirus-using-shared-subclonal-variants/>.
  35. Butler, C., Flu Papers Spark Row Over Credit for Data, *Nature* (2013), <http://www.nature.com/news/flu-papers-spark-row-over-credit-for-data-1.12901>
  - 36 Maxmen A. Huge Ebola data site takes shape. *Nature News.* 2017;549:15.
  - 37 Marais, F., Minkler, M., et al., A Community-Engaged Infection Prevention and Control Approach to Ebola, *Health Promotion International*, 2015. 441
  - 38 International Federation of Red Cross and Red Crescent Societies, Epidemic Ready: Community Engagement Key in Fight Against Ebola. 2017. [https://reliefweb.int/sites/reliefweb.int/files/resources/IFRC\\_CEA-in-Ebola-preparedness\\_Operational-case-study\\_FINAL.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/IFRC_CEA-in-Ebola-preparedness_Operational-case-study_FINAL.pdf)
  - 39 MacQueen, K., Anant, B., Frolich, J., Holzman, J., Sugarman, J., Evaluating Community Engagement in Global Health Research: the Need for Metrics. *BMC Medical Ethics.* 2015; 16: 44.
  - 40 Musesengwa, R., Chimbari, M. & Mukaratirwa, S. Initiating Community Engagement in an Ecohealth Research Project in Southern Africa, *S. Infect. Dis. Poverty*, 2017.
  - 41 Tambo, E., Kazienga, A. M. Talla, Chengho, C.F. & Fotsing, C. Digital Technology and Mobile Applications Impact on Zika and Ebola Epidemics Data Sharing and Emergency Response, *Journal of Health and Medical Informatics* (Mar. 7, 2017), <https://www.omicsonline.org/open-access/digital-technology-and-mobile-applications-impact-on-zika-and-ebolaepidemics-data-sharing-and-emergency-response-2157-7420-1000254.php?aid=89727>
  - 42 Jobanputra, K., Greig, J., Shankar, G., et al., Electronic Medical Records in Humanitarian Emergencies – the Development of an Ebola Clinical Information and Patient Management System. *F1000 Research.* 2016. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5357025/>.



43. Gillespie, A., Obregon, R., El Asawi, et al., Social Mobilization and Community Engagement Central to the Ebola Response in West Africa: Lessons for Future Public Health Emergencies, *Global Health: Science and Practice*. Dec. 23, 2016. 627. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5199179/>.
44. Wilkinson, A., Parker, M., Martineau, F. & M. Leach, Engaging “Communities”: Anthropological Insights from the West African Ebola Epidemic, *Royal Society Publishing*, 3 (Oct. 20, 2016), <http://rstb.royalsocietypublishing.org/content/royptb/372/1721/20160305.full.pdf>.
45. *Social Mobilization*, UNICEF (June 24, 2015), [https://www.unicef.org/cbsc/index\\_42347.html](https://www.unicef.org/cbsc/index_42347.html).
46. Cohen, A. *Sierra Leone’s Refugee All Stars are Refugees Again – From Ebola*, NPR (Nov. 6, 2014), <https://www.npr.org/sections/goatsandsoda/2014/11/06/362054623/sierra-leones-refugee-all-stars-are-refugees-again-from-ebola>.
47. Fisher III, W. & Geddes, K., Learning from Ebola: How Drug-Development Policy Could Help Stop Outbreaks of Infectious Diseases. 2015., [https://cyber.harvard.edu/people/tfisher/Learning\\_from\\_Ebola.pdf](https://cyber.harvard.edu/people/tfisher/Learning_from_Ebola.pdf).
48. Littler, K. et al., Progress in promoting data sharing in public health emergencies, *Bulletin of World Health Organization* (2017), <http://www.who.int/bulletin/volumes/95/4/17-192096/en/>.
49. Could Ebola vaccine delay be due to an intellectual property spat?, *CBC News* (2014), <http://www.cbc.ca/news/canada/manitoba/could-ebola-vaccine-delay-be-due-to-an-intellectual-property-spat-1.2786214>.
50. Pollack, A. Clinical Trial of Experimental Ebola Drug is Halted, *The New York Times* (2015), <https://www.nytimes.com/2015/06/20/health/clinical-trial-of-experimental-ebola-drug-is-halted.html>.
51. Boozary ASF, Farmer PE, Jha AK. The Ebola outbreak, fragile health systems, and quality as a cure. *JAMA, J Am Med Assoc*. 2014;312(18):1859–60.
52. WHO. The world health report 2000 - Health systems: improving performance. World Health Organization: 2000.
53. Hein, W., Response to the West African Ebola Outbreak (2014-16): A Failure of Global Health Governance? *The Governance of Disease Outbreaks International Health Law: Lessons from the Ebola Crisis and Beyond*. Vierck, Leonie, Villareal, Pedro and Weilert, A. Katerina Eds, Nomos. 2017.
54. Schreiber, L. Chasing an Epidemic: Coordinating Liberia's Response to Ebola, 2014-15. 2017. Princeton University.
55. Jr. Donald C. McNeil, "Nigeria’s Actions Seem to Contain Ebola Outbreak," *New York Times*, September 30, 2014.
56. Gire SK, Goba A, Andersen KG, Sealfon RS, Park DJ, Kanneh L, Jalloh S, Momoh M, Fullah M, Dudas G, Wohl S, Moses LM, Yozwiak NL, Winnicki S, Matranga CB, Malboeuf CM, Qu J, Gladden AD, Schaffner SF, Yang X, Jiang PP, Nekoui M, Colubri A, Coomber MR, Fonnies M, Moigboi A, Gbakie M, Kamara FK, Tucker V, Konuwa E, et al. Genomic surveillance elucidates Ebola virus origin and transmission during the 2014 outbreak. *Science*. 2014;345:1369–1372. doi: 10.1126/science.1259657.



57. Ross, E., Welch, G., and Angelides, P. Sierra Leone's Response to the Ebola Outbreak: Management Strategies and Key Responder Experiences. 2017.  
<https://www.chathamhouse.org/sites/default/files/publications/research/2017-03-31-sierra-leone-ebola-ross-welch-angelides-final.pdf>
58. Baize, S, Pannetier D, et al. Emergence of Zaire Ebola Virus Disease in Guinea. *NEJM* 2014; 371:1418-1425.  
[https://www.nejm.org/doi/10.1056/NEJMoa1404505?url\\_ver=Z39.88-2003&rfr\\_id=ori:rid:crossref.org&rfr\\_dat=cr\\_pub%3dwww.ncbi.nlm.nih.gov](https://www.nejm.org/doi/10.1056/NEJMoa1404505?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dwww.ncbi.nlm.nih.gov)
59. Pagano, H. and Poncin, M. Treating, Containing, Mobilizing. in Halabi, S., Gostin, L., and Crowley, J. *Global Management of Infectious Disease after Ebola*. 2017.
60. Olliaro P. Initiation and publication time-lags of treatment trials for Ebola virus disease. *The Lancet*. Vol 18:1. January 1, 2018.  
[https://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(17\)30698-9/fulltext](https://www.thelancet.com/journals/laninf/article/PIIS1473-3099(17)30698-9/fulltext)
61. Modjarrad K, Moorthy, et al. Developing Global Norms for Sharing Data and Results during Public Health Emergencies. *PLOS Medicine*. January 5, 2016.  
<https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001935#pmed.1001935.ref003>
62. Ebola's Legacy: UK Deficits and their lessons. 387(100) *Lancet* 403. 2016.
63. Modjarrad K, Moorthy VS, Millett P, Gsell P-S, Roth C, Kieny M-P (2016) Developing Global Norms for Sharing Data and Results during Public Health Emergencies. *PLoS Med* 13(1): e1001935. <https://doi.org/10.1371/journal.pmed.1001935>
64. Olliaro, P. Initiation and publication time-lags of treatment trials for Ebola virus disease. *Lancet Infectious Diseases*. 2018; 18: 28-29.  
[https://doi.org/10.1016/S1473-3099\(17\)30698-9](https://doi.org/10.1016/S1473-3099(17)30698-9).
65. Ross, E., Welch, G., and Angelides, P. Sierra Leone's Response to the Ebola Outbreak: Management Strategies and Key Responder Experiences. 2017.  
<https://www.chathamhouse.org/sites/default/files/publications/research/2017-03-31-sierra-leone-ebola-ross-welch-angelides-final.pdf>
66. WHO, 68h World Health Assembly, Document A68/25, Annex "Ebola Interim Assessment Panel" 3. 2015.  
[http://apps.who.int/gb/ebwha/pdf\\_files/WHA68/A68\\_25-en.pdf?ua=1](http://apps.who.int/gb/ebwha/pdf_files/WHA68/A68_25-en.pdf?ua=1).
67. Alpren C, Jalloh MF, Kaiser R, et al. The 117 call alert system in Sierra Leone: from rapid Ebola notification to routine death reporting. *BMJ Global Health*. 2017;2(3):e000392. doi:10.1136/bmjgh-2017-000392.
68. Erikson, S. Cell Phones Self and Other Problems with Big Data Detection and Containment during Epidemics. *Medical Anthropology Quarterly*. 2018; 1-25.
69. USAID. Social Mobilization Lessons Learned: The Ebola Response in Liberia. 2017.
70. World Health Organization. Ebola: experimental therapies and rumoured remedies: Ebola situation assessment. 2014 Aug 15 [cited 2014 Aug 22]. Available from: <http://www.who.int/mediacentre/news/ebola/15-august-2014/en>
71. Oyeyemi SO, Gabarron E, Wynn R. Ebola, Twitter, and misinformation: a dangerous combination? *BMJ* 2014;349:g6178.
72. Fung, I. et. al. Social Media's Initial Reaction to Information and Misinformation on Ebola, August 2014: Facts and Rumors. *Public Health Reports*. 2016; 131(3), 461-473.



73. New England Journal of Medicine. Ebola Virus. <https://www.nejm.org/ebola-virus>
74. BMJ. Ebola. <https://www.bmj.com/ebola>
75. Lancet. <https://www.thelancet.com/campaigns/ebola?code=lancet-site>
76. Fitzpatrick G, Decroo T, Draguez B, et al. Operational Research during the Ebola Emergency. *Emerging Infectious Diseases*. 2017;23(7):1057-1062. doi:10.3201/eid2307.161389.
77. cmrivers/ebola. GitHub. <https://github.com/cmrivers/ebola>
78. 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: 1797–1798. pmid:26843294.
79. World Health Organization. Report of the Ebola Interim Assessment Panel—May 2015. <http://www.who.int/csr/resources/publications/ebola/ebola-interim-assessment/en/>
80. <http://odim pact.org/files/case-studies-sierra-leone.pdf>