FIGHTING EBOLA WITH INFORMATION
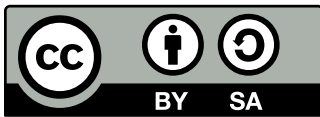
Learning from the Use of Data, Information, and Digital Technologies in the West Africa Ebola Outbreak Response

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FOREWORD

When the Ebola outbreak hit West Africa in late 2013, the world was caught unprepared. The consequence: over 30,000 Ebola cases, including approximately 11,000 dead, and billions of dollars lost across the global system.

In response to the outbreak, USAID joined with communities, governments, and organizations to help affected countries control and, ultimately, contain the disease. As part of celebrating this hard won achievement, the international community must reflect, learn, and act based on this experience to help ensure such a tragedy is not repeated.

This report is a contribution to that end. It focuses on one aspect of the multi-faceted response: the role of data and digital technologies. Grounded in over 130 interviews and peer review, the report surfaces a breadth of experiences and perspectives, and concludes with practical recommendations that health, humanitarian, and development actors should take to be better prepared for the next crisis.

Information was critical to the fight against Ebola. Both for responders, who needed detailed and timely data about the disease's spread, and for communities, who needed access to trusted and truthful information with which they could protect themselves and their loved ones. Yet, as we now know all too clearly, the technical, institutional, and human systems required to rapidly gather, transmit, analyze, use, and share Ebola-related data frequently were not sophisticated or robust enough to support the response in a timely manner.

We must strengthen these systems. This is essential both to keep pace with diseases that spread with the ferocity and velocity of Ebola, and to be more resilient in the face of future threats.

Although the focus of this report is the need for strengthened capacity, systems, and use of data, we recognize that this alone is not sufficient. Our hope is that these recommendations are incorporated alongside new knowledge of effective public health interventions, preparedness, and priorities for health system strengthening. Ultimately, our willingness to engage these challenges—on a daily basis and within public health systems—will be the best predictor of our success in stopping similar events.

Let us learn from and act upon these lessons to do justice both to those directly affected by Ebola, and to the efforts that ultimately brought to heel one of the most significant health and humanitarian crises of the early 21st century.

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EXECUTIVE SUMMARY

In December 2013, a little-known viral hemorrhagic fever in West Africa was detected in a forest region of Guinea. It was soon confirmed to be Ebola Virus Disease, an illness previously seen primarily in Central Africa. Within months, Ebola would become a global outbreak. To contain the disease, national and international actors needed access to timely, accurate, and precise data. Yet as the disease spread across Guinea and into the neighboring countries of Liberia and Sierra Leone, critical outbreak data often were missing, unclear, or contradictory. Unexplained peaks and valleys in Ebola case counts, for example, and dramatically differing forecasts of the disease's potential spread complicated the relief effort and raised important questions about why it was so difficult to track the disease.

This report details key findings from research focused on the collection, management, analysis, and use of paper-based and digital data and information comprising the Ebola outbreak response. It reveals common sources of the confusing data picture, particularly in the early days of the response, and examines the use of digital technologies to support data and information flows, considering both common barriers and insights from what worked. Building upon a qualitative research approach, including interviews with over 130 individuals engaged in the response, including representatives from NGOs, UN agencies, donor and national governments, and the technology and private sector between November 2014 and February 2016, the research addresses the following questions:

▶ **What contributed to the "fog of information"**[1] that characterized much of the early stages of the Ebola outbreak response?

▶ **What can be learned** from the use of data, information, and digital technologies during the Ebola outbreak response? How and where were they used effectively?

▶ **What should be done** to improve the use of data, information, and digital technologies in emergency contexts, to support long-term recovery, and to build resilience against future shocks?

Recalling the context in which the outbreak flourished and revisiting predictions of Ebola's spread sets the scene for analyzing the Ebola outbreak and response: three countries with porous borders, interconnected populations, and fragile health systems and infrastructure following years of civil conflict and war. In this context, Ebola quickly spread out of control, catching national and international actors unprepared, with regard both to the rapid rise in prominence of a rarely encountered viral hemorrhagic fever, and to the degree of coordination of actors, systems, and data that a hybrid public health and humanitarian emergency of this scale would entail.

A number of critical factors contributed to an unclear and asynchronous picture of the disease's spread— the **"fog of information"** that characterized the effective collection and use of data in the early days. These included: weak infrastructure, such as gaps in reliable electricity and/or digital connectivity; an absence of baseline data, including commonly-used unique citizen identifiers and comprehensive and accessible geographic maps; and the predominance of non-machine-readable data, including the collection of many

kinds of disease outbreak and response data on paper, and the publication of summary reports in non-machine-readable format, slowing and narrowing the use of these data. Coordination challenges surfaced in responding to a hybrid health and humanitarian emergency, the impact of non-aligned data standards, and a lack of interoperability between the numerous data systems used to manage data prior to and during the response also contributed to the unclear and asynchronous data picture. Finally, the outbreak underscored the importance of the cultural context and trusted affinity groups in delivering behavior change and other messaging, regardless of delivery channels.

Data about Ebola cases were structured, collected, and used in many complex forms, and frequently involved the time-consuming task of being transferred from paper to digital format. An array of data sets supported the response, including Ebola case data. Their definition, use, and management informed the Ebola response. Case data about individual patients, as well as caseload data composed of aggregated individual case data, were central to understanding the disease's trajectory and to formulating corresponding aspects of the operational response. Tensions arose regarding the collection and use of data, such as by health professionals treating patients on the one hand, and humanitarian responders tracking and responding to the effects the disease's spread on the other. Case data, once digitized, were more easily managed and used; however, the proliferation of data platforms negatively impacted on the response.

Nine case studies demonstrate the **flow of Ebola response data and information** via digital channels and the contributions and challenges of their use. Although digitized data and information flows did not constitute the norm, they did contribute meaningfully to the Ebola outbreak response in specific instances. When used effectively, they introduced both quantitative and qualitative differences in data and information flows. The case studies illustrate the differences the integration of digital technologies enabled, such as increasing the diversity of information flows (e.g. "up" for data collection, as well as horizontally among peer groups, and back "down" through feedback loops) among a greater plurality of actors (e.g., frontline health workers, citizens, governments, and "remote" responders).

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The **value proposition** for integrating digital technologies lies in enabling richer, more diverse, and more rapid data and information exchange, the benefits of which can accrue to health and humanitarian programs, particularly in crises. These include:

▶ increased accountability, **insights**, and **incentives**

▶ an ability to create **feedback loops** through the sharing of contextualized data and information back to the point of origin

▶ the ability to implement continuous learning and **adaptive programming**, in which activities are modified and, ideally, regularly adapted on the basis of real-time or near real-time data and information and

▶ the ability to make **better-informed decisions** at all levels

The use of digital technologies will not, as this research demonstrates, automatically confer these benefits. Indeed, the report finds that the barriers that impede the effective flow of data and information in paper-based environments must also be considered in the integration and use of digital technologies for data and information exchange, and for use in decision-making.

While many of the recommendations in the report require significant investments in human capacity and institutional policies and procedures to reap the benefits of data and digital technologies, certain **"quick wins"** (see Table 4) can be rapidly deployed in the next emergency to support responders and affected communities. These include adopting machine-readable forms, deploying pre-negotiated short codes, ensuring online- and offline-sync capacity for digital technologies, instituting GIS-enabled systems, and providing wifi and satellite-based mobile and broadband connectivity to health facilities and other key institutions.

To unlock the full value of digital technologies, increased attention to and investments in the human, institutional, and policy and regulatory enabling ecosystems are required. Specific **recommendations** include:

While many of the recommendations require significant investments in human capacity and institutional policies and procedures to reap the benefits of data and digital technologies, certain "quick wins" can be rapidly deployed in the next emergency to support responders and affected communities.

▶ **Invest in physical infrastructure that extends digital connectivity** in order to increase resilience in the context of health, humanitarian, and other crises.

▶ **Conduct baseline, country-wide ICT assessments** to gauge the reach, quality, and citizen access to mobile and broadband connectivity, and publish findings on shared repositories using machine-readable formats. This allows the prioritization of investments to extend the physical infrastructure that enables digital connectivity.

▶ **In an emergency, develop and implement emergency protocols for rapid updates to baseline country-wide ICT assessments** that gauge the reach, quality, and citizen access to mobile and broadband connectivity, and catalogue the effects of an emergency on baseline connectivity infrastructure and access. Doing so enables an understanding of the extent to which mobile and broadband technologies can support the response by rapidly identifying critical connectivity gaps.

Taken together, [these recommendations] will help strengthen the effective use of data and information to support health and humanitarian programming—whether in emergencies such as Ebola, in recovery, or to promote long-term resilience.

▶ **Build staff capacity and data literacy as well as institutional capacity** to leverage digital systems and real-time data in support of operations, programs, and decision-making. Effectively using data and digital technologies require more, not fewer, staff to coordinate and manage collection of information across multiple partners, to support use and adaptation of digital platforms, and — most importantly — to analyze data in order to inform decision-making.

▶ **Negotiate preparedness protocols with key actors** (governments, mobile network operators (MNOs), and regulatory bodies) to increase telecommunications network access in emergency situations. This will facilitate rapid collaboration with key actors and support the deployment of ICTs during an emergency response.

▶ **Support the development of digital health strategies connected to interoperable emergency preparedness protocols.** Where appropriate, linking emergency health data systems with national routine health data systems, such as disease surveillance, will make standing up emergency systems during a crisis easier and faster, and help to improve data quality.

▶ **Advance the ethical and responsible use of data and digital technology.** Good data practices include establishing protocols that protect individuals' privacy and security, including for vulnerable populations.

▶ **Agree upon and support the broad uptake of common data standards** to enable effective sharing of data across sectors, systems, and silos.

▶ **Build processes that work toward openness and interoperability.** Reduce fragmentation and duplication related to data and ICT to maximize investments and to ensure maximum value of data.

▶ **Encourage coordinated and sustained investments in interoperable data and data systems or platforms.** Minimize duplication of efforts and funding and co-invest to achieve scale.

▶ **Consider the use environment, including the digital infrastructure, sociocultural, and psychosocial context** in designing and deploying digital technologies. Ensure digital technologies are used in a manner that is relevant, appropriate, ethical, and efficient.

▶ **Insert feedback loops in the full lifecycle of project conceptualization,** from design and delivery to monitoring and evaluation. Increase the effectiveness of programming and improve humanitarian and development outcomes.

▶ **Design programs to incorporate digitized data and information flows.** Enable faster feedback and iteration, and expand the nodes of connection in order to increase the effectiveness of programming.

Implementing these recommendations will not be easy or quick. Taken together, however, they will help strengthen the effective use of data and information to support health and humanitarian programming—whether in emergencies such as Ebola, in recovery, or to promote long-term resilience.

INTRODUCTION

In December 2013, a little-known viral hemorrhagic fever was detected in the forest region of Guinea, triggering what would soon become a global outbreak. The Ebola Virus Disease (Ebola), a zoonotic disease, had jumped from animals to humans dozens of times since it was first detected in 1976. Most of what is known about the epidemiology of Ebola is derived from studies of outbreaks in Kikwit, Democratic Republic of Congo and Gulu, Uganda. Yet unlike all prior outbreaks, this one would reach into densely populated capital cities where it would mushroom into "large and explosive outbreaks,"[1] and go on to become a large-scale epidemic.

Ebola cases first moved from rural Guinea into the capital city, Conakry, and subsequently appeared in the capital cities of Monrovia, Liberia, and Freetown, Sierra Leone. Although the vast majority of cases originated in urban areas, rural areas were hit hard as well. This was particularly the case in the tri-border nexus of Guinea, Liberia, and Sierra Leone, where people frequently crossed borders because of trade and family connections. These countries were hit hardest due in part to weak health systems and physical infrastructure that remained undeveloped after years of war and civil conflict.[2] Nor were other countries immune, and the disease spread to Nigeria, Senegal, Mali and beyond.

The government of Guinea, where the first case had emerged deep in a forested region, officially announced its outbreak in March 2014. As the **outbreak escalated**, in August 2014 the World Health Organization (WHO) declared the Ebola outbreak a "Public Health Emergency of International Concern" (PHEIC).[3] Despite the declaration, the international response failed to keep pace with the disease's spread, due to multiple factors including: weak health systems, limited human resources for health, the presence of unknown chains of transmission, community resistance, unsafe burials, porous borders, and a mutation of the virus that caused increased infectivity and contributed to increased mortality in Liberia and Sierra Leone.[4] In September 2014, Joanne Liu, the International President of Médécins Sans Frontières (MSF), called the response "lethally inadequate," and urged the massive deployment of military and civilian teams.[5] Two weeks later, the United Nations established its first-ever emergency health mission, the UN Mission for Ebola Emergency Response (UNMEER).[6]

The fatal consequences of the relative unpreparedness of both national and international actors to respond to an outbreak of this ferocity and scale were quickly revealed. In early fall 2014, the number of people infected with Ebola continued to climb, doubling approximately every three weeks (see Figures 1–4). At the height of the crisis in Liberia in late September 2014, approximately 500 people were infected with Ebola in one week, with hundreds more exposed.[7] By the end of April 2016, the toll of the outbreak reached 30,057 Ebola cases and 10,990 deaths (see Table 1).

Photo @ UNMEER/Simon Ruf

TABLE 1: The Toll of Ebola in Guinea, Liberia, and Sierra Leone (March 1, 2014–April 30, 2016)

	Cumulative cases—probable, suspected, and confirmed+	Cumulative case— confirmed only	Cumulative deaths—probable, suspected, and confirmed+	Cumulative deaths— confirmed only
Guinea	3,814	3,358	2,544	2,088
Liberia	11,849	3,162	4,856	1,241*
Sierra Leone	14,394	8,706	3,590	3,956
Total	30,057**	15,226	10,990***	7,285

Source: CDC, based upon figures from the WHO together with the governments of Guinea (Ministère de la Santé Publique), Liberia (Ministry of Health, http://www.mohsw.gov.lr), and Sierra Leone (Ministry of Health and Sanitation, http://health.gov.sl/?page_id=583). Note that these data represent corrected figures based upon reclassification, retrospective investigation, and availability of laboratory results and differ from earlier published reports, including WHO figures from March 2016 (see also Legend below).

LEGEND

+   Includes probable, suspected, and confirmed cases (March 29, 2014–November 1, 2014); probable and confirmed (November 8, 2014–December 13, 2014); and confirmed only (December 20, 2014–April 30, 2016).

*   Confirmed deaths as of October 18, 2014. Updated figure not available.

**   The latest publicly-available WHO figure for confirmed, probable and suspected EVD cases in acutely-affected countries is 28,610 (March 27, 2016), as reported on the WHO website (http://apps.who.int/ebola/ebola-situation-reports). This includes 3,811 cases in Guinea, 10,675 in Liberia, and 14,124 in Sierra Leone.

*** The latest publicly-available WHO figure for confirmed, probable and suspected EVD-related deaths in acutely-affected countries is 11,323 (March 27, 2016), as reported on the WHO website (http://apps.who.int/ebola/ebola-situation-reports). This includes 2,543 deaths in Guinea, 4,809 in Liberia, and 3,956 in Sierra Leone.

FIGURE 1: Timeline of Key Events, New Cases, and Cumulative Ebola Cases and Deaths (West Africa)

West Africa
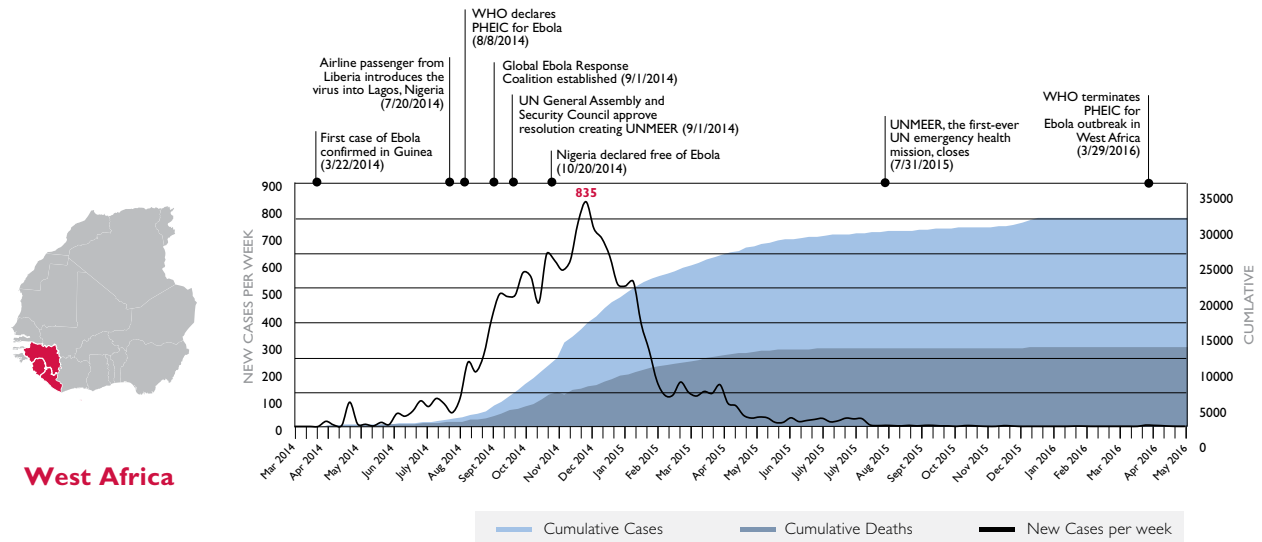
FIGURE 2: Timeline of Key Events, New Cases, and Cumulative Ebola Cases and Deaths (Guinea)
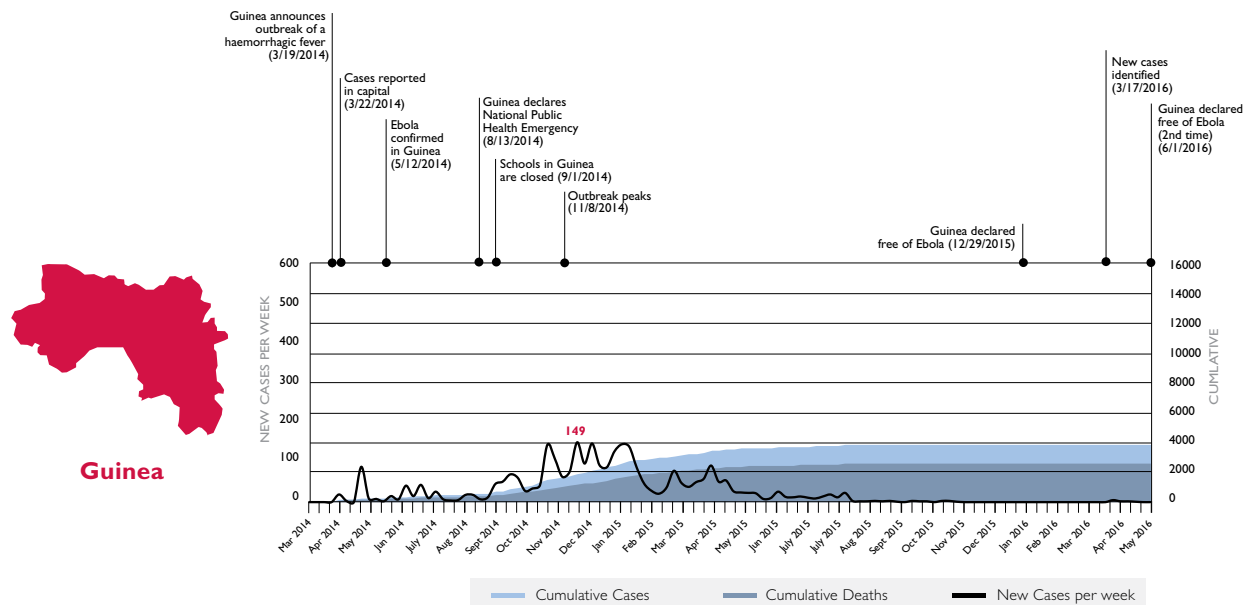
Guinea

Source for case data information in Figures 1-4 is the CDC, based upon figures from the WHO together with the governments of Guinea, Liberia, and Sierra Leone, as described in Table 1.

FIGURE 3: Timeline of Key Events, New Cases, and Cumulative Ebola Cases and Deaths (Liberia)

Liberia announces suspected cases (3/24/2014)

Ebola confirmed in Liberia (3/30/2014)

Cases reported in capital (6/17/2014)

Liberia closes schools and orders quarantine of worst-affected communities (7/30/2014)

State of emergency declared (8/6/2014)

President Obama announces establishment of 3,000-strong U.S. military command center (9/16/2014)

Outbreak peaks (9/20/2014)

Liberia ends its state of emergency (11/13/2014)

Liberian schools reopen (2/16/2015)

Liberia declared free of Ebola (5/9/2015)

New case identified (6/29/2015)

Liberia declared free of Ebola (2nd time) (9/3/2015)

New case identified (11/19/2015)

Liberia declared free of Ebola (3rd time) (1/14/2016)

New case confirmed (4/1/2016)

290

Liberia

Cumulative Cases   Cumulative Deaths   New Cases per week

FIGURE 4: Timeline of Key Events, New Cases, and Cumulative Ebola Cases and Deaths (Sierra Leone)

First Ebola case reported (5/24/2014)

Sierra Leone closes some schools (6/11/2014)

Case reported in capital (7/25/2014)

Government announces nationwide stay-at-home from September 19-21 (9/6/2014)

Outbreak peaks (11/15/2014)

Sierra Leone's President lifts movement restrictions (1/23/2015)

Sierra Leone declared free of Ebola (11/7/2015)

New Ebola case confirmed (1/15/2016)

Sierra Leone declared free of Ebola (2nd time) (3/17/2016)

534

Sierra Leone

Cumulative Cases   Cumulative Deaths   New Cases per week

17

THE PERILS OF FORECASTING THE SPREAD OF THE EBOLA EPIDEMIC

As international responders scrambled to cope with the Ebola outbreak, researchers worked to model the spread of the disease in order to better understand its potential scale and impact. In a September 2014 forecast, U.S. Centers for Disease Control and Prevention (CDC) researchers estimated that Sierra Leone and Liberia would have approximately 550,000 Ebola cases— and a worst-case scenario of 1.4 million cases when corrected for underreporting of cases—by January 2015.[8] A separate WHO estimate published in a September 2014 *New England Journal of Medicine* article estimated a cumulative total of just over 20,000 confirmed and probable cases in Guinea, Liberia, and Sierra Leone by early November 2014.[9] The dire estimates were published around the time the UN Security Council and General Assembly discussed the Ebola outbreak, and ultimately triggered the rapid scaling of the Ebola outbreak response in the fall of 2014.[10]

What accounts for these diverging estimates? To understand this variance, it is crucial to understand the assumptions built into the models, which can lead to either small or large differences in model estimates.

The Impact of Modeling Assumptions on Outbreak Forecasts

In the early fall 2014, those modeling the outbreak did not know whether the disease would spread in a linear or exponential fashion, or when the peak would occur. It was clear at the time that reaching zero Ebola cases in West Africa would take months. In September 2014, cases were doubling in Guinea every 15.7 days, in Liberia every 23.6 days, and every 30.2 days in Sierra Leone.[11]

Both the CDC and WHO models assumed the number of Ebola cases would increase exponentially, but other variations in the assumptions informing these two models resulted in divergent estimates. First, an important difference between the CDC and WHO models related to underreporting. The CDC forecast included a correction factor for underreporting of Ebola cases, whereas the WHO model did not. Based on an analysis from late August 2014, the CDC estimated this factor to be approximately 2.**5**. In other words, the CDC estimated the true case count was 2.5 times greater than the reported case count.[12]

A second difference between the CDC and WHO models was the timeframe used for the projection. At the time (August 2014), the CDC model was the only published model to extrapolate (with and without interventions to stop Ebola's spread) beyond December 2014. Other (non-public) estimates reached a projection similar to the upper CDC estimate of 1.4 million cases, assuming an exponential increase in cases, with the disease downturn occurring six months after the time the projection was released (estimated for February 2015) and an underreporting factor of 2.5.[13] In contrast, the WHO model forecasted only to late November/early December 2014.[14] If the WHO had extrapolated their estimate to approximately February 2015, the estimate of cases would have been about 400,000, without further scaling up of interventions. This is similar to the results of the CDC model.[15]

A third difference related to the impact of interventions to control and eventually stop the epidemic. The CDC model estimated the number of cases that might occur if no interventions were implemented as compared to cases that might occur with additional intervention, such as patient isolation in treatment units or safe burials. The WHO estimates assumed "no change in the control measures for the epidemic."[16] The CDC model suggested that approximately 70% of Ebola patients must be effectively isolated in either Ebola treatment units or in the community, with safe burials when needed.[17] Behavior change practices also proved essential to the control of the epidemic.[18]

Limited Availability of Case Data for Forecasting

For epidemiologists and researchers in and outside the formal response, gaining access to case data to predict the trajectory of the disease and eventual Ebola caseload presented both data and technical challenges. The most accurate disease models require individual case-level data about the date of exposure, diagnosis, and outcome (i.e., recovery or death) in order to understand disease behavior and transmission. These data were not always accessible, however, and available data frequently contained inconsistencies. Available public data did not include detailed case data for a variety of reasons, including patient privacy concerns, a lack of identifiers required to differentiate between unique Ebola cases, and in some instances, a lack of data sharing agreements.[19] Moreover, the publicly available situation reports containing case data were aggregated, released in intervals, and retroactively corrected to reflect updated information about probable, suspected, or confirmed cases. Finally, reporting delays made the incidence of Ebola difficult to accurately calculate. Together these factors obstructed a clear picture of **caseload data**—a crucial input in models produced to predict the disease's trajectory and eventual caseload.

Last but not least, a further aspect of the response that complicated the use of case data for disease forecasting was the publication of aggregated summaries in non-machine-readable PDF documents. As a result, caseload data had to be manually converted to Excel or .csv files to be of use to epidemiologists and others for research purposes. In one case, Caitlin Rivers, then a researcher at Virginia Tech, manually converted into Excel spreadsheets the data published in PDF files as the daily or weekly Situation Reports (Sit Reps). She posted these caseload data to GitHub, a website and tool that open-source software advocates and developers use to create, share, and re-use data and software code.[20] Until these data were publicly available, outside researchers were unable to verify or replicate existing forecasting models, nor were they easily able to create their own models. Such peer review from outside experts may have provided additional verification and analysis to help inform interventions designed to stop the spread of the disease.[21] Despite the perils of forecasting the Ebola epidemic, modeling was an important decision-making tool in planning and implementing interventions designed to stop the spread of Ebola.
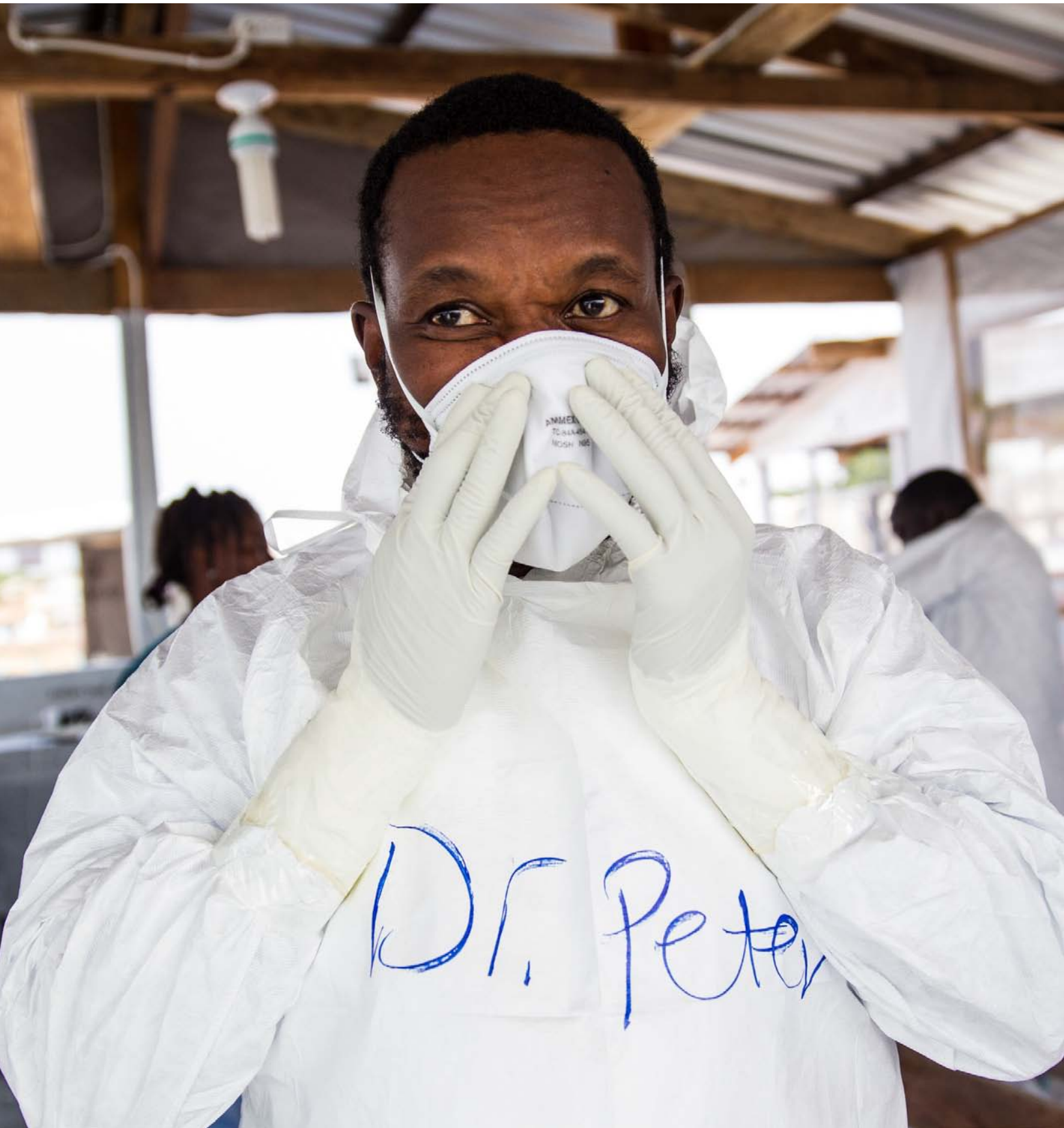
Photo @ USAID/Neil Brandvold

ABOUT THIS REPORT

As the Ebola outbreak in West Africa appeared to be spiraling out of control in September 2014, with unexplained peaks and valleys in Ebola case counts and dramatically differing forecasts of the potential spread of Ebola, then-USAID Administrator Rajiv Shah charged a group within USAID with identifying why the data picture was so unclear. The pages that follow detail the many factors that complicated the collection, management, and analysis of paper-based and digital data used in the Ebola outbreak response. These factors clouded a clear picture of caseload data as the outbreak evolved, and continued to stymie efforts to retroactively resolve data discrepancies even after the crisis phase of the response. Indeed, discrepancies in major data sources (e.g., laboratory data; databases used to track patient case data at the facility, local, or national level; national situation reports; and contact tracing lists) are unlikely to ever be fully reconciled.

To effectively contain the Ebola outbreak required multiple and coordinated interventions, including case management, disease surveillance, and contact tracing, as well as community engagement and social mobilization. The timely transfer of information about each of these interventions was critical to effective coordination and communication across sectors and among the range of actors involved in managing the response and ensuring recovery. How did digital technologies help to address this problem? At the height of the outbreak, **USAID** (and specifically the U.S. Global Development Lab's Center for Digital Development) received requests from partners operating in West Africa seeking to effectively integrate digital technologies into their response efforts. Those requests, and the corresponding interest and need for guidance, prompted this work.[22]

To better understand the root causes of an unclear data picture, and the opportunity of digital technology to strengthen information flows and data-driven decision-making, the report addresses the following questions:

▶ **What contributed to the "fog of information"**[23] that characterized much of the early stages of the Ebola outbreak response?

▶ **What can be learned** from the use of data and digital technologies during the Ebola outbreak response? How and where were data and digital technologies effectively used in the outbreak response?

▶ **What should be done** to strengthen the use of digital data and information flows in emergency contexts, to support long-term recovery, and to build resilience against future shocks like the recent Ebola outbreak in West Africa?

In answering these questions, the report highlights lessons and recommendations particularly for the **humanitarian assistance and health-focused members** of national and international organizations that respond to crises. These include:

▶ **responding organizations**, such as UN agencies and nongovernmental organizations (NGOs)

▶ **donors**, both bilateral and multilateral

▶ **local, national, and regional government actors** mounting an epidemic response in their countries

Although the authors recognize that a broader swath of actors (such as citizens, frontline workers, and remote responders) played critical roles in the Ebola outbreak response, the report focuses its recommendations—including those based on the engagement of these other actor groups—on major government and international responders.

LINKING TO BROADER CONVERSATIONS

This report builds upon other reports in recent years that have tracked and advanced the practice and discourse about information management, technology, and communications in both global health and humanitarian assistance, including those that elevate the importance of communicating with affected communities in health crises and emergency response operations. As early as 2005, the *World Disasters Report* focused on information in disasters and called for a more people-centered disaster response.[24] The 2007 *New Technologies in Emergencies and Conflicts* report[25] and the follow-on 2012 report, *Disaster Relief 2.0*,[26] examined how technology was reshaping information flows in emergency responses, and the growing role of the "digital humanitarians" (also referred to as the volunteer and technical community) in emergencies.[27] These and other reports explicitly acknowledge the explosive growth and use of mobile phones and other digital technologies globally, both in development programming and natural disasters. In alignment with the objectives of the UN Sustainable Development Goals, this movement has sought to harness the potential of mobile technology to "end isolation, amplify the voices of the disadvantaged, and ... connect even the poor to information and services that enable them to improve their livelihoods and quality of life."[28]

In the global health context, a reform movement has emerged in support of strengthened health systems.[29] More recently this has included a stronger focus on the *information systems* that undergird well-functioning health systems.[30] Yet, as the Ebola outbreak demonstrated, much work remains to be done. The West African Health Organization's (WAHO) Director-General Dr. Xavier Crespin noted that the Ebola outbreak "exposed the weaknesses of national health systems in general, and health information systems in particular," and called for strengthened mechanisms to quickly and reliably share information about epidemic-prone diseases at national and regional levels.[31] This effort includes work to harness the potential of mobile and electronic technologies to strengthen a variety of aspects of health systems and health information systems (HIS), from disease surveillance and response to issues related to health information and service delivery. It also encourages connecting citizens, health workers, and governments in real time. When used appropriately, this integration of digital technologies can lead to many benefits, including increased effectiveness of health services, and the expansion of health worker participation in community disease surveillance.[32]

The recommendations and lessons in this report identify both opportunities for and challenges to restructuring information flows in emergencies and how, over the long term, digitized data and information flows could be more dynamic, less hierarchical, and support greater resilience in the face of future disease outbreaks, natural disasters, or other emergencies. These recommendations and lessons buttress calls for reform tied to the May 2016 World Humanitarian Summit that have highlighted the importance of local actors in disasters and emergency response[33] and champion a system that must become more flexible and adaptable.[34]] The "Grand Bargain," which emerged from the Summit, represents a step forward toward these reforms and includes a commitment from donors to provide more flexible funding to local organizations and to publish transparent data about humanitarian funding.[35] Digital technologies can support these aims.

METHODOLOGY

The research adopted a mixed-method, qualitative approach, consisting primarily of semi-structured interviews, case study analysis, and a review of related literature and other lessons-learned reports and initiatives, with particular attention to those touching upon data, information flows, or digital systems.[36]

The authors conducted semi-structured interviews with more than 130 individuals between November 2014 and February 2016. Although not a representative sample of responders, interviewees included individuals from:

- ▶ national-level actors (including those within national ministries of health and the coordination bodies in the three most-affected countries)

- ▶ NGOs, international organizations (e.g., the International Federation of the Red Cross and Red Crescent, WAHO), and the UN system (e.g., UNMEER, the Office for the Coordination of Humanitarian Affairs (OCHA), the UN Children's Fund (UNICEF), and WHO)

- ▶ the digital humanitarians (e.g., Humanitarian OpenStreetMap, Digital Humanitarian Network)

- ▶ private sector actors (e.g., GSMA, sQuid)

- ▶ various USAID Bureaus involved in the response (Office of U.S. Foreign Disaster Assistance (OFDA), Global Health and Africa Bureaus, the U.S. Global Development Lab, the Ebola Secretariat/Africa Ebola Unit) and other U.S. Government responders (Department of State, Department of Defense, and the CDC)

Most of these interviews took place in person, in Washington, DC and New York; Accra, Ghana; Geneva, Switzerland; and during field visits to Conakry, Guinea, Freetown, Sierra Leone, and Monrovia, Liberia. Other interviews were conducted over the phone or by Skype. A list of those formally interviewed and their organizational affiliations is available in the **Appendix**. Interview questions focused on documenting examples of and challenges in managing data and information flows during the response, and understanding projects and activities that involved data or digital technologies to support Ebola response efforts. Interviews were coded and analyzed thematically and are referenced throughout the report.[37]

In addition to the perspective and insights gathered through formal interviews, field research, and a literature review, the insights in this report were informed by the authors' work at USAID. From September 2014 to August 2016, Larissa Fast was an American Association for the Advancement of Science (AAAS) Policy Fellow with the Center for Digital Development and Adele Waugaman is Senior Advisor for Digital Health in the USAID Global Health Bureau. The **authors** drew upon observations and direct participation in select USAID planning meetings and reporting, as well as access to and participation in a variety of U.S. government interagency and outside events related to the Ebola response.

Limitations

The research is limited in several respects. First, although the report captures a variety of aspects of the response over time, it is not comprehensive in its rendering of the various phases or aspects of the response. The response period covered in this research includes three key phases: (1) the initial declaration of the outbreak in March 2014 to the declaration of a PHEIC in August 2014; (2) the period of rapid transmission and dramatic increases in case numbers (summer to late fall 2014); and (3) the decline of cases beginning in 2015 and ending in 2016. Interviews for this report, which began in late 2014 and continued into early 2016, captured respondent's perceptions at various points in time, and included their recollections of past events and occurrences. On the one hand, the duration of the research enabled an investigation of issues related to the transition from emergency response to longer term recovery and resilience. On the other, it has presented challenges in terms of the retrospective recollections of events, shifting contexts, and perspectives over time.

Second, USAID aims to foster data-informed and data-driven decisions that are adaptive, transparent, responsible, responsive to, and inclusive of the needs of populations and decision-makers at all levels. This perspective has shaped the report and its findings. The research aimed to capture examples of programming that used data or information with the goal of enabling a more agile and flexible approach. It also sought to learn from examples of the use of digital technologies to try to shorten the timeframe between the collection, sharing, analysis, and subsequent use of data of all types; or to facilitate a more inclusive ecosystem by lowering barriers to regular communications with multiple actors, which in this context includes citizens, frontline health workers, and other key stakeholders who were central to the Ebola outbreak and response.

Given this approach, the study documents the opportunities and challenges of the use of data and digital technologies, rather than analyzing the underlying conditions that either supported or deterred their use in the first place. The report analyzes nine case studies as well as learnings and observations on this topic from more than 130 members of the response community. It does not provide a comprehensive assessment of the degree to which data, information, or digital technologies enabled a more effective response across the three affected countries. The study also does not capture all of the innovative examples of information flows or of the collection and use of data or digital technologies in the Ebola response.[38] The examples presented here capture persistent challenges and opportunities that surfaced repeatedly in interviews, and across the case studies featured in this report. Wherever possible, the authors have verified information and case studies with interviewees.

Finally, the study is primarily interview and participant-observation based. It is not designed to capture a detailed and field-based investigation of digitized data and information flows. Although the study did include field research in West Africa (Freetown, Conakry, and Monrovia), it was not possible to adequately capture perspectives of those outside of the formal response efforts or the perceptions of communities affected by Ebola. This represents a significant gap in the research.

We use the term "formal response" to refer to that implemented by government, international, and NGO actors who organized and implemented the response. We use the term "informal response" to refer to that leveraged by local communities, the volunteer and technical community, and other actors.

LIFTING THE FOG OF INFORMATION

What underlying factors contributed to the unclear data picture that characterized much of the Ebola outbreak response, particularly in the early days? Several interviewees referred to a "fog of information," describing the lack of timely, accurate, and accessible data, which clouded situational awareness, impeded effective decision-making, and stymied the response. This section summarizes common themes emerging across interviews that illustrate this fog. These themes demonstrate the impact of the physical, socio-cultural, organizational, and historical context of the Ebola outbreak on the response, including for data and information flows, and the use of data and digital systems.

'NO BLUEPRINT' FOR THE EBOLA RESPONSE

The WHO declaration in August 2014 of a PHEIC, and the humanitarian emergency sparked by the Ebola outbreak, demanded significant public health and humanitarian responses. The hybrid nature of the crisis as both a health and a humanitarian emergency increased coordination challenges in the response and contributed to confusion among response actors. Although many humanitarian agencies had experience managing infectious disease epidemics, such as cholera or measles, or other health crises, such as malaria, few had experience in managing an epidemic of this type and scale, or of managing the required health facilities. The characterization of the Ebola outbreak as a public health emergency meant that the secondary impacts of the crisis on local populations received less attention, particularly in the early months of the epidemic.[1]

> *"We have blueprints for crisis and conflict, but nobody had a blueprint for a major health crisis."*

As one interviewee put it, "*We have blueprints for crisis and conflict, but nobody had a blueprint for a major health crisis.*"[2] The complexity of responding to an epidemic in a densely populated urban environment, with increased potential to spread the disease, compounded this issue.[3] The fluidity and rapid pace of the outbreak forced responders to quickly adapt to changing circumstances. One humanitarian responder exclaimed, "*Everything happened so fast. We were chasing the disease, [and] had to change quickly to adapt [to] what was happening. It was not like [a] conflict [response].*"[4]

Although there was no set playbook for how to proceed in an epidemic of this type, scale, and speed, or of how to manage related secondary effects, some interviewees noted there were existing mechanisms and protocols that could have been better adapted and reused in the Ebola response.[5] On the health side, one veteran of health responses pointed out that the protocols for responding to infectious disease, and polio in particular, were not consistently deployed in this response, despite similarities in how to contain the two diseases. He noted, "*In middle of the outbreak, we were reinventing the wheel without taking into account and leveraging what exists. This is nonsense. We have case tracking for polio, with labs and contacts. This exists already. We can plan vaccination campaigns, which involve social mobilization. This knowledge was not used.*"[6] On the humanitarian side, many interviewees highlighted the absence of OCHA and the humanitarian cluster coordination system as contributing to confusion surrounding coordination and information sharing, and forcing a reinvention of the wheel when established practices already existed.[7]

CONSEQUENCES OF A SPECIALIZED UN MISSION

Within the UN system disease epidemics or pandemics are within the purview of the WHO, while coordination and information management in humanitarian emergencies fall under the remit of OCHA. To address the hybrid nature of the crisis and the perceived shortcomings of the WHO response in the early phases of the outbreak, the UN General Assembly passed a resolution creating UNMEER as a temporary mission to coordinate the UN's activities in support of a nationally-led Ebola response.[8] This decision had ripple effects across the entire response.

Many interviewees mentioned the negative impact of the absence of the OCHA-led humanitarian coordination system on the collection and sharing of data, particularly at the beginning of the response. In particular, the normal OCHA humanitarian coordination system identifies a lead agency for each of the major "clusters" of humanitarian response (e.g., health, emergency telecommunications, refugee camp management).[9] With many of the normal coordination channels absent, particularly in early phases, the collection and management of response-wide information suffered.

The governments of Guinea, Liberia, and Sierra Leone maintained a strong role in leading the response through their respective national coordinating bodies.[10] Each country organized its national coordinating body differently in its operations, information management, and coordination structures. In Liberia, for example, the national coordinating body known as the Incident Management System (IMS) was limited in terms of who and how many individuals could participate in coordination meetings. This was necessary both to maintain effective command and control in a chaotic environment and to physically fit everyone into the room. At the peak of the crisis, the government convened daily IMS meetings. IMS participation was limited to two individuals per agency, and included the heads of various working groups and partners that played key roles in the response. Friday meetings were open and designed as a "briefing" meeting. In addition, the WHO hosted open information-sharing meetings on Saturdays, which were open to all agencies.[11]

Without the typical humanitarian coordination systems or a clear pathway to engage with the national coordination bodies, many implementing organizations, both national and international, were excluded from discussions.[12] NGOs and other response actors that were absent from those conversations had a limited view of the changing landscape of the outbreak and response.[13] As a result, gaps and duplication in the response were less apparent and less easily resolved, especially during the chaotic early months of the crisis. For example, several interviewees mentioned that, especially at the beginning of the response, their organizations were the only ones operating in a particular part of the country.[14] One interviewee observed that controlling the dissemination of information in this way allowed governments to maintain control of the response.[15]

The absence of the typical humanitarian coordination system and the unique deployment of UNMEER as a coordinating body resulted in confusion about roles and responsibilities. A report investigating the international aid architecture in the Ebola response found that "UNMEER's status as a new entity/invention forced it to define itself in the midst of a full-blown emergency..., where major response actors, from donors and governments to [international NGOs], had little knowledge of its purpose, objectives, or how to work with it. As late as March and April 2015, key implementing NGOs had little understanding of UNMEER's role and functions."[16] Multiple interviewees shared their frustration with the absence of traditional coordinating mechanisms. One stated: "*The [usual humanitarian coordination] systems did exist, but we weren't allowed to use them.*"[17] Another said, "*OCHA has structure, it's predictable, people know what*

[OCHA is] going to do. ... You know what to expect and that predictability is critical. To reinvent everything was really difficult."[18]

Finally, the decision to stand up UNMEER using staff from the UN Department of Peacekeeping Operations (DPKO) influenced how data and information were shared in the response. Multiple interviewees highlighted the diverging data cultures between a humanitarian operation, in which information-sharing is an essential part of the mandate, and a peacekeeping mission, in which information is largely regarded in the context of privacy and security. As one humanitarian official said, "*DPKO does record keeping for the mission. They are not focused on public information ... or on making products for public consumption.*"[19] In contrast, OCHA regularly and openly distributes information, such as maps of agencies operating in a crisis (known as the "3Ws": who is where, when, doing what), to support response efforts. Another interviewee expressed a similar sentiment, indicating DPKO's approach to information management typically focused on "*information security and what should be classified. It is internal information management, not external.*"[20]

Photo @ UNMEER/Simon Ruf

A HYBRID HEALTH AND HUMANITARIAN EMERGENCY

Tensions Between Data Types and Uses

In discussing data use in the response, interviewees pointed out differences between operational data collected at a cluster level that were used to inform the activities of international and national actors, versus the more aggregated data used to influence advocacy and high-level planning efforts.[21] This bifurcation between detailed, local data and aggregated, usually national-level data is characteristic of other emergency responses. In the Ebola outbreak response, however, the characteristics and uses of case data were new in the context of a humanitarian emergency. The **data** required to understand the nature and transmission of the disease, particularly in the early days of the response, were detailed, cumbersome to health responders given the scale of this outbreak, and oriented toward a post-epidemic analysis as opposed to real-time operational usage. As Jeremy Konyndyk, director of the Office of U.S. Foreign Disaster Assistance, stated: "*One of the things we've struggled with is getting good operational epidemiological data. When you're fighting a disease like this it is important to have a real-time picture of where it is growing, falling, and at the national level, where it is spreading and receding. The nature of the disease is that the spread is so particularly localized. Where is key. If you have that, then you have a greater picture of which interventions are working or not paying off. With the lag, it is harder to know what is effective or not.*"[22]

The hybrid nature of a combined health and humanitarian emergency surfaced tensions between the types of data collected and used. Those providing care for patients in treatment units needed data about symptoms and treatment regimens for patients. Those coordinating the response needed data about active hotspots and quarantine locations, information about essential supplies, and basic case data to implement the operational response. Those working in and with communities needed accurate information about specific behaviors and other measures needed to stop the spread of Ebola. Yet few data systems were designed to house these various types of data, and the data systems in use often were weak and disorganized. With a few exceptions there were no widely accepted places where response actors could share their data.

According to one health expert, "Multiple disconnected health data systems posed a major challenge to containing the disease. Standalone digital systems were often found to be in place for critical data sets that needed to be interpreted together—such as those for contact tracing, case investigation, and treatment of patients. For example, a reporting system tracking payments for health workers didn't link up with a separate system tallying their work hours. This blocked payments for nurses and burial experts risking their lives and led many of them to refuse to continue working." [23]

In addition, within the health domain, interviewees distinguished between the needs and skill sets of field epidemiologists and research epidemiologists. The former focused on investigating individual cases, and the latter on analyzing individual and aggregated data to understand the incidence and transmission of the disease.[24] Despite these distinctions, all **data types** were interrelated and needed to support an effective response.

Finally, the hybrid nature of the Ebola emergency illustrated the differential impacts based on the type and granularity of data required. Whereas the operational side of most humanitarian responses can be managed using aggregated, often anonymized, data (e.g., estimated numbers of displaced persons in order to provide shelter, food, or non-food items), the Ebola outbreak required specific and detailed data. This included data about the health of individuals believed or confirmed to have contracted the disease, and the locations of those individuals with whom sick persons had come into contact. Aggregated information about groups of patients informed everything from district or national-level caseload data, vaccination programs, and epidemiological research about Ebola, to social mobilization efforts, the location of treatment centers, and food security programming. Yet detailed individual-level data also were critical to the response. In the case of contact tracing, a critical component of containing the outbreak, this comprised detailed data about individuals who had come into contact with an Ebola patient and who needed to be monitored for signs of Ebola for the 21-day incubation period. All these data needed to be managed and effectively used. Information about any one individual patient was linked to treatment, laboratory results, contact tracing, and isolation. Each of these sectors' responder groups required tailored data with different levels of granularity.

Mapping the Outbreak

Another distinguishing factor of this hybrid emergency was the need to identify and track specific locations—of patients, health facilities, and supplies. In humanitarian responses to natural disasters or armed conflicts, aid agencies usually dispatch large amounts of food and services to a centralized location, such as a village or refugee or internally displaced persons camp. By contrast, in the Ebola outbreak response the food aid to quarantined households, for example, required the precise targeting of food and supplies to a single household, with hundreds of geographically dispersed distributions across the three most-affected countries. Response organizations in the three countries began collecting or using geographic information at various points in time; as a result geographic information may or may not have been associated with datasets.[26]

A lack of readily available and detailed maps, particularly for the remote rural and the densely populated urban areas, compounded this need for timely, up-to-date, and specific geolocation data. In some cases, maps with relevant information, such as health facilities, were not readily available to all responders. This resulted in duplication of effort as multiple entities reproduced the same information.[27] Initiatives such as the Ebola GeoNode[28] and the **Humanitarian Data Exchange**[29] attempted to alleviate this problem by providing open and widely accessible maps and other datasets.

For geographic information, GIS specialists needed shape files and information about the locations of health facilities, village names, and P-codes[30] for three separate countries. Respondents in all three countries mentioned that village names are often the same or have similar spellings.[31] The use of P-codes made it possible to eliminate data entry errors in cases where villages lacked names, shared names, or had multiple spellings due to local conventions or language. For example, French names for Liberian cities differed from the Liberian version, where Ganta became Gompa and Sanniquellie became Sannicoly. Employing a unique P-code for a village eliminated this problem. One interviewee indicated that the EpiInfo database **Viral Hemorrhagic Fever (VHF) module** used to track caseload data was customized for Guinea place names and spellings. It was then imported for Liberia, without the same customization. This led to errors in the location information associated with some cases in the VHF module.[32]

Lack of consistent location-specific identifiers also posed a problem in urban areas. In Monrovia and Freetown, which both saw major outbreaks, houses often lacked distinct street names or addresses. Moreover, street names commonly were spelled different ways, and a single street name could be used in multiple locations. As a result, responders could not rely on street or family names to locate suspected or probable cases and their contacts. The lack of specific and accurate geographic information complicated a variety of aspects of the response, such as dispatching contact tracers, burial teams, and even for notifying loved ones of the location of a deceased family member. One responder explained, *"One address might be shared with many families. There was some formal system but on the whole, you could have one number with five to six families sharing the same address."*[33] Even after the emergency phase of the response ended, this continued to hamper efforts to notify family members, particularly in cases where place or family names were incorrect or missing.

FIGURE 5: Map of USG Response to the Ebola Outbreak in West Africa
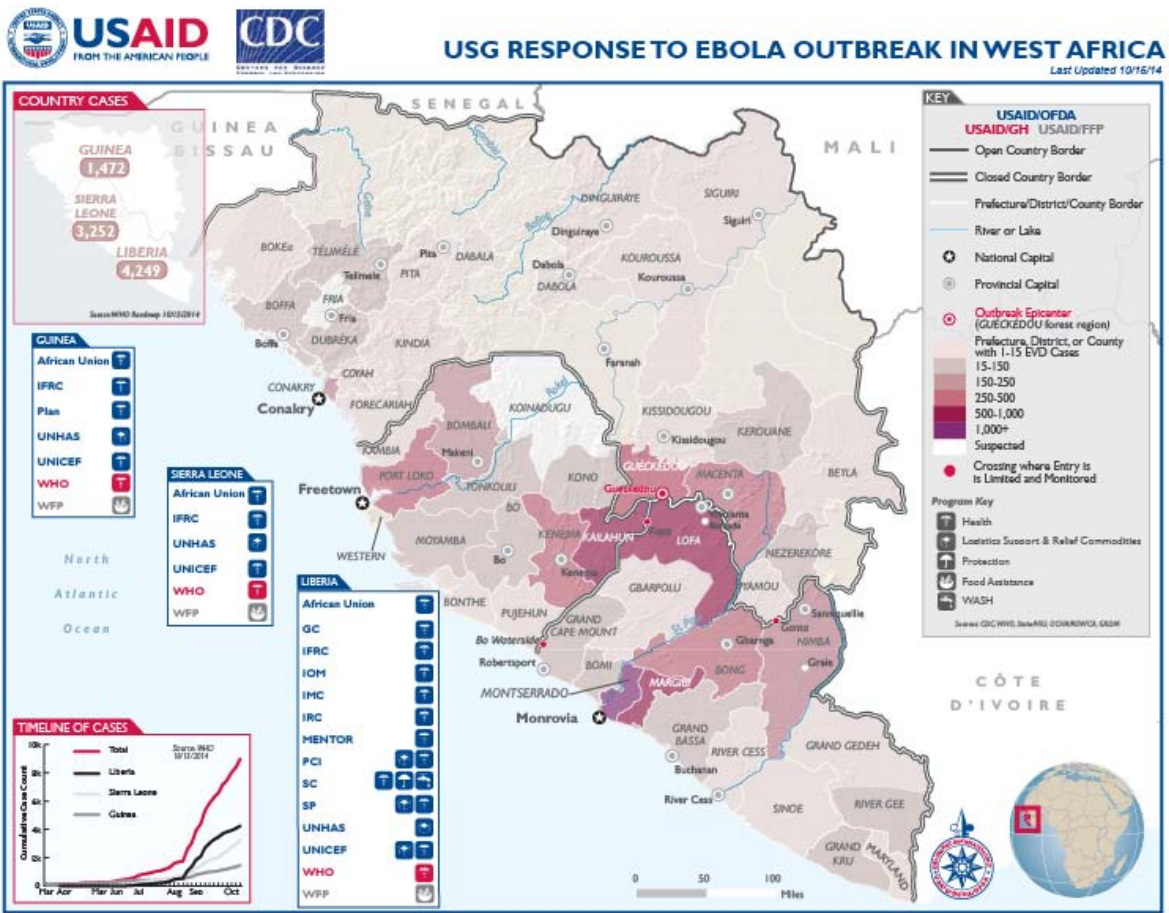
USAID's Office of U.S. Foreign Disaster Assistance, which led the U.S. response to the Ebola outbreak, created a series of maps to indicate the location of Ebola caseloads, as well as the work of implementing partners. Map credit: USAID's Office of U.S. Foreign Disaster Assistance.

Inconsistent Use of Unique Identifiers

Inconsistent use of unique identifiers for people also hampered the response within and across the three most-affected countries. Unique identifiers, such as a national identification number or unique code associated with government-provided services, match a specific person with a single identifying code. These identifiers, as well as correct names and addresses, are important in both emergencies and longer-term development—not only for data linkage and research purposes, but also for evaluation, public health programs, health service delivery, policy development and decision-making, and improving and saving lives.

In the countries most affected by the Ebola outbreak, multiple conventions existed to create unique identifiers, which varied depending on the organization and circumstances. For example, in the VHF module, laboratory samples each had a unique "LabID'" and each patient a unique "EpiID," making it possible to associate any given patient with multiple laboratory results. In some cases, however, individuals were assigned LabIDs instead of EpiIDs.[34] In all three countries this created difficulties in efficiently or correctly associating a variety of datasets (e.g., laboratory data, patient care data, contact tracing data, burial data) with individual patients. Moreover, at the height of the response, it was not possible to adequately train all individuals collecting patient data about the importance of correctly using unique identifiers. According to one interviewee, "*There were many challenges with implementing and not understanding the purpose of unique IDs. For example, we discovered 100 people who had the same unique ID and realized [one health center] had a form with a unique ID and then they photocopied the form. So you had 100 people with the same unique identifier. We only realized later the need to provide clear guidance on how this should be implemented.*"[35]

This challenge was compounded by common naming conventions. Many people in the three most-affected countries share first or surnames. Multiple interviewees cited this as further complicating efforts to correctly associate information with the appropriate individuals. In one instance, an interviewee recounted how a common name and a lack of unique identifiers affected contact tracing efforts. Without unique patient identifiers or place names, one responder asked, "*How do you differentiate between 10 Mohammed Diallos?*"[36] Another pointed to the inverse problem: in many cases patients presented with symptoms at different clinics, resulting in their inclusion in a database multiple times, each time with a different location. In these cases, an individual patient could appear in a database multiple times, possibly with varying spellings or ages. Verifying and cross-checking master lists for this kind of duplication has presented an enormous challenge, yet are essential for using these data for follow-up interventions as well as research.[37] Though compounded in the context of the weak health systems that characterized the Ebola-affected countries, such processes would be challenging even in countries with stronger health information infrastructure.

Tension Between Urgency of Action and Patient Privacy

The requirement to collect detailed individual data ran headlong into the imperative to act quickly during the height of the response, leading to data collection and use being prioritized over the identification and mitigation of individual privacy and security concerns. One health official noted that the "*response was managed by getting lab results and CIFs [case investigation forms] to everyone all at once.*"[38] In some instances, this resulted in the sharing of information, including personally identifiable information (PII), without safeguards for patient privacy or confidentiality. Many interviewees indicated that responders shared patient information, often including PII, over email accounts or Google documents that were accessible to anyone with the link.[39]

In the **Ebola treatment units**, personal details were sometimes openly shared out of necessity. For many clinical staff, who are trained to protect patient privacy and dignity, this caused distress. One doctor noted, "*We were shouting information over the fence, saying this person has died, this one has diarrhea... This is a violation of patient confidentiality. As a doctor, you really feel this.*"[40] In other instances, concerns for patient privacy trumped relatives' access to information about the location of family members who were taken to treatment centers. The inability to discover where relatives were taken or what happened to them also fed rumors and increased people's fear and distrust of the response.[41]

USING CALL DETAIL RECORDS (CDRs) IN HUMANITARIAN CRISES

The field of CDR analytics for social good is growing rapidly. With CDRs, it has become possible to "follow" and map the movements and interactions of individuals or groups of individuals—or, rather, of their mobile phone or SIM card—to look for patterns and trends, especially when combined with other datasets. At the height of the Ebola epidemic some organizations called for and started exploring the use of mobile phone CDRs to support outbreak response efforts. Their intent was to access real-time, often aggregated, data about population movements in order to better target response efforts, and to enable predictive modeling of the disease's spread based upon mobility patterns. The analysis of these aggregated data can provide relevant insights for future outbreaks and humanitarian emergencies.

Despite the valuable insights this particular category of "big data" can reveal, concerns about CDR data use remain. These include adequately ensuring individual privacy, even when using anonymized CDRs, establishing the value of CDR data to model and predict the spread of infectious diseases, including Ebola, and developing the appropriate legal and regulatory frameworks for sharing CDR while protecting proprietary data and user privacy.

To date, no coherent and comprehensive set of regulations or guidelines for use of CDR analytics exists. In emergencies, mobile network operators (MNOs) receive multiple and uncoordinated requests for services (e.g., free SMS messages or access to CDR data) and typically respond on a case-by-case basis. Current practice, policies, and legal agreements often are not suited to manage the risks or fully realize the opportunities of using CDR data. Although most agree that CDR analytics must be responsibly used for social good, it is not clear what ethical frameworks should apply, particularly because ethical concerns extend beyond privacy to those of equity and justice.[42]

For example, concerns over the legal ownership—property rights—of CDR data, the importance of user consent, and risk of liability from civil or human rights suits, even under emergency situations, led the Liberian government to decide against releasing CDR data during the emergency.[43] Conscious of the fragile balance between the public value and the privacy risks and concerns of CDR analysis, during the outbreak in Sierra Leone, however, UNICEF, together with UN Global Pulse, worked to negotiate protocols to allow the analysis of aggregated mobility patterns based on CDR data to support the response. They approached the National Ebola Response Committee (NERC), UNMEER, and the Government of Sierra Leone to allow the analysis of mobility aggregations based upon CDR data under certain conditions (e.g., the data remained proprietary and in the control of the mobile network operators (MNOs), and only mobility aggregations were released for analysis in order to protect user privacy). The next issue, however, was setting up both the infrastructure to create mobility aggregations on the MNO's premises and the proper channels to share these data with the data science teams of UNICEF and Global Pulse. While some MNOs had internal capacity and experience with aggregating CDRs, others relied upon third parties (such as Real Impact Analytics) to analyze their data for commercial purposes.

Deciding which data aggregations provided value to the response and setting up the infrastructure to create, share, and use them took time. According to Manuel Garcia Herranz, Data Scientist for UNICEF who worked on the CDR analysis, *"Over four months we worked with partners to identify what aggregations can bring them value, and defined the privacy, sensitivity and governance protocols that make data-sharing possible while protecting individuals' privacy. It took another 3 months to set up the capacity, technical infrastructure, secure connections, and initial analysis to inform the response. This is a long time, but it's a big breakthrough. It was the first time we have been able to get real-time CDR aggregations during an epidemic, and we've been able to make a good case for why we need to set up capacity in advance of an epidemic."* As this case demonstrates, using CDR data and aggregations present significant capacity issues as well as appropriate policy and legal hurdles that require negotiation and preparation in advance of emergency operations.

Photo @ UNICEF

A COUNTRY-SPECIFIC AND REGIONAL RESPONSE

Impact of Regional History and Language

A prominent feature of the Ebola response was its country-specific nature juxtaposed against a broader, regional outbreak. One official involved in the response remarked, *"Data came just from a country-specific lens. But Ebola is moving across the region—it is not confined to geo-political boundaries. People and the virus didn't respect this."*[44] The challenges this presented were particularly apparent along border areas, where the monitoring of outbreaks and population movements required coordination both within and across affected countries. The complexity of border surveillance at numerous sites on land, at sea, and by air, with thousands of individual crossings, required significant coordination across multiple actors as well as capacity building, including training and monitoring of those conducting the surveillance activities. Across the three countries, the International Organization for Migration (IOM) adopted a mostly paper-based system of monitoring the location and direction of people's movements together with basic demographics. This enabled them to identify hotspots, times, and places of particularly high movement across borders. In most instances, the use of paper—even in implementing one of the largest and longest border screening activities—proved sustainable, efficient, and practical, given the challenges of the rainy season or lack of electricity to charge electronic devices. In Sierra Leone, IOM did use solar-power tablets to collect data, which were uploaded into a central database.[45]

In addition to a history of tension in the region, historical and language differences both across and within the three most-affected countries affected data use and collection. One UN official noted that although the outbreak required a regional response, *"Operationally you're talking about different cultures, coordination mechanisms, and situations."* She continued, *"…these are three countries with a history of not getting along very well. This history undermined the collaboration that was needed."*[46] In addition, whereas English is spoken in both Sierra Leone and Liberia, French is the dominant western language in Guinea. Within each country, dozens of local languages and dialects are spoken.[47] This, and the **mapping challenges** cited earlier meant that it was not possible to simply replicate aspects of the response within or between countries without appropriate contextualization. Social mobilization messages had to be translated into multiple languages and interpreted within a country-specific and cultural context. Taken together, these factors increased the complexity of the response.

> *"Data came just from a country-specific lens. But Ebola is moving across the region—it is not confined to geo-political boundaries. People and the virus didn't respect this."*

A Climate of Fear and the Importance of Trust

To stop the spread of a disease like Ebola requires information about the disease and its transmission. Social mobilization and health promotion, therefore, comprised a central pillar of the response.[48] In all three countries, the presence or absence of trust influenced the ability to collect data about individual patients and to affect community behaviors. One government official observed, *"There were many [community] leaders who were not convinced. This wasn't good for the population that didn't trust us. Up to now there are still people who do not believe in Ebola, who think it's not true."*[49]

Although trust and trusted networks always play a critical role in data and information flows,[50] the role of trust was accentuated in this context in West Africa, with all three of the most-affected countries recently transitioning from a period of war or civil conflict. This legacy fueled rampant misinformation, rumors, and what became known in Guinea as *la réticence*—a reluctance, or in some cases opposition, to cooperation with Ebola responders due to the legacy of fear and mistrust of government and foreign actors.[51] One study concluded, "Communities are not uncooperative because they are backward or uneducated. On the contrary, they harbor a distrust of Ebola response efforts that is completely rational, given their experience during recent decades of misrule and political tumult. … Such complex historical circumstances fuel distrust of formal power structures—and Ebola response efforts. Rumors abound that Ebola has been deliberately propagated as a ploy for entrenched interests to pocket money donated for the response."[52] One international responder in Guinea indicated that in some cases patients refused to provide their names when receiving treatment because of *la réticence*.[53] Another individual working in Sierra Leone noted that the response was *"complicated by Ebola being such an instigator of fear—people don't want to give information or provide the wrong information, such as the location of house because they don't want their possessions to be burned."*[54] In the reporting of cases it was unclear from the case investigation forms (CIFs) whether an empty data field was accurate or simply missing due to widespread fear and mistrust. According to a UN official, *"You had not just reticence but life-threatening reticence."* He immediately followed this comment with, *"You don't know if it is an empty field [in a form] because there is no risk factor or because it wasn't filled out."*[55]

In addition, to be effective, the response often had to be tailored to specific areas of a country. One interviewee involved in community engagement efforts in Guinea noted, *"If you are meeting people in Haute-Guinée [the north part of the country] they listen to the elder. Elders are the source of wisdom and it is the elder who speaks. In Bas-Guinée [the southern part of the country], the person who is important is the person sending money to buy the rice. We need to make sure we adapt strategy in terms of the source of information."*[56]

PROLONGED CRISIS PHASE

'Building the Plane While Flying It'

Many interviewees discussed the difficulty of having to develop solutions while the emergency was underway. The duration of the response created challenges as well as opportunities for course correction and adaptation. Interviewees pointed to several effects of the outbreak duration on the response. For instance, although the response initially was slow to engage at-risk communities and to consider cultural practices and beliefs, as the response progressed organizations grew in their understanding of the importance of this engagement. This understanding eventually led to the expansion and escalation of health promotion messaging efforts.[57]

Other organizations, as detailed in the case studies of Real-Time Information Flows, used digital technologies to respond to changing circumstances. This allowed them to increase their understanding of the disease's progression, and to use real-time or near real-time information to make critical programming adaptations. For example, the Red Cross used updated maps of positive and negative Ebola cases visualized on a dashboard to determine where to focus their burial and social mobilization teams, and digital systems to gather daily reporting about everything from personal protective equipment (PPE) to lunch money.[58]

Photo © UNMEER/Simon Ruf

Staff Turnover

Interviewees repeatedly highlighted the negative effects of frequent international staff turnover, in terms of the demands this placed on national staff leading the response, the negative implications for trusted relationships, and for continuity of the response overall.[59] One NGO reported seven country directors in the space of several months.[60] For CDC staff, the maximum length of stay without additional training was 29 days for one deployment. One national Ministry of Health (MOH) official quickly tired of the constant staff transitions and insisted that the CDC cycle the same people through the Ministry to provide support.[61] The constant staff turnover resulted in a continual disruption to learning and uptake of data collection and management systems. One responder observed that staff turnover meant that international responders "*did not see what resulted [from their actions or decisions] or the chronic or recurring issues that weren't changing.*" He continued, observing that the short-term rotations compromised the ability "*to see problems through*" or follow up on issues.[62]

LESSONS

Examining the physical, socio-cultural, organizational, and historical context of the Ebola outbreak highlights a series of lessons from the Ebola outbreak response, and for health and humanitarian preparedness and response more generally.

▶ **The Ebola outbreak entailed a prolonged yet fast-paced crisis response that enabled innovation and iteration on the one hand, but challenged the response with high turnover of international staff on the other.** One interviewee likened the response to "*a marathon and not a sprint. It was a long haul and people weren't ready for it.*"[63] With regard to data and information flows, this both enabled adaptation over time, as responders modified their interventions, particularly related to behavior change messaging, and management approach. The prolonged crisis phase also negatively affected continuity of the response due to high frequency of international staff turnover.

▶ **The publication of critical outbreak data in non-machine readable format slowed and narrowed the use of these data** by actors who could have helped to contextualize the data and provide insight that could inform the response. This included epidemiologists and researchers who needed access to case data for predictive modeling. More timely data leads to better use of data, which leads to higher quality data, as evidenced by the **Ebola Geo-Node** and **HDX** examples.

▶ **The outbreak magnified the shortcomings of existing health systems**, including health *information* systems. Weaknesses in existing health information systems, a foundational component of public health delivery, made it difficult for governments of affected countries to understand health needs, target health interventions, allocate resources, and otherwise efficiently respond to the Ebola outbreak.

▶ **Gaps in access to reliable electricity and/or digital connectivity contributed to significant delays in transmitting time-sensitive data.** Temporary, emergency satellite-based communications systems met urgent responder needs but did not address either connectivity needs of the local population or longer term connectivity needs.

▶ **Other ecosystem constraints that affected the collection and use of data included a lack of basic infrastructure**, such as roads. Seasonal changes affected connectivity and transmission of timely

data as well as the delivery of resources, including non-digital data (such as CIFs and laboratory specimens) to and from rural areas, because the roads were impassable.

▶ **Where digital or physical infrastructure barriers or other constraints made the use of digital technologies impossible**, **paper-based systems were a reliable alternative**—although at the cost of timeliness—particularly when data collection was reduced to the minimum necessary to support operational interventions.

▶ **Information constraints affecting data and information flows included a lack of comprehensive and widely accessible digital maps, and commonly used unique citizen identifiers**—elements that are critical to support digitization of data and information as well as health and other service delivery. Non-aligned naming conventions for places and people magnified the effect of the inconsistencies of unique identifiers, while a lack of widely accessible maps of affected areas and non-aligned conventions for place names, for example, stymied efforts to keep electronic records of commodities, health clinics, and traced contacts.

▶ **Addressing privacy concerns for patients and contacts and negotiating agreement about critical datasets, particularly those that include PII in CDR data, take time**. These are best addressed as part of preparedness protocols in advance of emergencies.

▶ **The sociocultural context mattered**, with delivery of data and information via digital technologies achieving full value only when tailored to take account of variations in local language, customs, cultures, and user context, including literacy and user behavior patterns.

▶ **Effective behavior change and other messaging, whether delivered using digital technologies, word-of-mouth, or other channels proved most effective when delivered through existing affinity networks, by trusted messengers, and when structured to convey empathy**. Messages that failed to do so amplified fear and mistrust, leading to unintended consequences, including the hiding of cases, secret burials, and in some extreme cases violence against health and other response workers.

MAKING THE CONNECTION: EMPATHY, TRUST, AND DIGITAL TECHNOLOGIES

Ebola response behavior change messaging, regardless of the channel through which it was delivered, fared best when it bore empathy in mind. A doctor working with an international NGO in Sierra Leone said, "*When we told them 'don't touch' [your loved ones], we failed to humanize something that is quite inhuman. We can't make the mistake again—of neglecting empathy with those experiencing death in their families, and in their communities.*" Where concerns about contagion prevented physical contact, in some cases digital technologies were used to help bridge the divide. In some treatment centers, responders provided mobile phones or tablets to patients in order to be able to connect them with loved ones outside of the treatment units, providing emotional support for patients and demystifying for families what happened inside of treatment units. Trust also played a critical role in the response, with messages being best received when they were delivered by trusted messengers and among existing affinity groups.

Photo @ USAID/Neil Brandvold

DATA USE AND DIGITIZATION

This section takes a close look at how case data—their definition, use, and management—influenced the Ebola response. Both case data about individual patients and caseload data, which comprised aggregated individual case data, were central to understanding the disease's trajectory and to formulating corresponding aspects of the operational response. As one health expert explained, "*Infectious disease requires strong operational linkage of interventions. The case investigation team has to provide information to the contact tracers and burial teams, and laboratories are providing results back to everyone. The data on epidemiology has to go to social mobilization folks. This is not technical but operational links are critical for this type of response.*"[1]

Data about individual patients suspected of contracting Ebola were usually collected via a CIF. The data on these forms informed the range of operational activities associated with the response efforts. Information about contacts became the basis for tracing other potential Ebola cases (contact tracing); documentation about presenting symptoms, daily vital signs, and other health data became the basis for both patient treatment and epidemiological research; geographic data about an individual patient's location were crucial for everything from isolation or quarantine for family members to social mobilization activities and the dispatch of ambulances or burial teams.

The exchange of case data is also broadly reflective of how formal response actors (such as governments, international actors, and large NGOs) exchanged other types of data in mounting and deploying the response. Similarly, the challenges facing the collection of case data mirror those affecting the use of other data sets (e.g., laboratory tests, supply chain and logistics information about medical equipment and other supplies, or survey data about people's knowledge, attitudes, and practices (KAP) related to Ebola) used in the response.

Photo @ UMNS/Mike DuBose

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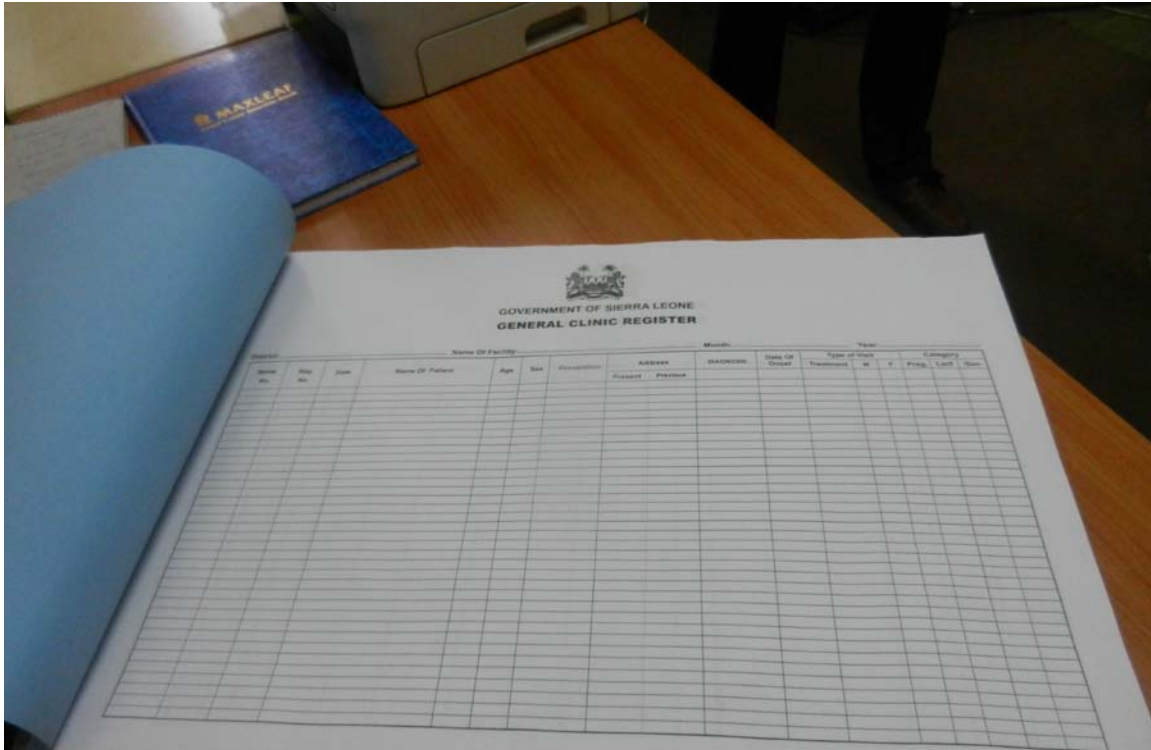
CASE DATA DEFINITION AND USE

Terminology

Individual patients were characterized as falling into one of three categories: suspected, probable, or confirmed Ebola positive.

► A **suspected** case was any person, alive or dead who had symptoms and known contact with a suspected, probable, or confirmed Ebola case, a dead or sick animal, or any person with unexplained bleeding or any sudden, unexplained death.

► A **probable** case was any suspected case evaluated by a clinician, or any person who died from "suspected" Ebola and had an epidemiological link to a confirmed case but was not tested and did not have laboratory confirmation of the disease.

► A **confirmed** case was any probable or suspected case that was confirmed when a sample from that patient tested positive for Ebola virus in the laboratory.[2]

Although these terms were standardized across the response, the interpretation of the terms differed across countries and organizations.

THE COMPLICATIONS OF COUNTING AND DEFINING EBOLA CASES

Compiling Ebola Caseload Data

Compiling data for this report about the toll of Ebola proved especially complicated. Readers may note that the numbers in this report differ from those in other sources, and that the report includes several sets of numbers (see Tables 1 and 2). As this section outlines, the Ebola case numbers differed, depending on whether the source included only confirmed cases, or confirmed, probable, and suspected cases (see **Table 1**, The Toll of Ebola, which contrasts these numbers). Whereas cumulative numbers were more dramatic and illustrated the scale of the response, the weekly case counts provided a picture of the state of the epidemic as it happened.

As laboratory testing facilities became more available and accessible, the accuracy of case counts improved and individual cases moved from classifications as either probable or suspected to confirmed cases or, if the result was negative, to non-cases. This affected the tallies of Ebola cases and deaths, across sources and dates, even though the patterns and trends remained relatively consistent. For these reasons, constructing the cumulative toll of the outbreak will remain a challenge; the numbers will likely never be fully reconciled. As one official suggested, capturing weekly case counts as opposed to the cumulative numbers represented a worthy tradeoff. "*We were putting in the hands of responders the best data possible. For the world, getting an accurate picture was not going to happen.*"[3] Although an acute issue at the start of the Ebola outbreak, data collection did improve as the outbreak progressed even though many of the data analysis challenges outlined in this report persisted.

Table 2, below, illustrates these changes over time, due to reclassification (e.g., a case moving from probable or suspected to confirmed, due to laboratory test results) and retrospective investigations. It serves as a reminder of the data picture closer to the peak of the Ebola outbreak in West Africa and of the "fog" that characterized the early days of Ebola case data collection.

TABLE 2: Comparing Cumulative Ebola Case Data and "Peak Weeks" over Time

	CUMULATIVE EBOLA CASE DATA REPORTING DURING THE EPIDEMIC WHO/CDC, as of December 10, 2014[1]			CUMULATIVE EBOLA CASE DATA REPORTING AFTER THE EPIDEMIC CDC/national governments, as of April 30, 2016[2]		
	Total # of Ebola cases	Week of peak cases	# of cases during peak week	Total # of Ebola cases	Week of peak cases	# of cases during peak week
Guinea	2,292	October 5–11, 2014	292	3,814	November 8–15, 2014	149
Liberia	7,719	September 14–20, 2014	509	11,849	September 20–27, 2014	290
Sierra Leone	7,897	November 9–15, 2014	748	14,394	November 15–22, 2014	534
Total	**17,908**	—	—	**30,057**	—	—

[1]Cases from March 29, 2014–November 30, 201**4**. See CDC Morbidity and Mortality Weekly Report (MMWR), "Update: Ebola Virus Disease Epidemic — West Africa, December 2014," Centers for Disease Control and Prevention, (December 2014), v. 63, n. 50:1199-120**1**. **http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6350a4.htm**, (accessed May 18, 2016).
[2]Cases from March 29, 2014, through April 201**6**. U.S. CDC, based upon figures from the WHO together with the governments of Guinea, Liberia, and Sierra Leone. Data as of April 3**0**. 2016, and reported in Table 1 in this report.

Defining Ebola Cases

In addition to the challenges of compiling case data, the case definitions of Ebola changed between and within countries and over the course of the outbreak.[4] All three countries used the WHO case definitions as a starting point. Yet interviewees reported definitions sometimes changed without warning or without ensuring district surveillance officers (DSO) and others were aware of or understood how to interpret the changes. This made case designations difficult. Those making the designations did not always understand the distinctions between the terms used for Ebola case definition (i.e., probable, suspected, confirmed), and not all probable or suspected cases were eventually reclassified as a confirmed case or for negative results, a non-case, even after the end of the outbreak. According to the WHO classification guidelines, all probable and suspected cases should have been confirmed by laboratory tests, ideally within seven days. Yet variables such as the availability of laboratory testing, the accuracy of the test, and when an individual was tested influenced when, whether, and how individual cases would shift between the categories of probable, suspected, and confirmed. At the height of the epidemic, delays in the manual input of data meant that these reclassifications would happen in batches. According to one official, "*They would reassess a bunch of probable cases and they would become suspect or confirmed. I'm guessing that was due to a backlog of laboratory cases.*"[5] As a result, the aggregated numbers of confirmed cases could shift from week to week, which created confusion with the caseload data counts.[6]

Variables such as the availability of laboratory testing, the accuracy of the test, and when an individual was tested influenced when, whether, and how individual cases would shift between the categories of probable, suspected, and confirmed.

GUINEA

In Guinea, "probable" cases were only assigned when the individual in question was dead, and the cause of death was assumed to be Ebola.[7] A "suspected" case referred to a person who was sick and who met the case definition for Ebola at the time. Only those cases with a positive laboratory test were designated as confirmed cases. Individuals from certain geographic locations (i.e., préfectures with a confirmed Ebola case in the previous 21 days) were designated as suspected cases.[8] Case definitions changed multiple times in Guinea, sometimes without official approval or without notifying all health care providers of the changes. In one instance, a préfecture changed the definition without a change at the national level.[9]

LIBERIA

Liberia's Ministry of Health established the Ebola case definitions in use during the outbreak, based upon the WHO guidelines. In May 2016, well after the end of the epidemic, the Liberian MOH defined standard case definitions for priority diseases, including Ebola, as part of its Integrated Disease Surveillance and Response (IDSR) guidelines. Health workers conducted ongoing and systematic monitoring of disease in order to improve public health, known as disease surveillance and response. This routine surveillance definition of a suspected Ebola case required fewer symptoms than the more sensitive definition that officials used during the outbreak.[10] This change emerged, in part, from a recognition that integrating Ebola disease surveillance into routine surveillance activities would assist the earlier detection and containment of future Ebola outbreaks.

SIERRA LEONE

The initial case definitions for suspected, probable, and confirmed Ebola cases originated with the WHO. In August 2014, the Sierra Leone Ministry of Health, with guidance from the WHO, changed the definitions to **those** described above. Like Liberia and Guinea, the case definitions were inconsistently applied across health facilities and treatment units, and were not always well understood by those completing the CIF or entering data into the VHF module database, which led to variation in how case data were interpreted and recorded.[11]

Case Data Use

Health officials at the county, préfecture, or district level used case data to dispatch relevant operational responders, such as contact tracers and burial teams. These data also were aggregated and transmitted, often via email or daily or weekly phone calls, to the national level where they became the basis for aggregated country-level Situation Reports (SitReps). SitReps were the primary vehicle through which national governments, together with WHO and CDC, provided formal reporting about aggregated data on the outbreak and response on daily, weekly, and monthly bases. These SitReps were disseminated and cited in media stories and used to inform high-level national and international discussions about the Ebola outbreak and response efforts (see Figures 6–9).

The publication of case data in aggregated form in PDF SitReps meant that the raw case data, graphics, and charts in these formal, public reporting documents were not easily accessible. The PDFs were neither machine readable nor could the data readily be transformed into other formats. This limited the ease with which other actors could use these data, requiring that data be manually re-entered before they could be **re-used for analysis and reporting**,[12] or transformed into **new charts and graphs**. One interviewee succinctly stated, "*People will make a PDF SitRep out of a spreadsheet, and that's the end of the spreadsheet*,"[13] a reference to the lost ability to easily access or alter data electronically once they moved into PDF format.

FIGURES 6–9

GUINEA

Screenshot of "Données épidémiologiques" table, from the Rapport de la Situation Epidémiologique for October 1, 2014

SIERRA LEONE

Screenshot of Table 2 from Govt of Sierra Leone MOH Ebola Virus Disease Sit-Rep (v 246), January 29, 2015

LIBERIA

Screenshot of "Cases" Table, from Liberia MOH Ebola SitRep (n. 141) for October 3, 2014

WHO

Table 1: Cases of Ebola virus disease in Guinea, Liberia, and Sierra Leone

Country	Case definition	Cases	Deaths
Guinea	Confirmed	977	562
	Probable	177	177
	Suspected	45	0
	All	1199	739
Liberia	Confirmed	931*	934*
	Probable	1713	677
	Suspected	1190	458
	All	3834	2069
Sierra Leone	Confirmed	2179	575
	Probable	37	37
	Suspected	221	11
	All	2437	623
Total		7470	3431

*In Liberia, three more confirmed deaths have been reported than have confirmed cases. In addition, the total number of confirmed cases is a relatively small proportion of all cases in Liberia, compared with Guinea and Sierra Leone. Laboratory capacity for case confirmation is being increased. Data are based on official information reported by Ministries of Health up to the end of 1 October 2014 for Guinea and Sierra Leone, and 30 September 2014 for Liberia. These numbers are subject to change due to on-going reclassification, retrospective investigation and availability of laboratory results.

Screenshot of Table 1 from WHO Ebola Response Roadmap Update, October 3, 2014

FORMS AND DATA

Case data, whether in paper or digital format, originated at various collection points. They were recorded by different actors and traveled among response entities in a variety of complex ways.

Case data, whether in paper or digital format, originated at various collection points. They were recorded by different actors and traveled among response entities in a variety of complex ways. One interviewee in Sierra Leone characterized data flows in this way: "*Data flow was nuanced across districts; it varied by district, and between countries. The reason for that was because of the number of different ways that a case form could be completed and lab results generated. You could have an Ebola case be an ill person arriving at hospital or a ... dead body picked up by burial teams.*" In the former, responders would complete a CIF whereas a laboratory test would define the latter as an Ebola case, or a non-case.[14] Although the primary flow of case data remained the same across countries (from treatment unit to district/county/préfecture to national level), the flow differed by response actor and the type of data being shared. For example, in Guinea, WHO managed case data, which préfecture officials sent to a central, national-level repository where a limited number of data managers entered data. In Sierra Leone, the CDC managed case data in the **EpiInfo VHF module**. In Liberia, case data were managed by the Ministry of Health, with support from the CDC and WHO. In each of these cases, however, the data belonged to the respective national ministry of health.[15]

Collecting Case Data—Caseload Investigation Forms (CIFs)

Case data, a primary data source used to inform the response, usually were collected on paper CIFs at the point of identification as probable, suspected, or confirmed Ebola cases. The primary Ebola CIF used in this outbreak was originally developed for and used in previous Ebola outbreaks in Uganda and the Democratic Republic of Congo. The CIF was based on the data tracked in the VHF disease surveillance module for EpiInfo.[16] Case data, however, could be collected multiple times, primarily because routine ministry of health-level surveillance for malaria, cholera, or other infectious diseases occurred *separately from* the overall response. As a result, case data of various types in all three countries were collected in multiple formats (both paper and digital) in treatment units by those providing care, by those responsible for routine health ministry disease surveillance (supported by WHO), as well as by those investigating Ebola cases or tracing contacts of Ebola cases as part of the overall Ebola outbreak response.[17]

As mentioned above, a number of variables in the response had an impact on whether, how, and the number of times CIF data were collected. For example, where, when, and how a person was identified as a probable, suspected, or confirmed Ebola case affected the amount and type of information collected in CIFs. Interviewees indicated CIFs were not always completed, as in instances in which a patient was too ill to answer questions, and family members were unavailable or unwilling to provide information. At times responders were too overwhelmed with cases to complete CIFs for each patient, as was the case in many Ebola treatment centers at the height of the outbreak. If an individual presented with symptoms at multiple facilities on different dates, one individual might be associated with several CIFs. Finally, deceased patients were tested for Ebola and had lab results, which data managers at the national or county level later associated with a unique patient ID. Their CIF indicated their status as a confirmed Ebola case or as a non-case, and contained varying degrees of completeness depending upon the information case investigators were able to discover about the deceased.[18] These forms were eventually manually transcribed into electronic format and compiled either in Excel spreadsheets or in digital databases.

FIGURE 10: Country-level Data Flow for Guinea
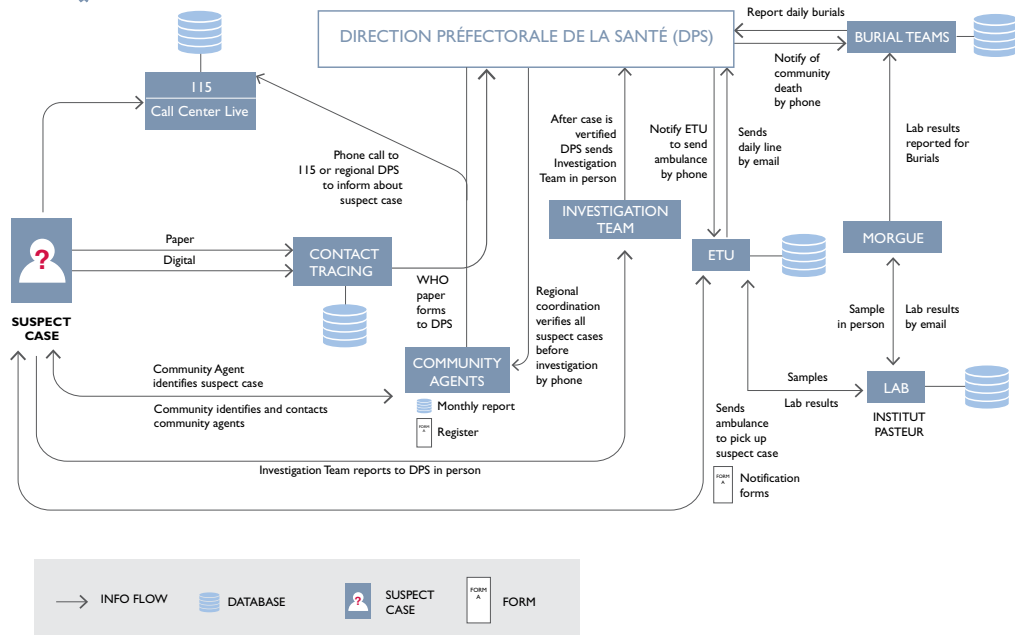
FIGURE 11: Country-level Data Flow for Liberia

FIGURE 12: Country-level Data Flow for Sierra Leone
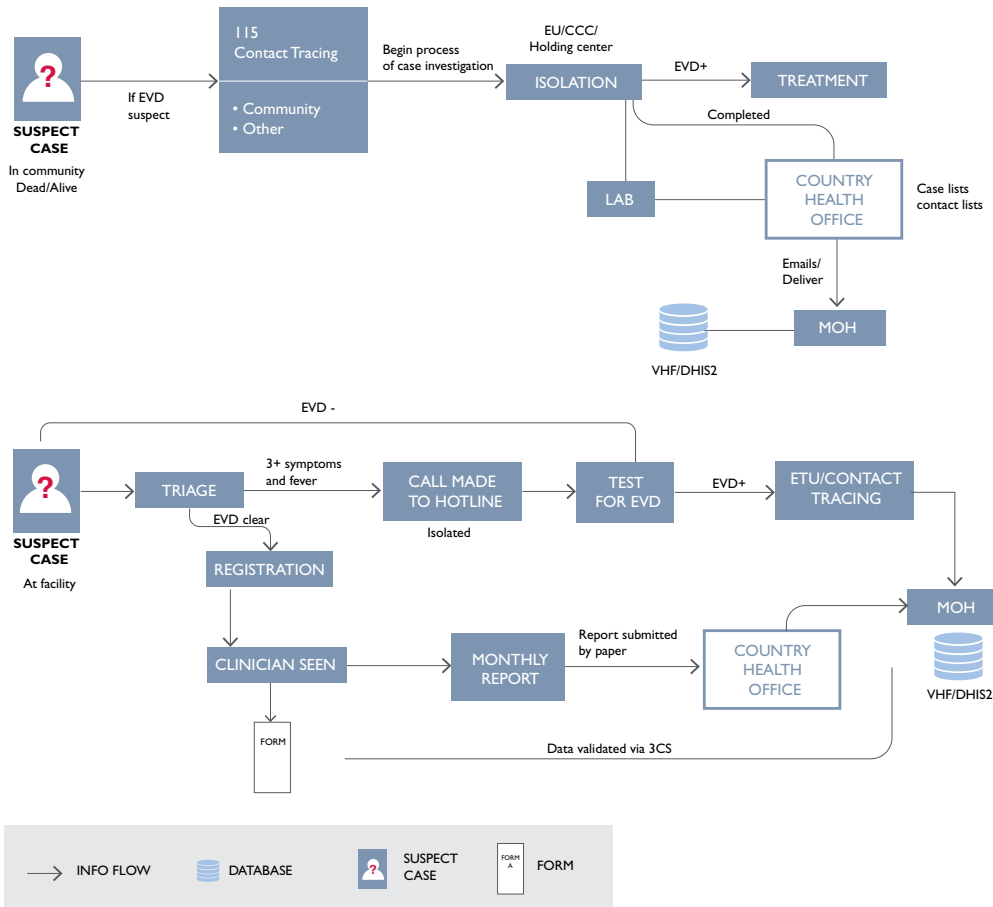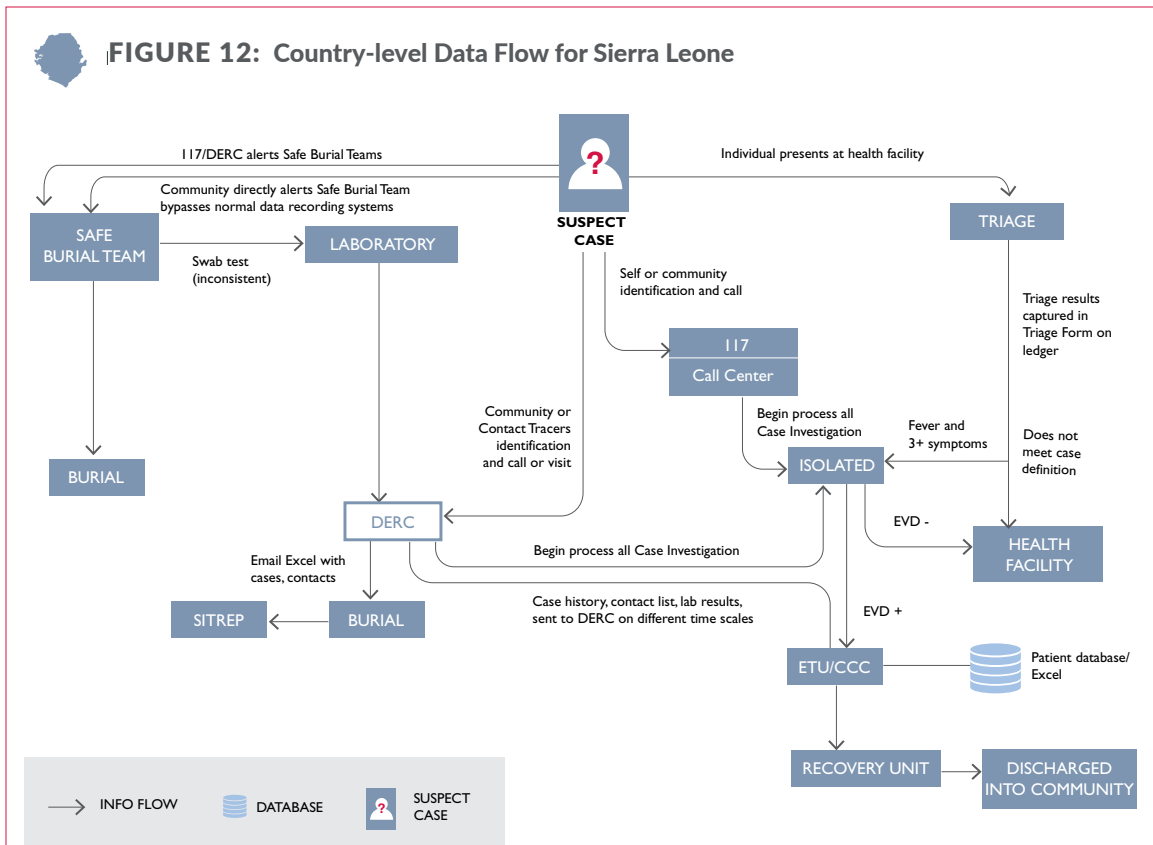
Figures 10–12 are adapted with permission from Gobee Group, "Regional, Real-Time Data Infrastructure for the Ebola Response: An Assessment of On-the-Ground Data Systems and Realistic Opportunities for Transformation in Guinea, Liberia, and Sierra Leone," July 2015. Original figures on pp. 23-25.

Non-standardized Use of Forms

The paper CIF had a corresponding digital format in the EpiInfo VHF module that essentially mirrored the paper form.[19] The paper-based format used at the outset of the outbreak and response was 11 pages with eight sections. Sections included patient information, clinical signs and symptoms, hospitalization information, epidemiological risk factors and exposure, case reporter information, patient outcome, and final case classification. In fall 2014, the paper and the corresponding digital version of the form used in the EpiInfo VHF module were condensed to a shorter version covering symptoms, dates of onset, travel history, and exposure history, and lab samples.[20] The shortened form facilitated data entry, since data managers had fewer data points to digitize. Even so, the forms were not always completed or accurately completed, for myriad reasons including time, resources, or staff capacity.[21]

In addition, the information collected in the CIFs was not consistently digitized or used across actors. In Sierra Leone, toward the end of the response when widespread transmission had stopped, some districts stopped using the CIFs and would only complete the CIF associated with the process of swabbing deceased individuals or suspected cases. One official explained how this affected both the collection of CIF data and its digitization: "*The swabber and DSO would both respond to a death. In reality the swabber was usually there first and then the DSO. ... Some districts have both at the same time, some just a swabber.... Some use both a CIF and a swabbing form. Either way some information is captured, but if there is no CIF then the case doesn't get to VHF. Any time there is a CIF, the CIF goes to a data manager who enters this into the*

VHF."[22] If no one entered the CIF into the VHF, digitization did not occur. In general, both duplication of case entry or non-digitization of CIFs proved problematic for the compilation, analysis, and use of case data to support the response.

Tension between Levels of Detail of Data Required

The CIF, which became the basis for the case data collected for the response, was designed by and for epidemiological purposes for those seeking to capture the precise and detailed patient-level data required to understand the incidence, transmission, and clinical presentation of Ebola. In the early days, however, it was impossible to capture this level of detail for the number of patients in the Ebola treatment units where medical staff worked under incredible time pressure and in difficult environments. One medical doctor providing care at an Ebola treatment center in Sierra Leone said, "*Information collected on paper forms was built for research purposes, not for patient care. We were given case information forms with pages of data in size 10 font that we were meant to collect. But the clinicians didn't have time to report this level of detail, and so it was never captured.*"[23] Another health official in Liberia echoed this sentiment with regard to the degree of detail required in the VHF forms, "*VHF was a research tool with lots of variables.*" She continued, "*The wrong data system was set up with best intentions.*"[24]

> *In the early days it was impossible to capture [precise and detailed patient-level data] for the number of patients in the Ebola treatment units where medical staff worked under incredible time pressure and in difficult environments.*

Although burdensome for the frontline health care workers, this level of detail is crucial for understanding the epidemiology, and subsequent prevention and treatment of Ebola. In the words of one epidemiologist, "*The clinical definition of [an Ebola] case here was very different than what we had seen before. Prior to this outbreak, we would say hemorrhage was the defining feature of Ebola. But we didn't have this here. Here it was vomiting and diarrhea and general pain. People had incredible weakness.*" His colleague elaborated on the importance of this level of detail: "*With this, the case definition changes. If you don't document all this, you can't find [this information]. ... you would lose it.*"[25] Knowing how a disease spreads, how rapidly it spreads (e.g., in a linear fashion or exponentially), and the patterns of its spread are all part of the epidemiology of a disease.[26] This knowledge, in turn, informs the type of interventions needed to stop transmission, how rapidly responders should intervene, and where and who responders should target first. In the case of Ebola, epidemiologists had very few answers to these questions prior to this outbreak.

Multiple Reporting Requirements

The requirement for many managing treatment centers to submit various reports to multiple entities compounded these challenges. To the central response coordination bodies, they reported available beds, and case and patient care data; to donors they provided grant-related data. One NGO official explained these reporting requirements, saying, "*We made large tables with current [Ebola] status by age, how many patients were in suspect/confirmed wards, who transited between wards, and numbers for discharge and death. ... [Our headquarters] wanted what changed that day but [our donor] wanted statistics for that day in the entire center, and also the cumulative total for entire center since our opening. Because this was too complicated, we took the reports that included the most information and made two-page reports that we sent to everyone.*"[27] Multiple interviewees highlighted the burden of reporting to multiple entities, including within and outside of their agency (to donors and coordinating bodies), much of which required different information in varying formats.[28]

MOVING FROM PAPER TO DIGITAL

Impact of Human Error and Time Delays

As with many other kinds of data collected in the outbreak response, case data were collected on paper, primarily at the community or district/county/préfecture level. In these instances, community or front-line health workers collected the data, and subsequently transmitted them to the county, district, or préfecture and then to the national coordinating body. One responder in Sierra Leone noted, however, *"Not every district was running its own data entry. If the district had a low number of people or limited human resources, then they'd be doing data entry elsewhere."*[29] In many places, data entry clerks—usually referred to as data managers—from WHO or the national coordination bodies supported these officials. At the district or national level, these data managers manually entered relevant data from thousands of pages of information about individual Ebola cases into one of three digital tools used to track Ebola cases: Excel spreadsheets and/or a designated database, such as the EpiInfo VHF module or the **District Health System 2 (DHIS2) Ebola Module**.[30]

The process of manually digitizing case data led to human error and time delays that affected the quality of case count reporting. Numerous interviewees highlighted the possibilities for human error and inconsistent reporting that emerged in the data entry process. At the beginning of the response, the VHF module supported free-form text cells as opposed to dropdown menus. For example, with a free text cell, those doing data entry could provide an exact age or a range, making automatic comparisons impossible across cases. During the fall of 2014 the CDC modified the module, in part to eliminate or at least minimize transcription errors and to facilitate comparisons.[31]

The significant time required to enter relevant data into digital format likewise affected data quality and use. In an analysis of on-the-ground data systems, the Gobee Group tested the time required to manually digitize data and the resulting effect on data quality. In testing 80 forms, they found the following:

"Scanning the forms to have their data pulled out automatically was 38 times faster than data entry completed by hand. While it took 153 minutes for the team to manually input the data, scanning the forms took only four minutes. Although accuracy for number-based data was roughly the same for both processes, letter-based data was 21 percent more accurate when scanned."[32] Unsurprisingly, given the amount of data during the height of the outbreak, a WHO official indicated that in September 2014, the data entry required to maintain the VHF module in Liberia was three weeks behind the data reported in the SitReps.[33] Similarly, the CDC reported a time lag of one to two weeks between VHF entry and data submission to the national level in Sierra Leone.[34]

Excel-based Data Management

Interviewees frequently referred to Excel spreadsheets as the unofficial data management tool of the response. "*Excel was the unsung hero of the Ebola response*," one interviewee said.[35] Because Excel spreadsheets are often used for reporting and monitoring health, humanitarian, and development activities, many organizations adopted Excel to manage case data. Both for instances in which digital databases were not used and, frequently when they were, Excel spreadsheets were central tools by which digitized data were shared, stored, and managed. To compile aggregated caseload data, the WHO provided a spreadsheet template with guidance about data collection, which organizations modified to meet their own reporting needs. According to one official, "*The spreadsheets did have a standard variable list. These were used by organizations, and they were adding extra variables on the end.*"[36]

In most cases, case data collected on paper were manually entered in Excel and/or the EpiInfo VHF module (depending on the country) and then shared with community or district/county/préfecture-level health teams or sent directly to the national coordination bodies, where they were aggregated and reported in caseload data statistics. Even so, multiple interviewees signalled the importance of training since computer and digital literacy were not widespread among local staff.[37]

EpiInfo Viral Hemorrhagic Fever (VHF) Module/EpiInfo (Guinea and Sierra Leone)

Both Sierra Leone and Guinea used the EpiInfo VHF module to track overall caseload data throughout the response.[38] The VHF module, however, was designed to track cluster outbreak investigations and not as a national disease surveillance system. As a result, the VHF module originally functioned on a single computer. Because the outbreak was geographically dispersed and required data entry from multiple locations, during the response it was redesigned to support distributed data entry. This allowed data entry and aggregation from multiple computers and locations into a single, centralized database, housed at the national level. In principle, data managers in the community health teams or district health offices would manually input data from their paper CIF forms into the centralized VHF database, which then could be accessed at the national level.

Even so, users reported challenges related to connectivity, version control, and system updates.[39] For example, within the VHF module, when district-level officials updated their data with new information, the update could overwrite and replace the existing data, including any changes or modifications. Consequently, in some instances when national-level data managers corrected data, their data cleaning corrections were lost in the process. Others reported challenges with having the relevant technical expertise in country to update the VHF module as new versions came out, or to train new people in VHF data entry.[40]

The District Health Information Software 2 (DHIS2) Database (Liberia)

Unlike Sierra Leone and Guinea, which used the VHF module throughout the outbreak, Liberia changed how it collected caseload data.[41] In the summer of 2014, the CDC EpiInfo team set up the VHF module and trained staff from the Liberian Ministry of Health in its use. The VHF database was housed in Lofa county, where the outbreak was centered at the time, and at the Ministry of Health building in Monrovia. The data were mostly CIF data, but individual records often lacked contact tracing and lab data.[42] As the fall progressed, cases mounted into the hundreds and it became apparent that the VHF data entry was weeks behind, limiting the system's use for reporting and decision making. In the words of one health official, "*The outbreak outgrew the VHF as a solution.*"[43]

As the fall progressed, cases mounted into the hundreds and it became apparent that the VHF data entry was weeks behind, limiting the system's use for reporting and decision making.

Three years prior to the outbreak, Liberia had adopted a national health information management system called DHIS2, a system designed to track health facilities, monitor and evaluate select health programs, and analyze and visualize data.[44] Given the issues with data entry, in the fall of 2014 Liberian officials decided to jettison the VHF system in favor of developing an Ebola-specific disease module for DHIS**2**. Although DHIS2 had only been deployed for aggregated data (versus individual data, as in the Ebola VHF module), DHIS2 developers from the University of Oslo created a new module tracking Ebola patients and contacts that catered to the revised and shortened CIF, which was deployed in late 2014.[45] In the interim, Liberian Ministry of Health and the supporting CDC and WHO officials managed the Liberian case data with paper forms coupled with Excel spreadsheets and Google drive.[46]

Designing the new module was fraught with complications. The urgency of the situation meant that the outside technical team from the University of Oslo had to scramble to quickly assemble a team to support the work. Most of the team worked virtually from abroad but one technical coordinator was deployed to Liberia. Poor connectivity and the perception of danger associated with foreigners traveling to Liberia at the time (September through November 2014) further complicated the work. In addition, developers had to consider ways to link in the VHF module case data throughout the response; in the end the VHF data were entered manually into the new DHIS2 module. Key officials were trained on using the new module but continued adjustments to the module (and associated training) occurred throughout the fall until it was deployed in late 201**4**. According to Knut Staring, the developer deployed to Monrovia, "*The constant stream of updates interfered quite substantially with the development of the new module. Because of the great urgency it had not been engineered to be generic and easy to change.*"[47]

Impact of Infection Prevention and Control (IPC) Measures on Digitization in Treatment Centers

The physical constraints required by stringent infection prevention and control (IPC) measures necessary to stop Ebola transmission complicated data collection and digitization within the treatment centers themselves. As a result, digitization almost always occurred as the second step of data collection, with paper as the first step. The physical constraints included: limited time periods during which doctors were permitted to remain in the infectious "red zones" due to the personal protective equipment worn in extreme heat without temperature control; the physical separation of red zones housing Ebola patients
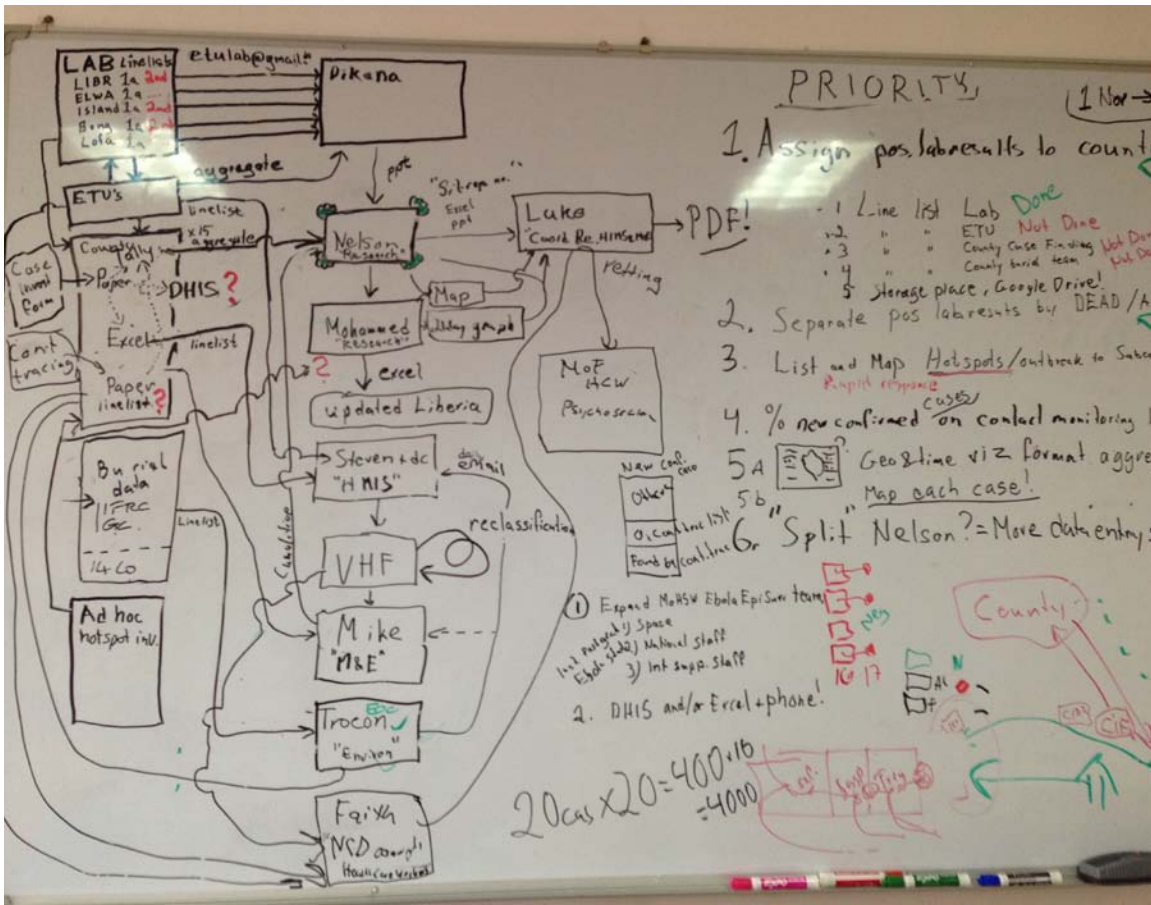
to the uncontaminated "green zones"; and the requirement to burn or disinfect through a chlorine rinse anything moving between zones. Most frontline health care workers prioritized patient care over reporting during their limited time inside the red zone.[48]

Due to these constraints, it was not possible to follow normal patient care protocol in which charts are kept with individual patients, enabling doctors and nurses to document their treatment and leave an accessible record for other clinicians to view. Instead, those running treatment centers developed a variety of coping strategies, many of which depended on connectivity within the facility, as well as people's access to and familiarity with equipment and technology.[49]

In the most basic centers, physicians in the red zone would dictate patient information to individuals in the green zone, or write down essential patient information and leave it in a place viewable by those outside the red zone. Health care workers in treatment centers with chalk or white boards ensured the boards were visible to those in the green zone. This allowed someone to take a picture or transcribe the information by hand into patient charts kept outside the red zone. In these cases, patient information could be transcribed two or more times, thereby increasing the possibilities for error. One medical doctor working in a treatment center in the fall of 2014 estimated that this process of documenting patient treatment took several hours per day: the clinician would document the treatment in the red zone, then orally report to someone outside the red zone, and that individual would transcribe the information to the patient's chart. This process would be repeated at least once for each patient during each of the three daily shifts.[50]

A PROLIFERATION OF PLATFORMS AND TOOLS

Each of the three most-affected countries collected and reported its aggregated caseload data differently, adopting different structures, mechanisms, and procedures to coordinate the response. The ministries of health, WHO, and CDC all released both national counts and regional totals for the outbreak.[51] The reporting and the timing of release of these data sometimes differed. In addition to the collection and management of case data use of VHF and DHIS2 for aggregated caseload data, multiple forms, formats, and platforms were used in collecting data related to the various pillars of the response, such as case investigation, social mobilization/community engagement, and infection prevention and control.[52]

Across the response, organizations deployed digital technologies to manage treatment centers, case information, contact tracing, burials, and other key activities. These technologies ranged from Google documents, Excel spreadsheets, Dropbox, open-source—often free—software (e.g., OpenDataKit (ODK), KoboToolbox, Voozanoo, OpenMRS), proprietary software (e.g., Magpi, Sense Followup/ID, Tableau, iForm), as well as combinations of these tools. This resulted in a non-aligned approach to data collection, storage, and management. Various accounts have tracked the breadth of digital tools used across the response. As one report described, "Over the course of the epidemic, the operational infrastructure of the response involved more than 50 independent technology tools. One group catalogued more than 300 separate initiatives to engage the public," a number of which intended to do so using digital tools.[53]

Although the functionality they offered enabled users to meet a variety of needs, the proliferation of tools and platforms and a lack of commonly used standards and data sharing between them contributed to the lack of readily available data needed to create a common picture of the outbreak and the corresponding response.[54] Moreover, many of the information collection systems that organizations set up during the response were not linked to national systems or national capacity. One responder collecting data about community attitudes in Sierra Leone recounted a conversation with a national official. He reported, "*The question I got from the NERC coordinator was, 'This is all good, but what are you doing to ensure that these platforms are integrated into national response system?'*" He continued, "*There are different organizations doing different pieces of data collection. Some of these things even in an emergency context have to be thought out, ideally in the preparedness phase.*"[55]

In other ways, the fact that the response played out over time and across multiple countries made it possible to use and reuse tools and to employ fixes from one country to another. One interviewee pointed out that the early peaks in Liberia made it possible to employ lessons learned in Liberia in the other two countries. In another example, a glitch in the VHF module that temporarily de-linked laboratory test results from the associated patient affected both Sierra Leone and Guinea. Responders were able to use the fix developed for Guinea in Sierra Leone as well.[56]

Although some organizations that operated treatment centers based their patient data collection in these centers on the CIF forms, others developed data systems that responded to their own specific workflows or needs. Within Ebola treatment centers in particular, organizations developed customized software systems to manage patient records and enable the transfer of information from contaminated areas of treatment centers. One NGO official remarked, "*It was so hard to accurately get information out of the red zone. If we could get high-quality information out, then we could improve our understanding, and also patient care.*"[57]

Some of the digital technologies employed open-source or interoperable platforms—in the sense of being technically integrated with other systems—but interviewees reported that many of these systems were

standalone systems.[58] Even though some of these systems used standards and open-source tools, such as OpenMRS, OpenHIE, and DHIS2, the number of standalone data collection and management systems deployed resulted in a lack of interoperability between systems. This proliferation of systems also created difficulties in centralizing data, and complicated efforts to align information infrastructures used to support the operational response. *"The challenge is getting data that can 'talk' to itself—across different actors and types of data,"* said one interviewee.[59]

Finally, many of the newly developed systems or platforms were one-off instances that functioned more like pilots in that many were new, and none were deployed at scale. The effort and time required to develop, test, and deploy new digital systems meant that many of the systems were ready only after the caseload had declined. An NGO official, who had been involved in deploying a pilot system, said, *"It was hard to understand how long and complicated it would be to do a digital system."*[60] Multiple interviewees mentioned that they underestimated the amount of time, effort, and human resources required to develop, deploy, and manage these systems, particularly in the middle of the response that escalated from dozens to over one hundred Ebola cases in a week.[61]

When used, however, they enabled efficiencies and adaptations that met identified needs from frontline responders. For example, the Red Cross used maps of Ebola cases to quickly and efficiently deploy social mobilization and burial teams to Ebola hot spots. Using mobile phones and GPS software allowed them to track where they picked up and buried people. *"We were collecting hundreds of bodies, and reporting about 20 people per week without names at the peak of the crisis,"* said one Red Cross official. To promote accountability and address this issue, they worked with the software company to quickly integrate an additional feature—photographs—to help identify people in cases where they lacked names for the deceased. The latter feature was important in helping relatives locate family members who died during Ebola outbreak.[62] These and other benefits of digital technologies are explored more fully in the following section.

Photo @ USAID/Neil Brandvold

LESSONS

This discussion of the collection, management, and analysis of case and caseload data in the Ebola response paints a picture of the myriad challenges that complicated efforts to efficiently and effectively track case data in particular. It highlights a series of lessons regarding data and information flows, and for health and humanitarian preparedness and response more generally.

▶ **Limited mobile and Internet connectivity hampered the sharing and digitization of case data as well as other types of data used in the response. Where limitations in digital connectivity were understood, solutions could be designed accordingly**, such as mobile credit top-ups for health workers to facilitate reporting of case data. As one interviewee said, "*In order to generate good data, first you have to understand the situation and environment, where data is being produced. Some days, 7 out of 15 counties weren't reporting [case data]. The reason was simple: they did not have Internet or scratch cards [for mobile top-ups].*"[63]

▶ **In environments with limited digital connectivity, solutions that functioned in both online and offline environments were essential.** One responder noted, "*The [electronic medical records] system we built worked for our site but wouldn't sync offline. That is a useful feature. … The situation for patients changes so quickly—it is nontrivial to say that I'll do this offline but then there are really important time stamps that don't get captured.*"[64] Agreeing upon a simple and straightforward paper-based data collection approach at the beginning of the response, prior to digitization, could have enabled comparable data across paper and digitized datasets, and facilitated the implementation of digitization where connectivity existed.

EXTENDING CONNECTIVITY IN AN EMERGENCY

The use of VSAT and BGAN satellites to rapidly deploy access to communications in areas without Internet or mobile network coverage has been common practice in response to sudden onset emergencies like natural disasters, and was repeated to extend connectivity to responding entities during the Ebola outbreak. This satellite-based communications model presents two significant challenges: high costs to establish and use, and a lack of sustainability once international partners who traditionally deploy the satellites leave.

The 2014 arrival of an undersea fiber optic broadband Internet cable along the coast of West Africa presented the opportunity for an alternative model of extending connectivity: a point-to-point wifi network. The Ebola Response Connectivity Initiative (ERCI), a consortium made up of a diverse group of telecommunications and technology organizations, leveraged this model to extend access to the Internet in Ebola hotspots in Liberia and Sierra Leone. The initiative forged relationships with MNOs to use existing cell phone towers to set up the point-to-point wifi connections, and within three months established over 100 communications centers for health clinics and other areas staffed by responding organizations.

In addition to the involvement of international partners Facebook, Cisco, NetHope, EveryLayer, and Inveneo, the initiative included local technology companies, such as Damsel in Sierra Leone, that were certified to provide ongoing hardware, software, and system maintenance. Although these in-country partners solved one portion of the challenge of maintaining this network over time, financial sustainability challenges remain once international donor funding ends. Furthermore, while the initiative succeeded in boosting connectivity for response actors, it did not extend the reach of communications to extension workers and average citizens, leaving a critical gap still to be filled.

▶ **Technological challenges included version control and lack of in-country expertise to troubleshoot problems that arose with the digital technologies in use**.

▶ **Existing digital information systems were under- or unprepared to deal with the data demands of the response.** The VHF module, designed to support single and limited outbreaks, faltered under the weight of the unprecedented spike in Ebola cases. Existing investments in health information systems in the region had focused primarily on engineering support for one-off projects, rather than on long-term capacity building, systems maintenance, and systems adaptation to meet needs identified at the national level. As a result, fledgling national information systems struggled to meet the data aggregation and reporting needs of the response.

▶ **None of the three most-affected countries had interlinked emergency and routine surveillance systems, nor were disease surveillance and response integrated with national health information systems**. According to one interviewee, "*The routine public health surveillance systems were sufficient to generate trend analysis for seasonality, but they weren't highly sensitive. … We still have routine and emergency surveillance separate.*"[65] This made it difficult to automatically sound the alarm when the outbreak occurred.

▶ **Data and corresponding data flows often were siloed and duplicative. This resulted in a proliferation of distinct and non-interoperable platforms to collect and manage data.** For case data, separate reporting of routine disease surveillance and Ebola case data resulted in multiple sources of data. Yet this was true of other data types and data collection systems as well, including health or humanitarian program and evaluation information. One report on Sierra Leone noted, "Three distinct streams of information management were in operation during the response: via technical coordinators and programme managers, via [Monitoring, Evaluation, Accountability and Learning] staff and via communications staff. These streams did not appear to be strongly linked."[66]

▶ **The issue of who "owned" the data, and the related question of who could share data, surfaced as crucial questions in relation to a variety of sources of data, particularly at the beginning of the response.** For case data, a general consensus existed that the national ministries of health owned these data. Yet the ownership, sharing, and publication rules of subsets of these data were less clear. For example, who "owned" data about individual patients in a treatment unit, and, therefore, who could publish analysis about these patients? Once data were shared in a publicly accessible format, who owned these data? What policies, procedures, or gatekeeping functions should be in place to formally request access to data?

▶ **Data collection tools for cross-response activities, such as case data reporting, contact tracing, and laboratory tests, needed to be standardized with a minimal set of data points/ indicators and distributed widely.** The urgency of the crisis, combined with the lack of flexibility in many of the data collection systems meant that updates and technological fixes were not easily implemented.

▶ **The lack of a robust unique identifier system was a great hindrance to data integration across data sets** (e.g., case data, contact tracing, burials, family notification, laboratory data), **as was the lack of machine-readable data**. Compatibility of data standards and systems was an issue between countries, but even more so within countries.

▶ **Human capacity issues related to the collection and management of data and information affected the response in a variety of ways.** These included the data burden (e.g., referring to the time required and human error introduced with multiple transcriptions, including from one paper form to another or from paper to digital format as well as multiple reporting streams); limited capacity to collect, manage, and analyze data; and inadequate time, human resources, or supporting institutional policies and processes required to effectively manage and use the volume and velocity of data collected.

▶ **Outbreak responses require research**. During the Ebola response (as with a number of other public health crises) it was essential for research to happen during, not only after the response—given the need to understand how the virus was mutating, how that affected chains of transmission, and the large numbers of unknowns related to the efficacy of medical countermeasures (treatment and vaccines) for Ebola.

Photo @ USAID/Neil Brandvold

REAL TIME INFORMATION FLOWS

Although digitized data and information flows did not constitute the norm, they did contribute meaningfully to the Ebola outbreak response in specific instances, and introduced both quantitative and qualitative differences in data and information flows in the response when used. The following case studies[1] provide snapshots of the use and impact of digital technologies in the Ebola outbreak response. These case studies identify:

▶ **What:** What was the tool, platform, or service used?

▶ **Why:** In what context was the digital technology used, and for what purpose?

▶ **Who:** Who were the primary actors engaged in use of the technology or technologies?

▶ **How:** How did the digital technology or technologies function?

▶ **Analysis:** What outcomes and insights resulted?

▶ **Challenges:** What challenges did actors encounter?

The case studies are organized by actor groups participating in the information and/or data exchange, including:

▶ **national governments**

▶ **traditional response and donor organizations** (such as foreign donors, NGOs, and intergovernmental organizations like UN agencies)

▶ **frontline workers** (such as community health workers or contact tracers)

▶ **citizens and affected populations**, and

▶ **"remote" responders supporting the formal response** (such as the digital humanitarians, members of diaspora groups, and context experts)

CONNECTING FRONTLINE WORKERS AND GOVERNMENTS

mHero: SMS between Frontline Health Workers and the Central Health Ministry in Liberia

What: The Mobile Health Worker Electronic Response and Outreach (dubbed mHero) system launched in pilot form in Liberia in November 2014 to meet the need for real-time data and information exchange between the central Ministry of Health and frontline health workers. It aimed to strengthen the government's health information system with up-to-date information about health worker location and availability on the one hand, and to provide critical information to support health workers on the frontlines of the crisis on the other. In doing so it created a two-way flow of information between health workers and response organizers in real time.

Governments lacked a clear picture of where health workers were located and what services they were providing to their clients, and where health workers were located. To fight Ebola, governments needed real-time, up-to-date information on the availability, location, and needs of their health workforce.

Why: Health workers played a critical role on the frontlines of the Ebola outbreak response. For responding organizations, whether national or international, frontline health workers served as critical eyes and ears and identified cases as they emerged, and helped to treat the ill. In their work to combat the spread of Ebola, health workers of all kinds faced a significant risk of contracting the virus. Varying estimates calculated health workers› risk of Ebola exposure at between 21 percent and 42 percent higher than that of the average citizen in the three most-affected countries in West Africa.[2] Consequently, many health workers fell ill; others abandoned or moved their posts.

In many countries, including those most affected by the Ebola outbreak, governments lacked a clear picture of where health workers were located and what services they were providing to their clients, and where health workers were located. To fight Ebola, governments needed real-time, up-to-date information on the availability, location, and needs of their health workforce (e.g., did they have sufficient personal protective equipment?). Health workers, in turn, needed access to information about how to protect themselves against the virus and to share critical data about the disease's spread.

Who: In the Liberia deployment, mHero was launched by the national health ministry with a consortium of partners, including UNICEF, IntraHealth, and K4Health.[3] Prior to the outbreak, the Ministry of Health had been collaborating with IntraHealth and UNICEF on a digital health[4] worker database called iHRIS (a modified abbreviation of the open source "Human Resources Information Solutions" platform), and an SMS messaging system called RapidPro. mHero was planned and designed to enable interoperability between these two systems.

How: mHero is a mobile phone-based communication system that for the first time connected central ministry staff with frontline health workers via two-way text messages using the basic mobile phones that most health workers already owned. The platform allowed them to receive critical information in real time.

mHero integrated the existing iHRIS and RapidPro platforms, leveraging iHRIS to access the mobile phone numbers of government frontline health workers, and RapidPro SMS messaging to enable communication via text message that could be delivered to all or a targeted subset of those in the iHRIS database. It uses the principles and standards of OpenHIE[5] to aggregate key data from human resource information systems and securely share and validate health worker information. mHero can share data with the DHIS2 web-based health information management system. In Liberia, mHero enabled nuanced and tailored messaging to health workers based upon their qualifications, position, location, specialty, and how recently they had been trained. Another game-changing aspect of this innovation was its ability to enable health workers to initiate direct and real-time contact with health officials—allowing data and information to be "pushed" by health workers, in addition to "pulled" at the request of health officials.[6] This functionality is particularly critical in the context of detecting and monitoring a disease outbreak.

ANALYSIS

▶ **The mHero pilot was used to validate frontline workers' contact information and get a real-time picture of worker location and availability.** By the pilot's close in December of 2014, the health ministry had used mHero to reach nearly 500 health workers at facilities in four counties. The ministry used these SMS exchanges to validate health workers' contact information, including their phone numbers, locations, job titles, supervisor information, and health facility association.

▶ **The Ministry of Health adapted mHero for over three dozen uses over the course of the response and recovery.** Health ministry officials used the pilot to update personnel records in iHRIS, rapidly building the government's capacity to engage real-time information with frontline health workers in the future. Between November 2014 and July 2016, over 40 mHero deployments[7] reached more than 7,000 health workers, showing increased use by both frontline health workers—including civil servant and community volunteer health workers—and central ministry staff.

▶ **The Ministry of Health adapted mHero to enable messages to be initiated by health workers, as well as by the central ministry.** As the use of mHero evolved over the course of the response, the government began to lay plans to incorporate SMS messages originating with health workers. *"I think it is about time we find a way the health workers can communicate directly to us. A health worker may have some burning issues to share, but we may [be] missing his or her concerns,"* said Stephen Gbanyan, Director of Health Management Information Systems in the health ministry.[8]

"I think it is about time we find a way the health workers can communicate directly to us. A health worker may have some burning issues to share, but we may [be] missing his or her concerns."

▶ **The Ministry of Health has incorporated mHero into its draft digital health strategy.** In December 2015, the Ministry of Health formally integrated mHero into Liberia's draft Health Information System (HIS) and ICT Strategic Plan for 2016-2021, which upon formalization would make its use an official part of the government's health strategy and health information system architecture.[9]

CHALLENGES

The piloting and increased adoption of mHero by the Liberian Ministry of Health faced challenges, as did each of the other case studies profiled in this section. Here we provide a closer look at these constraints the lessons that resulted. In subsequent case studies, this section is condensed into a high-level summary.

TABLE 3: Constraints and Lessons from the mHero Case

Constraints	Lessons
Technological Constraints	
The mHero system required a specially negotiated shortcode to operate.	• Negotiating shortcodes can be time consuming. Before a crisis hits, relevant government actors should secure access to one or more shortcodes, such as for communications between governments and health workers. • Ideally, shortcode use should be operationalized as part of routine workflows to raise awareness of and trust in this communications channel before an emergency hits.
At the time of the Ebola outbreak, Liberia's mobile network infrastructure reached approximately 69% of the country's population.*	• Building out the physical infrastructure that extends digital connectivity before a crisis leads to stronger ability to gather data and information in real time to manage and mitigate after effects of an emergency. • A rapid assessment of communications infrastructure can be done quickly at the onset of a crisis to enable quick fixes and planning to mitigate weaknesses, as necessary.
Crises affect the quality and reach of mobile networks, which in turn can directly impact the effectiveness of SMS-based channels.	• Governments should negotiate with mobile network operators for crisis-related shortcode messages to be prioritized in messaging queues. • All actors should have low tech and non-digital back-up options for relaying critical information in cases in which mobile networks are overwhelmed or inoperable.
Existing systems that record health workers' mobile numbers did not regularly refresh those numbers, meaning many in the iHRIS database were out of date.	• It is critical to understand how user behavior will affect the design and requirements of a digital system. In this case, health workers (as with others) frequently used more than one SIM card and phone number.To design for this variability, mechanisms that gather health worker phone numbers must establish a process--ideally an automated one-- to regularly update those numbers.
Ministry of Health ownership was critical to ensuring that data collected by mHero could be integrated into government workflows and decision-making.	• Facilitate government ownership and capacity to build and manage two-way communications with extension workers before a crisis hits.
mHero required interoperability with other platforms: iHRIS, as well as DHIS2, Liberia's digital health information system.	• Analyze how data will be used for decision-making, and build APIs that enable interoperability with relevant databases and digital platforms.
Funding for the mHero deployment was largely through one-off Ebola response grants, creating vulnerabilities in longer term deployment and use.	• Use tools that have broad utility in a crisis period and beyond, and identify sustainable business models that support their use over the long term.

Constraints	Lessons
Human and Institutional Capacity Constraints	
Health workers were not accustomed to receiving text messages from the government health ministry.	• To increase understanding and uptake, pair use of digital channels with a communications campaign that builds awareness and trust. • Content must be curated to build and deliver messages in a way carefully considers the user experience. This requires time, resources, and dedicated expertise.
Although health workers received a thank you message to acknowledge their response, they were not given information about how their responses would be used to support the outbreak response.	• Feedback loops, in which contextualized data and information is sent back to the point of origin, create incentives for health workers to participate in further information exchange. For example, if a health worker reported on numbers of suspected Ebola cases seen in a day, the health ministry could send a message back the following day on how many suspected Ebola cases her county reported overall.
The health ministry was unaccustomed to receiving real-time SMS data from its workforce, requiring new technical expertise and workflow processes. Managing the mHero workflow and linking it to internal processes required training, two dedicated Ministry of Health staff, and two IntraHealth staff who worked from the ministry office.	• Understand the existing and plan for required capacity at the staff/technical level, and at the institutional/policy and processes level, to fully utilize digital solutions--particularly when they require a departure from normal operations. • Allocate time and adequate human resources to process data and build capacity, including change management processes at the institutional level. • Ensure adequate access to technical staff over the lifetime of the digital technology's deployment to enable maintenance of and fixes to software and hardware as needed.
Ecosystem Constraints	
In Liberia, use of SMS is less common than voice calls, contributing to low response rates among health workers. In addition, many workers were not accustomed to free text messages, leading some to avoid replying for fear of incurring charges.	• Consider user behavior, and the necessary behavior change incentives and strategy if deploying a digital solution requires activities or actions that deviate from normal user behavior.
Data flows coming through the digital mHero channel needed to be merged with a variety of primarily paper-based information systems (e.g., lab results reporting, disease surveillance, routine health management information reporting), requiring harmonization with paper-based systems within and between multiple health ministry offices.	• Consider how data produced through digital channels will harmonize with data that are still collected through paper-based systems, and the workflows that merging these two data and information sources will require.

*NetHope, GBI and USAID, "Information and Communications Technology Response to the Ebola Crisis: Desk Review and Recommendations for Private Sector Engagement". (Washington, DC: USAID; NetHope/GBI, 2014), xii, **http:// solutionscenter.nethope.org/assets/collaterals/USAID_LiberiaICTDeskReview_Final_Nov414.pdf**

CommCare Contact Tracing 2.0: Data Exchange between Contact Tracers and the Health Ministry in Guinea

What: In Guinea a consortium of partners, including the Guinean Ministry of Health, piloted and then expanded the use of the CommCare contact tracing tool to gather and share critical case data. An online dashboard provided by Tableau[10] was used to visualize contact tracing data in real time.

Why: Contact tracing was essential to containing the spread of Ebola. In most instances contact tracers used paper forms that were physically transported to a centralized location for manual digitization by a data entry clerk. This frequently resulted in a lag time between when contact tracers collected the case data, and when those data became available for decision-making. This was particularly the case in Guinea where many cases occurred in remote and transient communities.[11]

Who: Partners included the Guinean government, the tech company Dimagi, the Earth Institute at Columbia University, and the UN Population Fund (UNFPA). Data gathered through the contact tracing app and visualized on Tableau dashboards were available for access by government response managers in préfecture-level offices and at the National Ebola Coordination Unit.[12]

A variety of international partners supported the project. Ericsson, the Paul Allen Foundation, and UNMEER donated smartphones; Solektra International donated solar chargers to power phones used in off-grid areas and panels to enable regular access to power in the government offices where CommCare data were used. UNFPA facilitated the purchase of SIM cards for a closed user group and for 500MB of data per month, and the Earth Institute provided computers and USB modems to government staff as necessary.[13]

How: A subset of government health staff who supervised contact tracing activities were selected by government and UN agency partners for training on the CommCare contact tracing software application. The app created digital records of the Ebola contact registration form, which captured information such as type of case (i.e., probable, suspected, confirmed), symptoms, GPS location of affected households, and alerts for cases in which individuals were registered with high temperatures or Ebola symptoms. The app enabled longitudinal tracking of individuals over time, an important feature given the need to trace contacts on a daily basis over the 21 days required to determine whether or not a contact had contracted Ebola.

ANALYSIS

▶ **The CommCare Contact Tracing app was used in five of the eight préfectures in Guinea** (Boffa, Conakry, Coyah, Dubreka, Forecariah) after first being piloted in December 2014.

▶ **The app collected nearly 30,000 contact tracing forms.** As of early 2016, approximately 440 contact tracers and supervisors had registered on the tool, of which 281 submitted approximately 19,000 contacts to be traced for location and signs of Ebola, using the CommCare contact tracing app. A total of approximately 280,000 forms were submitted documenting multiple contact tracing visits to the 19,000 contacts identified.

▶ **Improvements cited in the use of the CommCare contact tracing app over paper forms included: reduction of time and human error, and increased reliability, data verification, and contact tracer accountability.** For example, in addition to increasing the rapidity with which frontline health care managers could see contact tracing data being collected, the use of the

linked contact tracing app and Tableau data visualization platform supported accountability of contact tracers through the use of timestamps and GPS location on smartphones to enable real-time verification of household visits.[14] "*Contact tracers don't visit people who [may be] sick because they are afraid*," one partner said.[15] The use of GPS enabled managers to monitor contact tracer compliance and to identify which contacts received daily visits. One district health manager reported: "*The first thing I do every morning is check the dashboard on my computer. The GPS helps me know where my contact tracers have been and where they haven't been, so I can see if there are issues and follow up.*"[16]

▶ **Contact tracers used the digital tool in conjunction with the paper forms**; paper forms remained the official, required reporting mechanism during the outbreak.[17]

CHALLENGES

▶ **A lack of standardized contact tracing protocols and metrics led to confusion about the type of information to be collected and measured**. Based on learning from use in the Ebola outbreak response, Dimagi re-released the app as a version 2.0 for deployment in subsequent epidemiological outbreaks.

▶ **Because users did not have experience regularly using digitized data that appeared at a higher volume and velocity than paper-based data**, data collected through the app were not always put to immediate use. Although the app enabled digital data collection, using these data represented a further challenge. An analysis of the tool found that, "While government staff members were especially enthusiastic about the wealth of data that could be used for supervision of contact tracers, actual use of the data was limited. Local government managers often had many competing interests and responsibilities, and thus relied instead on supervisors to report issues to them rather than exploring the data directly."[18]

▶ **An Earth Institute assessment of the pilot identified numerous challenges**, including: availability of local staff to support phone configuration and hardware management; the time required to configure the Tableau dashboard, which was built by volunteer consultants; coordination and management challenges among the diverse array of project partners; limited use of the resulting data by government managers; unclear privacy regulations governing patient data; and the lack of a formal government health information system into which contact tracing data could be integrated.[19]

▶ **Difficulties around technical issues like battery life and mobile signal** required that contact tracers also use paper forms for back up. "*Contact tracers in Port Loko, Sierra Leone, told us they preferred the mobile tool, and felt like the mobile submissions were communicated more quickly to decision-makers acting on the data. The mobile CommCare application also allowed for closer contact tracer supervision, and supervisors could be quickly alerted if a tracer was not making their rounds, or making fewer visits than expected*," said Courtney Kelly of Dimagi.[20]

▶ **The unique combination of volunteer efforts and donated materials would make it difficult to scale this particular model,** although it did demonstrate within the constraints of an emergency response that digitized data could supplement existing paper-based contact tracing data flows.

CONNECTING RESPONSE ORGANIZATIONS AND EXTENSION WORKERS

**Ebola Community Action Platform (ECAP):
Using ODK and Mobile Messaging to Communicate between
Social Mobilizers and NGOs in Liberia**

"Peer-to-peer networks like WhatsApp enabled young people to learn from each other, and encouraged staff to persevere in difficult contexts. Many [social mobilizers] were motivated to go the extra mile to hard-to-reach communities because they could share photos and their experience across the ECAP social mobilizer [network] and receive support from project staff."

What: To capture and share this situational information in real time, the ECAP program collected knowledge, attitudes, and practices (KAP) data from more than 2 million people in approximately 3,300 communities across Liberia. Over 800 social mobilizers collected KAP data using smartphones donated by the Paul Allen Foundation, and loaded with ODK and the WhatsApp peer-to-peer and group messaging app. To provide broad and open visibility into the changing landscape of community-level Ebola information needs, ECAP visualized aggregated KAP data through a public and easily accessible online platform.[21]

In addition to this digital component, ECAP adopted analog and word-of-mouth mechanisms to amplify and expand its messaging. ECAP used billboards and radio broadcasts across all 15 counties in Liberia, as well as posters, handouts, and person-to-person drama activities at the community level.

Why: Targeted social mobilization among at-risk communities was critical to bending the curve of new Ebola cases in West Africa. To better understand the appropriate formulation of behavior change messages required in Liberia, response organizations needed continuously updated information about community-level knowledge, attitudes, and practices about the disease.

Who: ECAP was developed by Mercy Corps and Population Services International (PSI) with contributions from 77 partner organizations, many of which were Liberian NGOs. ECAP also partnered with the organization IREX to reach community radio stations across the country.

How: In the digital portion of the ECAP program, social mobilizers using smartphones completed and submitted community-level KAP survey data on a monthly basis via ODK. In addition, social mobilizers used the WhatsApp platform for peer-to-peer messaging and group learning. In a sometimes unstable telecommunications environment, the WhatsApp platform enabled a layer of message delivery verification (i.e., small checks next to messages indicating whether messages were sent, delivered, and read). Because each of the project's communities were geo-coded, the dashboard included up-to-date maps that included community KAP data.

For the analog elements of the program, ECAP partner PSI Liberia used billboards to reach people outside of the target communities in which ECAP worked to reinforce community-level messaging. The billboards featured health ministry-approved cartoons, which linked to specific ECAP mobilization topics. For radio, ECAP partner IREX Liberia worked directly with community radio stations to reach listeners in their local dialects, using familiar voices.

ANALYSIS

▶ **The ECAP program had broad reach through a diverse group of national and international partners.** It aggregated and visualized KAP data collected by over 800 social mobilizers who surveyed more than two million people in approximately 3,300 communities throughout Liberia.

▶ **The program strategically employed a hybrid communications approach that used both digital and low- or no-tech channels to reach the broadest possible audience.** Early ECAP data confirmed radio was the most trusted source of information on the unfolding Ebola crisis, and highlighted the reach and impact of community radio stations in Liberia.[22] Billboards and local dramas organized to relay critical behavior change messages also were used to reinforce the community-level work of social mobilizers. Mercy Corps Monitoring, Evaluation, Research and Learning Manager Sophie Roden attributed the success of this multi-partner and multi-channel approach to its focus on a few key consistent messages that stayed the same regardless of partner or distribution channel.

▶ **The program used both open source and proprietary tools**—open source (such as ODK) to serve basic data collection needs and proprietary messaging (such as WhatsApp) to reach a wide group of users at scale.

▶ **The program embraced a strategic approach to open data** by sharing visualizations of aggregated KAP data on a publicly accessible platform for broad use by actors supporting the outbreak response. This created horizontal, peer-to-peer information flows among response actors to increase access to behavior change data and information.

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▶ **The program used peer-to-peer information flows among social mobilizers and created feedback loops that unlocked new incentives.** Use of peer-to-peer networking through the WhatsApp platform also produced the unintended benefit of serving as an important source of motivational encouragement for social mobilizers. Mercy Corps learning manager Sophie Roden described this benefit, saying, "*Peer-to-peer networks like WhatsApp enabled young people to learn from each other, and encouraged staff to persevere in difficult contexts. Many [social mobilizers] were motivated to go the extra mile to hard-to-reach communities because they could share photos and their experience across the ECAP social mobilizer [network] and receive support from project staff.*"

▶ **The program used peer-to-peer information flows among citizens to share and address common questions.** Radio also created an important opportunity for dialogue and debate at the local level. Partner radio stations hosted regular call-in talk shows on Ebola-related topics, with experts—usually a medical professional or Ministry of Health representative—serving as guests. Community members would call in to have their questions and concerns addressed.

▶ **The program used feedback loops to adapt programming.** In addition to gathering a near real-time assessment of critical and quickly changing community information needs, the targeted insights of the ECAP platform and network were used to refine behavior change messages and adapt programming. In the words of a representative of one national partner organization in Liberia, this enabled "*discuss[ion] at the national level and among [partner organizations of] what is happening, what are the challenges, and [to] recommend a way forward.*"[23] Roden described how the real-time insights were used to adapt programming, saying, "*The aim was to constantly change the messages to reflect what people knew. But we discovered that in the second round [of the learning surveys] that [the social mobilizers] didn't fully understand the messages in the first round. So we had to reinforce the messages and then add some new material. The third round was better.*"

CHALLENGES

▶ **Despite the rich data that the ECAP program produced, it is not possible to know which aspects or channels of behavior change programming were most essential to turning the tide of new cases.** Digital behavior change communications did enable real-time adjustments of behavior change messaging, however, based on changing sentiments and information.

▶ **As with other programs using digital technologies in the Ebola outbreak response, technical glitches affected digital aspects of the programming.** In particular, mobile data connections were sparse in rural areas resulting in delayed or undelivered messages—particularly in the southeast of the country, where mobile network connectivity gaps were larger.

▶ **RapidPro, the SMS platform the program initially had intended to use to send messages and reminders to social mobilizers faltered** in the early stages of the response. According to Jeff Wishnie, Senior Director of Program Technology at Mercy Corps, "*Out of 10 [text messages] sent only a few would get through.*"

▶ **The WhatsApp platform also suffered setbacks, requiring staff time for workarounds.** The software client installed on social mobilizers' smartphones would periodically need to be upgraded, resulting in temporary discontinuity for affected users. Updating Whatsapp content to receive new messages in rural areas became problematic due to limited connectivity.

The WhatsApp message cache[24] would usually only update in populated areas with mobile broadband connectivity, leaving many social mobilizers working in rural environments disconnected from the platform.

▶ **The use of donated smartphones that were not commonly used locally meant there was a lack of locally available staff trained in IT troubleshooting.** "*For the first few months when a phone went down that was it,*" Roden said. In some cases ECAP staff had to troubleshoot themselves. In one instance, when a new version of WhatsApp had to be installed on all 800 smartphones, the team created a video instructing social mobilizers how to download and install the new version of WhatsApp, providing on-the-job-training.

▶ **The use of a data visualization platform combining data from multiple sources required a strong team of data analytics and visualization experts.** This presented a challenge to international partners managing the data during the emergency phase of the response, and is a potential barrier to the program's longer term success when it is handed over to national partners.

NAYMOTE: ADAPTING EXISTING NETWORKS FOR COMMUNITY MOBILIZATION

Naymote, an election monitoring organization in Liberia, partnered with Mercy Corps and PSI as part of the ECAP program. Naymote repurposed its network of community organizers, originally created to monitor elections, to support the community mobilization efforts. Staff from the Naymote call center called citizens already part of their network of supporters to inquire about the situation in local communities. They then shared this information with the local county or health offices to mobilize resources. For instance, when they received reports of dead bodies lying uncollected in the streets, they reported this to the Ministry of Health. When rumors were identified, such as one referring to Ebola as a government plot to get money, Naymote staff invited members of Parliament to get on the phone to answer questions. One staff member said, "*Community organizing is important for health. Mobile phones enabled us to connect ordinary people who got to talk to people in positions of leadership. This was very helpful in dispelling rumors.*"[25]

Although phones played a key role in Naymote's work—indeed, the team also passed along information about toll free Ebola hotlines provided by MNOs—the team also adopted multiple strategies to reach communities. For off-grid areas, Naymote held Ebola prevention trainings using a projector transported by truck between communities. Documentaries prepared specifically to support the response, including one with a clip of President Obama talking about the Ebola outbreak to help lend credence to the threat Ebola posed, were also translated into local dialects.

United Methodist Communications: SMS Campaign between Pastors and Bishops in Liberia and Sierra Leone

What: As the Ebola outbreak surged in Liberia and in Sierra Leone, pastors in local United Methodist Churches received "messages of hope"—inspirational Bible verses as well as information about the disease—via text messages sent from their national bishop. The text messages were sent using the SMS broadcast tool FrontlineSMS.[26]

Why: The Ebola crisis touched all parts of society, and required trusted messengers to counter prevailing rumors about the source and attributes of the disease. A pastor based in Sierra Leone explained, *"Initially there was a lot of denial about Ebola."*[27]

Who: The bishops' offices of the United Methodist Church in Sierra Leone and Liberia partnered with United Methodist Communications headquarters, based in Nashville, Tennessee, to send the messages. The partners used an online spreadsheet to craft, edit, and approve messages, which were then dispatched via SMS to pastors and community leaders in each country.

How: Prior to the Ebola outbreak, the church already had in place a list of its pastors' mobile phone numbers, and the capacity to communicate with pastors via text message. As part of its Ebola outbreak response, the church complemented its SMS campaign engaging pastors with TV advertisements that reached urban audiences, and screened broadcasts using a projector transported by truck that reached off-grid and offline rural communities.
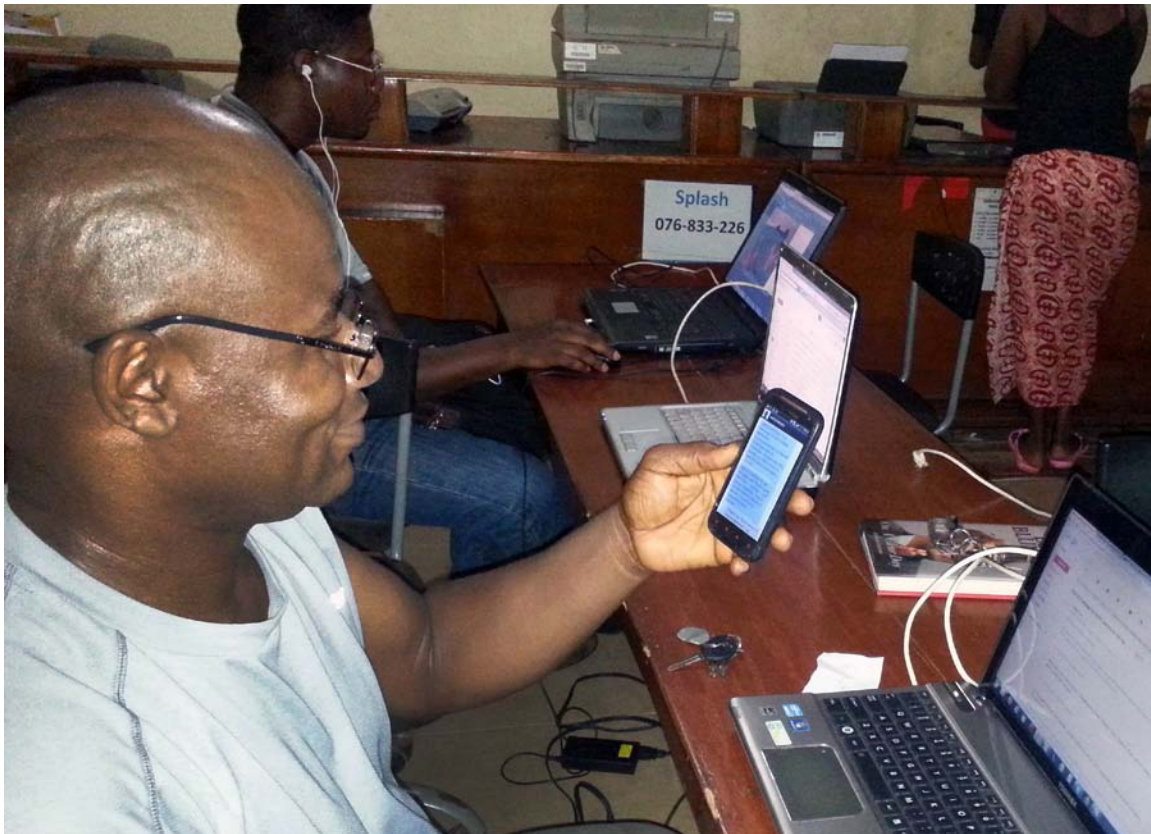
Photo @ United Methodist Communications

ANALYSIS

► **Between August 2014 and October 2015, over 600 church and community leaders in Liberia and Sierra Leone received more than 550 messages.**

► **In addition to providing facts about Ebola, the text messages played an important role in supporting and motivating pastors who played a key role in supporting their communities.** One pastor in Liberia's Kokoya district, which was placed under quarantine during the outbreak, recounted how the text messages gave him courage to persevere in dark moments. In a time when his community faced fear, sickness, loss, and restricted movement, he told a colleague, *"When I feel depressed about what is happening around me as a result of the Ebola crisis, I pick up my phone and read the text messages from the very first text message to the end."*[28]

► **Those receiving text messages included pastors whose congregations reached into areas with limited or no access to mobile networks.** Particularly in these cases, the pastors' ability to weave messages into meetings of the congregation served as an important vehicle to deliver information to those individuals beyond the reach of digital networks and devices.

► **The program used a hybrid communications approach, integrating radio call-in shows to enable feedback loops at the community level.** Through a partnership with Radio ELUM, a Methodist radio station based in Liberia's capital city of Monrovia, the church aired select questions in radio broadcasts that featured local experts who addressed these questions. This created a feedback loop by which trusted, local authorities provided accurate information to communities.

► **Trust, and trusted messengers, played a critical role in delivering behavior change communications regardless of communications channel.** Phileas Jusu, a Sierra Leone-based communicator employed by United Methodist Communications described the importance of trusted messengers and networks, saying, *"We developed messages about avoiding physical contact and used aired broadcasts carried over national TV as a way to suggest a new form of greeting, with arms crossed over chest and bowing. This was a major cultural shift as people were used to touching. But when the bishop went on TV with other religious leaders doing it, it became more accepted."*[29]

CHALLENGES

► **At first the program enabled only one-way, top-down communications.** As the program evolved and the demand for two-way communications became clear, the program integrated two-way messaging functionality that enabled pastors to pose questions to the bishop's office. This revealed important local perceptions about Ebola. One response, for example, asked if Ebola was an American means of population control in Africa.

► **Particularly in a climate of fear and mistrust, pastors at first were wary of messages sent without attribution.** Neelley Hicks, director of the ICT4D Church Initiatives program at United Methodist Communications in Nashville said, *"We learned right away the importance of adding the bishop›s name to the text messages so that the recipients could identify the source of information as a trusted contact."*[30]

> *"When I feel depressed about what is happening around me as a result of the Ebola crisis, I pick up my phone and read the text messages from the very first text message to the end."*

CONNECTING RESPONSE ORGANIZATIONS AND CITIZENS

DeySay Rumor Tracking: SMS Exchange between Citizens and NGOs in Liberia

What: The DeySay[31] SMS platform in Liberia served to detect and manage rumors in near real time. At the community level, information, including rumors, moved by word-of-mouth, radio, and phone.

Why: Identifying and correcting rumors was a critical part of controlling the Ebola outbreak. In rural villages and urban centers alike, communications among citizens played a critical role in sharing both information and misinformation. Using trusted messengers and channels was essential to correcting misinformation.

Who: Internews, an NGO working to support local media and provide crucial news and information to communities, operated in partnership with the Liberian National Red Cross Society, UNICEF, and Project Concern International.

How: The DeySay project sought first to understand the state of knowledge about Ebola, and second to improve access to accurate information for citizens by sharing regular updates on rumor tracking with the humanitarian community. DeySay collected information from hundreds of health workers, NGOs, and volunteers in Liberia through an SMS short code, which UNICEF provided free of charge. When those participating in the system became aware of a rumor, they submitted it via text message to the short code, which relayed the messages to a central coordination hub in Monrovia. There, the project team analyzed rumors for content and location trends, and developed new messages to counter misinformation and misunderstandings. These insights and new messages were shared with local media partners for rapid dissemination in the target area via radio, community engagement, and other channels. DeySay also produced a weekly newsletter updating the landscape of prevalent rumors and their geographic locations, offering official response organizations and local media alike a way to identify and respond to misinformation about Ebola at the community level.

ANALYSIS

► **The digital component made it possible for organizations to quickly analyze and respond to rumors.** One organization partnering with the DeySey network received several messages regarding the Ebola treatment units it operated. In one instance, the organization received feedback that community members living near a treatment unit were concerned about the smoke rising from an incinerator, giving rise to a rumor that bodies were being burned there. After learning of the rumor, the organization removed a tarp that had blocked the community's view of the incinerator, enabling passersby to see that the organization was burning contaminated materials, not bodies. In other instances, community volunteers were able to investigate, understand, and then address rumors related to higher mortality rates in specific treatment units.[32]

► **The ability to rapidly adapt behavior change messaging in response to rumors represented another advantage of the program's digital component.** For example, during a vaccination program in schools a rumor in rural northern Liberia near the Guinean border broke out that the vaccinated children were taken by ambulance and hospitalized.[33] The rumor originated after a child in a public school in the area was diagnosed with a high fever. When the ambulance arrived to transport the sick child for care, students panicked and fled, and within the hour parents throughout the region were rushing to local schools and removing their children. To counteract the rumor, the false information was communicated to local radio stations, which broadcast the reported rumor and clarified the situation. In an added step, local health teams made school visits. As a result, parents returned their children to school and the rumor was stopped before it could spread and do further harm.[34]

► **Though it is not always possible to produce immediate and uniform behavior change, this case study provides a good example in which a hybrid approach combining the use of digital, radio, and word of mouth communications worked** to quickly address a rumor by connecting to people through communications channels with broad reach.

"When dealing with complex issues like Ebola, you have to start with what information is most critical to the local population, not with what you want them to know about your service."

Boxes documenting Ebola-related rumors in Sierra Leone.

CHALLENGES

▶ **An initial attempt to establish an independent short code for the DeySay program was abandoned in favor of a partnership with UNICEF in order to use a short code they had previously negotiated**. In particular, it was difficult to create a single short code that would be accessible to subscribers across multiple MNOs. The UNICEF partnership also granted the DeySay program use of their SMS aggregator (RapidPro). This did not enable direct access, however, which meant the DeySay project team could not themselves do troubleshooting or modify workflows in the system. Similarly, UNICEF held the relationship with MNOs, limiting the ability of DeySay program team to ask questions or request support.

▶ **When the DeySay project team arrived in Monrovia, rumors were rampant and trusted information was in short supply.** *"To determine the most trusted sources of information we used an information ecosystem model,"* explained Anahi Ayala Iacucci, Internews Country Director in Liberia.[35] Through a partnership with Geopoll, the Internews team sent monthly SMS surveys to around 200 citizens in each of five regions. The surveys gathered regularly updated responses about the most trusted sources of information, whether government, media (including radio, TV, and print), civil society, or other channels. The survey showed that although trust in other channels varied, local radio remained one of the most trusted sources of information throughout the height of the outbreak. The surveys also asked people what information they needed. *"Listening to what people need speaks to the principle of 'design with the user,'"* Mark Frohardt, Internews Senior Vice President for Design and Learning, said. *"When dealing with complex issues like Ebola, you have to start with what information is most critical to the local population, not with what you want them to know about your service. A clear understanding of needs and context increases the amount of requested information and understanding of messaging from services providers,"* he added.[36]

▶ **Many social mobilization efforts during the response used broadcast media as a one-way channel to blast information out, rather than partnering with local media to leverage radio programming's ability to host a dialogue with the community.** Internews maintained a behind-the-scenes role for the duration of the DeySay program, engaging 16 media partners in convenings that explained how the DeySay rumor tracking system worked, gathering journalists' feedback, and then letting each media outlet decide whether and how to use the information. Three to four weeks later, most media partners were running dedicated radio programs using the DeySay information to address local rumors. The Internews team also provided journalists with available information that could be used to counter rumors. By the end of the program, nearly 200 media stations had opted to participate.

▶ **One challenge the program faced was how to discuss rumors without inadvertently further spreading them.** Internews conducted trainings for journalists to address this, and to provide critical context to the disease. *"We brought journalists to Monrovia and a training with the World Health Organization and the Ministry of Health to explain how diseases like Ebola work,"* said Iacucci. *"The journalists loved it; nobody had taken the time to explain it to them, yet they had the job of trying to explain to their audiences. The training was designed to try to take complex epidemiological and medical terms and break them down in a way that would be relatable and understandable,"* she added.[37]

U-Report: SMS between Citizens and a UN Agency in Liberia

What: U-Report, an SMS platform designed to facilitate citizen engagement and community-led develop-ment, engages youth "U-Reporters" to provide information about their local context and, in return, pro-vides information back to U-Reporters that they can use to work for change locally. The tool is designed to increase awareness of local needs, and transparency and accountability in development programming and services.[38]

Why: Lack of trusted information about Ebola was a major factor contributing to the disease's transmis-sion. To inform behavior change and social mobilization campaigns, response organizations needed to understand local knowledge, attitudes, and practices about the disease.

Who: UNICEF created the U-Report platform in 2011 and was using it at scale in five sub-Saharan African countries prior to the Ebola outbreak. When the outbreak struck, UNICEF leveraged an existing U-Report deployment in Nigeria where over 100,000 youth were already engaged, and set up new systems in Liberia and Sierra Leone.[39] In Liberia, UNICEF partnered with the Federations of Liberian Youth (FLY), active in all 15 counties in Liberia, to help recruit U-Reporters.

How: The U-Report platform used a short code provided by the Liberian Telecommunications Authority[40] and linked it to the open source RapidPro text messaging platform.[41] Young people opted in, and received polls and information via this free short code. Through U-Report, UNICEF aggregated real-time informa-tion about young people's perceptions and concerns about Ebola and visualized responses on a public website to help inform behavior change efforts. U-Reporters were recruited in partnership with FLY through the use of social mobilizers, targeted campaigning, mobile vans, in-person meetings (e.g., town halls, churches, schools, mosques), as well as radio advertisements and promotion via call-in radio shows across 21 radio stations in Liberia.[42]

Photo @ UNICEF

ANALYSIS

▶ **Between November 2014, when the U-Report program was launched in Liberia, and June 2015, almost 51,000 youth had registered in Liberia to become U-Reporters.**

▶ **In Monrovia, UNICEF used a human-centered design approach by partnering with representatives of the target audience, in this case teenage girls, to script survey questions querying knowledge, attitudes, and sentiments about Ebola.** As a result of this collaboration, originally drafted survey questions such as "What has changed the most in your community because of Ebola?" were adapted to a more colloquial format used by texting teens (e.g., "wat bother U d most abt Ebola?") In addition, a steering committee of youth representatives worked with UNICEF to identify weekly topics for the campaigns.

▶ **During the crisis, UNICEF's Communication for Development behavior change teams used U-Report data to support community engagement work**, in some cases to adapt and reposition some of UNICEF's interventions and messages. The platform also was used to assess the effectiveness of radio campaigns to alert people to new outbreaks.[43]

▶ **In the recovery period, UNICEF used the platform to query sentiments and gather knowledge about related topics, such as school reopenings.** The target audience was expanded to include teachers, women, and religious leaders.[44] Beyond the outbreak, U-Report remains an important platform for youth and citizen engagement. It is now being used in Guinea to address other public health issues, such as HIV/AIDS, as well as gender-based violence and women's financial empowerment.[45]

▶ **UNICEF had experience using the U-Report platform during a prior Ebola outbreak, where it illustrated the important "sensing" value that citizen-led communications channels offered.** In July 2012, an active U-Report deployment in Uganda began receiving messages from U-Reporters asking about that outbreak. Messages included:

- "IN OUR AREA THERE'S A PARSON DIPHICATING BLOOD? FEELING FEVER ISN'T THIS SIGN OF EBOLA P'SE HELP"
- "Our district Kibaale has been affected by an unknown disease but doctors are suspecting it to be Ebola disease"[46]

CHALLENGES

▶ **Getting the U-Report short code up and running took time and multiple negotiations.** Particularly in the context of the hectic early stages of the Ebola outbreak response, obtaining a short code for the U-Report project was difficult. Multiple organizations were making requests of mobile network operators, overwhelming the staff of those companies that already were strained by the toll of the outbreak and the demands of the response. UNICEF ultimately went to the Liberian health ministry to secure support for the short code.

▶ **Even once the short code was established, there were delays in rolling out the short code across multiple MNOs.** To work around the varying timelines on which mobile operators were able to begin making the short code active on their networks, the UNICEF team took a phased approach and started operating the short code on networks as they became available, rather than waiting to launch the short code simultaneously across all networks.

Social Mobilisation Action Consortium (SMAC): Using ODK and Mobile Messaging to Communicate between NGOs, Social Mobilizers, and Communities in Sierra Leone

What: The Social Mobilisation Action Consortium (SMAC) launched to collect and transmit information about the Ebola outbreak in ways that allowed communities to engage and ask questions. SMAC members recruited, trained, deployed and worked with community mobilizers, religious leaders, traditional healers, radio stations, and community leaders to provide targeted and accurate information to community members. In addition, SMAC members developed a process to receive information about sick cases and deaths in communities as well as other community-level information. The process evolved to run off mobile devices.

Why: As the outbreak escalated in Sierra Leone, it became apparent that a gap existed between coordination of the Ebola outbreak response and social mobilization interventions at the district level. This resulted in a lack of understanding about what was happening in affected communities, and what people were saying and doing about the disease.

Who: SMAC was an alliance of national and international NGOs and other partners, including GOAL, Restless Development, FOCUS 1000, BBC Media Action, and the CDC. All had been involved in the response before coming together as a consortium. For example, FOCUS 1000 had begun to conduct KAP surveys in August 2014. These surveys allowed greater understanding of the local perceptions and response to the Ebola outbreak, supported the design of more appropriate social mobilization interventions, and enabled tracking of knowledge, attitudes, and behavior changes across the response. FOCUS 1000, in partnership with CDC and UNICEF, conducted four KAP surveys during the course of the outbreak. The latter three were conducted using mobile devices.

Although all members collaborated on social mobilization activities, each organization brought niche specializations to the consortium's work. GOAL and Restless Development led the work with community mobilizers (many of whom were also community health workers) using the Community-Led Ebola Action approach. FOCUS 1000 provided grassroots connections to influential community leaders and led the work with religious leaders and traditional healers. BBC Media Action linked SMAC to and led the work with local radio stations. The CDC provided technical support.

How: Although SMAC's initial community-based reporting used paper forms, with funding from the Bill & Melinda Gates Foundation SMAC was able to move to a digital data collection system and expand the reach and type of data collected. The initial paper-based forms were streamlined into the digital system,

Photo @ SMAC

with added questions and indicators. According to Mohammed Jalloh, former Senior Program Manager for FOCUS 1000 and lead on SMAC's digital data collection system, *"The digital work built off of what we had done. It was never about the new cool technologies. Many people find the cool software and then figure out how to use it. For us it was the opposite—these are challenges and this is how technology can help us solve them."*[47]

For the project, SMAC built a unique, customized Digital Data Collection System (DDCS) using a combination of software—ODK, KoboCollect, and TextIT. The system allowed SMAC's vast network of stakeholders to submit actionable Ebola-related data from thousands of targeted, sometimes remote, communities across the country and facilitated two-way daily communication with all phone users.

Social mobilizers (including community mobilizers, religious leaders, and radio station managers) used mobile phones to collect daily alerts about suspected Ebola cases and any deaths in the community. These data were submitted through SMS into the DDCS system, which generated an automated response with an appropriate course of action (e.g., notifying the nationwide "117" hotline or the local hotline for reporting cases) and allowed for follow-up (e.g., SMAC could follow up with the hotline or to report back to the community). The daily alerts were shared with district-level officials tracking the disease.

Second, the mobile phones allowed for ongoing reporting from social mobilizers who submitted weekly performance data about SMAC activities, community perceptions of Ebola, and information about burials and deaths in their communities. The digital technologies SMAC used allowed project staff to customize the surveys for each different group of social mobilizers.

ANALYSIS

► **The SMAC project provided access to phones and training on the DDCS to over 2,500 people.** Fifty master trainers, 1,475 community mobilizers, 1,036 religious leaders, and 36 partner radio stations (in pairs or individually) received access to phones and were trained to use the DDCS and send real-time, community-based surveillance data, including information about deaths and suspected cases.

► **SMAC compiled and shared weekly reports with key local and national response actors that highlighted concerns and feedback from communities** and provided updates on SMAC's community engagement in the priority districts.

► **Accountability and reporting back to communities represented one major benefit of the daily alert process.** SMAC staff suggested that prompt actions helped to save lives and strengthen trust between the communities and service providers. They reported on and used examples of actions that were delayed to advocate for service improvements. According to Katharine Owen, the SMAC Director, *"We had concerns about establishing a parallel system with the daily alerts. But we discovered people might say they called 117 when actually they didn't. But they still wanted to tell someone. Or we might find [the case] had been called in, and there was nothing happening. … Or where it had been reported, our people on the ground were able to report back to communities what was happening. … Whether the case was in the [formal case data collection] system or not, there is value in getting the information into the system or in being accountable and reporting back. This is important to maintain trust."*[48]

▶ **SMAC used their digitally connected network of social mobilizers and other community leaders to help assess the efficacy of messaging during a nationwide "stay-at-home,"** during which citizens were encouraged not to leave their homes. During the stay-at-home, the government conducted a House-to-House campaign designed to educate people about Ebola and conduct disease surveillance. The second stay-at-home included a nationwide plan to distribute hand soap, but officials ran out of soap. Using its network, SMAC gathered and analyzed community perceptions (over 40,000 records) of the second lockdown and reported their findings to the NERC. According to Owen, *"The data were able to demonstrate that if you promise everyone soap and not everyone gets soap, that is what they remember rather than the message given."*

▶ **Reusing and adapting survey software and analysis tools enabled significant savings in time and effort.** FOCUS 1000, a SMAC member, conducted four KAP surveys in Sierra Leone, including three with mobile devices, that supported the overall Ebola response efforts. In addition to the KAP surveys in Sierra Leone, members of the FOCUS 1000 team trained another local NGO in Guinea, Sante Plus, with support from the CDC, to conduct a similar national KAP survey in Guinea in August 2015. Previous KAP work from Sierra Leone allowed the Guinea team to reuse and adapt the surveys and the analytical frameworks, saving time and effort. Using programmed tablets, the Guinea KAP data were collected from over 6,000 respondents across all eight administrative regions in Guinea within one month. The collected data were then swiftly analyzed with pre-programmed statistical analysis code, and key findings presented to the Guinea Ebola Coordination Center within three days after receiving the data.

CHALLENGES

▶ **Despite the benefits, SMAC staff reported several challenges in deploying digital technologies.** First, connectivity presented issues. The mobile phone network would break down, and the technical assistants for the mobile network operators were based outside of Sierra Leone. This caused delays for SMAC activities. It also took several months to set up the short code and functionality of the system to provide voice and data connections to all social mobilizers in the program. During the project, SMAC switched to a locally based provider to speed up the troubleshooting process, but then had to migrate the phones in a phased fashion to maintain services.

▶ **SMAC staff identified the "human element"—the training and support needed to take advantage of digital technologies—as another challenge.** *"We underestimated the human resources needed to do real-time data,"* reported Jalloh. Staff indicated that despite the goal of using real-time data to inform decisions, this was difficult. Jalloh noted, *"The use of the system during the House-to-House campaign to get feedback from communities was perhaps the best illustration of real-time usage of the system wherein findings were shared daily with the NERC to inform decision-making."*

▶ **Another issue was cost.** SMAC's activities required significant up-front financial resources to purchase the mobile phones and pay for recurrent costs associated with the data plans necessary for the surveys and the short code for the alert system. In addition, there were "hidden costs" in the form of hiring people to enter data and space to house staff members. Finally, SMAC staff spoke about the challenges of managing the devices. This included training people to use them, providing technical support when the devices broke, and decisions about what to do with the devices after the program ended.

▶ **SMAC staff reported that the amount of data represented a significant issue.** For the daily alerts, they hired "alert interns" who helped to manage the data. The interns were able to follow up to collect more detailed information to put into a dashboard, which was shared with district-level officials.

CONNECTING OTHER ACTORS

Skype Information Management/Geographic Information Systems (IM/GIS Group): Online Coordination and Data Exchange among Response Workers (Global)

What: The Skype IM/GIS channel was established in late August 2014 by the Digital Humanitarian Network (DHN) to meet this need.[49] A variety of actors involved in health and humanitarian aspects of the Ebola response coordinated and delivered geospatial data sets to meet information management needs shared using this channel.

Why: Particularly during the early days of the 2014 Ebola outbreak, response organizations identified a need for detailed mapping of health, operational, and other information. Unfortunately, available or actionable data sets were limited, and there was no widely accepted, formal channel to request or share geolocation information.

Who: Members of the DHN, a network of the digital humanitarians who leverage digital skills to support humanitarian responses,[50] created the Skype IM/GIS channel to facilitate coordination between formal humanitarian aid actors and this network of digital experts. According to Roxanne Moore, who served as DHN Ebola coordinator from December 2014 through June 2015, *"The Skype group was an online group that was created organically. Prior to that, there was not an open space to collaborate. ... It was very chaotic."*[51] Participants in the Skype IM/GIS group included DHN members as well as staff of a variety of national and international organizations.

How: The channel served as a clearinghouse for requests for geographical and other information, and the tasking of creating new datasets and maps needed to support the response. This included mapping previously unmapped areas in Ebola-affected countries, and creating overlays such as: the location of Ebola treatment units and community care clinics; the population density of affected areas; border crossing points between affected countries and border crossing data; road blockades and quarantined areas where passage was restricted; and Ebola case and death counts by locality.[52] Many of these datasets were later shared on the Ebola GeoNode or **HDX**.

ANALYSIS

▶ **By August 2015 over 230 individuals from approximately 100 organizations had joined the Skype IM/GIS Group**, some in their official capacity and others as off-hours volunteers. Up until May 2015 the group continued to host regular data exchanges, although increasingly about broader health and other needs that accompanied the affected countries' recovery after the crisis phase of the Ebola response.[53]

▶ **The IM/GIS channel supplemented existing, formal coordination mechanisms**, and was used by many, including response workers in country, staff of international organizations working abroad, and members of the digital humanitarian community around the globe. This "open" model of ecosystem engagement enabled relevant actors to self-identify and self-organize around information needs largely outside of the context of formal mechanisms for information sharing by the response community.

▶ **One of the primary advantages of the open Skype group was the ability to connect a range of remote and operational responders, often across multiple sectors of activity** (e.g., health, technology, GIS). According to Moore, *"Having such a large Skype group is a huge deal. We've never had anything this large. You had the U.S. government talking to NGOs talking to VTCs [volunteer and technical communities] talking to UN agencies. The de-siloing of [information sharing among] organizations is exciting."* In this way, the Ebola response illustrated changes in how actors communicated.

▶ **DHN members engaged more with each other and with a broader range response actors than in prior crises in which they had been deployed**, due in part to OCHA's limited operationalization in the response, a result of the creation of **UNMEER**. This represented both a maturation of the digital humanitarian community and the longer timeframe of the Ebola response.[54] It also highlighted the opportunity for the formal humanitarian and health communities to think more holistically about how to embrace open models for ecosystem engagement, including with the digital humanitarian community, in its work moving forward.

CHALLENGES

▶ **Although numerous links existed between the IM/GIS group participants and formal response mechanisms and actors, a significant disconnect existed between formal and informal communications channels.** This meant that some valuable information was lost.

▶ **The disconnect between communications on this channel and formal response mechanisms, and the lack of a widely accepted clearinghouse for operational data contributed to gaps in awareness of existing tools and duplication of effort.** For example, several interviewees involved in the formal response were unaware of the mapping efforts of the digital humanitarians or of the existence of the Skype IM/GIS group.[55]

▶ **The health aspects of the Ebola response posed a new set of issues, particularly around terminology and data privacy.** *"A health response is difficult, since we needed to learn how to de-identify health information, learn new terminology, and account for time length [of the response],"* reported Moore.

DIGITAL NETWORKS: INTERNET-BASED EXCHANGE OF REAL-TIME CONTEXTUAL INFORMATION

Context experts with deep and long-term expertise in the languages, cultural traditions, and social, economic, and political histories of Guinea, Liberia, and Sierra Leone and with expertise in public health and emergency response contributed substantively to the social engagement and behavior change efforts. These individuals included social scientists—particularly cultural and medical anthropologists—former Peace Corps volunteers, and members of the diaspora.

Many of these experts were based elsewhere or unable to travel to the affected countries yet wanted to contribute. They mobilized networks using email, websites, Skype, listservs, and other Internet-based platforms to provide advice from remote locations in a timely way and with the clear goal of supporting a contextually relevant response.

Notably, many UN agencies and NGOs embedded anthropologists in their emergency operations teams. UNMEER hired an anthropologist to work across the response and affected countries, and other agencies, including the CDC and MSF, hired behavioral and social scientists to work on social mobilization efforts.[56] In Guinea, at least four anthropologists were embedded in treatment units to assist with psychosocial efforts and to conduct research. The UK Department for International Development (DFID) funded research, policy-focused blogs, and a web-based platform—the Ebola Response Anthropology Platform—that aimed to facilitate a more effective, iterative, and adaptive response.[57] A similar network, the Emergency Ebola Anthropology initiative was established in the United States.

The expertise of these individuals was crucial in helping to ensure a contextually appropriate response and in countering the resistance that Ebola teams faced in affected communities. For example, in the early days of the response, burial teams used black body bags, whereas in Muslim communities in these countries the color white signified mourning.[58] The use of black body bags subsequently changed with feedback from these experts and affected communities, leading to the use of culturally appropriate white body bags. According to one health official, among other things the expertise of anthropologists and other behavioral scientists shifted understandings about the burial practices of different groups, and facilitated more clarity and precision in communications with affected communities. As a result, he said, *"Messaging changed and became more adaptive and sensitive."*[59]

The contextual and qualitative knowledge supplemented much of the epidemiological data used in the response. Juliet Bedford, the anthropologist who was embedded with UNMEER and then UNICEF, explained how she engaged networks of anthropologists: *"I was asked specific questions [from responders] and would get those out to the network. We crowdsourced information and, working with a few key people, created a rapid synthesis and turned it into two-page briefs. We provided focused papers with key considerations. … It was about getting information to the right people at the right time for strategy meetings."* In addition, members of the remote networks wrote to her with questions and

suggestions for responders, based upon their contextual knowledge. For example, did responders consider the effect of the rains on social mobility, and hence the disease's transmission, or the use of roadblocks in a post-war context? She would then flag these issues for the response's senior leadership, at both the global and country levels. The network produced a series of short two-page papers in English and French on topics of relevance for responders (e.g., handling bodies, mobilizing youth, clinical trials, and community resistance).[60]

Photo @ UNMEER/Simon Ruf

Humanitarian Data Exchange (HDX): Online Data Exchange among Response Organizations (Global)

What: The HDX, an open-source platform designed to serve as a central repository for both public and restricted humanitarian data sets, was under development when the Ebola outbreak struck.[61] Although the tool was new, it became a repository for many of the data sets collected during the response.

Why: Although many organizations collected extensive amounts of data as part of the Ebola outbreak response, many of these datasets were not shared or easily accessible. According to Sarah Telford, manager of the Humanitarian Data Exchange (HDX), the goal of the platform was to *"try to change the culture of guardedness around information sharing ... and to solve the problem of making [response] data more immediately accessible."*[62]

Who: OCHA launched HDX in July 2014, just prior to the official WHO declaration of a PHEIC.

How: OCHA managed the HDX platform, inviting individuals to register through their organization to become "data contributors." Contributors, in turn, were responsible for providing "metadata" (e.g., when and where data were collected, and by whom) and for keeping their datasets up to date. Due to organizational policies or other privacy concerns, some organizations used a privacy setting to enable data sharing only among their staff. UNMEER, for example, requested and used a closed portion of the platform. The majority of HDX data sets were available in machine-readable formats that enabled the aggregation, analysis, and visualization of the data, facilitating the use of data for making decisions.

"The lack of standards makes it so that you can't create a common operational data picture based on multiple sources and types of data. You can only look at it data set by data set."

ANALYSIS

▶ **Although use of HDX occurred primarily in limited pockets, the platform did amass a significant number of datasets and a considerable usership.** According to one official, *"HDX has helped a lot as a very visible platform. People can see in one place, here's the data."*[63] As of March 2016, HDX had nearly 60 public data sets, and 23 private data sets related to the Ebola response, contributed by 29 organizations. Those data sets have been downloaded nearly 18,000 times, and HDX users have downloaded the vast majority (72 percent) of data sets at least 10 times. Of those more commonly accessed data sets, 30 have been downloaded at least 100 times, and 3 have been downloaded over 1,000 times. Those downloaded over a thousand times were maintained by HDX, OCHA's West and Central Africa office, and UNMEER. Two contained epidemiological data and the other contained data about Ebola treatment centers.

▶ **To fill the data gap about the location of Ebola treatment units, in August 2014 volunteers scanned the Internet looking for these data.** Simon Johnson of the British Red Cross geo-coded these treatment units and visualized their locations on a dashboard.[64] Once these secondary data were posted to HDX as open data, other organizations provided feedback, including more precise location data. For Liberia, the U.S. Department of Defense added detailed plans of the proposed location and anticipated opening dates for new treatment units. In this way, opening these data and posting to a central location improved the accuracy of the data and prompted new uses for the data.

FIGURE 13: Ebola 3W Dashboard
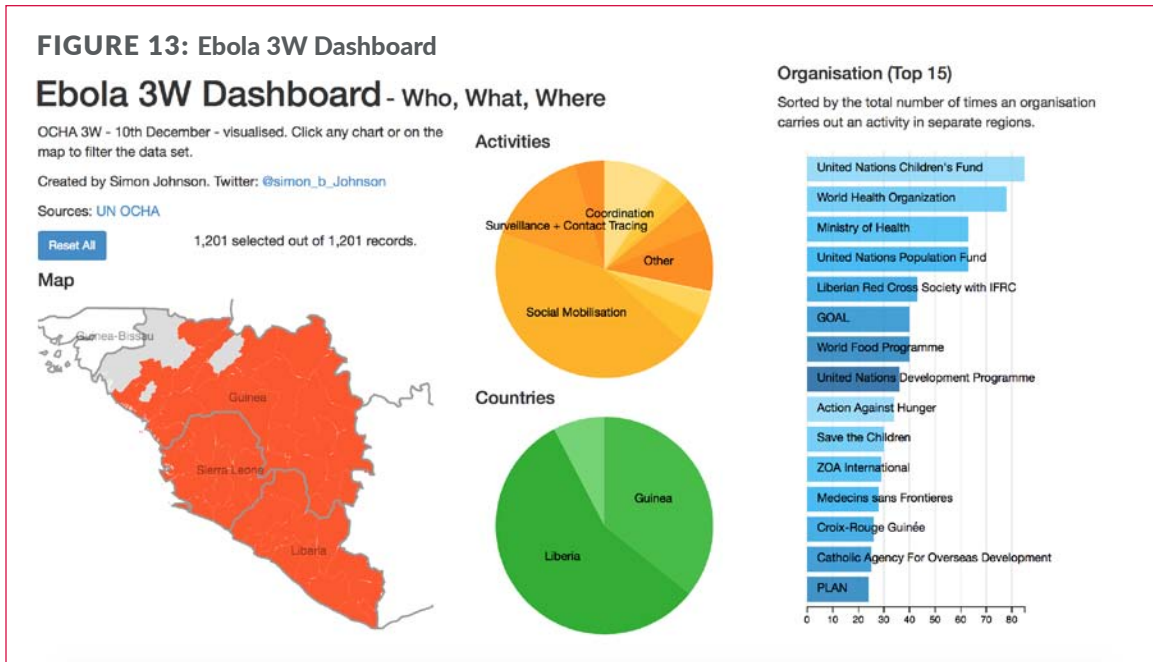
Snapshot of Ebola 3W dashboard, by Simon Johnson, December 10, 2014, accessed September 9, 2016, **https://simonbjohnson.github.io/Ebola-3W-Dashboard/**.

▶ **The platform made it possible to gather datasets from a variety of sources and contributors.** These included formal response organizations (UNMEER, WHO, OCHA's West and Central Africa Offices, NGOs, and the U.S. Department of Defense) as well as digital humanitarians (the Humanitarian OpenStreetMap Team and Standby Task Force).[65]

▶ **A pilot program involving data collection about IPC in Guinea enabled tracking of IPC training efforts across response actors.** OCHA and HDX, in conjunction with the Guinean Ebola coordination center, USAID, and IPC partners, launched the pilot in order to respond to a senior Guinean government official's inquiry about how many individuals in Guinea had received training in IPC. Using a participatory process to identify key indicators, the group agreed on a common matrix using an Excel spreadsheet with pre-populated indicators and dropdown options (e.g., location data and health facilities) to minimize the time required to update the spreadsheet and data entry errors. The spreadsheet was posted on Dropbox, allowing broad access to all partners. Partners updated their information on a weekly basis and HDX analyzed and visualized the data.

CHALLENGES

▶ **A lack of established standards made it difficult to compare and compile different data sets.** *"The lack of standards makes it so that you can't create a common operational data picture based on multiple sources and types of data,"* explained Telford. *"You can only look at it data set by data set,"* she said. In addition to needing data in common formats, response actors needed data in a common language—such as by standardizing the use of whether a treatment unit was documented as a clinic, a hospital, or a mobile health facility. The Humanitarian Exchange Language (HXL), also created by OCHA, developed a shorthand version for language-based standards by adding a row of hashtags to help make terminology compatible across data sets (e.g., #gender to refer to a column of data about the gender of beneficiaries). Yet because HXL was not widely used by actors publishing data sets to HDX, it was difficult to merge multiple data sets, such as adding a health facility layer to a map illustrating the availability of Internet coverage.

▶ **HDX had launched in beta form just prior to the Ebola outbreak, so it was not widely known or used at that time.** *"There is an exhaustion in our community [from seeing too many] unsustainable platforms that become data graveyards,"* said Telford. *"HDX was a new platform, so there was a little bit of hesitation [where people wondered if] this was another one-off. That prevented people from wanting to share their data,"* she added. The HDX team sought to address this concern by being responsive to data providers' needs, including helping data contributors ensure the metadata[66] were entered correctly, and in providing troubleshooting support in getting data sets uploaded to the platform.

▶ **There is not yet a widely established culture of data sharing in the humanitarian community.** Since the practice of publishing machine-readable data sets to shared access platforms is still relatively new, the mechanisms or incentives did not yet exist for data producers to publish appropriately anonymized data sets.[67] Yet for those groups that did contribute data, there were multiple examples of shared, consumable, open data sets that created value. In one example, the *New York Times* used the machine-readable Ebola case and death data set (available on HDX) to create an interactive map that was featured on the homepage of the news outlet's website for a day. This was an example, Telford believed, of data use by third parties to reach audiences that data contributors alone never could have reached.

▶ **A dearth of data literacy among humanitarians** meant that in addition to streamlining requested data, HDX staff needed to provide capacity building by proactively engaging organizations to train them on how to use the platform as well as to prompt them to input their information, requiring significant staff time. *"We're a narrative-based culture, [so] this was a real challenge,"* Telford said. According to another official who worked on a data collection effort posted on HDX, *"I realized the problem is a capacity issue. The ones that were regularly contributing data had a focal point who is responsible and accountable."*[68] The need for stronger data literacy was especially acute among national staff in the most-affected countries in West Africa, creating a heavy reliance on international partners that slowed the use of data to support the response.

MISSED OPPORTUNITIES

The vast majority of data and information exchange in the Ebola outbreak response happened in the context of verbal, radio, and paper-based communications. In this context, how does one assess or test the value of digital technologies in the Ebola outbreak response? Providing evidence of the value of a missed opportunity would require measuring chains of information transmission that, due to a variety of constraints, simply did not exist in the response. Two sets of insights emerge from the response.

Insights from Paper-based Information Flows

To understand where information did not flow, it is useful to ask: Who did not receive information that could have been beneficial to the response? In this analysis, an obvious starting point is to consider the most widely used one-way vertical flow of information "up": case data reporting.

As detailed in the **Data Use and Digitization** section, case data largely flowed one way and up from local to national and international decision-makers. An NGO official in Sierra Leone observed, *"[We had] a very top-down, vertical approach. We can't be just vertical."*[69] To realize the value of digitized information, vertical communications should be seen as the start, not the end, of an information exchange. Ideally communications should entail two-way information exchange (both "up" and "down"), as well as horizontal exchanges among peer groups, and benefit from communication among multiple nodes.

What if, for example, aggregate case counts, once gathered at the top of the information pyramid, had been regularly and deliberately shared back "down" to health workers reporting the data? *"One thing we're emphasizing is flipping the information flows so that they are community-driven rather than top-down,"* one government official said of efforts to strengthen the response.[70] One can imagine how contextualized data returned to the point of data origin—such as a rise in Ebola caseload in a neighboring district—might have empowered health workers with important situational awareness that could have improved local preparation and decision-making. Where, for example, could behavior change communications efforts have been best focused to help stem the spread of the disease? And where might critical supplies like personal protective equipment, need to be pre-positioned? Although in some cases such exchange did happen, it was not widespread or consistent across the response.

Separately, many interviewees observed how the vertical, upward flow of information often occurred without clear understanding on the part of data collectors about how such data would be used. The example of the misuse of unique identifiers described **above** illustrates how a lack of contextualized understanding of data use negatively affected the quality of data and further affected the delivery of services. A lack of contextualization also reduced incentives for data collectors to understand the purpose and potential impact of the data they collected. One national official articulated how reversing the flow of information could help to create ownership and a culture of data use, beginning with those collecting the data: *"If you want to engender a culture of data collection and reporting, and improv[e] the quality of the data, you must provide reasons why that data should be collected. ... Let [data collectors] understand that data is their data. ... If you expect that person to report just counts—number of cholera cases, malaria, etc.—let them be able to compare if it was higher this month compared to last month. If it is higher, what's the reason, what can I do in the facility to ensure it's not high next time. ... Even at county level they're just sending it forward."*[71]

This contextualization of data for data collectors, such as frontline and other health workers, would require a fundamental paradigm shift in the way health data are collected, analyzed, and used. Perhaps more aptly, it would require a paradigm shift in the larger practice of global public health for decision-making by expanding the role of local health workers from agents of local data collection and service delivery to agents of local decision-making, who are empowered with contextualized insights in real or near-real time.

Insights from Digital Information Flows Beyond the Formal Response

Even within the context of digitized data and information flows, there were missed opportunities to maximize the value of digitization. Some of these missed opportunities—including the lack of interoperability between digital systems, minimal use of machine-readable forms, and the lack of networked digital data-entry systems—were identified earlier in this report.

Other examples from outside the formal response delivered by governments, donors, and response organizations also show where digitized information flows added value, but were not fully leveraged in the response. Formal and informal responders adopted widely used communications enabling many-to-many communications—platforms like Google documents, Skype, and WhatsApp—to exchange information with a variety of individuals experiencing the crisis or participating in the Ebola outbreak response. Yet due to organizational and institutional restrictions on the use of communications platforms,[72] many did so acting in their individual capacity. The sharing of information within these channels, therefore, occurred informally and outside of official coordination channels.

Because knowledge about these channels spread via social networks and word of mouth, many response actors were unaware of the existence of these channels. The disconnect between communications on these channels and formal response mechanisms, and the lack of a widely accepted clearinghouse for operational data, contributed to gaps in awareness of existing tools and duplication of effort.

At the global level, staff members of government, UN agency, NGO, and other response actors joined a Skype chat group, often using personal accounts, to identify and share common geographic and other Ebola response information management needs. As detailed in the **Skype IM/GIS Group** case study, this group functioned as an informal (i.e., non-authorized) Skype chat group that created horizontal, and multi-directional information flow across a range of actors. At its peak, the Skype group included a total of 232 active users from 92 organizations. Requests for information ranged from GIS data on health facilities in the most-affected countries and Ebola case data to population distributions and movement restrictions or blockades.[73]

At the community level, United Methodist ministers communicated with one another and other members of their community directly through a self-organized **WhatsApp channel**. These horizontal, two-way information flows created feedback loops that enabled the immediate sharing of local and time-sensitive information. In at least one case this led to directly actionable insights that likely saved lives with the rerouting of an Ebola patient from an unprepared clinic to a hospital that was able to provide treatment.[74]

The use of these informal channels demonstrates the value of real-time, peer-to-peer horizontal information sharing among actor groups, such as responders and community leaders, and the breadth of the individuals' networks sharing information relevant to the operational response. Where insights were exchanged on these channels outside of the context of the formal response, critical insights frequently were lost.

TABLE 4: Commonly Used Technology Tools in the Ebola Response

Technology	Definition and Use	Benefit	Example
SMS	SMS stands for Short Message Service and is commonly referred to as a "text message." Most cell phones and mobile network providers enable cell phone users to send SMS messages of up to 160 characters in length to another device connected by a mobile network or wifi signal.	SMS is a cost effective way to communicate with frontline health workers and field staff using bulk messaging.	mHero: The Liberian Ministry of Health uses SMS messages to communicate with its remote health workforce in real-time.
Wifi	Wifi is a technology that uses radio waves to wirelessly connect computers, smartphones, and other devices to the Internet and to one another within a set area of physical proximity.	Wifi can extend connectivity to anyone within reach of the wifi signal. If installed at a central location. Wifi can be shared among multiple responders.	Ebola Connectivity Response Initiative (ECRI): This consortium of partners leveraged an undersea fiber optic cable to extend connectivity through a point-to-point wifi network, extending Internet access to health clinics and responding organizations in remote areas.
Short code	Short codes are short telephone numbers that can be used from a cell phone to enable SMS or multimedia messages to be sent from particular entities to mobile network subscribers, and vice versa. Short codes that work across multiple mobile network operators are referred to as common short codes.	Short codes can be reverse billed, which allows the sender (e.g., a health ministry, UN agency, or other entity) to pay the cost of the message. Short codes can be disseminated widely.	U-Report: UNICEF used a short code-based SMS platform to facilitate youth engagement in identifying common knowledge, attitude, and perceptions about Ebola to inform messaging about preventing Ebola's spread.
Sync capacity	Sync capacity refers to being able to input data when the computer is or is not connected to the Internet. All data can be automatically updated when the computer is connected through wifi, satellite, or other technology (e.g., VSAT/BGAN).	In places where connectivity or power is sparse, data can be automatically uploaded and harmonized across multiple computers or locations.	Sense: In Nigeria, contact tracers used smartphones with this software, which allowed both on- and offline data collection in areas with limited mobile network connectivity.
Geographic Information Systems (GIS)	GIS tracks and identifies a precise physical location for people or buildings.	GIS can be configured to automatically and accurately locate patients or Ebola contacts, as well as health facilities or other services.	CommCare: Adding geolocation information to contact tracers' mobile data collection forms increased transparency and accountability for data collected.

Technology	Definition and Use	Benefit	Example
Machine-readable forms	PDF and other documents can be captured as images or in a format that allows a computer to "read" and interpret each individual word in the text. The latter makes it possible for automated capture in text to fill in forms without manually retyping the information.	Machine-readable forms reduce the time and human error in manual entry of data data from paper to digital form and	HDX:The Humanitarian Data Exchange served as an online data repository, with the majority of published data available in machine-readable formats that enabled the aggregation, analysis, and visualization of data.
VSAT/ BGAN	Both Very Small Aperture Terminals (VSATs) and Broadband Global Area Networks (BGANs) provide portable Internet connectivity using a satellite signal. They are easily installed but limited in their capacity.	VSAT/BGAN provide short-term and targeted connectivity solutions to responders that can be installed at health facilities or other locations.	UN Emergency Telecommunications Cluster (ETC): To meet immediate connectivity needs of responders providing health and humanitarian assistance, the ETC deployed satellite-based communications stations in each of the three most Ebola-affected countries.

LESSONS

The real-time information flows profiled above suggest a series of lessons from the Ebola outbreak response, and for health and humanitarian preparedness and response more generally.

► **The use of digital technologies in the response enabled access to more timely data across large distances and diverse actor groups.** This was particularly critical in the context of gaining rapid access to case data and to behavior change communications, both of which were critical to containing the disease.

► **Digital technologies enabled peer-to-peer, horizontal messaging at scale, and the transfer of data and information "up" as well as "down" and "up and down" through feedback loops.** Yet many digital programs did not use digital technology to its full potential in this respect, frequently because tools and platforms leveraging this functionality were launched just prior to the outbreak (e.g., mHero, HDX) and not used at scale during the course of the response.

► **Creating a two-way, real-time exchange between the central health ministry and its workforce enabled a significant transformation in the response.** It enabled the government to benefit from a real-time sensing capacity, and to provide health workers with context to the data they produced, creating new insights, incentives, and accountability.

► **Health workers played a critical surveillance role in detecting disease outbreaks and their spread, and when empowered with digital technologies they could report these data in a timely way.** Yet even where they had access to mobile networks, health workers lacked basic digital literacy or the trained enumerator skills necessary to gather survey data.

▶ **The introduction of digital technologies does not remove the need for human capacity and leadership; indeed, in many cases, it magnifies it.** The Ebola crisis exposed critical gaps in the human capacity needed in the outbreak response. This capacity gap slowed the outbreak response and hindered the ability to rapidly gather, share, and use digitized data flows for decision-making.

▶ **Specifically, the data demands of the outbreak response highlighted the need for greater investments in a cadre of data experts** with a wide variety of technical skills, including software engineering, data management, analytics, visualization expertise, and workflow integration. This human capacity gap was most acute at the national level, but apparent among international responding organizations as well.

▶ **The demands of the response made it difficult to build national capacity while meeting operational needs**, emphasizing the importance of building this capacity in preparedness for future emergencies.

▶ **In the context of largely paper-based health data systems at the national level, there was little established practice or demand for leveraging real-time insights from digital data.** This meant that national actors frequently were unprepared or underprepared for the integration of digitized data both from a process and a policy (including workflows and decision-making) perspective.

▶ **The most-affected countries possessed fledgling digital health systems that, in most cases, were built to address specific diseases or aspects of public health delivery (e.g., HIV/AIDS or reproductive and maternal health) rather than an integrated health systems approach.** This siloed and vertical orientation of information was a barrier to a holistic picture of public health data and the ability to make rapid, data-driven decisions during the outbreak response. This will continue to impair health outcomes until standalone systems are better integrated.

▶ **Some of the most successful uses of digital data and information flows were those that took a hybrid approach**, incorporating word-of-mouth, paper-based, and analog channels alongside the use of digital technologies. Programs such as Naymote or DeySay were able to reach both online and offline communities, and yielded rich, locally relevant data.

▶ **Interoperability between digital systems can unlock powerful advantages, but takes time and requires careful attention to standards and terminology in addition to technical platform integrations.**

▶ **Other challenges facing digitized data and information flows included a lack of standards, or lax adherence to standards in an emergency context, limited use of machine-readable data, and a lack of networked digital data entry systems.**

▶ **Many digital health programs received a surge of attention and funding due to the resources unleashed with the declaration of a public health emergency; most times these resources are one-off.** Ongoing program needs will require continued donor support and/or new business models to be sustainable over time. In some cases, the program was possible only due to significant donation of in-kind resources that are likely not replicable outside of the context of an emergency.

RECOMMENDATIONS

THE VALUE PROPOSITION OF DATA AND DIGITAL TECHNOLOGIES

The response to the Ebola outbreak in West Africa shone a spotlight on the critical importance of timely and accurate data and information flows to combat the disease's spread and deliver effective and targeted action. The majority of data and information moved by voice, radio, or paper. Where digital technologies were used they permitted critical, time-sensitive data and information to quickly scale the distances of space and time. In addition to the *quantitative* efficiencies gained, digital technologies also enabled important *qualitative* differences.

Advantages of Digitized Data and Information Exchange

Why does the digitization of data and information matter? In the context of a fast-moving disease outbreak like Ebola, the timeliness of information is critical to an effective response.[1] The *quantitative* efficiencies of digitized data include the ability to more quickly collect, manage, and share data and information. Perhaps even more compelling, however, are several important distinctions that permit digital technologies to enable *qualitatively* different action.

Specifically, by enabling the rapid exchange of data and information across the scales of distance and time, digitization enables qualitatively different information and data exchange due to an increased:

- ► **Plurality** of actors participating in connected and real-time or near real-time information exchange, including:
  - national governments
  - traditional response and donor organizations (such as foreign governments, NGOs, and intergovernmental organizations like UN agencies)
  - frontline or extension workers (such as community health workers, contact tracers) –citizens/affected populations
  - "remote" responders supporting the formal response (such as the digital humanitarians, members of diaspora groups, and context experts)

- ► **Directionality** of information exchange, including:
  - "up," as in case data reporting up to a centralized point
  - "down," as in SMS behavior change messages down to many decentralized points
  - "up" and "down," as in tools or programs that exchanged information in both directions
  - "horizontal," as in communications within or between peer groups active in the response

- ► **Nodes**[2] of information exchange, whether:
  - one-to-many, or many-to-one (as in SMS questions from health ministries to health workers, and responses from health workers back to the ministry)
  - many-to-many (as in the case of chat platforms, such as Skype and WhatsApp, being used by response workers for informal, real-time coordination)[3]

Implications for Decision-Making and Programming

The above qualitative distinctions in the way data and information move in a digital context create a variety of opportunities for improved decision-making. These include:

► Increased accountability, incentives, and insights:
- **accountability**, such as through timestamps and/or global positioning system (GPS) identification on the point of data collection, or in the real-time or near real-time availability of data for program managers, making it possible to manage people and resources in a timely way
- **insights**, such as sharing back contextualized data and information to the point of origin, which can enable better-informed local decision-making
- **incentives**, such as through horizontal, peer-to-peer information exchange that created motivation to take on difficult and at times dangerous tasks

► Increased **ease of sharing data and information** and **devolution of decision-making**, both down to many decentralized points and horizontally among peer groups, which facilitated information sharing across data silos and supported coordination

► Increased ability to **create continuous two-way feedback loops** through the sharing of contextualized data and information back to the point of origin

► Increased ability to **implement continuous learning and adaptive programming**, in which a program or activity is modified and adapted in real- or near real-time, according to the right information processed at the right time by relevant decision makers

FIGHTING EBOLA WITH DIGITAL: INSIGHTS FROM NIGERIA'S SUCCESS STORY

How might the Ebola outbreak have unfolded differently had stronger digital health systems been in place throughout West Africa? Ebola hit hardest in Guinea, Liberia, and Sierra Leone. But it also affected the neighboring countries of Nigeria, Senegal, and Mali, where outbreaks were quickly contained. What accounted for the difference in Ebola caseloads? A variety of factors played a role: stronger health systems, a functioning Emergency Operations Center (EOC), a strong health workforce and overall better preparedness, which together affected the overall response. Although data digitization by itself did not lead to the successful control of Ebola in Nigeria, a closer look at Nigeria's success story shows, among other factors, the critical importance of preparedness plans for health emergencies, and the value of timely adaptations of existing disease outbreak protocols and existing digital health infrastructure.[4]

Ebola made its way to Nigeria when, in July 2014, an infected Liberian man traveled to Lagos by airplane, setting off a chain of transmission that infected a total of 19 people, killing seven. According to the WHO, after the first Ebola case was confirmed health officials were able to quickly adapt existing health technologies and infrastructures to respond.[5]

To combat the Ebola outbreak, Nigerian officials modified their existing polio outbreak system and a corresponding preparedness plan. The use of the IHR[6] reporting meant that Nigerian officials were quickly notified of the arrival of the Ebola case and consequently were able to mobilize a timely response. Based on prior government experience using an Incident Management System to handle health crises, including a recent polio outbreak, the Nigerian government appointed an incident commander and set up an EOC that is largely credited with playing a central role in containing the Ebola outbreak.

A key aspect of the EOC's immediate operations was the rapid tracing of contacts. Nigeria's index patient generated a total of seven fatalities, 19 cases, and 894 contacts who were monitored for symptom development through approximately 18,500 face-to-face visits by contact tracers.[7] Working in partnership with eHealth Africa (eHA) and other partners, the EOC put into motion a digitally supported, real-time digital workflow to increase the rapidity with which critical and time-sensitive contact tracing data would be available for decision-making. This digital approach to tracking, aggregating, and visualizing contact tracing data in the Nigerian response used a suite of tools, including ODK, FormHub, ArcGIS, and eHA's Sense android app, which was developed during the response to capture 21-day follow up information—the critical window of time required to confirm that someone potentially exposed to the Ebola virus had not been infected.[8]

An NGO official working on digital health systems at the time of the outbreak reported, "*We knew that in Lagos, where the infection was, poor mobile phone network connectivity meant that to have real-time data we need[ed] to give [contact tracers] smartphones preloaded with [contact tracing] software. That's how the teams were able to respond immediately, and how everyone who needed information got it.*"

The Sense tools functioned in both online and offline environments, enabling data collected by contact tracers in offline areas to automatically sync as soon as their smartphones were brought back in range of a functioning mobile network. Contact tracers were equipped with phones preloaded with credit for calls, SMS, and mobile data. Credit was topped up automatically, removing the potential barrier of lack of credit in submitting contact tracing reports. Sense tools also made it possible to generate a multitude of dashboards for various stakeholders and to auto-generate notifications to key decision-makers.[9]

In contrast, in all three countries most affected by Ebola, health workers entered information about contacts primarily on paper, which data managers then manually transferred to electronic format. This resulted in situation reports based on data that ranged between three days and two weeks old,[10] a critical delay in the face of a fast-moving disease.

Nigeria's existing and more robust health systems and health information systems, as well as its strong digital infrastructure, were essential to its ability to rapidly identify and isolate cases, halting the spread of the disease before it spiraled out of control. The existence of digital tools, capacity, and systems enabled the adaptation and immediate use of integrated disease surveillance and reporting systems. Together, these resources and actions enabled officials to prevent a catastrophic outbreak in Lagos, one of Africa's most populous cities. Nigeria's response to Ebola highlights the critical role of appropriate technologies, adaptability, and preparedness planning in ensuring health system resilience.

RECOMMENDATIONS

These distinctions in how data and information for decision-making are gathered and shared can provide important benefits, including enabling better informed and more targeted and effective service delivery by understanding rapidly evolving needs from a variety of perspectives. Yet in the Ebola outbreak response—as is true elsewhere in development, global health, and humanitarian assistance—the full potential of digital technology to improve programs and outcomes has yet to be reached. The following recommendations elucidate practical next steps that humanitarian aid, development, and health actors can take to act upon the lessons identified in the body of this report.

FIGURE 14: Recommendations in Focus
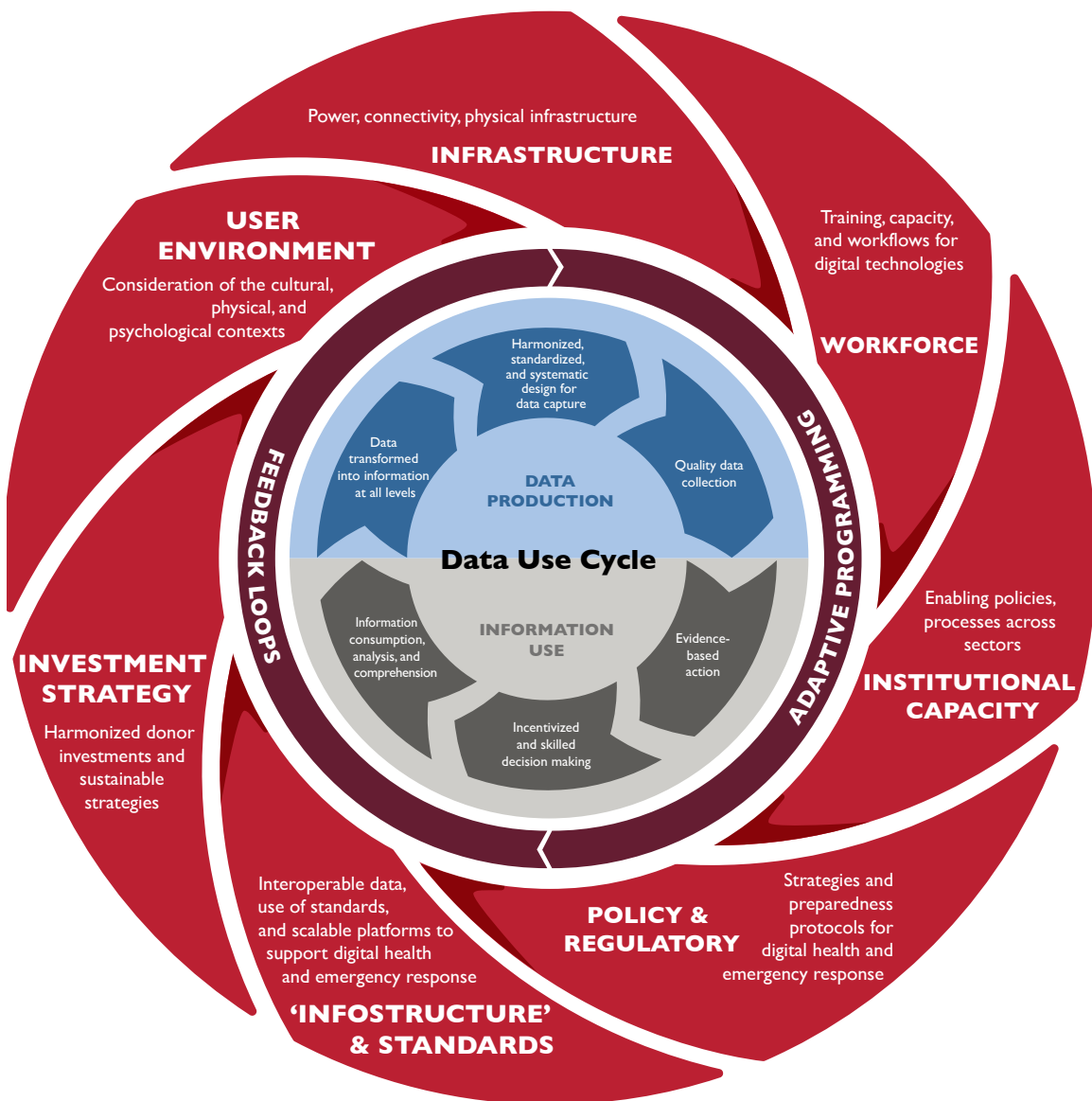
Figure adapted from the Data Use Partnership Theory of Change, by PATH and Vital Wave, **http://www.path.org/publications/files/DHS_theory_of_change_rptv2.pdf**. Adapted and used with permission.

Assess and Invest in Digital Connectivity Infrastructure

Timely and accurate data and information flows were most possible with digital technologies, yet in many parts of the three most-affected countries digital networks were unreliable or simply unavailable. Investments in extending the reach of digital connectivity should be seen as a fundamental component of strengthening resilience to future health and humanitarian emergencies.

RECOMMENDATION: Invest in physical infrastructure that extends digital connectivity.

RATIONALE: Increase resilience in the context of health, humanitarian, and other crises

SUGGESTIONS FOR OPERATIONALIZATION

► **Explore partnerships to create business models** that work, potentially including development funding, to build out infrastructure in areas where market incentives do not otherwise exist.[12]

► **Create incentives to expand digital infrastructure.** This could include public-private partnerships, subsidies, or tax-based incentives to help MNOs reach rural communities.[13]

► **When building out digital infrastructure, consider power and seek alternative models to enable reliable power.** Solar panels, for example, could be outfitted to key government ministries, prioritizing those responsible for managing critical data sets in emergencies, and to district health facilities.

► **Encourage infrastructure sharing,** such as base stations, to decrease the cost of network expansion. This might require incentives, such as tax breaks, to encourage sharing.

► **Encourage long-term thinking and scale in network investments so that emergency-related investments in digital infrastructure last beyond the emergency phase**.

► **Explore alternative models to extend connectivity**, such as TV white space, and balloon-, drone-, or low-orbiting satellite-based Internet connectivity to extend coverage in remote or hard-to-reach areas.

"The last 15 years have seen a revolution in ICT and mobile technologies. Ebola shone a spotlight on the ineffectiveness of past health systems strengthening efforts; there is growing evidence that ICT and mobile are a vital part of the solution to build resilient health systems." [11]

FIGURE 15: Predicted Zoonotic Niche of Ebola as Compared to GSM Network Coverage for West Africa

West Africa: Predicted Zoonotic Niche of Ebola Virus and GSM Network Coverage

GSM Network Coverage
No GSM Network Coverage Data Available

10% 20% 30% 40% 50% 60% 70% 80% 90%
Environmental suitability of occurrence

Data Sources
GSM Network Coverage: © Collins Bartholomew Ltd, 2014
Prediction Surface: Institute for Health Metrics
and Evaluation. Spatial Epidemiology of Ebola
Virus Disease - VizHub, Adapted and Updated
from Pigott et. al, 2014 published in eLife

Map created by the USAID GeoCenter, 2016

Names and boundary representation are not necessarily authoritative. GSM Network Coverage Only Shown Where Data Available.

RECOMMENDATION: Conduct baseline, country-wide ICT assessments to gauge the reach, quality, and citizen access to mobile and broadband connectivity, and publish findings on shared repositories using machine-readable formats.

RATIONALE: Understand where to prioritize investments to extend the physical infrastructure that enables digital connectivity.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Work with mobile network operators and Internet service providers to develop protocols for reporting data that identify connectivity "cold spots"** in order to prioritize them for delivery and easy identification in an emergency scenario.

▶ **Support the development and deployment of a baseline ICT assessment framework, and an online repository for such assessments to be shared publicly.** Assessment categories might include: citizen literacy and digital technology uptake and common citizen digital use patterns; mobile and Internet network reach and capacity by geographic area; e-payments infrastructure capacity to deliver payments to frontline workers and other actors; national health information systems' capacity to manage routine and health crisis-related data; and a mapping of other commonly used digital information systems that can be used for real-time data and e-payments management.

▶ **Support the development, sharing, and adoption of standards to assess consumer access and the reach of digital technology.** This could include emergency response protocols that enable the rapid assessment of the potential of an emergency scenario (whether conflict, disaster, and/or health related) to affect mobile and Internet network capacity, as well as the likelihood of response demands to burden existing physical infrastructure.

RECOMMENDATION: In an emergency, develop and implement emergency protocols for rapid updates to baseline country-wide ICT assessments gauging the reach, quality, and citizen access to mobile and broadband connectivity.

RATIONALE: Understand to what extent mobile and broadband technologies can support the response, by cataloguing the effects of an emergency on baseline connectivity infrastructure and access and seeking ways to rapidly fill critical connectivity gaps.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Develop and share protocols for quickly assessing the ICT infrastructure** in a country as an essential component of emergency preparedness and response.

▶ **Identify and designate a lead agency to implement the protocol** on behalf of the international community.

▶ **Include as part of the rapid ICT assessment updates to the baseline assessment** of mobile and Internet network capacity and latency by geographic area, and the operational and business viability of MNOs in an emergency. Such assessments could update the baseline ICT assessment with critical post-disruption updates, and could be automatically triggered with the activation of the deployment of the Emergency Telecommunications Cluster in a humanitarian emergency.[14]

▶ **Encourage aid workers to download and use applications that report the availability of mobile networks** to crowdsource a picture of network connectivity. These apps could be linked to apps such as OCHA's HumanitarianID[15] or others designed for use in emergency situations.

Assess and Invest in Workforce Capacity

Using digital technologies does not remove the need for human capacity; it increases it. The Ebola outbreak illustrated the critical need for technological literacy and capacity, specifically that of staff and national communities of practice who were best positioned to deploy quickly and support long-term recovery efforts. The best time to build human capacity, however, is before an emergency hits. The data and information demands of the response made it difficult to build national capacity while meeting operational needs. Moreover, the volume and velocity of data and information collected and shared occasioned the need for specific expertise, including a cadre of epidemiologists, data scientists, data visualization specialists, and data analysts to manage, interpret, and render data useable.

RECOMMENDATION: Build staff technical capacity and data literacy.

RATIONALE: Leverage digital systems and real-time data in support of operations, programs, and decision-making

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Assess existing staff capacity in data and digital literacy, informatics, software engineering, and other technical areas**, identifying where staff capacity is thin.

▶ **Build capacity of existing staff and retain new staff with relevant expertise** to support a cadre of data and digital experts with specialized knowledge of digitized data collection, sharing, management, analysis, and use for decision-making to help quickly aggregate, manage, and interpret (digital) data. Many response actors—NGOs and donors—need to recruit for and grow their workforce's technical capacity. This includes: technical capacity to collect, manage, and analyze data in an ethical and responsible way; methodological expertise requiring a clear understanding and awareness of what data to collect and how; the capacity to input and manage large quantities of data; and mastery of data analysis and visualization.

"The tech team that should have been on the ground wasn't there. We needed someone with technology and health expertise. You can't have a tech person who hasn't worked in health do this. You need technology and health and development people to ask the tough questions. This wasn't happening."[16]

▶ **Support the development of technical capacity among host country national governments and at the regional level**, such as through technical associations. During the Ebola outbreak, the most-affected countries had to request and wait for technical assistance from outside experts to adapt their HIS to track Ebola cases. Critical time, information, and ground in the fight against Ebola were lost waiting for outside experts to make these adaptations.

▶ **Support digital literacy and the regular use of digital technologies within national governments, local organizations, and response agencies**, both to strengthen health systems with routine reporting and to enable proficient use of digital technologies in the context of an emergency response.

▶ **Deploy data managers and analysts in an emergency** alongside sector experts to provide critical data capacity needed to support operations and decision-making.

▶ **Invest in and grow niche expertise.** The data demands of the Ebola outbreak response required unique and hard-to-find skill sets that encompassed global health, epidemiology, data science, and technology expertise. Although the combination of sector and technological expertise is rare, it is valuable to governments and response organizations, both in ongoing program management and during crises.

▶ **Address the salary competition governments face in the retention of top technical talent.** Alternative models could include limited-term fellowship positions or senior executive service[17] models with pay at slightly higher rates than normal government salaries.

BUILDING TECHNICAL CAPACITY IN THE REGION: THE WEST AFRICAN HEALTH INFORMATICS TEAM

Recognizing the urgent need for a cadre of technical experts to support digital health platforms in West Africa, governments and regional organizations there are partnering with USAID to improve public regional health informatics capacity. At the request of WAHO and the 15 members of the Economic Community of West African States (ECOWAS), USAID is supporting a team of local software engineers and informatics experts to build the organization's health informatics expertise. The project, commencing Fall 2016, is setting up a regional team of experts with the aim of making immediate improvements in national and regional HIS that will help strengthen public health systems and build local software developer capacity to support long-term sustainability of HIS investments in the region.

Assess and Invest in Institutional Capacity

The Ebola outbreak illustrated the critical need for increased institutional capacity. The volume and velocity of data and information challenged institutional capacity to effectively collect, manage, and use these data and related digital systems. Specifically, institutions—both in-country and internationally—often lacked the policies, processes, and workflows required to enable real-time or near real-time information to drive decision-making and enable an adaptive approach to programming.

RECOMMENDATION: Build institutional capacity to leverage digital systems and real-time data.

RATIONALE: Leverage digital systems and real-time data in support of operations, programs, and decision-making

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Assess existing institutional capacity to leverage digitized data and information flows, and to enable adaptive, data-driven programming**, noting where deficits exist.

▶ **Implement change management strategies to increase institutional capacity** to address existing deficits. This may include organizational policies, processes, staff positions, workflows, and budgets required for implementation (see textbox on opposite page).

▶ **Designate an internal champion** to shepherd the change management strategy, and to regularly assess how expenditures need to be realigned to meet changing needs.

▶ **Establish a national digital health committee** or technical working group to guide and support the deployment of digital health information systems.

INSTITUTIONAL CHANGE MANAGEMENT STRATEGIES FOR DIGITAL TECHNOLOGIES

The 2016 report *From Principle to Practice: Implementing the Principles for Digital Development* provides guidance about the institutional reform processes needed to keep pace with the changes the integration of modern ICTs present for the international development, global health, and humanitarian assistance sectors—a field some refer to as "digital development."[18] Although a relatively new phenomenon, the integration of tools like the mobile phone is increasingly widespread and demands the following:

► To fully mature, the field of digital development must be recognized as its own interdisciplinary field that **requires professionalization and institutionalization**, involving specialized and dedicated training as well as institutional reforms.

► Institutions should treat digital development as a **cross-cutting and foundational** field, using it to improve program delivery and development outcomes by (1) integrating digital development strategies early, and (2) tying digital development data to adaptive programming. This may require modified or new workflows.

► Institutions must have a **vision and strategy for implementation** that is adequately resourced, enabled by supporting policies and processes, and supported by an implementation or institutionalization strategy, with milestones identified to measure progress.

► Institutions should **assess whether existing policies and processes support adherence to this strategy**. Where existing policies and procedures inhibit the integration of best practice, organizations should set reforms in motion.

► Institutions should **assess staff and technical capacity to implement the strategy** across operations and programs, and at various stages of implementation.

► Institutions should **integrate best practice by building staff capacity across sectors and geographies, and operational units**, such as through trainings and supporting knowledge exchange among staff, making best practice sector- and business-process specific.

► Organizations should **monitor and measure success in implementation of the strategy,** building in opportunities to reward success and learn from failure, with corresponding incentives.

Assess and Advance the Enabling Policy and Regulatory Environment

The Ebola outbreak response highlighted a series of deficits related to the policy and regulatory environment to support the use of digitized data and information flows. These included tensions between data sharing needs on the one hand, and privacy and security concerns on the other, and the need for emergency preparedness protocols for data and digital information management. Although privacy protection and ethics often stand alone as separate recommendations, putting them into practice and making them meaningful requires that these considerations be integrated into policy and regulatory processes and protocols, as well as capacity-building activities. Addressing these policy and regulatory deficits requires the development of preparedness protocols in advance of an emergency that could be triggered with the declaration of a PHEIC or a Level-3 Humanitarian Emergency.

RECOMMENDATION: Negotiate preparedness protocols with key actors (governments, MNOs, and regulatory bodies) to increase network access in emergency situations.

RATIONALE: Enable an understanding of the capacity and limitations of mobile network connectivity, facilitate rapid collaboration with key actors, and support the deployment of ICTs during an emergency response.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **In advance of an emergency, negotiate a process to secure the public availability of connectivity maps** of mobile network providers operating in countries affected by an emergency. (See related baseline ICT assessment recommendation above.)

▶ **In advance of an emergency, negotiate with MNOs to obtain short codes** that can be used to support an emergency response, and those that can be used to support ongoing SMS-based communication between ministries and their remote workforce, particularly for health and social sector programs.

▶ **Short codes should have reverse billing capacity**, so that charges for messages sent over the system are borne by a government or other specialized agency, not the individuals receiving and sending responses.

▶ **Ensure emergency short codes are given priority on mobile networks** so that if network capacity is limited these messages will still be delivered.

▶ **Designate emergency response short codes to be distributed to and accessible by response organizations** in emergency settings. Some organizations could be pre-approved to reduce the vetting process in an emergency context.

▶ **Negotiate protocols to share aggregated mobility patterns from mobile CDRs** to assist emergency responders.

RECOMMENDATION: Support the development of digital health strategies connected to interoperable emergency preparedness protocols

RATIONALE: Link emergency health data systems with national routine health data systems, such as disease surveillance, to make standing up emergency systems during a crisis easier and faster, and to improve data quality.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Design protocols for emergency data-standards development to simplify and harmonize data collection in a crisis**. For example, a joint public health advisory board for a particular crisis could be tasked with agreeing upon developing common working standards (e.g., case definitions, indicators) within a period of days of the declaration of a PHEIC or a Level-3 Humanitarian Emergency. This body should work with existing humanitarian coordination bodies, such as OCHA and the humanitarian health cluster led by WHO, to designate or create temporary standards for the specific emergency, if needed. Immediately following the announcement of public health advisory board designated standards, an associated technology advisory board would then be responsible for developing and publicly posting the associated software code to ensure interoperability of these data across commonly used data systems.

▶ **During a crisis, emergency data standards should be reviewed on a periodic basis** (such as once a month) to assess and update standards, and to push out related changes.

▶ **Leading international health authorities, such as WHO and CDC, should publish working emergency data standards and liaise with country governments to adopt them**. This process would be facilitated by groundwork laid in advance to create awareness of and to formalize this process so that all parties are prepared to expect and quickly implement new data standards as needed. Such a process could be linked to the negotiation of data sharing protocols or the IHR. Governments, multilaterals, and donors could contractually enforce the adoption of those standards in software and data analysis related to the response.

▶ **Assess and strengthen national health information systems,** with a particular focus on interoperable, country-level digital information systems.

▶ **Establish toll-free URLs that allow health workers and other emergency responders to access certain websites or IP addresses**. For example, the website domain for the national HIS (such as DHIS2) could be toll free, allowing clinics and health workers to access the site even without data credit on their phones. Alternatively, an ODK server could be toll-free, allowing enumerators to continue to submit data and download new forms regardless of the data available on their phones. These sites could be reverse billed and paid for via a central body such as a ministry of health.

▶ **Confer upon an established national digital health committee or technical working group a special role to advise on implementing a national digital health strategy in emergencies**, and update it as needed.

▶ **In an emergency, conduct country-level rapid assessments of available digital platforms and identify those that should serve as primary tools to support the response**. Ensure these are widely available to responders, together with guidelines and supporting standard operating procedures guiding digital platform use.

▶ **Develop or adapt existing standards related to unique identifiers for an emergency outbreak**. The lack of robust unique identifiers for patients represented a significant hindrance to data integration across data sets and systems. Having pre-negotiated guidance in establishing unique identifiers could have mitigated this problem.

▶ **Integrate "disease surveillance and reporting" data and systems with national health information systems** so that disease outbreak data can be readily collected alongside and compared to routine health data.

▶ In routine and outbreak disease surveillance reporting, **ensure that missing data are reported as missing and not as zero cases**. In the early stages of the outbreak in Liberia, some counties were unable to report their cases. These were counted as zero cases, leading to fluctuations in case data reporting.[19]

▶ **In building new health information systems, adapting existing systems, and linking existing systems, support and leverage global public goods** (including open and reusable frameworks, processes, systems, and tools) to minimize duplication of effort and wasted resources.

▶ **Support revisions to the IHR to expand WHO Member State required reporting to facilitate infectious disease data sharing.**[20] Specifically**,** global notification of domestic disease outbreaks should be expanded from those for the plague, cholera, and yellow fever to a more comprehensive list of infectious diseases of importance to international public health, such as Ebola. Notifications of disease outbreaks should be routinely published in a format that is machine readable and available to the public.

▶ **Develop country-specific emergency outbreak protocols**, including the use of digital technologies. These protocols should identify existing forms and platforms, outline standard operating procedures, and make them available for use by responders.

RECOMMENDATION: Advance the ethical and responsible use of data and digital technology.

RATIONALE: Promote good data practices, including establishing protocols that protect individuals' privacy and security, including for vulnerable populations

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Develop processes and protocols that respect individual data privacy and facilitate data sharing**. Integrate privacy risk and ethical analysis into processes for aligning data collection and use from the beginning.

▶ **Promote policies that encourage responsible data sharing and ownership for different types of response data**, and the circumstances under which special processes would apply.

▶ **Adapt policies and processes to include risk and benefit analysis for sharing different types of data** (e.g., data owned by an MNO versus a government versus an NGO) among actors in an emergency.[21]

▶ **Invest in resources for and capacity building to enable responsible collection, use, and management of data**, including the necessary information security tools, policies, and human resources. (See recommendations above related to "**Institutional Capacity**" and "**Workforce Capacity**.")

▶ **Negotiate a protocol to share case data, with full protection of personally identifiable information, to pre-approved actors** (e.g., academics, response agencies) in order facilitate disease modeling upon declaration of a PHEIC.

▶ **Develop a methodology to assess risks and benefits of data use** (collecting, storing, managing, sharing) in emergencies that could be tailored by emergency type (conflict, natural disaster, health emergency).
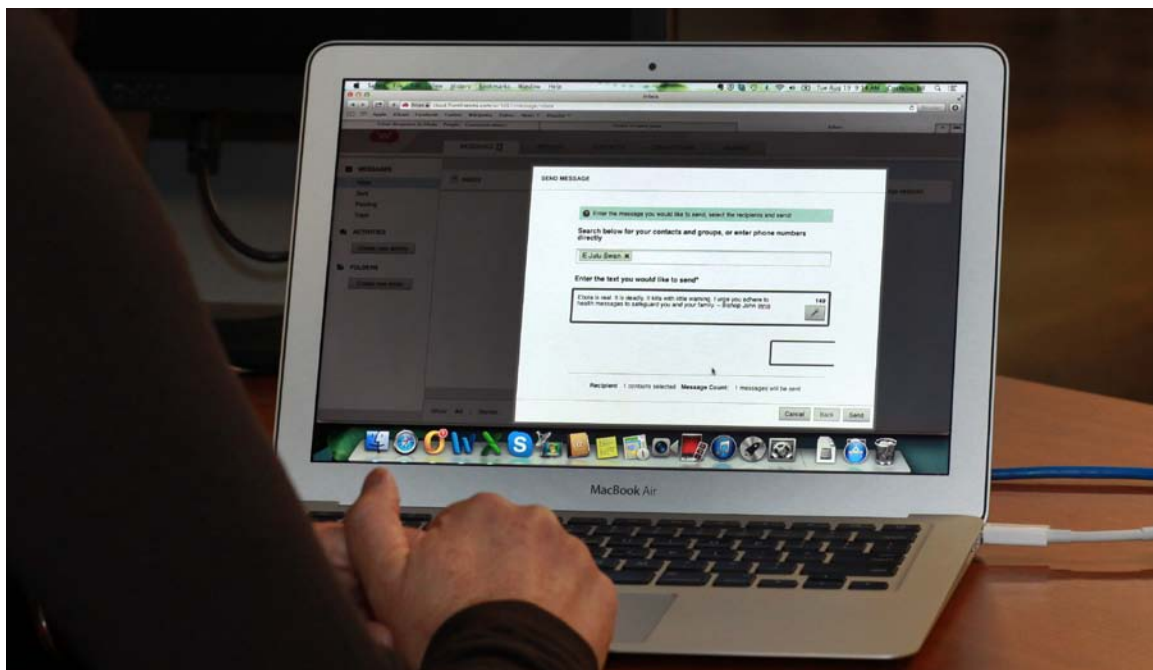
Advance Data "Infostructure" and Standards

The response demonstrated a direct correlation between strong and interoperable information systems, and the ability to deliver a targeted and sustainable response. A proliferation of platforms for data management and use—many of which could not easily be linked to or used with other platforms—fragmented a unified picture of health and humanitarian needs. Greater awareness of, attention to, and investments in interoperability, including both through technical and standards development, is critical to unlocking the full value of digitized data flows.

RECOMMENDATION: Agree upon and support the broad uptake of common data standards.

RATIONALE: Enable effective sharing of data across sectors, systems, and silos.

SUGGESTIONS FOR OPERATIONALIZATION

► **Understand common barriers to paper-based data and information flows**, since these are likely to impact digital information and data flows as well.

► **Support the mapping of public infrastructure**, such as hospitals, clinics, or schools. Include these maps as part of the "common operational datasets" that are available to response actors at the beginning of an emergency situation.

► **Integrate GIS into preparedness protocols related to data standardization and data collection**.

► **Collect only what is needed**. In adopting digitized data collection and use, the types of data collected should first match the information needs of those collecting and using the data.

► **Identify and agree upon data standards, including harmonized disease case definitions and reporting formats** in preparation for potential future outbreaks. This will help to decrease confusion among responders, facilitate data aggregation over the course of an outbreak, and minimize the data burden on frontline responders. Where these data standards have not yet been agreed upon, see the recommendation regarding the creation of **emergency data standards**.

"In the early phases of the response, operational responders needed fast and shallow but broad operational data combined with statistically relevant sentinel site data for epidemiological purposes. We tried to get both all of the time and got neither. A more rationalized approach would be to design an information strategy based on minimal indicators for action and invest in key places for deeper information." [22]

► **Convene discussions about data standards that cut across sector silos** (e.g., health, WASH, education, logistics) **and skill sets** (e.g., technologists/developers, operational humanitarians, development practitioners, researchers). Such discussions could eliminate some issues that arose from non-aligned data standards and interoperability challenges.

► **In advance of or at the outset of an emergency, gather relevant stakeholders to develop minimum data collection standards**, particularly in the early phases of the emergency. Defining the minimum viable product and baseline data, including definitions and standards for data collection, can minimize the

data burden and help increase the likelihood that data collected are of higher quality (due to reduced competing demands for data collection) and of the broadest possible utility to response and other actors.

▶ **Governments and multilateral partners in this space should strongly encourage and, ideally, contractually require funded organizations to adopt and implement harmonized data standards** for both paper and digital technology-based systems.

▶ **Data sharing and use agreements for intra- and international exchange (such as between and among national governments and international agencies) should be automatically triggered** with the declaration of a Public Health Emergency of International Concern or a Level-3 Emergency.

▶ **Contribute to periodic reports documenting the maturity of digital and information systems**, such as the ITU's annual eHealth survey or the Demographic and Health Survey program,[23] to enable continuously updated indexing of the capability and reach of country-level "infostructure."

RECOMMENDATION: Build processes that work toward openness and interoperability.

RATIONALE: Reduce fragmentation and duplication related to data and ICT to maximize investments and to ensure maximum value of data.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **To enable open sharing and to facilitate re-use of data, ensure published data are machine readable**. If data are published in a non-machine-readable format, such as many PDF documents, release the same data simultaneously in a machine-readable format such as .csv-compatible spreadsheets.

▶ **Identify, modify, and implement policies that support sharing of line-list case data or machine-readable data**, ideally by default.

▶ **When creating new data policies or practices, build on existing international standards**.[24]

▶ For datasets relevant to emergency response, **use HXL[25]** as a starting point for terminology and taxonomies to enable data sharing. To institutionalize its use, donors could require its adoption as part of standard data collection in grants and contracts for emergency operations. HXL was developed collaboratively by and for humanitarians to simplify the aggregation of diverse datasets. The HXL hashtag-based approach is broadly relevant and should be expanded for use across other sectors and datasets.

▶ **Set up an easily accessible website for standardized forms (with version numbers) and key messages**.

▶ **Data standards must proactively address the question of who "owns" data, and not only the products that result from use or analysis of data** (e.g., research papers or reports).

▶ **Publish data early and often**, enabling others to cross-check and confirm data (e.g., in the case of GIS locations of health facilities).

"Technology must be interoperable and future-focused. Experience indicates that interoperability between systems is critical. Increased use of Application Program Interfaces (APIs) is needed to connect systems (it's not about seeking to create one large system at a country level); sustainable solutions are not tied to quickly obsolete technologies. For example, the technology underpinning future health systems must be able to cope with the innovation that new phones and other mobile devices enable. This approach requires thinking about the underpinning 'infostructure' where there is less emphasis on sharing specific data and more on connecting the systems that support data to be shared."[26]

Increase Coordination of Digital Health Investments

To date, disparate interest groups have driven digital health platforms and strategies to meet their own needs rather than approaching investments from a systems-level perspective. To derive the greatest possible value from investments in digital systems, more unified and structured funding approaches are needed.

RECOMMENDATION: Encourage coordinated and sustained investments in interoperable data and data systems or platforms.

RATIONALE: Minimize duplication of efforts and funding and co-invest to achieve scale.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Prioritize investments in interoperable platforms and systems** to increase the ability of country governments and other actors to readily compare and share data that originate from difference sources.

▶ **Build upon existing open, adaptable processes, standards, tools, and platforms, whenever possible**. Particularly during emergencies, the most useful innovations frequently are those that make incremental changes to existing tools, processes, and operations. Where broader changes and breakthrough innovations do occur in a crisis response, often they grow to be implemented at scale only during the recovery phase of the response or thereafter.

▶ **Invest in digital health knowledge-sharing systems, tools, and processes that can be accessed by a variety of global health, humanitarian, and development partners.** This could include repositories of commonly used, open source tools, maturity indexes of national digital health ecosystems, documentation of processes and planning, decision-support tools (such as checklists), guiding policies, and frameworks, such as enterprise architecture frameworks that can bring greater coherence to the proliferation of platforms and tools in use in many countries.

▶ **Invest in and provide other needed support to intra- and inter-donor coordination around digital health technologies** to promote aligned policies and actions, such as through technical

working groups within donor organizations and among donors, as in the example of Health Data Collaborative's Digital Health and Interoperability Working Group.[27]

▶ **Create funding mechanisms and models that enable co-funding among donors and both build and sustain digital health commons** so that related platforms, systems, frameworks, and tools are more sustainable than the current program, sector, and/or disease vertical-oriented funding streams may allow.

▶ **Create review boards for spending on digital health through collaborative funding mechanisms** to provide input, feedback, and guidance on digital health investments and deployments. Members might include representation from donors, governments, technical experts, and civil society groups who together offer cross-sector insights.

▶ **Support more collaborative, participatory design and investment, and build processes in donor-funded development work** to reduce parallel investments, such as through co-design among local and global development partners, and mechanisms that enable pooling of financial resources and technical expertise.

▶ **Ensure that funded efforts build on national systems, reuse existing tools, and align with emergent local standards whenever possible**.

▶ **Encourage sustained donor coordination** around the use of data and data systems and platforms, not to support a single system but to build in policies and processes that work toward openness and interoperability and reduce fragmentation and duplication related to ICT.

▶ **Integrate explicit guidance that adheres to established best practice, such as the Principles for Digital Development,[28]** in requests for proposals and other development **funding application processes**. In the reviewing proposals, award technical points to proposals that adhere to best practice.

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Understand and Use Digital Technologies in Context

Use digital technologies appropriately in context. Oftentimes this may mean using digital technologies alongside voice, paper-based, or analog channels. It always means using digital in a manner that is appropriate given the local sociocultural environment and end-user needs.

RECOMMENDATION: Consider the use environment, including the physical, digital infrastructure, sociocultural, and psychosocial context, in designing and deploying digital technologies.

RATIONALE: Ensure digital technologies are used in a manner that is relevant, appropriate, ethical, and efficient.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Incorporate human-centered design processes into the deployment of digital technologies** in humanitarian and development contexts, to ensure that the technology is accessible and any data and information it relays are appropriate to the context.

▶ **Consider rates of literacy, phone ownership, and access to power** among intended audiences when designing digital information programming, including SMS-based communications. (See related **baseline ICT assessment** recommendation.)

▶ **Use hybrid communication approaches** (e.g., digital in combination with print, radio, television) that reflect and are appropriate to the country and cultural context, in a way that reinforces messages across multiple channels.

▶ **When using digital approaches, ensure that they work in both online and offline environments**, such as the use of mobile data collection programs that automatically sync data collected in offline environments once reconnected to wifi or a mobile signal.

▶ **When using mobile applications that require phone numbers, such as mHero or uReport, incorporate a process to regularly update users' phone numbers**.

▶ **When developing digital systems, consider barriers to paper-based information flows** (e.g., lack of roads, rainy season) since they are likely to impact digitized data and information flows as well.

▶ **In designing digitally-supported programs, draw on available information about consumer use patterns, literacy, and numeracy**. Design digital programs with the understanding that digital tools are not a panacea and reflect the information environment in which they are used.

▶ **When building data collection systems, design with a degree of flexibility** to enable adaptation based upon circumstances and the specific requirements of a particular outbreak.

▶ **Analyze what national systems are in place to handle information and data, and what capacity exists to act on it**. Understand the capacity and limitations of the existing digital ecosystem and design digital programming accordingly.

▶ **Whether using digital or paper-based tools, frame messaging according to the local cultural context and leverage existing trust networks to maximize impact**. It is important not to forget empathy in developing messaging, especially when sent through digital channels.

▶ **Employ digital technologies to support psychosocial needs where face-to-face contact is not possible.** In a number of circumstances, organizations operating treatment centers facilitated digital connections (e.g., Skype or video-conferencing) between family members who were unable to meet face to face. These virtual connections helped to address the emotional needs of patients.

▶ **In building new digital technology systems, adapting existing systems, and linking existing systems, support and leverage global public goods** (including open and reusable frameworks, processes, systems, and tools) to minimize duplication of effort and wasted resources.

Employ Feedback Loops and Adaptive Programming[29]

Where digital technologies are used they introduce an opportunity to leverage real-time or near real-time insights to support decision-making. The Principles for Digital Development, reflecting broader trends within both the humanitarian and development sectors, call for "data-driven development" or "evidence-based decision making" that designs projects so that evidence can be measured at key milestones to evaluate impact, and uses the availability of timely data to inform agile management decisions at all levels.[30]

RECOMMENDATION: Use feedback loops in the full lifecycle of aid conceptualization, from design and delivery to monitoring and evaluation.

RATIONALE: Increase the effectiveness of programming and improve humanitarian and development outcomes.

SUGGESTIONS FOR OPERATIONALIZATION

▶ **Treat information and information sharing as an essential activity in an emergency response**, as pivotal as providing food, water, or shelter in emergency response, recovery, and in longer-term resilience planning. This requires ensuring affected communities have regular access to vital and up-to-date information about the crisis and response, conveyed in culturally relevant and appropriate formats, from the beginning of an emergency.

▶ **Design programs to create bidirectional feedback loops from the outset.** Digital data flows can support bidirectional communications and feedback loops. By providing data collectors with the assurance that the data they collect will be returned to them with contextualized information that can support informed decision-making at the point of data origin, these digitized, bidirectional feedback loops can help to create incentives for regular and high quality data collection. Feedback loops also promote accountability and generate new insights, such as in data and information flows both "up" and "down" between government ministries and their remote workforce, and/or between local communities and response organizations.

▶ **Use digital data flows to support a plurality of communications and feedback between responders,** such as those among peer groups or health workers from across the range of response actors. Such communications can support a variety of functions, including community needs and actions, routine disease surveillance, and health information systems strengthening.

▶ Design and implement flexible programs that allow faster feedback and proactive iteration throughout the program cycle.

CALL TO ACTION

Significant reforms are needed to unlock the full potential of data, information, and digital technologies to strengthen global health and humanitarian assistance. Acting on the lessons of the Ebola outbreak response suggests that health and humanitarian actors must:

▶ Recognize and identify information as a valuable commodity for preparedness, response, and resilience

▶ Invest in the infrastructure required for digital connectivity, as elements of preparedness, response, and resilience

▶ Invest in workforce and institutional capacity, and in the enabling policy and regulatory environments to enable and capture the full value of real-time, or near real-time, information flows

▶ Advance harmonized data standards and interoperability guidelines and practice to enable data systems to "speak to" one another

▶ Coordinate investments in digital health programs to avoid duplication and fragmentation

▶ Build capacity to design and deliver digitally supported programs in a way that adheres to best practice, such as that embodied in the Principles for Digital Development (e.g., design with the user, understand the ecosystem, build for sustainability)[1]

▶ Leverage the lowered barriers of access to communications to more regularly engage nontraditional actors, such as citizens, frontline workers, and remote responders, in health and aid programming design, delivery, and evaluation

▶ Use real-time or near-real time data and information flows to incorporate feedback and insights from localized data collection to adapt and improve programming and to create the opportunity to devolve decision-making to the point of data collection

Strengthened data and information flows present an opportunity to redefine the future of health and humanitarian aid programming. Although the potential this transformation represents is tremendous, it only can be achieved if a vision for change is accompanied by a plan for implementation. The **recommendations** in this report aim to help chart a path toward achieving this vision, by capturing learning from and suggesting practical steps to implement the lessons of the Ebola response. This will be critical for continued recovery efforts, and, importantly, to support the longer term systems strengthening that is necessary to build resilience to future crises.

Strengthened data and information flows present an opportunity to redefine the future of health and humanitarian aid programming. Although the potential this transformation represents is tremendous, it only can be achieved if a vision for change is accompanied by a plan for implementation.

ENDNOTES

Executive Summary

1. "Fog of information" is a variation of the term "fog of war," first attributed to the Prussian military strategist Carl von Clausewitz and more recently popularized in the documentary film of that title that explored the difficulties of decision-making in the midst of conflict, when full situational awareness is often absent. We adopt this term, which several interviewees used, to describe the lack of timely, accurate, and accessible data, which clouded situational awareness, impeded effective decision-making, and stymied the response.

Introduction

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7. According to WHO data from December 2014, the peaks occurred in Liberia (509 cases), Sierra Leone (748 cases), and Guinea (292 cases) at epidemiologic weeks 38 (September 14–20), 46 (November 9–15), and 41 (October 5–11), respectively. See *CDC Morbidity and Mortality Weekly Report* (MMWR), "Update: Ebola Virus Disease Epidemic — West Africa, December 2014," Centers for Disease Control and Prevention, 2014, accessed May 18, 2016, **http://www.cdc.gov/mmwr/**

preview/mmwrhtml/mm6350a4.htm. For more on the complexities of data, see Table 2 and the discussion about case **data**.

8. Martin Meltzer et al., "Estimating the Future Number of Cases in the Ebola Epidemic." *CDC Morbidity and Mortality Weekly Report* (MMWR) v. 63, n. 3 (September 26, 2014), Supplement: **3. http://www.cdc.gov/mmwr/pdf/other/su6303.pdf**. See also Martin Meltzer et al., "Modeling in Real Time During the Ebola Response." *CDC Morbidity and Mortality Weekly Report* (MMWR), v. 63, n. 3 (July 2016): S85–S89 and Thomas R. Frieden and Inger K. Damon. "Ebola in West Africa – CDC's Role in Epidemic Detection, Control, and Prevention." Emerging Infectious Diseases 21, n.11 (November 2015): 1897–1905.

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19. Interviews with national and international responders, June 2015. The lack of data sharing agreements presented as an issue most prominently at the beginning of the emergency, and was not universal. For example, although not initially in place, the U.S. CDC quickly implemented data sharing agreements with each of the national governments and with the WHO (email correspondence with CDC officials, August 2016).

20. Interview with Caitlin Rivers, June 2015.

21. Thanks to Parviez Hosseini and Beth Linas, as well as Martin Meltzer, Leah Fischer, and Scott Santibanez for their comments on this section.

22. This work builds upon two prior publications commissioned by the U.S. Global Development Lab. The first is an October 2014 assessment of the reach and capacity of information and communication technology (ICT) infrastructure in Liberia, including the use of software systems to support various aspects of the response. The assessment details how, as the Ebola outbreak progressed, mobile network capacity was strained by dropping revenues, rising operating costs, and skyrocketing demand by the international response. (NetHope, GBI, and USAID, "Information and Communications Technology Response to the Ebola Crisis: Desk Review and Recommendations for Private Sector Engagement," (Washington, DC: USAID; NetHope/GBI, 2014), http://bit.ly/1U3DqC4). The second is a July 2015 report assessing the capacity of digital infrastructure in each of the three countries hardest hit by the Ebola crisis to leverage digital systems for the response. Gobee Group, "Regional, Real-Time Data Infrastructure for the Ebola Response: An Assessment of On-the-Ground Data Systems and Realistic Opportunities for Transformation in Guinea, Liberia, and Sierra Leone," July 2015. See also a blog post of the same title by Eric King, "Fighting Ebola with Information," USAID Impact Blog, May 28, 2015, https://blog.usaid.gov/2015/05/fighting-ebola-with-information/.

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38. For example, in this report we only briefly mention supply chain and laboratory data, and do not provide details about many of the innovations created during the response. These include Google's development with MSF of a sanitizable tablet for Ebola treatment center medical records, or the USAID Ebola Grand Challenge for Development that resulted in the development of new innovations to improve point of care, such as the "Smart Band-Aid" and the Drip-Assist technology. Nor do we address data issues related to vaccine or clinical trials and research during or after the response. See Médécins Sans Frontières, "Ebola: MSF and Google develop 'Ebola-proof' tablets," *Stories from the Frontline*, March 23, 2015, accessed May 18, 2016, http://www.msf.org.uk/article/ebola-msf-and-google-develop-ebola-proof-tablets; USAID, "United States Announces Results of Grand Challenge to Fight Ebola," press release, December 12, 2014, accessed September 5, 2016, https://www.usaid.gov/news-information/press-releases/dec-12-2014-united-states-announces-results-grand-challenge-fight-ebola; Lance Ulanoff, "This smart 'band-aid' could help the world beat Ebola," *Mashable*, March 14, 2015, accessed September 21, 2016, http://mashable.com/2015/03/14/smart-band-aid-ebola/#p4PlvxlJSgq6; USAID, "DripAssist: Shift Labs," Ebola Grand Challenge, accessed September 21, 2016, http://www.ebolagrandchallenge.net/drip-assist-1/. See also Phil Sneiderman, "John Hopkins, DuPont Join Forces to Produce Improved Ebola Protection Suit," *Johns Hopkins Magazine*, September 28, 2015, accessed September 1, 2016, http://hub.jhu.edu/2015/09/28/hopkins-dupont-ebola-garment-partnership.

Lifting the Fog of Information

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7. Interviews with international responders, January 2015. Although OCHA did provide support to the Ebola-affected countries early in 2014 and many of its staff members were seconded to UNMEER, this was less than would have been the case in a Level 3 emergency. (A "Level 3" emergency is the UN classification for the largest and most severe crises, a designation that triggers the deployment of surge staff and dedicated leadership). The UNMEER Lessons Learned exercise on coordination concluded: "Even if another entity is deployed in the lead of a crisis response, the coordination toolkit of the Office for the Coordination of Humanitarian Affairs still adds value and should be leveraged." UN General Assembly, Seventieth Session, Agenda item 133, *Lessons Learned Exercise on the Coordination Activities of the United Nations Mission for Ebola Emergency Response*, prepared by the Secretary-General in pursuance of General Assembly Resolution 69/274B (13), A/70/737, 2016, accessed April 15, 2016, http://reliefweb.int/sites/reliefweb.int/files/resources/N1606127.pdf.

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11. Interview with international responders in Liberia, May 2015 and January 2016.

12. Interview with international responders in Liberia, May 2015 and January 2016.

13. Interview with international responders, May and December 2015.

14. Interviews with NGO responders, February 2016.

15. Interview with international responder, January 2016.

16. Marc DuBois and others, *The Ebola response in West Africa*, 27-28. The UNMEER Lessons Learned exercise echoes this conclusion. See UN General Assembly, Seventieth Session, Agenda item 133, "Lessons Learned Exercise on the Coordination Activities of the United Nations Mission for Ebola Emergency Response," 2016.

17. Interview with international responder, December 2015.

18. Interview with UN official, May 2015.

19. Interview with humanitarian official, January 2015. One USAID official pointed out that UN peacekeeping missions are funded by assessed dues, whereas humanitarian operations are funded with voluntary contributions. This could have influenced the operational culture and how the Mission initially engaged with the public.

20. Interview with UN official, May 2015.

21. Interviews with international responders, January, March, April, May, and June 2015.

22. Interview with Jeremy Konyndyk, January 2015.

23. Correspondence with an international health official, August 2016.

24. Conversation with international health officials, January 2016.

25. Interview with international official, February 2016.

26. Email correspondence with health officials, August 2016.

27. Interviews with international responders, September 2015 and January 2016.

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31. Interviews with responders, January and February 2015, February 2016.

32. Interview with CDC official, February 2016.

33. Interview with NGO official, January 2016.

34. Interview with CDC official, February 2016.

35. Interview with health official, February 2016.

36. Interview with international responder, February 2016.

37. Interview with international responders, January 2015 and February 2016. As of February 2016, national government, WHO, and CDC officials were in the process of cleaning and verifying the Ebola datasets.

38. Interview with health official, February 2016.

39. Interviewees with international officials in Sierra Leone and Liberia, October 2015, January and February 2016.

40. Interview with medical professional, October 2015. A similar sentiment was expressed in another interview with a medical professional, February 2016.

41. Interview with international responder, December 2015.

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44. Interview with USG official, February 2015.

45. Interview with IOM officials, February 2016. The IOM program in Sierra Leone continues as a regional effort in partnership with the US CDC, under the Global Health Security Agenda.

46. Interview with UN official, May 2015.

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48. Each country identified different pillars. For the health components, these included case management and isolation, safe burial, contact tracing, social mobilization, and infection prevention and control. Interview with USG official, December 2015.

49. Interview with national government official, May 2015.

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53. Interview with NGO official, February 2016.

54. Interview with international official, January 2015.

55. Interview with UN official, February 2016.

56. Interview with NGO official, February 2016

57. The ODI report observed: "Ebola exposed the dangers of not getting it right when it came to engagement with the local community: into an atmosphere of intense distrust and fear, early efforts inserted news of an incurable killer disease, using foreigners (international and national) to tell remote villages about Ebola without telling them what they could do about it, and PPE-clad teams removing villagers who were never seen again. The resulting amplification of distrust, fear and resistance all boosted rather than reduced transmission." Marc DuBois and others, *The Ebola Response in West Africa*, 34**.** See also ACAPS, *Ebola Outbreak, Sierra Leone: Communication: Challenges and Good Practices*, ALNAP (2015), accessed April 20, 2016, **http://reliefweb.int/sites/reliefweb.int/files/resources/s-sierra-leone-ebola-outbreak-communications-challenges-and-good-practices.pdf**.

58. Interview with Amanda McClelland, December 2015.

59. Interviews with various responders, January and September 2015, January and February 2016. Multiple interviewees also mentioned the difficulty in recruiting experienced professionals to respond, especially in the very early days of the crisis.

60. Interview with NGO official, May 2015.

61. Interview with CDC official, February 2016.

62. Interview with international health official, January 2016.

63. Interview with international responder, September 2015.

Data Use and Digitization

1. Interview with health official, January 2016.

2. World Health Organization, "Case Definition Recommendations for Ebola or Marburg Virus Diseases," 2014, August 9, **http://www.who.int/csr/resources/publications/ebola/ebola-case-definition-contact-en.pdf?ua=1&ua=1.**

3. Interview with international health official, February 2016; interviews with WHO and CDC officials, February 2016.

4. These definitions were compiled with the assistance of the CDC. See also World Health Organization, "Ebola and Marburg virus disease epidemics: preparedness, alert, control, and evaluation," interim manual version 1.2, August 2014, accessed August 9, 2014, **http://www.who.int/csr/disease/ebola/manual_EVD/en/**; and World Health Organization, "WHO: Ebola Response Roadmap Situation Report," October 1, 2014, accessed August 11, 2016, **http://apps.who.int/iris/bitstream/10665/135600/1/roadmapsitrep_1Oct2014_eng.pdf**.

5. Interview with WHO and CDC officials, February 2016.

6. Note that the archive of WHO SitReps across the three countries is available at: World Health Organization, "Ebola Situation Reports: Archive," updated June 2016, accessed May 9, 2016, **http://www.who.int/csr/disease/ebola/situation-reports/archive/en/**.

7. Eventually the term "probable" cases was discontinued and no longer used in Guinea.

8. World Health Organization, "Définition des cas suspects aucours de la phase 3 de l'épidémie de la MVE [Ebola]," December 15, 2015.

9. Email correspondence with CDC officials, August 2016.

10. Ministry of Health, Liberia, World Health Organization, and U.S. Centers for Disease Control and Prevention (2016). National Technical Guidelines Integrated Disease Surveillance and Response Liberia. Monrovia, Republic of Liberia, 183.

11. For more on Ebola definitions in Sierra Leone, see Patricia M. Dietz et al., "Epidemiology and risk factors for Ebola virus disease in Sierra Leone-23 May 2014 to 31 January 2015," *Clinical Infectious Disease* 61, no.11 (2015): 1648-1654.

12. In part based on the experience from Ebola, leading scientific publishers have pledged to make data related to the Zika outbreak openly available, to enable research and analysis to support clinical interventions. See Gretchen Vogel, "A Plea for Open Science on Zika," Science, February 16, 2016, accessed September 13, 2016, **http://www.sciencemag.org/news/2016/02/plea-open-science-zika**.

13. Interview with international responder, February 201**5.** Lab data, however, were typically tracked and shared in Excel, making these data more easily disseminated or re-used.

14. Interview with international responder, June 2015.

15. Correspondence with CDC officials, August 2016.

16. EpiInfo was originally developed by the CDC and is a set of open software tools commonly used by researchers and health professionals to track, analyze, and visualize disease surveillance and epidemiological information (e.g., patient symptoms, modes of disease transmission). Although it is open, downloadable software, it is not open-source software, meaning the source code is not publicly available online.

17. Interview with international health official, February 2016.

18. Confirmed cases, by definition, had confirmation via laboratory tests. (Interviews with various responders, February 2016). Starting in October of 2014, anyone who died in these

countries was supposed to receive a safe and dignified burial by burial teams, regardless of whether they showed any Ebola symptoms. All those who died were supposed to be tested, "swabbed," for Ebola. If positive, these individuals were included in the aggregated counts. See World Health Organization, "Field Situation: How to conduct safe and dignified burial of a patient who has died from suspected or confirmed Ebola virus disease," October 2014, accessed September 29, 2016, **http://apps.who. int/iris/bitstream/10665/137379/1/WHO_EVD_GUIDANCE_ Burials_14.2_eng.pdf?ua=1**.

19. Interview with CDC official, February 2016.

20. Interview with CDC officials, February 2016.

21. Correspondence with CDC officials, August 2016.

22. Interview with CDC official, February 2016.

23. Interview with NGO medical doctor, October 2015.

24. Interview with health official, February 2016.

25. Interviews with epidemiologists, February 2016.

26. In September 2014, David Nabarro, the Senior UN System Coordinator for Ebola, indicated the disease was exponentially spreading and doubling approximately every three weeks. See United Nations Security Council, 7268th Meeting (PM), "With Spreads of Ebola Outpacing Response, Security Council Adopts Resolution 2177 (2014) Urging Immediate Action, End to Isolation of Affected States," Meeting Coverage, September 18, 2014, **https://www.un.org/press/en/2014/sc11566.doc.htm**.

27. Interview with NGO official working in Ebola treatment center, October 2015.

28. Interviews with national and international responders, January, March, and May 2015, January and February 2016.

29. Interview with CDC official, June 2015.

30. For instance, if a district had 30 Ebola cases in one week and the CIF form was 10 pages, this would require manual data entry of 300 pages of information, much of which would also require cross-checking to avoid duplication.

31. Interview with CDC officials, June 2015 and February 2016.

32. Mahad Ibrahim, "Ebola's Paper Trail," *Motherboard* (July 15, 2015), accessed April 27, 2016, **http://motherboard.vice.com/ read/ebolas-paper-trail**.

33. Interview with Esther Hamblion, WHO, and other officials involved with case data collection in Liberia, February 2016.

34. Correspondence with CDC officials, August 2016.

35. Interview with international responder, April 2015.

36. Interview with WHO official, February 2016.

37. Interviews with international responders, June and October 2015, February 2016.

38. Interview with various officials involved in caseload data collection in Guinea and Sierra Leone, June 2015, January and February 2016.

39. Interviews with CDC officials, February 2016.

40. Interviews with CDC officials, April 2015 and February 2016.

41. Interviews with individuals involved in caseload data

collection in Liberia, April and May 2015, January and February 2016.

42. Interview with USG official, February 2016.

43. Interview with health official, February 2016.

44. District Health Information Software 2, see "DHIS 2.23 is here," DHIS2, **https://www.dhis2.org**. At the core, strengthening HIS involves establishing a culture of data-driven decision-making. It also involves standardizing indicator definitions and allowing the various subsets of the system to "speak to" or interoperate with other subsets in order to access holistic data (e.g., making it possible to link health worker registries to health facility registries, or supply chain logistics to link to health facility registries).

45. Interview with officials involved, April and May 2015, February 2016.

46. Interviews with Liberian and USG officials, April 2015 and February 2016.

47. Email correspondence with Knut Staring, September 2016.

48. Interviews with NGO, international organization, and health officials working in treatment units, February 2016.

49. See Jeff Neiman, "OpenMRS Ebola Case Study: Fighting Ebola with Open Source Collaboration," August 31, 2016, **http://openmrs.org/2016/08/openmrs-ebola-case-study/**; see also the following articles which describe data collection and clinical outcomes for patients: John S Schieffelin et al., "Clinical Illness and Outcomes in Patients with Ebola in Sierra Leone," *New England Journal of Medicine* 371, no. 22 (2014): 2092-100, doi: **10.1056/NEJMoa**1411680; Gabriel Fitzpatrick et al., "The Contribution of Ebola Viral Load at Admission and Other Patient Characteristics to Mortality in a Médecins Sans Frontières Ebola Case Management Centre, Kailahun, Sierra Leone, June-October 2014," *Journal of Infectious Diseases* 212, no. 11 (2015): 1752-8, doi: **10.1093/infdis/jiv**304; and Elhadj Ibrahima Bah et al., "Clinical Presentation of Patients with Ebola Virus Disease in Conakry, Guinea," *New England Journal of Medicine* 372, no.1 (2015): 40-47, doi: **10.1056/NEJMoa**1411249.

50. Interview with medical doctor, January 2015.

51. World Health Organization, "Ebola Situation Reports," accessed May 18, 2016, **http://apps.who.int/ebola/ebola-situation-reports**. See also the national MOH Situation Reports and CDC Ebola outbreak updates, available from **http://www. cdc.gov/vhf/ebola/outbreaks/2014-west-africa/previous-updates.html**.

52. Other digital tools for case management were used, such as eHealth Africa's Sense software suite, which was used for contact tracing in Nigeria, Sierra Leone, and Liberia, or Dimagi's CommCare, which was used for contact tracing in Guinea.

53. Sean Martin McDonald, Ebola: A Big Data Disaster - Privacy, Property, and the Law of Disaster Experimentation, CIS papers (Delhi: The Center for Internet and Society, 2016), 14, **http:// cis-india.org/papers/ebola-a-big-data-disaster**.

54. In May 2015, the USAID Development Informatics team and partners identified approximately 150 uses of HIS platforms across all of West Africa, some of which were used in multiple countries. This list was not comprehensive of all digital platforms used in the health sector, nor did it include non-health-focused platforms, such as the WFP mobile Vulnerability Assessment and Mapping tool developed for and used in WFP programs in

all three most-affected countries. Interview with WFP officials, February 2016. See "MVAM: The Blog, Mobile Technology for WFP's Food Security Monitoring," World Food Programme, http://mvam.org. Also interviews with officials, December 2014 and June 2015.

55. Interview with international responder, November 2015.

56. Interview with NGO official, February 2016; also with CDC officials, February 2016.

57. Interview with NGO official, October 2015.

58. Interviews with international responders, December 2014, April 2015 and February 2016.

59. Interview with USG official, January 2015; see also Sean McDonald, Ebola: A Big Data Disaster, 14.

60. Interview with NGO official, October 2015.

61]Interviews with national and international responders, December 2015 and February 2016.

62. Interview with Amanda McClelland, December 2015.

63. Interview with national official, April 2015.

64. Interview with NGO official, October 2015.

65. Interview with international health official, February 2016.

66. John Adams, Anne Lloyd, and Carolyn Miller, *The Oxfam Ebola Response in Liberia and Sierra Leone: An Evaluation Report for the Disasters Emergency committee* (Oxford, UK: Oxfam, 2015), 23, accessed September 29, 2016, http://policy-practice.oxfam.org.uk/publications/the-oxfam-ebola-response-in-liberia-and-sierra-leone-an-evaluation-report-for-t-560602.

Real-Time Information Flows

1. Case studies explored in this report are those that surfaced through the interview process and, as mentioned in the Methodology section, are neither comprehensive nor fully representative of the diversity of tools used. The case studies in this section were selected because they illustrate different types and flows of data and information in a digitized, real-time or near real-time environment. We do not investigate paper-based or analog information flows in this section.

2. In its report, "Health Worker Ebola Infections in Guinea, Liberia and Sierra Leone" (WHO/EVD/SDS/REPORT/2015.1 (2015): 1-15. World Health Organization, May 21, 2015, http://www.who.int/hrh/documents/21may2015_web_final.pdf), WHO estimated the risk of infection at "between 21 to 32 times higher in health workers compared with non-health workers." Of note, and as an example of the varying figures documenting the response, the CDC's October 2015, Morbidity and Mortality Weekly Report (MMWR) on the Ebola outbreak in Guinea indicated that "incidences of Ebola infection among healthcare workers [were. 42.2 times higher than among non-HCWs." See Margaret Grinnell et al., "Ebola Virus Disease in Health Care Workers--Guinea", 2014. Issue brief no. 38. Vol. 64. *Morbidity and Mortality Weekly Report*. Centers for Disease Control and Prevention, October 2, 2015, accessed March 28, 2016, https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6438a6.htm.

3. IntraHealth and K4Health's participation in the program was supported by USAID funding. In particular, IntraHealth's accelerated work on mHero as part of the Ebola outbreak response

won the support of USAID's the Fighting Ebola Grand Challenge led by the Center for Accelerating Innovation and Impact (CII) in USAID's Global Health Bureau and supported by USAID.

4. Digital health refers to the use of any digital technologies to enable better collection and use of data, improved quality and reach of health service delivery, and better decision-making by governments, health workers, and individuals. When used in accordance with best practice, such as that embodied in the Principles for Digital Development, digital health can help governments better understand and respond to public health needs, and empower individuals to make better choices to improve quality of life for themselves and their families. Digital health comprises the domains of eHealth and mHealth, and includes the adaptation, use, and support of digital technologies including wireless technologies (e.g., cellular, GPS, wifi, Bluetooth), mobile devices (e.g., mobile phones, tablets, laptops, SIM-enabled devices, "smart" medical devices), sensors and embedded technologies (i.e. the Internet of things), as well as fixed digital devices, equipment, and infrastructure (e.g., desktops, servers, fixed broadband).

5. See www.ohie.org for more information about Open Health Information Exchange.

6. The iHRIS database was under development in Liberia and Guinea when the Ebola outbreak struck.

7. These 40-plus deployments are in addition to the identification of 33 "use cases," or distinct purposes for mHero deployments.

8. As cited in Emily Nicholson, "Spotlight: Liberia's Great Strides to Scale the mHero Platform," IntraHealth, USAID, and UNICEF, February 2016, 3, http://www.intrahealth.org/files/media/spotlight-liberias-great-strides-to-scale-the-mhero-platform/mHeroSpotlight3.pdf.

9. Emily Nicholson, "Spotlight: Liberia's Great Strides to Scale the mHero Platform," IntraHealth, USAID, and UNICEF, February 2016, 2-3, http://www.intrahealth.org/files/media/spotlight-liberias-great-strides-to-scale-the-mhero-platform/mHeroSpotlight3.pdf.

10. For more information about Tableau and the Tableau Foundation, see http://www.tableaufoundation.org/.

11. Jilian A Sacks et al., "Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea," Global Health: Science and Practice 3, no. 4 (2015): 646, doi: 10.9745/GHSP-D-15-00207, http://www.ghspjournal.org/content/3/4/646.full.pdf+html.

12. Sacks et al., Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:647.

13. Sacks et al., Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:651-652.

14. Sacks et al., Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:646-659.

15. Interview with international responder, May 2015.

16. Conversation with Guinean district health manager, July 2015.

17. Sacks et al., Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:646-659.

18. Sacks et al., Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:646-659.

19. Sacks et al, Introduction of Mobile Health Tools to Support Ebola Surveillance and Contact Tracing in Guinea 3:655-658.

20. Email correspondence with authors, August 2016. As noted above, all interviewees are cited anonymously to protect confidentiality, except in relevant instances, such as these case studies that identify organizations thereby compromising anonymity. All case studies have been cross-checked with relevant actors, including permission to identify individuals by name.

21. The ECAP case study is compiled from interviews with Sophie Roden, Jeff Wishnie, and Michael Catalano, April and May 2015. Also email correspondence with authors, July and August 2016 and remarks by Sophie Roden during the "OpenResponse ICT Webinar" hosted by Dimagi. The webinar examined lessons learned by eight partners providing ICT-based services in support of the Ebola outbreak response, and was held online on December 3, 2015. See also http://www.ecapliberia.org/.

22. Mercy Corps, "National Radio Reach Survey - A study on radio and ECAP 2 health messages in Liberia," (Portland, OR: Mercy Corps, 2016), accessed September 21, 2016, http://www.ecapliberia.org/images/pdfs/USAID2015LiberiaECAPIIRadioSurvey.pdf.

23. Interview with staff from national NGO, February 2016.

24. A cache is a temporary data storage area that enables Internet browsers to retrieve information about past data downloads from specific websites. This is particularly critical in instances in which users move between on- and offline environments.

25. Interview with Naymote staff members, February 2016.

26. For more information see http://www.frontlinesms.com/.

27. Interview with Julu Swen, United Methodist Communications communicator in Liberia, September 2015.

28. Remark by Reverend Benedict Greene (District Superintendent, Kokoya District) shared with Julu Swen, United Methodist Communications communicator in Liberia, and relayed via interview on September 17, 2015. Quote from Rev. Greene used with his approval.

29. Phileas Jusu (Sierra Leone-based Communicator, United Methodists Communications) remarks at the Game Changers Summit in Nashville, September 17, 2015.

30. Neelley Hicks, e-mail message to authors, May 31, 2016.

31. The name "DeySay" is derived from colloquial Liberian English referring to how people speak about rumors.

32. Interview with Anahi Ayala Iacucci, Senior Advisor for the Internews Center for Innovation and Learning, February 2016.

33. Anahi Ayala Iacucci, "Combating Rumors About Ebola: SMS Done Right," Internews, March 26, 2015, accessed September 21, 2016, https://medium.com/local-voices-global-change/combatting-rumors-about-ebola-sms-done-right-da1da1b222e8#.1zqmx5y4i.

34. Anahi Ayala Iacucci, "Combating Rumors About Ebola: SMS Done Right," Internews, March 26, 2015, accessed September 21, 2016, https://medium.com/local-voices-global-change/combatting-rumors-about-ebola-sms-done-right-da1da1b222e8#.1zqmx5y4i.

35. Interview with Anahi Ayala Iacucci and Mark Frohardt, Internews, September 2016.

36. Interview with Anahi Ayala Iacucci and Mark Frohardt, Internews, September 2016.

37. Interview with Anahi Ayala Iacucci and Mark Frohardt, Internews, September 2016.

38. UNICEF, "Communication for Development: Responding to Ebola in Liberia," accessed June 25, 2016, http://www.unicef.org/cbsc/index_73157.html.

39. Rebecca Levine et al., "mHealth Compendium," *African Strategies for Health* 5 (June 2015): 20, https://www.msh.org/sites/msh.org/files/2015_08_msh_mhealth_compendium_volume5.pdf. For an example of U-Report's use during the Ebola outbreak response in Sierra Leone, see http://sierraleone.ureport.in/poll/431.

40. UNICEF Stories, "UNICEF develops critical Ebola data flow," originally published in the New Dawn on October 27, 2014, http://www.unicefstories.org/2014/10/28/unicef-develops-critical-ebola-data-flow/. See also http://www.huffingtonpost.com/2015/03/05/u-report-liberia-ebola_n_6802048.html.

41. "RapidPro: An Open Source Communication Platform," UNICEF Innovation, accessed May 7, 2016, https://community.rapidpro.io/. RapidPro is an open source version of TextIT.

42. UNICEF, "Communication for Development: Responding to Ebola in Liberia," accessed June 25, 2016, http://www.unicef.org/cbsc/index_73157.html.

43. Interview with Rafael Obregon, December 2015.

44. UNICEF, "Communication for Development: Responding to Ebola in Liberia," accessed June 25, 2016, http://www.unicef.org/cbsc/index_73157.html.

45. Interview with UNICEF officials, February 2016 and email communication to authors, July 2016.

46. Maria Luisa Sotomayor (Member of the U-Report coordination team), email communication to authors, May 6, 2015.

47. Interview with Mohammed Jalloh, February 2016.

48. Interview with Katharine Owen, February 2016.

49. The DHN was launched in 2012 to support information sharing between formal aid actors and the informal digital humanitarian community. This was expanded in 2014 for the Ebola response through DFID support.

50. The DHN was created by Andrej Verity of OCHA and Patrick Meier, a founder of the "crisis mappers" community. For more information, see "DH Network," Digital Humanitarian Network, accessed June 3, 2016, http://digitalhumanitarians.com/.

51. Interview with Roxanne Moore, April 2015.

52. Information sourced from an analysis prepared in summer 2015 by interns working with Benson Wilder, geographer/analyst at the U.S. Department of State.

53. A month-by-month analysis of data and information exchange on the Skype group is available in an unpublished Excel spreadsheet managed by Roxanne Moore of DHN.

54. Interview with Roxanne Moore, April 2015.

55. Interview with international responders, January and February 2016.

56. Interviews with anthropologists and NGO officials, November and December 2015, February 2016; see also World Health Organization, "Anthropologists Work with Ebola-affected

Communities in Mali," Features, January 2015, http://www.who.int/features/2015/anthropologists-ebola-mali/en/.

57. This platform, coordinated by anthropologists at the Institute for Development Studies, Universities of Sussex and Exeter, and the London School of Hygiene and Tropical Medicine. See "Ebola", Institute of Development Studies, accessed May 31, 2016, http://www.ids.ac.uk/idsresearch/ebola and "Recent Addition," Ebola Response Anthropology Platform, accessed May 31, 2016, http://www.ebola-anthropology.net/. This platform addressed the following issues: Identifying and diagnosing cases; management of the dead; caring for the sick; clinical trials; preparedness, and; communication and engagement.

58. Lisa Cobb, "Anthropology and Ebola Communication," Ebola Communication Network, January 6, 2015, http://ebolacommunicationnetwork.org/anthropology-and-ebola-communication/.

59. Interview with health promotion official, November 2015.

60. Interview with Juliet Bedford, November 2015. The papers are downloadable from http://www.anthrologica.com/unmeer-west-africa.html.

61. "The Humanitarian Data Exchange," HDX, accessed May 31, 2016, https://data.humdata.org/.

62. Interview with Sarah Telford, January 2015. This case study is compiled from interviews with Telford in January 2015 and September 2016, and with David Megginson, also with HDX, in February 2015.

63. Interview with USG official, February 2015.

64. Simon Johnson, "Ebola 3W Dashboard," December 10, 2014, accessed September 9, 2016, https://simonbjohnson.github.io/Ebola-3W-Dashboard/.

65. Email correspondence with Javier Teran (HDX), March 2016.

66. Metadata provides contextual information about other data, such as when those data were collected, by whom, and any dates on which data were modified.

67. HDX will not, for example, accept any data sets that include personally identifiable information.

68. Interview with UN official, February 2016.

69. Interview with NGO official in Sierra Leone, February 2016.

70. Interview with national official, April 2015.

71. Interview with national health official, May 2015.

72. Mikel Maron and Julia Kim, "Crisis data coordination: Lessons learned from the Ebola data calls hosted by the U.S. Government," Unpublished report, 2015 (Washington: U.S. Department of State).

73. Roxanne Moore, "After action report: IM/GIS Ebola communications on Skype," Digital Humanitarian Network, August 2015.

74. Interview with international responder, September 2015.

Recommendations

1. An article published in the Public Library of Science (PLoS) highlights the need for ICT in Ebola case surveillance, including case investigation, management, and strategic planning, and the use of open software (ODK and FormHub) in the Nigerian outbreak. The authors conclude: "A remarkable improvement was recorded in the reporting of daily follow-up of contacts after the deployment of the integrated real time technology." Daniel Tom-Aba et al. "Innovative Technological Approach to Ebola Virus Disease Outbreak Response in Nigeria Using the Open Data Kit and Form Hub Technology" PLoS One. 2015; 10(6): e0131000. Published online 2015 Jun 26. doi: 10.1371/journal.pone.0131000 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482726/.

2. Here we refer to nodes and networks as in the sense of social network analysis, which maps, measures, and analyzes the patterns of information flows between people or groups.

3. Analyzing the role of digital technologies in providing varying levels of complexity and directionality in communications within and between various actor groups is not new. The 2009 report New Technologies in Emergencies and Conflicts notes, "The report also makes distinctions in terms of the format of the communications. While the underlying communications technology may be radio, mobile, or internet, it is useful to [note. how the information is conveyed, whether: one-to-many (broadcast—radio, television, web, mobile applications (apps) and services, short message service (SMS) broadcast); one-to-one (mobile voice and SMS); or many-to-many, such as social networks (online or mobile internet, mapping, and crowdsourcing)." Diane Coyle and Patrick Meier. New Technologies in Emergencies and Conflicts, 6.

4. Nigeria case example compiled from interviews with multiple health officials, January, May, June, and September 2015.

5. See World Health Organization, "WHO Declares End of Ebola Outbreak in Nigeria," Statement, October 20, 2014, accessed May 28, 2016, http://www.who.int/mediacentre/news/statements/2014/nigeria-ends-ebola/en/.

6. The IHR are legal instruments, signed by 196 countries, designed to detect and prevent public health crises. See "International Health Regulations," World Health Organization, accessed May 28, 2016, http://www.who.int/topics/international_health_regulations/en/.

7. Faisal Shuaib et al., "Ebola Virus Disease Outbreak—Nigeria, July September 2014," *Morbidity and Mortality Weekly Report* (MMWR) 63, no.39 (2014): 867–872, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6339a5.htm?s_cid=mm6339a5_w.

8. Daniel Tom-Aba et al. "Innovative Technological Approach to Ebola Virus Disease Outbreak Response in Nigeria Using the Open Data Kit and Form Hub Technology" PLoS One. 2015; 10(6): e0131000. Published online June 26, 2015. doi: 10.1371/journal.pone.0131000 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482726/.

9. Email correspondence with NGO official, October 2016.

10. Interview with NGO official, January 2015.

11. Wilton Park/mPowering Frontline Health Workers, "(Re)Building Health Systems in West Africa: What Role for ICT and Mobile Technologies? Monday 15–Wednesday 17 June 2015, WP1409," July 2015, 2, http://www.wiltonpark.org.uk/wp-content/uploads/WP1409-Report.pdf.

12. An example of such a partnership is that announced in September 2016 among the Government of Liberia, Google,

and USAID to bring high-speed communications infrastructure to Monrovia, Liberia. See "Liberia To Work With Google, USAID To: Increase Broadband Access In Monrovia," *Daily Observer*, September 22, 2016, accessed November 8, 2016, **http://www.liberianobserver.com/business/liberia-work-google-usaid-increase-broadband-access-monrovia.**

13. The regulatory environment plays an important role in facilitating these incentives, especially in terms of mobile base stations policies, extending fiber access, and regulating spectrum to facilitate rural access to Internet and broadband services.

14. See "The Emergency Telecommunications Cluster (ETC)," *Inter-Agency Standing Committee*, accessed November 8, 2016, **https://www.etcluster.org/.**

15. For more information, see "Welcome to Humanitarian ID," *Office for the Coordination of Humanitarian Affairs* (OCHA), accessed November 8, 2016, **http://www.humanitarian.id.**

16. Interview with international health official, May 2015.

17. The Senior Executive Service is a cadre of government positions below top presidential appointees who "possess well-honed executive skills" and are remunerated at rates of pay that tend to be higher than other federal government service employees. For more information, see **https://www.opm.gov/policy-data-oversight/senior-executive-service/**.

18. Adapted from Adele Waugaman, *From Principle to Practice: Implementing the Principles for Digital Development: Perspectives and Recommendations from the Practitioner Community*. Washington, DC: The Principles for Digital Development Working Group, January 2016, p. 62.

19. Interviews with national and international officials familiar with Liberia case data collection, December 2014, April 2015, and February 2016.

20. For more information on ongoing revisions to the IHR, see World Health Organization, "Global infectious disease surveillance," Fact sheet N200, **http://www.who.int/mediacentre/factsheets/fs200/en/.**

21. For more information, see: United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA), *Building Data Responsibility into Humanitarian Action*, OCHA Policy and Studies Series, May 2016.

22. Correspondence with USG official, July 2016.

23. More information about the DHS is available at **http://www.dhsprogram.com.**

24. For example, the International Organization for Standardization (ISO) has developed internationally recognized standards for everything from risk management and occupational safety, to country codes and medical devices: **http://www.iso.org/iso/home.html.** Also the International Aid Transparency Initiative standards on aid spending (**http://www.aidtransparency.net/**).

25. "Humanitarian Exchange Language," HXL Standard, accessed June 8, 2016, **http://hxlstandard.org/standard/1_0final/.**

26. Wilton Park/mPowering Frontline Health Workers, "(Re) Building Health Systems in West Africa: What Role for ICT and Mobile Technologies? Monday 15 – Wednesday 17 June 2015, WP1409," July 2015, 3, **http://www.wiltonpark.org.uk/wp-content/uploads/WP1409-Report.pdf.**

27. For more information, see **http://www.healthdatacollaborative.org/news/article/taming-the-wild-west-of-digital-health-data-linking-systems-to-strengthen-global-health-outcomes-76/.**

28. For more information see **http://www.digitalprinciples.org.**

29. See **https://www.globalinnovationexchange.org/learning-adapt.**

30. See **http://digitalprinciples.org/be-data-driven/.**

Call to Action

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APPENDIX: LIST OF INTERVIEWEES

This research would not have been possible without the time and insights of over 130 people from more than 60 organizations interviewed for this research. We are grateful to the following individuals who contributed their time, insights, and perspectives. Numerous others shared their stories but asked to remain anonymous; they are not included in the list below. Individuals are listed with their affiliation at the time of interview.

Last Name, First Name: Affiliation

Amponsah, Monica: OCHA

Arafa, Sherif: IOM

Bae, Ji: eHealth Africa

Baike, Bruce: Inveneo

Bailey, Christopher: WHO

Bangura, Mohamed: GOAL

Barry, Mamadou Bailo: UNICEF

Bawo, Luke -MOH/Liberia

Bedford, Juliet: Anthropologica

Berg, Matt: Ona

Bishop, Nick: IOM

Blevins, Chad: USAID

Bolletino, Vincenzo: Harvard Humanitarian
    Initiative

Braddock, Jocelyn: Catholic Relief Services

Burton, Joseph: U.S. Department of State

Caleo, Grazia: MSF

Caley, Luke: DFID

Campo, Stuart: UNICEF

Carlson, Sabina: IOM

Carroll, Dennis: USAID

Catalano, Michael: Mercy Corps

Celades, Eduardo: WHO

Chan, Jennifer: NetHope

Cheah, Patrick: GOAL

Chokki-Laleye, Felicité: WAHO

Cleon, Joshua: Naymote

Comes, Tina: Disaster Resilience Lab

Crowley, John: World Bank/Global Facility for
    Disaster Reduction and Recovery (GFDRR)

Davies, Benetta: Naymote

DeVries, Piet: Global Communities

Diallo, Alpha Samba: UNICEF

Dijkerman, Dirk: USAID

Doshi, Samir: USAID

DuBois, Marc: Independent consultant

Last Name, First Name: Affiliation

Dumbuya, Alhassan: GOAL

Dunbar, Nelson: MOH/Liberia

Faure, Marie-Elisabeth: WFP

Ferraro, Nazzarena: OCHA

Flock, Jim: ACDI/VOCA

Fluder, Jen: USAID

Frohardt, Mark: InterNews

Gage, Kate: USAID

Gembara, Al: USAID

Glasow, Jerry: U.S. Department of Defense

Gordon, Patrick: OCHA

Hamblion, Esther: WHO

Helland, Anna: Johns Hopkins Center for
    Communication Programs

Herranz, Manuel Garcia: UNICEF

Hicks, Neelley: United Methodist Communications

Higgins, Eilidh: International Rescue Committee

Hoffman, Bill: World Economic Forum

Hulse, Matthew: USAID

Hutchfield, David: Grameen Foundation

Ir Gigo, Abdel Nasser: Earth Institute, Columbia
    University

Jaisinghani, Priya: USAID

Jalloh, Mohamed: FOCUS 1000/SMAC

Jarwolo, Eddie: Naymote

Jazayeri, Darius: ThoughtWork

Johnson, Simon: British Red Cross

Jusu, Phileas: United Methodist Communications

Kabah, Samuka: Naymote

Kaiser, Nils: eHealth Africa

Karege, Clément: OCHA

Karlyn, Andrew: USAID

King, Eric: USAID

Kinkade, Carl: CDC

Konyndyk, Jeremy: USAID

Koroma, Julius: GOAL

Last Name, First Name: Affiliation

Lacey-Hall, Oliver: OCHA

Lamb, Sarah: MSF

Larsen, Lynette: UNMEER

Lash, Ryan: CDC

Leson, Heather: Qatar Computing Research
    Institute

Mahmood, Jemilah: OCHA/World Humanitarian
    Summit

Manning, Craig: CDC

Margie, Paul: Harris, Wiltshire & Grannis LLP

Maron, Mikel: U.S. Department of State

Martell, Lise: CDC

Matthews, Hilton: GOAL

McCann, Sheena: Concern Worldwide

McClelland, Amanda: International Federation of
    Red Cross and Red Crescent Societies

McKewon, Simon: sQuid

Megginson, David: OCHA

Mehl, Garrett: WHO

Mesfin, Samuel -WHO

Moore, Roxanne: Digital Humanitarian Network

Mukenge, Guillaume Bakadi: Johns Hopkins
    Center for Communication Programs

Ndoye, Babacar: MOH/Senegal

Nyahn Jr., Jzohn Alexander: Chess Liberia

Nyenswah, Tolbert: IMS/Liberia

Obregon, Rafael: UNICEF

Okoko, Lungi: USAID

Olubunmi, Ojo: MOH/Nigeria

Owen, Katharine: GOAL/SMAC

Oza, Shefali: Save the Children International

Pendarvis, Justin: USAID

Rader, Patricia: USAID

Ransom, Ray: CDC

Reid, Kyla: GSMA

Rivers, Caitlin: Virginia Tech University

Roden, Sophie: Mercy Corps

Rosling, Hans: Karolinska Institutet

Schaefer, Merrick: USAID

Selanikio, Joel: Magpi

Sene, Jean-Baptiste: UNICEF

Serlemitsos, Elizabeth: Johns Hopkins Center for
    Communication Programs

Last Name, First Name: Affiliation

Shashati, Habib: WFP

Sidikou, Fatouma Mabeye: Women and Health
    Alliance International

Sortino, Salvatore: IOM

Staring, Knut: University of Oslo/Health
    Information Systems Programme

Stone, Erin: International Rescue Committee

Swen, Julu: United Methodist Communications

Taliesin, Brian: PATH

Telford, Sarah: OCHA

Thompson, Adam: eHealth Africa

Tran, Alex: GOAL

van der Walle, Bartel: Disaster Resilience Lab

VanRoekel, Steven: USAID

Veltsos, Philippe: Novel-T Sàrl

Villaceves, Jeffrey: UNMEER

Waddell, Anthony: Liberia Governance and
    Economic Management Support

Walia, Sonia: USAID

Warren, Wade: USAID

Washburn, Faith: CDC

White, Jamila: eHealth Africa

Wilder, Benson: U.S. Department of State

Wishnie, Jeff: Mercy Corps

Yewondwossen, Assefa -UNMEER

Zingeser, Jim: CDC

Zinner, Lauren Shear: Clinton Health Access
    Initiative

ABOUT THE AUTHORS

Larissa Fast was an AAAS Science and Technology Policy Fellow, working at the U.S. Global Development Lab as Learning Lead for the Ebola team from September 2014 through August 201**6**. She is a 2016-2017 Fulbright-Schuman Research Scholar in the United Kingdom and Sweden.

Dr. Fast is a scholar and practitioner, with two decades of experience working at the intersection of research, policy, and practice related to humanitarianism, conflict, violence, and peacebuilding. She is an internationally recognized expert on the causes of and responses to violence against conflict interveners, such as aid workers and peacebuilders, and has published extensively on the topic in both academic and policy-focused formats. Her book, *Aid in Danger: The Perils and Promise of Humanitarianism* (2014, University of Pennsylvania Press) explores the causes of and responses to violence against aid workers. Dr. Fast has published in the *International Review of the Red Cross*, *Disasters*, the *European Journal of International Relations*, and other journals. Previously she was a faculty member at the Kroc Institute, University of Notre Dame. She has consulted and worked for aid agencies and other international organizations, primarily in North America and Africa. Her research has been funded by the Swiss Development Corporation, the United States Institute of Peace, and USAID/OFDA.

Adele Waugaman is Senior Advisor, Digital Health in the USAID Global Health Bureau's Center for Accelerating Impact and Innovation. She conducted the majority of this research and writing while a consultant to the U.S. Global Development Lab through FHI 360's Mobile Solutions Technical Assistance and Research (mSTAR) program.

Ms. Waugaman is an affiliated expert and former fellow at the Harvard Humanitarian Initiative. A frequent commentator on technology and development trends, Ms. Waugaman has spoken at a variety of international conferences on technology, philanthropy, health, and development, and appeared in news outlets, including the BBC, *Financial Times*, *New York Times*, National Public Radio, and *Wall Street Journal*. As a consultant, she provided strategic, technical, and advisory support to organizations using communications technologies to strengthen global health, humanitarian assistance, and global development. Prior to launching her consulting practice in 2012, she was Senior Director of Technology Partnerships at the United Nations Foundation, where she managed a $30 million partnership with Vodafone that leveraged advances in ICTs to strengthen global health and humanitarian

work. In that capacity she oversaw the award-winning Access to Communications publication series, including *Disaster Relief 2.0: The Future of Information Sharing in Humanitarian Emergencies*. Together these reports charted how advances in communications technologies created opportunities to make aid and development work more inclusive and effective.

ABOUT USAID AND THE EBOLA RESPONSE

The U.S. government (USG) support for the Ebola outbreak response was led by the U.S. Agency for International Development in close coordination with a number of U.S. agencies, including the Department of State, Department of Defense, and multiple arms of the Department of Health and Human Services, including the Centers for Disease Control and Prevention, the National Institutes of Health, and the U.S. Public Health Service Commissioned Corps. In total, the USG provided $2,594,884,810 (combined USAID, Department of Defense, and CDC funding) for the Ebola outbreak response in fiscal years 2014-2016.[1]

THE U.S. AGENCY FOR INTERNATIONAL DEVELOPMENT (USAID)

USAID is the lead U.S. government agency for international development. USAID's mission is partnering to end extreme poverty and promote resilient, democratic societies while advancing U.S. security and prosperity. This study was commissioned by the U.S. Global Development Lab within USAID, in close collaboration with other USAID teams, including the Global Health Bureau, the Office of U.S. Foreign Disaster Assistance and the Africa Bureau, each of which played an important role in USAID's Ebola response and recovery efforts, as described below.

The Office of U.S. Foreign Disaster Assistance

The Office of U.S. Foreign Disaster Assistance (OFDA) within USAID is responsible for leading and coordinating the U.S. government's response to disasters overseas. OFDA responds to an average of 65 disasters in more than 50 countries every year to ensure aid reaches people affected by humanitarian crises, such as earthquakes, volcanoes, floods, drought, conflict, and major public health epidemics. As the lead USG office for the response, OFDA deployed a field-based Disaster Assistance Response Team (DART) on August 5, 2014, and established a corresponding Response Management Team (RMT) based in Washington, DC. The DART—including disaster response and medical experts from USAID, CDC, and other USG agencies—identified key needs stemming from the Ebola outbreak, amplified humanitarian response efforts, and coordinated all USG efforts to support the Ebola response. Seventeen months later, and following a steady decrease in Ebola cases, the DART and RMT demobilized on January 4, 2016. As of the time of publication, USAID/OFDA staff have remained in the region to ensure continued capacity to respond to new Ebola cases and facilitate the transition from relief to recovery.

Africa Ebola Unit

In March 2015, USAID established the Africa Ebola Unit (AEU) to lead Ebola Recovery efforts within USAID and to coordinate closely with the Africa Bureau to succeed the Ebola Task Force and Secretariat—the initial coordinating entity for the response and recovery within USAID—which closed in May 2015. Like the Task Force that preceded it, the AEU was charged with overseeing coordination of Ebola-related activities within USAID, across the USG inter-agency, and with the wider international community. In

addition, the AEU worked with other USAID units to provide support to USAID Missions and implement a robust set of development programs designed to address the secondary impacts of the outbreak and ensure that Guinea, Sierra Leone, Liberia, and other countries in the region would be prepared to effectively prevent, detect, and respond to future outbreaks. USAID's Ebola recovery activities fall into the following categories:

▶ **Food Security:** Using a market-based approach to support households, communities, and agricultural markets to recover from the food security impacts of Ebola.

▶ **Critical Non-Ebola Health Services:** Ensuring that health facilities are restored and fully functioning to provide basic health services, including immunization, maternal and child health, and water and sanitation.

▶ **Health Systems Recovery:** Restarting and helping to rebuild health systems so they are better prepared to respond appropriately and adequately to future public health crises by institutionalizing infection prevention and control practices, rebuilding communities' trust in the health care system, and strengthening supply chain management, health governance and management, human resources, and health financing.

▶ **Governance and Economic Crisis Mitigation:** Strengthening host governments' ability to provide needed services, attract private sector investment in local economies, and empower civil society.

▶ **Innovation, Technology, and Partnerships:** Seeking to extend the impact and sustainability of USAID's Ebola recovery programs through collaboration with private sector partners; sourcing innovations from a global community of solvers to address the most intractable challenges of the response; and working closely with governments and partners to address the breakdown in communications infrastructure and health information systems that contributed to weaknesses in health systems and hampered the response.

▶ **Global Health Security:** Strengthening infectious disease prevention, detection, and response measures in affected countries, including strengthening health institutions and personnel, building emergency management response capacity, and expanding surveillance and laboratory systems.

▶ **Ebola Transmission Prevention and Survivor Support:** Facilitating the provision of Ebola transmission prevention and survivor support in the three Ebola-affected countries, such as by supporting survivor research, programs to manage and assess viral persistence among survivors, and basic primary care and specialized medical services for survivors.

As of September 30, 2016, the AEU's responsibilities were transferred to the Africa Bureau's Office of West African Affairs, which will continue the oversight role for implementation of Ebola recovery activities in the field, and coordination across the Agency with bureaus and independent offices involved in Ebola recovery activities.

Global Health Bureau

The USAID Global Health (GH) Bureau response and recovery activities included partnerships with host country governments and international actors like the WHO, and strategic investments to rebuild health systems to make them resilient to future shocks. The latter includes: strengthening commodity and supply chains; improving management and local governance of the health sector; improving the use of digital technologies and health information; and creating sustainable solutions for a qualified health workforce.

In addition, the Global Health Bureau's Center for Accelerating Innovation and Impact (CII), led the "Fighting Ebola: A Grand Challenge for Development," which invited innovators from around the world to submit ideas focused on improving the tools used by health workers in the fight against Ebola in West Africa. Launched by President Barack Obama, and in partnership with the White House Office of Science and Technology Policy, the CDC, and the U.S. Department of Defense, this $8.9 million Challenge identified breakthrough innovations that addressed specific barriers faced by those on the frontlines of the Ebola epidemic. From over 1,500 ideas submitted from around the world, USG experts and international partners selected 14 promising innovations, identified for their potential to reinforce the response to the current Ebola outbreak as well as future epidemics. The selected innovations fell into six categories: suits and protective layers, health care worker tools (including **Commcare** and **mHero**) reimagined health care settings, decontaminants, behavior change, and information communication technology.

The U.S. Global Development Lab

The U.S. Global Development Lab (Lab) serves as an innovation hub at USAID. It has a dual mission to produce breakthrough development innovations by sourcing, testing, and scaling proven solutions to reach hundreds of millions of people, and to accelerate the transformation of the development enterprise by opening development to people everywhere with good ideas, promoting new and deepening existing partnerships, bringing data and evidence to bear, and harnessing scientific and technological advances. The Lab supported USAID's Ebola recovery efforts in a variety of ways, including programs designed to expand communications infrastructure, strengthen health information systems, and increase the use of digital tools that support health care workers and leaders in the region. USAID-supported HIS programs have assisted Guinea, Liberia, and Sierra Leone with improved data collection and decision-making, increasing their ability to detect and respond to future health security threats in a data-driven way.

Read more about USAID and Ebola Recovery work at **https://www.usaid.gov/ebola**

GLOSSARY

AAAS: American Association for the Advancement of Science

API: Application Programming Interface

App: Application

BGAN: Broadband Global Area Network

CDC: Centers for Disease Control and Prevention (USA)

CDR: Call-Detail Record

CIF: Case Investigation Form

CLEA: Community-Led Ebola Action (Sierra Leone)

COD: Common Operational Dataset

DERC: District Ebola Response Center (Sierra Leone)

DDCS: Digital Data Collection System

DFID: Department for International Development (UK)

DHIS2: District Health Information Software (Liberia)

DHN: Digital Humanitarian Network

Digital Health: Digital health is the use of any digital technologies to enable better collection and use of data, improved quality and reach of health service delivery, and better decision-making by governments, health workers and individuals. When used in accordance with best practice, such as that embodied in the Principles for Digital Development, digital health can help governments better understand and respond to public health needs, and empower individuals to make better choices to improve quality of life for themselves and their families. Digital health comprises the domains of eHealth and mHealth, and includes the adaptation, use, and support of digital technologies including wireless technologies (e.g., cellular, GPS, wifi, Bluetooth), mobile devices (e.g., mobile phones, tablets, laptops, SIM-enabled devices, "smart" medical devices), sensors and embedded technologies (i.e. the Internet of things), as well as fixed digital devices, equipment, and infrastructure (e.g., desktops, servers, fixed broadband)

DPKO: Department of Peacekeeping Operations (UN)

DPS: Direction Préfectorale de la Santé (Guinea)

DSO: District Surveillance Officer

ECAP: Ebola Community Action Platform (Liberia)

ECOWAS: Economic Community of West African States

EOC: Emergency Operations Center

EpiInfo: Software for public health practitioners and researchers used for disease outbreak investigations and surveillance

ERCI: Ebola Response Connectivity Initiative

ETC: Ebola Treatment Center

ETU: Ebola Treatment Unit

EVD: Ebola Virus Disease

FLY: Federations of Liberian Youth

GBI: Global Broadband and Innovations Alliance

GFDRR: Global Facility for Disaster Reduction and Recovery (World Bank)

GIS: Geographic Information System

GPS: Global Positioning System

GSMA: Global System for Mobile Communications Association

HDX: Humanitarian Data Exchange (UN)

HIS: Health Information System. A national HIS is designed to provide information support at all levels of a health system (e.g., patient, community, facility, district/county, national). It includes population-level data as well as facility and community data, such as service or administrative records about health workers, logistics, and financial records

HMIS: Health Management Information System. An HMIS refers to a subset of the HIS, specifically focused on aggregate service delivery records, such as number of pregnant women receiving antenatal care, malaria cases, etc.

HXL: Humanitarian Exchange Language

ICT: Information and Communications Technology

IDSR: Integrated Disease Surveillance and Response

iHRIS: Integrated Human Resources Information Solutions

IM/GIS: Information Management/Geographic Information System

IMS: incident Management System (Liberia)

IHR: International Health Regulations

IOM: International Organization for Migration

IP: Internet Protocol is a numerical label assigned to each computer device on a network.

ITU: International Telecommunications Union (UN)

KAP: Knowledge, Attitudes, and Practices

Level 3 Emergency: A "Level 3" emergency is the UN classification for the largest and most severe crises, a designation that triggers the deployment of surge staff and dedicated leadership

mHero: Mobile Health Worker Electronic Response and Outreach System

MOH: Ministry of Health

MMS: Multimedia Messaging Service

MMWR: *Morbidity and Mortality Weekly Report* (CDC publication)

MNO: Mobile Network Operator

MSF: Médécins Sans Frontières (also known as Doctors without Borders)

mSTAR: Mobile Solutions Technical Assistance and Research

NERC: National Ebola Response Committee (Sierra Leone)

NGO: Nongovernmental Organization

OCHA: Office for the Coordination of Humanitarian Affairs (UN)

ODK: Open Data Kit

OFDA: Office of U.S. Foreign Disaster Assistance (USAID)

OpenHIE: Open Health Information Exchange

OpenMRS: Open Medical Records System

P-code: A unique geographic identifier code for place names

PHEIC: Public Health Emergency of International Concern

PII: Personally Identifiable Information

PPE: Personal Protective Equipment

PSI: Population Services International (USA)

SDB: Safe and Dignified Burial

Short code: a shortened telephone number used to address Multiple Messaging Service (MMS) and Short Message Service (SMS) messages, for which charges can be reversed

SIM: Subscriber Identity Module

SitReps: Situation Reports

SMAC: Social Mobilization Action Consortium (Sierra Leone)

SMS: Short Message Service

UI: Unique Identifier

UNFPA: United Nations Population Fund (UN)

UNICEF: United Nations Children's Fund (UN)

UNMEER: United Nations Management of Ebola Emergency Response (UN)

URL: Uniform Resource Locator is a reference to an Internet location or website

USAID: United States Agency for International Development (USA)

VHF: Viral Hemorrhagic Fever

VHF/EpiInfo: Viral Hemorrhagic Fever module of EpiInfo

VSAT: Very Small Aperture Terminal

WAHO: West African Health Organization

WASH: Water, Sanitation, and Hygiene

WFP: World Food Program (UN)

WHO: World Health Organization (UN)

Wifi: Any wireless local area network

Photo @ SMAC