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Information-Sharing and Disease Reporting in a New Era of International Frameworks and Communication Technology: Middle East Respiratory Syndrome Coronavirus and Ebola Virus Disease Outbreaks

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1. The Problem

Context

Emerging infectious disease outbreaks amidst accelerating globalization have pressed policy-makers to reinvent the health systems and communication structures developed to protect people and nations during public health events. For over 150 years, nations have negotiated measures to prevent cross-border disease spread. Approaches that endured through the 20th century focused on notification procedures and information-sharing

for a few specific diseases, allowing nations to implement basic control measures at ports and borders.

Countries relied on two basic mechanisms for information-sharing: (1) communication with international organizations, which would in turn facilitate the dissemination of reports to other states and constituents according to the terms of formal agreements, or (2) reporting of information directly to trading partners or near neighbours. Alternatively, countries might choose not to share information at all, gambling that public scrutiny from national or regional press would be unlikely to single out any one source before an event escalated into a multi-focal problem.

The 2003 severe acute respiratory syndrome (SARS) epidemic, in particular, highlighted the risks of the last strategy. The sudden spread of SARS via international air travel emphasized the need to accelerate development of tools for rapid disease detection and reporting, risk communications, and coordinated response on a global scale. The SARS outbreak also occurred on the cusp of a revolution in knowledge sharing: the emergence of novel pathways for individuals to share information locally that can be discovered globally through public search engines and then disseminated (without objective evaluation) by individuals, institutions, and communities of practice or interest, largely independently of governments or international organizations. Since the SARS outbreak, widespread access to information-sharing platforms through increasingly ubiquitous mobile devices has transformed social and business dynamics worldwide. The cohort of relatively defined global mass media platforms has now fragmented into thousands of competing voices, and governments as well as individuals now expect to communicate through informal social networks in addition to more formal channels.

This chapter discusses how the transformation of communications technologies and information culture have affected the sharing of information regarding potential public health events of international concern since the revised International Health Regulations (IHR) entered into force in 2007, and the implications for information-sharing through formal international frameworks. This changing information technology environment is in many ways outstripping formal notification and risk communications processes, which in turn affects the ways in which governments, the international public health community, and the public learn

of and respond to public health events. This chapter examines this changing paradigm through case studies of the Middle East respiratory syndrome coronavirus and Ebola virus disease outbreaks between 2012–2016.

2. Players and their Roles

2.1 Historical Communications

Governments have been negotiating new mechanisms for international public health cooperation and information-sharing on disease events that might disrupt trade since the 19th century. Infectious diseases spread with trade and travel, and as new technologies transformed land and sea transport and key Asian economies opened their markets, people and everyday goods began to move more rapidly among expanded trade networks.[1] In response to devastating outbreaks of cholera and other emerging infections, governments imposed variously effective quarantine and isolation measures to protect their own interests. The need to shield trade and travel while protecting public health inspired the maritime powers to seek standards for interventions and mutual reporting mechanisms, culminating in increasingly comprehensive international agreements.[2]

The "Spanish flu" pandemic of 1918 and the impact of infectious diseases on vulnerable populations during World War II helped escalate demands for more formal policies for information-sharing and effective governance of the collective response to public health events.[3,4] This underpinned the creation of the World Health Organization (WHO) in 1948 as a specialized agency of the United Nations. WHO constitution established the organization's authority to direct and coordinate international health activities under the direction of its policy-making arm, the World Health Assembly (WHA).[5] In 1951, various international agreements from the preceding decades were consolidated into the International Sanitary Regulations (later updated and renamed the International Health Regulations in 1969), which created a single standard for the notification of infectious diseases, a regime that at its most comprehensive addressed six priority diseases of concern: smallpox, relapsing fever, typhus, cholera, plague, and yellow fever.[6] The global health landscape continued to

evolve as the smallpox eradication campaign, changing behaviors, and access to antibiotics, vaccines, and pesticides changed the equation for historically relevant pathogens. When last amended in 1981, the IHR (1969) required states to report on the first local or imported case of cholera, plague, or yellow fever in a non-infected area to WHO within 24 hours by "telegram or telex."[7]

As the public health significance of these diseases to resource-rich states waned, so did the political will to encourage compliance by less-developed nations that had little to gain from information-sharing. At the same time, changing human, animal, and vector interactions, environmental pressures, and increasingly commonplace international trade and travel gave rise to new health risks. By the 1990s, experts had begun to call for more robust and flexible measures for detecting and reporting emerging public health threats. In 1995, the WHA adopted Resolutions WHA 48.13, urging Member States to strengthen national surveillance for emerging and re-emerging infectious diseases, and WHA 48.7, calling on WHO Director-General to begin the process of revising the IHR to support more effective collective responses to emerging disease threats.[8,9] Even given the urgency expressed in these resolutions, WHO and its Member States required another 10 years of expert consultations and inter-governmental negotiations, as well as another emerging infection crisis, to address the technical and political challenges of changing the notification system and overhauling the IHR.[10,11]

2.2 Changes in Global Communication Technologies and Information Platforms

The 1990s witnessed a transformation of communications platforms and technologies, which in many ways called into question the monopoly of governmental and inter-governmental organizations over the sharing of public health information, materials, and resources and also added to the urgency of revising WHO's frameworks related to information-sharing.

The advent and integration of the Internet into daily life affected business, research, education, and entertainment norms. Between 2000 and 2013, the number of Internet users worldwide increased from just under 361 million to over 2.8 billion.[12] Asia alone added more than 1 billion

Internet users in this timeframe, resulting in the vastly increased penetration of 24-hour news cycles and other sources of information to new audiences.[12] The ability to access the Internet via handheld mobile devices has been a key factor in this increased coverage, enabling service providers in countries with limited resources to bypass traditional telecommunications infrastructure and jump directly to developing mobile platforms.

There are almost as many mobile phone subscriptions in existence as there are people worldwide, with coverage even in less economically developed regions high and growing. In Africa, for example, mobile phone penetration is estimated at 67%; throughout the world, smartphones now sell more briskly than non-Internet-capable phones.[13] The rise of social media in the early 21st century has, for the first time, allowed the general public to participate in the deliberate creation and dissemination of news for international consumption. Social network penetration is on track to match that of the Internet, with over 2.3 billion active users of various information-sharing platforms as of January 2016.[13]

2.3 How Communications Advances have Transformed Public Health

From a public health standpoint, these communications advances have enabled access to and dissemination of information about infectious disease outbreaks or events of public health relevance. Electronic information collection platforms integrated into central databases offered new tools to support public health surveillance, with the potential to increase the completeness and timeliness of notifiable disease reporting. At the same time, the growing ability to access and analyze an ever-growing body of information presented a promising new approach to provide early warning of unusual events.[14]

Indeed, WHO quickly recognized the importance of integrating novel sources of data offered by new electronic media into its epidemiological surveillance tools. In 1997, WHO collaborated with Public Health Canada to create the Global Public Health Intelligence Network (GPHIN), which monitored news-feed aggregators and other media sources in real time to identify reports of possible disease outbreaks worldwide.[15] However, the framework that would allow WHO to use these data in alerting countries

to possible public health emergencies of potential international concern (PHEIC) or to act on the information to investigate suspected events, lagged behind.

In the past 10 years, technological advances have facilitated the increasing trend towards decentralization of public health data, with private companies, local interest groups, and even individuals now able to access and share information which previously had been almost exclusively managed by national and international public health agencies. Accuracy, and particularly data validation, is a critical issue with respect to informal data collection and dissemination technologies; while the concept of collating, analyzing, and sharing information relevant to public health from traditional and non-traditional sources is straightforward, crowd-generated queries and information can be notoriously unreliable. This has implications for the inclusion of publicly generated information in syndromic surveillance and in rumor monitoring for event-based surveillance. Nevertheless, research has indicated that reasonably high levels of sensitivity can be obtained through Internet search algorithms for collecting information on outbreaks and other public health events, particularly if the algorithms contain certain self-validation processes, augmented by internal data checking.[16]

Such information may have enormous public health value: in 2009, Google demonstrated as a proof of concept that Internet queries might provide early warning of influenza outbreaks at the national and state level,[17] even if significant questions remain about how such data can be used as an adjunct to local disease surveillance data.[18] Further, projects and voluntary programs such as ProMED-mail[19] and HealthMap,[20] both of which routinely scan "crowd-sourced" informal media and Internet sources for public health information, provide data that is at least partially validated through expert review.

However beneficial, this proliferation of media sources not only strains the ability of national and international health authorities to monitor reports of potential public health risks on new media and communications platforms without algorithms and tools, but also limits the options for controlling the accuracy of circulating information regarding such risks. In the "echo chamber" of the online media cycle, referencing of individual research published on blogs and websites, and even excerpts of

mainstream research reports taken out of context, can result in the widespread dissemination of misinformation that appears authoritative.

There are a number of conspicuous examples of public health issues that have suffered from the mingling of speculation and fragmented hypotheses and observations via the Internet and social media. The anti-vaccine lobby is a prominent and powerful example of how biased or selective data repetition can foster alarmism, influencing public opinions to conclusions that can be extremely difficult to overcome or realign through traditional risk communications strategies.[21]

3. Challenges Faced and Outcomes

3.1 An impetus for Change: SARS

Beyond the new technological developments that revolutionized information-sharing, it was in fact an infectious disease event that proved critical for shaping how emerging technologies, and particularly data gathering, would be integrated into WHO's new framework for coordinated information-sharing with Member States related to public health emergencies.

SARS first emerged in November 2002, when rumors suggested an epidemic of atypical pneumonia in China's Guangdong Province. Although closely investigated and well communicated within the Chinese health system,[22] China failed to disclose the emergence of the disease that would become known as severe acute respiratory syndrome to the international community until March 2003, when a physician who had treated infected patients in Guangdong Province developed symptoms himself while visiting Hong Kong. He infected at least 13 guests and visitors to the hotel where he stayed, eventually seeding disease clusters in healthcare workers, patients, and their close contacts in Hong Kong, Vietnam, Singapore, and Canada. SARS ultimately spread to about 25 countries, largely via air travel, before public health interventions interrupted the outbreak — which caused about 8,000 cases, almost 800 deaths, and economic losses estimated at US$30–50 billion.[23,24]

WHO's then-Director-General Gro Harlem Brundtland delved into the unfinished toolkit for global health governance, issuing advisories about SARS-affected regions and coordinating international efforts to

understand and contain the outbreak. Because SARS was not a notifiable disease under the IHR (1969), China had no legal obligation to report cases to WHO, and WHO had no legal authority to request or require information from China in response to unofficial reports. Informal sources had begun to report on the emergence of a strange new disease via text messaging, websites, and local media as early as February 2003.[22] However, based on the contemporary WHO regulations, WHO could not act without formal notification from the Chinese government. These facts, particularly in the face of international indignation related to the slow pace of information outflow during the SARS outbreak, helped reinvigorate the IHR revision process,[25] and led to a broader discussion of how international public health activities could and should incorporate new information platforms into their communications networks.

3.2 IHR (2005): A New Framework for Information-Sharing

After many years of negotiation and discussion, many of the concerns about transparent information-sharing were finally formalized through the adoption of the revised IHR in May 2005 by the 58th WHA.[26] When the revised IHR (2005) entered into force in June 2007, the international community was still attempting to address gaps detected during and after the SARS crisis. For this reason, the IHR (2005) mandate transparent and timely reporting of public health emergencies *and* require countries to develop and maintain the capacities to detect, assess, report, and respond to such events. The revised IHR emphasize the containment of public health threats when and where they occur rather than solely at borders, conferring new obligations on countries to strengthen their core capacities to detect and respond to health crises and on WHO to coordinate collective responses to public health emergencies. Rather than a fixed list of diseases, the revised IHR contain an algorithm (the Annex 2 decision instrument) to guide national health authorities through a contextual risk assessment of events. The success of this more flexible approach depends on national and sub-national capacities for disease detection, assessment, reporting, and response — capacities that are very uneven worldwide.[26]

In practice, the IHR (2005) constitute a framework for information-sharing among national stakeholders and with the international

community. The IHR (2005) mandate that each Member State appoint a National IHR Focal Point (NFP) to be accessible at all times (24 hours a day, 7 days each week), not only as the point of contact during health crises but for all information-sharing regarding IHR (2005) implementation. The NFP provides a channel for open dialogue on public health risks and capacities among Member States, and fosters a sense of accountability to national decision-makers as well as to WHO.[26]

The communication channel for information sharing established by the IHR (2005) is deliberately designed to be two-way: NFPs are required to report events to WHO, but WHO is also legally allowed to ask for information from countries, via the NFP, if there is concern related to an emerging public health threat. Article 6 of the IHR (2005) calls on States Parties to notify WHO "by the most efficient means of communication available, by way of the National IHR Focal Point, and within 24 hours" of determining that an event might constitute a PHEIC using the Annex 2 decision instrument, and to continue sharing relevant public health information on the impact and/or response to the unfolding event.[26] States Parties can also consult with WHO on public health events that do not meet the threshold for notification, particularly when information is inadequate for a full risk assessment (Article 8).[26]

Article 9 of the revised IHR also granted WHO new authorities to utilize data gathered from two previously off-limits sources: reports from national officials about public health risks *outside* of their own territories, and reports from unofficial sources (e.g., non-governmental organizations, traditional media, or Internet-based information networks) after seeking verification from and collaboration with the affected State Party. Article 11 calls on WHO to share information collected from these official and unofficial sources with States Parties and appropriate inter-governmental organizations "as soon as possible and by the most efficient means available, in confidence" in the following scenarios: (1) an event has been determined to constitute a PHEIC; (2) an event has demonstrably already spread internationally (per WHO evaluation); (3) the affected State Party appears unlikely to prevent international spread either because of the characteristics of the disease itself or the affected State Party is unable to carry out effective control measures; or (4) "the nature and scope" of international trade and travel involved in the event requires an international response.[26] Article 11 also allows WHO to share information

subsequently with the public "if other information about the same event has already become publicly available and there is a need for the dissemination of authoritative and independent information."[26] These authorities, and the delicacy of seeking the cooperation of States Parties, affects the process by which WHO detects, investigates, and finally declares a PHEIC.[26]

3.3 To Declare or not to Declare: Public Health Emergencies of International Concern (PHEIC)

According to the IHR (2005), a PHEIC is defined as "an extraordinary event which is determined, as provided in these Regulations: (i) to constitute a public health risk to other States through the international spread of disease; and (ii) to potentially require a coordinated international response."[26] The purpose of such a declaration is not just to alert the world to an unfolding event of public health importance such that nations can strengthen their own preparedness, but also to marshal resources and initiate a coordinated global response.

According to the articles described above, WHO can now seek information on unfolding public health events rather than passively awaiting official notification from a sovereign state. WHO can also request that national officials verify such reports within 24 hours — if a government refuses to cooperate despite evidence that an event may constitute a PHEIC, WHO can share even unofficial information with other States Parties as necessary to coordinate an effective international response. To encourage the flow of information *and* protect against immoderate reactions, WHO protects the confidentiality of information for countries that willingly report potential PHEICs unless it is necessary to disclose "for the purposes of assessing and managing a public health risk."[26]

Although WHO must consult with the relevant government(s), the Director-General determines whether an event constitutes a PHEIC based on all available information, including the advice of an "Emergency Committee" of subject matter experts that he/she can convene in response to the crisis. The Emergency Committee can also provide guidance on appropriate, evidence-based national responses. The Director-General issues such guidance as "temporary recommendations" that automatically expire after three months unless extended, modified, or terminated

earlier.[26] From its conception in 2007 until June 2016, WHO had only declared four PHEICs: the 2009 H1N1 influenza pandemic,[27] the resurgence of wild poliovirus in early 2014,[28] the West Africa outbreak of Ebola virus disease (EVD) in 2014, and the clusters of microcephaly and neurological disease, associated with the Zika virus outbreak in the Western Hemisphere, declared in February 2016.[29]

Despite these deliberative steps for declaration, the process has not been without controversy. The 2009 H1N1 influenza pandemic resulted in fewer severe illnesses and deaths than anticipated in most planning scenarios. As a result, critics accused WHO of exaggerating the importance of the outbreak by declaring a PHEIC.[30,31] The polio PHEIC could also be considered an untraditional use of the declaration, as the declaration itself was not in response to a massive re-emergence of the disease, but instead to rally political support in targeted states to take appropriate control actions. Conversely, WHO also drew criticism for the weeks-long delay between international recognition of the severity of the EVD outbreak in West Africa by June 2014 and the declaration of a PHEIC in August 2014. Some observers have suggested that WHO's justification for rapidly declaring clusters of microcephaly and Guillain-Barré syndrome a PHEIC, despite the paucity of credible scientific evidence available at the time, represented an attempt to counter criticism for the sluggish response to Ebola through aggressive preemptive action.[32,33] Of equal significance is when the Director-General does not declare a PHEIC; although the outbreak of Middle East respiratory syndrome coronavirus (MERS-CoV), which commenced in 2012, has continued to claim lives periodically with numerous exported cases, WHO Director-General has not declared MERS a PHEIC (as of June 2016).

How WHO chooses to raise awareness and international support by either declaring or not declaring a PHEIC is proving to be a fluid process. The actions (or inactions) of other stakeholders and international bodies, either with or without the support of WHO, also has an important impact on how a public health event unfolds. The flow of information among governments, the public, donors, and WHO has fluctuated, not necessarily progressively, throughout public health events in the last decade.

Given the copious amounts of data available through informal channels in addition to the formal notification process under IHR (2005), questions

remain about how best to utilize information streams to support effective and timely international responses to public health events — and how these parallel paths might influence global health diplomacy in practice. The following two sections examine the cases of MERS and the initial stages of the West Africa EVD outbreak in closer detail, particularly looking at the notification process and the timelines for formal and informal reporting of emerging health events.

3.4 Middle East Respiratory Syndrome — How to Share Information, and How Much?

MERS, a viral respiratory illness caused by the MERS coronavirus (MERS-CoV), was first identified from samples collected in the Kingdom of Saudi Arabia (KSA) in 2012.[34] As of 2016, cases and clusters of nosocomial or familial transmission have been confirmed in countries across the Middle East (Iran, Jordan, Kuwait, Lebanon, Oman, Qatar, KSA, United Arab Emirates, Bahrain and Yemen), Africa (Algeria, Egypt, and Tunisia), Europe (Austria, France, Germany, Greece, Italy, the Netherlands, Turkey, and the United Kingdom), Asia (Malaysia, South Korea, China Thailand and the Philippines), and North America (the United States).[35] As of 1st June 2016, WHO reported a cumulative 1,733 laboratory-confirmed cases of MERS-CoV infection (of which 1,383 occurred in KSA), including 628 deaths.[36,37]

MERS appeared immediately as a serious public health threat due to its high case fatality rate and lack of initial understanding about virus transmission and reservoirs. The KSA initially reported sporadically on cases of MERS, relying primarily on informal reporting channels with regional partners and modes such as press releases, rather than reporting directly to WHO in accordance with the IHR. While the first case was detected in mid-2012, the disease was not reported to WHO until September that year when another case was diagnosed in the United Kingdom and compared with a sample sent by the KSA to the Netherlands, where a laboratory collaboration had identified the etiological agent as a novel coronavirus several months previously.[38] From September 2012, WHO began to monitor the situation and developed a working case definition for Member States.

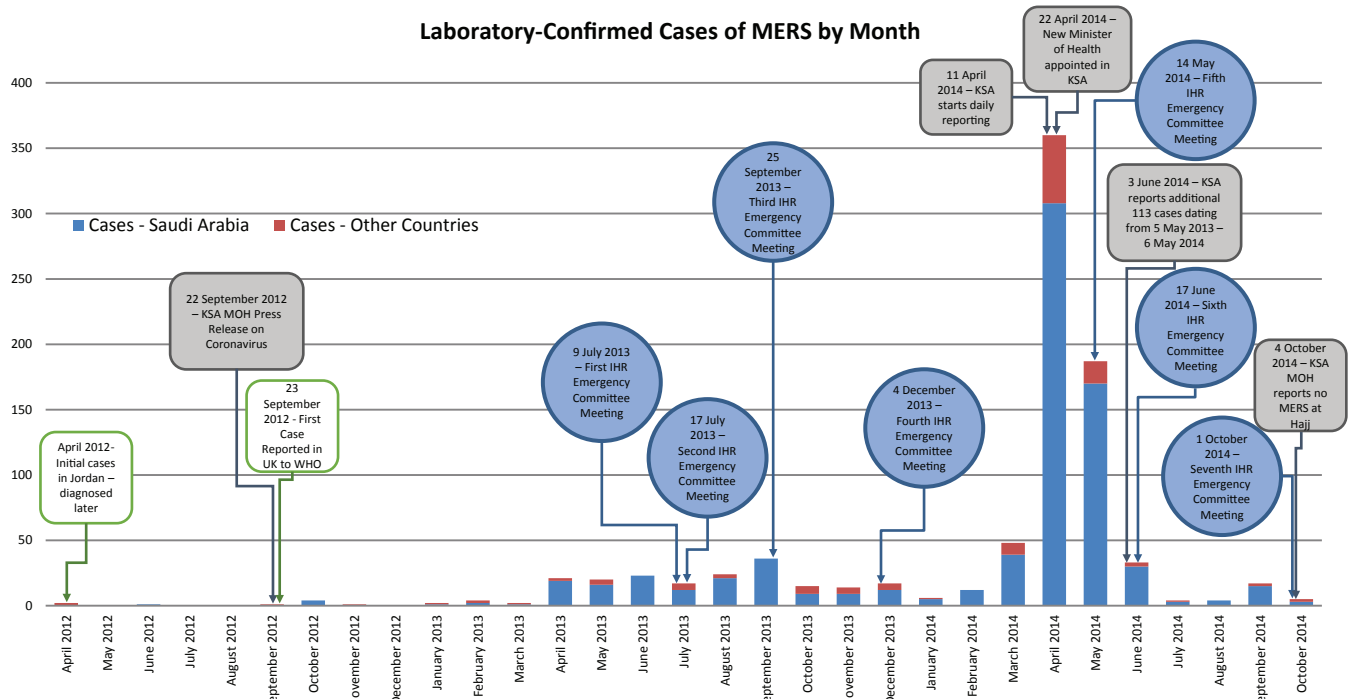

Figure 6.1.

Note: Includes all cases reported in WHO Disease Outbreak News as of 31st October 2014. In some cases, month of symptom onset is approximate as detailed information was not consistently available.

Sources: WHO; Kingdom of Saudi Arabia Ministry of Health.

In May 2013, the KSA requested a WHO joint mission to assess the current situation and provide recommendations on the response to MERS.[39] As cases climbed steadily throughout 2013, the KSA consistently reported cases and developed a "Command and Control" center on the national Ministry of Health website that gave information on prevention and confirmed outbreaks. In July 2013, WHO convened two Emergency Committee meetings on MERS with representation from the KSA as well as subject matter experts (9th and 17th July). At the second meeting, Emergency Committee members agreed that the conditions for a PHEIC had not yet been met; WHO Director-General accepted this recommendation. However, the experts provided technical advice on a number of areas related to further efforts that would be needed to investigate and control the outbreak, including additional research into transmission and other epidemiological studies.

In early June 2014, Saudi officials suddenly reported an additional 113 cases, including 92 deaths, tacitly confirming a previous underreporting of 20% that abruptly updated total cases from 575 to 688.[40] This lapse in reporting was blamed on poor communication, inefficiencies in surveillance and case identification by laboratories and hospitals up to the Ministry level, and ultimately contributed to leadership changes within the Ministry of Health (including dismissal of the health minister and his deputy in April). The KSA Ministry of Health continues to report additional historical cases and share this data with WHO; a retrospective analysis, in September 2014, included a case-by-case review to better understand how to capture patient data in a more timely and complete way. This study has also increased efforts to communicate to healthcare workers the requirement for quick and accurate reporting of case information. As of June 2016, the Control & Command Center within KSA's Ministry of Health continues to provide daily updates on MERS, including negative (zero case) reporting, and has made statistics on case numbers, deaths, and transmission chains available on a public website.

Current understanding assumes that the current pattern of disease results from repeated introductions of the virus from camels to people, resulting in limited human-to-human transmission through close contact, but rarely in sustained transmission. The persistence of risk factors makes it likely that cases resulting from zoonotic transmission will continue to

occur in the Middle East, leading to limited community transmission and possibly significant healthcare-associated infections, and with a significant likelihood of export to other countries by tourists, travellers, guest workers, or pilgrims. The was highlighted in May 2015, when a 68-year old South Korean man returned home from a business trip in the Middle East. He developed symptoms about a week after his return, visiting several health facilities prior to being admitted to a large tertiary care hospital. In the process, he transmitted the virus to other patients, healthcare workers (HCW), and hospital visitors. Nine days after he initially sought medical care, he was diagnosed with MERS. Several of those who contracted MERS-CoV from this patient subsequently transmitted the virus to dozens of contacts. Overall, 186 cases were confirmed, of which 36 died.[35]

As of June 2016, WHO Director-General had convened 10 additional meetings of the IHR Emergency Committee. Throughout, WHO has indicated that it is closely monitoring the situation as there are global cases of MERS, but the Director-General has refrained from declaring the situation a PHEIC. WHO initially cited several factors, including falling case rates through 2014, as evidence that efforts to reduce international spread had proved effective without a formal declaration. The 2015 experience in South Korea, together with new cases reported in KSA, Jordan and UAE around the time of the 2015 Hajj, promoted WHO's Emergency Committee at the time of its tenth meeting to acknowledge heightened concern regarding MERS. In particular, the Emergency Committee cited insufficient awareness about the dangers posed by the virus, insufficient engagement by the all relevant sectors, and insufficient implementation of scalable infection control measures as key factors coontributing to the overall situation. The Emergency Committee also emphasized the importance of timely sharing of information, noting to date such information sharing, particularly of viral surveillance and research data from affected countries, had remained limited. However, the Emergency Committee maintained that the situation did not warrant declaration of a PHEIC.[41]

After relying on periodic public announcements and other informal communications to report MERS cases at the outset of the epidemic, the KSA's health authorities shifted over a two-year period to more regular updates to WHO and the public. Whether MERS would have been declared a PHEIC if the KSA had initially used formal reporting of cases to WHO as its

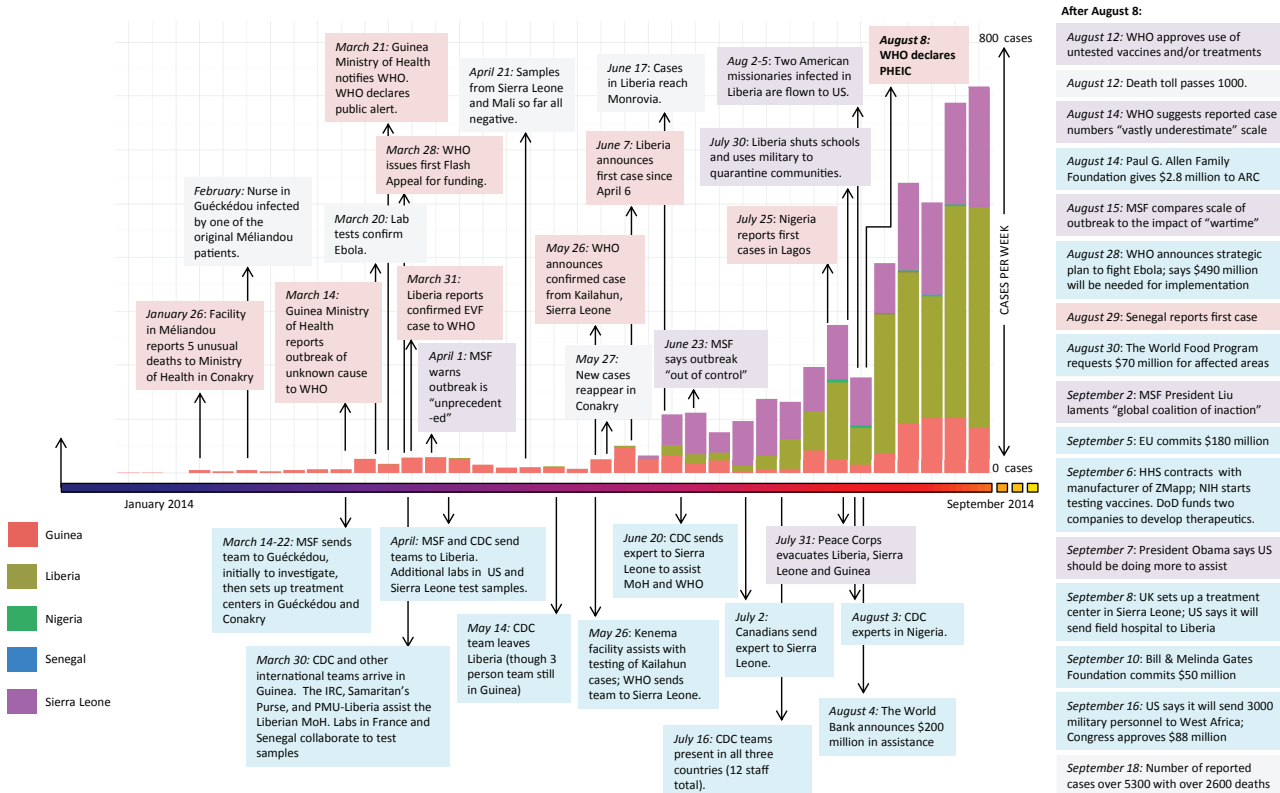

Figure 6.2. Ebola Outbreak in West Africa: Timeline of Events.

primary avenue of information-sharing on cases, rather than announcing cases through public but unstructured channels, can be a matter only for speculation. However, the use of informal disease reporting unquestionably changed the dynamic for risk communications regarding the MERS outbreak, and may have influenced the decisions of WHO Director-General and advisors in making the determination of an international emergency. Moreover, if the international community had needed to play a role in the coordination of response, particularly if the outbreak intensified, the lack of official reporting might have reduced WHO's ability to call for outside donor and non-governmental organization (NGO) support. In this case, questions remain about whether public disclosure of an unfolding disease event through formal and informal media supersedes obligations for formal notification to WHO — functionally, if not officially.

3.5 West Africa Ebola Virus Disease — Information-Sharing for International Response

As of June 2016, the outbreak of EVD in West Africa had caused more than 28,000 confirmed, probable and suspected cases and over 11,000 deaths. The epidemic spread through Guinea, Liberia, and Sierra Leone in the spring of 2014 and by the fall of 2014 involved widespread local transmission throughout nearly all districts of the three countries, including densely populated urban areas.[42] Beyond the weaknesses of the health systems in all three countries which impaired efforts to interrupt community transmissions and contain the outbreak, a key factor in the outbreak's emergence and spread was the tragic delay in detection and reporting of the initial cases.

Reports suggest that the index case for the outbreak was a two-year old boy from Méliandou, in Guéckédou prefecture of Guinea, who died from the disease on 28th December 2013. Several members of his family were also infected and subsequently set off multiple chains of transmission that created the wider outbreak.[43] At the end of January 2014, a doctor alerted the prefectural health authorities about a series of unusual patient deaths in the area. From Guéckédou, the message was duly passed up the chain to the Ministry of Health in Conakry early in February,[44] but almost two months passed before the cause of disease was accurately identified as

Ebola virus. In mid-March, the Guinean Ministry of Health formally reported the unusual outbreak to WHO; two teams, one of which included staff from Médecins Sans Frontières (MSF), an international medical and humanitarian aid group, set out within a few days to investigate the cases. A MSF doctor in Brussels, upon reading the case reports from this field expedition, was the first to suspect that it was EVD. Samples were sent to two European high containment laboratories, which confirmed the presence of Ebola virus;[43] Guinea's NFP subsequently reported the findings to WHO on 21st March 2014 through official channels, and WHO issued a public alert the next day.[45]

The investigation and reporting chains operated relatively efficiently once Guinean health officials notified WHO of the outbreak, and likewise as soon as laboratory confirmation of Ebola virus was made. However, the failure of the public health system in Guinea to detect the outbreak promptly, and moreover to recognize it as an unusual event that warranted immediate reporting, created delays that cost lives and allowed the outbreak to spread across borders. Gaps in disease surveillance (compounded by the remote location of the outbreak) meant that few outside of the prefecture or central health offices in Conakry were aware of the outbreak before official statements were released by the Guinean Ministry of Health.

In contrast to SARS, neither the international news media nor social media significantly pre-empted official announcements related to the disease, including WHO's public alert on 22nd March. Indeed, the first signs of the outbreak reported in the international media stem from approximately 14th March, when an official from the Guinean Ministry of Health spoke to state media about an outbreak of an unknown disease, which had the hallmarks of a viral hemorrhagic fever but which was suspected to be Lassa fever virus (a disease endemic to the Mano River region).[46] Further news reports began to circulate between 19th and 20th March, when the same Ministry of Health official made a subsequent statement related to the outbreak, and for the first time mentioned the suspicion that Ebola virus could be the causative agent; the statement also noted that samples had been sent to France and Senegal for confirmatory testing.[47] By the time of WHO announcement on 22nd March, many news outlets had picked up the story, with particular emphasis placed on the novelty of an EVD outbreak in West, rather than Central, Africa. The United States

Centers for Disease Control and Prevention's (CDC) first report on the outbreak dates from 25th March.[48]

Despite the delays in initial notification of the outbreak, the course of information-sharing within Guinea and notification to WHO followed traditional reporting channels as outlined in the IHR. In contrast, as the outbreak began to spread and overwhelm Guinea's already-fragile health system, the magnitude of the outbreak and the need to mobilize international support was publicized to the media primarily from sources on the ground, notably humanitarian NGOs such as MSF, rather than WHO. Even when formal IHR notification procedures are carried out for initial information gathering and reporting of a disease outbreak, these channels can be later superseded by informal reporting, particularly related to appealing for and coordination of international response efforts.

MSF deployed resources for the emergency outbreak response immediately upon the confirmation of EVD on 22nd March (founded on a team that had already been working in Guinea to deal with a large malaria outbreak). From this point, MSF highlighted key developments in the EVD response through press releases on its website (which serves as a tool for advocacy and resource mobilization in addition to information-sharing).[49] By 1st April, MSF publications characterized the outbreak as "unprecedented," noting in particular the challenges associated with its already wide geographical spread within Guinea, and had mobilized large numbers of staff and equipment.[50]

Despite MSF's public warnings, WHO's Director-General did not initiate the process of determining whether the event constituted a PHEIC under the IHR (2005) during the early stages of the outbreak. Instead, recognizing that international donor support would be needed to support response efforts and repeat actions undertaken during an outbreak of wildtype poliovirus earlier in 2014, WHO declared a "Flash Appeal" on 28th March for funds and assistance from international donors to tackle the burgeoning EVD crisis. This appeal was largely ignored by the international community, including some of the agencies that typically are at the forefront of medical response and outbreak control efforts. For example, the CDC often assists other nations in both the laboratory and epidemiological investigation aspects of outbreak response, particularly involving especially dangerous pathogens. When a single suspected case

of Marburg virus, a hemorrhagic fever virus closely related to Ebola virus, was reported in Uganda in July 2007, CDC sent a six-person multidisciplinary team of health, veterinary, and laboratory experts to Uganda to investigate. On 22nd June 2014, MSF — the only aid organization treating EVD patients in West Africa at that time — described the EVD outbreak as "out of control," with more than one hundred new cases per week.[51,52] In stark contrast to the 2007 Marburg scenario, by July 2014 CDC had a mere 12 staff members on the ground, spread between Guinea, Liberia, and a single expert in Sierra Leone.

International assistance in the period from March to August 2014 primarily consisted of in-kind provision of expertise and support with laboratory testing of suspected cases. In a rare example of a cash commitment during this period, the World Bank declared at the beginning of August that it was prepared to make up to US$200 million available to the affected countries; by this point in time, the clamor for WHO and the international community to "do more" had grown to a crescendo within the international media.

WHO finally declared a PHEIC on 8th August 2014, but as the global media had already been widely reporting on the severity of the outbreak, WHO was criticized for the late announcement. WHO officials defended the decision to delay the declaration. Dr. Keiji Fukuda, WHO Assistant Director-General for Health Security, noted that while sufficient evidence might have been available for an earlier decision, "we're always having to balance, because if you're perceived as crying wolf it doesn't help."[53] In March 2015, WHO Director General commissioned an independent expert panel to review WHO's actions; the report, released in July 2015, criticized organizational shortcomings in WHO, but also acknowledged other challenges that contributed to the delayed and underwhelming international response. WHO Secretariat welcomed the findings and committed to addressing the recommendations.[54,55]

Despite the pressure for WHO to declare a PHEIC, the declaration itself did not actually result in a surge of donor support or international assistance. Part of the delay was due to donor insistence on a coordinated plan for contributions, and it took WHO until the end of August to develop a "response road map" outlining a coordinated plan for outbreak response,

with an estimated price tag of almost US$500 million. Donors began to make large-scale commitments over several weeks following publication of the roadmap. The United Nations, during the Security Council's first emergency meeting related to a public health threat, took leadership for coordinating the response effort on the ground by deploying the United Nations Mission for Ebola Emergency Response (UNMEER) on 18th September 2014, concurrently releasing an itemized response plan and appeal for funding from donors to contribute to the coordinated effort.[56]

The initial contributions after publication of WHO's roadmap consisted primarily of smaller-scale donations from foundations,[57] wealthy individuals,[58] and additional in-kind support from public health agencies. Ironically, some of this support was likely in response to other events related to the outbreak, such as the identification of suspected cases of Ebola virus in Nigeria in late July and the two American missionaries who were medically evacuated to the United States after contracting EVD in Liberia (an event which was extensively publicized in United States media), and was not at all related to WHO's declaration of a PHEIC or the subsequent roadmap. In addition, on 15th August, the President of MSF International, Dr. Joanne Liu, made an impassioned statement for assistance, deploring the inadequate response to date.[59] Other MSF officials similarly made public statements, highlighting the irresponsibility and lack of compassion of the international community for not doing more to assist.[60] The media picked up this narrative, often in concert with MSF, emphasizing the lack of international leadership.[61]

An important point to note in the above scenario is that the NGO community, rather than WHO, became the face of the outbreak. By the time of WHO Director-General's declaration of a PHEIC, media attention had already been raised, and the declaration precipitated careful rather than immediate declarations of donor support for the EVD outbreak response effort. Weeks lapsed between the declaration and publication of WHO's roadmap on EVD outbreak response, which provided increased clarity on the request to external donors and offered insights on how such support would be coordinated to avoid duplication of effort and make the most of resources. Despite ample criticism of its delayed performance, WHO was not completely eclipsed in providing

international leadership related to the response effort. The international NGO community could advocate for more resources for outbreak response, but each organization could speak authoritatively only to the projected needs of its own programs and activities. Unlike States Parties, which under the IHR (2005) must appoint the NFP to serve as the direct point of contact to WHO, the NGO and donor community has no such network of clearly defined points of contact for communication during public health events — although NGOs can submit informal reports to WHO, the reciprocal connection is conspicuously missing. Questions remain about whether more effective information-sharing among WHO, MSF, and the wider donor community during the early stages of the outbreak (and, in parallel, an earlier PHEIC declaration) might have catalyzed more timely and robust donor support, and a more coordinated response that might have controlled the epidemic before it spread throughout Liberia, Guinea, and Sierra Leone — and with travellers and infected health workers to the United States and Europe.

4. Lessons Learned

The last decade of emerging infectious disease outbreaks has demonstrated the importance of formalized communication frameworks between governments and WHO, as well as the significance of empowering international organizations to utilize new communications technologies and platforms as effectively as possible. These new approaches to information-sharing can allow rapid identification of emerging public health events and prompt sharing of data for action, while channelling information through formal reporting mechanisms can help confirm the accuracy and legitimacy of disseminated information. Public access to information also burdens international organizations with responsibilities to balance the need to maintain confidentiality of information shared by governments in good faith for collaborative risk assessment with demands for transparency, against a backdrop of many competing voices from verified sources to informal channels. National and international public health authorities continue to develop new approaches and risk communication strategies to tackle health information and misinformation that spread through new media platforms like wildfire.

The examples of MERS and EVD in West Africa highlight challenges to the current paradigm, particularly with respect to the mechanisms for declaring a PHEIC and the outcomes of such a declaration. The revised IHR allow WHO to capture information from reports other than formal notifications and consultations, a mechanism designed to give WHO additional leverage when a State Party lacks either the will or the capacities to detect, assess, report, and respond promptly to a potential public health emergency of international concern. Only a decade ago, stakeholders revising the IHR could not have foreseen how quickly information technologies and services would conversely allow not only institutions but individuals to bypass WHO's own monopoly on information dissemination.

This has implications for perceptions and uses of the PHEIC declaration process. When faced with an event that appears on the surface to meet all definitions of a public health emergency of international concern, but which has already been publicized widely (spurring actions at the national level), is the power of WHO Director-General to declare a PHEIC still relevant? The diverse use of the PHEIC declaration and the collective global responses — concerns over definitions of severity versus geographic spread with pandemic H1N1 influenza A, whether "emergency" invocations should apply to the polio endgame, if it was the right time to make a declaration for the spread of Zika virus in the Western Hemisphere, even without conclusive evidence of the impact continued meetings without a formal declaration for MERS-CoV, and a patently slow acknowledgment of the EVD crisis in West Africa — give no clear insights into the best pattern for using WHO's governance tools in an era of instant information for all, a challenge that will only grow more acute with the development of "big data" troves and tools.

5. Conclusion

As the revised IHR recognized the availability and desirability of collecting information from unofficial sources, WHO's guidance going forward must recognize the roles of non-governmental actors — ranging from direct service providers to major donors — and find ways to share confidential information with these stakeholders in a way that allows for timely action. Increasing WHO's ability to communicate and inform the

world of impending events has the potential to speed up the process by which nations respond, individually and collectively, to public health emergencies and, perhaps even more importantly, to reaffirm WHO's role as the international leader in public health issues.

6. Contributors' Biographies

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