GEORGETOWN UNIVERSITY
Georgetown University Medical Center
Center for Global Health Science and Security

MERS-CoV Data Sharing Case Study Report

November 2018

1. Introduction

a. Background to the ongoing MERS-CoV outbreak:

In September 2012, Dr Ali Mohamed Zaki reported the isolation of a novel betacoronavirus on ProMED-mail, the internet infectious disease alert system run by the International Society for Infectious Diseases.[1] The patient, a 60-year-old male from Saudi Arabia presenting with pneumonia-like symptoms died from an unknown viral infection in June 2012.[2] Later dubbed the Middle East Respiratory Syndrome Coronavirus (MERS-CoV),[3] this emerging infectious disease has now been responsible for more than 2,200 laboratory-confirmed infections in people from 27 countries, and close to 800 deaths.[4] The vast majority of these cases have been recorded in Saudi Arabia, however MERS-CoV is considered a severe emerging disease with the potential to cause a major global health emergency.[5]

Epidemiological investigations have revealed that primary human infections with MERS-CoV are often, but not always associated with contact with dromedary camels around the Arabian Peninsula.[6] Human-to-human transmission of MERS-CoV has been responsible for case clusters in family groups and healthcare facilities. The incidence of hospital-acquired infections have been reduced with the employment of strict infection control measures,[7] and the international public health community remain on high alert for new introductions. In 2015, South Korea saw the largest outbreak of MERS-CoV outside of the Eastern Mediterranean with 186 confirmed cases and 38 deaths.[7] New cases of MERS-CoV infection continue to be reported mostly from the Eastern Mediterranean. With a case fatality rate of around 35%,[4] and no specific treatments or vaccines, MERS-CoV remains a global research and development priority.[5]

There is much that remains unknown about MERS-CoV. More than five years after the initial clusters were reported, scientists still do not know the evolutionary origins of the virus or the exact route of transmission. There are no licensed vaccines or MERS-specific treatments on the market.[8] Dromedary camels appear to be the "most likely source of animal-to-human transmission",[9] although their exact role in the transmission cycle is still unclear. Questions remain as to why there are high levels of seropositive (i.e. virus-exposed) dromedary camels in Africa, but as yet no evidence of locally acquired human infections in these regions.[10] Additionally, the role of asymptomatic patients in human-to-human transmission events is still ambiguous.[6] Given the major knowledge gaps associated with MERS-CoV, global collaboration and data sharing continue to be vital to understanding and controlling this novel infectious disease.

b. Data-sharing during the MERS-CoV outbreak:

Issues related to data-sharing have been cited as one of the main obstacles in responding to the ongoing MERS-CoV situation.[11–13] The collaborative research response that was a hallmark of the Severe Acute Respiratory Syndrome (SARS) coronavirus epidemic in 2003 was not seen in the response to MERS.[14] Investigations into the initial MERS outbreak in Saudi Arabia were said to be "marked by bitter disagreements between public health authorities and scientists about the virus' discovery and the ensuing publications, processes, and patenting of products".[15] In their statement regarding the tenth meeting of the International Health Regulations (IHR) Emergency Committee regarding MERS in September 2015, the WHO reported that "[t]imely sharing of detailed information of public health importance, including from research studies conducted in the affected countries, and virological surveillance, remains limited and has fallen short of expectations."[16] The perceived inadequacies of

Saudi Arabia's data sharing practices resulted in additional pressure on South Korea during their 2015 outbreak to assist in addressing the extensive MERS-CoV knowledge gaps.[17] MERS-related data sharing became a fraught geopolitical and international relations issue.

As an emerging pathogen first discovered less than a decade ago, the outbreak of MERS-CoV is an insightful case study for contemporaneous data sharing practices during public health emergencies. The research response in the early days of the outbreak involved the isolation and identification of the novel coronavirus, epidemiological investigations and the development of diagnostics. Later stages of the research response are ongoing and involve investigations into viral pathogenesis, the animal reservoir species, transmission dynamics, the efficacy of known antiviral drugs against MERS-CoV and the development and testing of vaccines. An effective outbreak and research response requires the sharing of many types of data, ranging from surveillance and epidemiological information, risk assessments, healthcare facility and emergency management information, observational and experimental studies, clinical trials, viral genomic data and anthropological insights. Garnering insights into the data sharing practices relating to the research response to MERS-CoV therefore necessitates engaging a wide range of stakeholders, including clinicians, infectious disease specialists, public health authorities, government officials, data scientists, and vaccine developers. Furthermore, journalists, science reporters and even science bloggers form a vital information conduit between specialists and the concerned public. Engagement with diverse stakeholders provides the broadest possible picture of formal and informal data sharing practices through bilateral and multilateral arrangements, between actors at local, national and international levels.

The data sharing practices associated with the MERS-CoV research response was plagued by many of the same problems encountered during other public health emergencies. There were problems associated with ill-defined norms around data sharing, uncertainty about which parties were responsible for sharing certain data and who should bear the associated costs of data curation and maintenance, intellectual property considerations of commercial parties, pressure to publish in scientific journals before data was released to the public, technical barriers associated with appropriately disseminating and securing the data, as well as concerns about data reliability and suitability. There were also data and information sharing issues that were specific to the outbreak and research response to MERS-CoV precisely because it is a newly emerging pathogen. For instance, there were disputes between parties trying to exercise competing legal rights over the MERS virus and controlling access to virus samples, and there were cultural factors that impacted how data were collected and disseminated. An exploration of the data sharing issues that were unique to the MERS-CoV outbreak and research response may be helpful in shaping effective data sharing practices in future outbreaks of emerging infectious diseases.

c. Background to this Report:

This report was commissioned by the Wellcome Trust and the UK's Department for International Development to analyse the data sharing practices of multiple stakeholders during the ongoing response to the MERS-CoV outbreak. This case study of data sharing during a public health emergency caused by an emerging pathogen without a licensed intervention will be used to better understand the barriers and enablers to data sharing and how these inform the research response to such outbreaks.

The report team conducted 14 semi-structured interviews ranging in duration from 39 to 76 minutes. The average interview length was 57 minutes. Interviewees were identified from media coverage of the MERS-CoV outbreak and applicable scientific literature. Additional interviewees were identified during the interview process. Interviewees were from the United States of America, South Korea,

China, the Netherlands, Switzerland, Canada, United Kingdom and Australia, representing a range of stakeholders including clinicians, public health officials, virologists, epidemiologists, data scientists, government employees, international relations scholars, anthropologists, vaccine developers, journalists, science communicators and members of the World Health Organization. Consent was sought from the interviewees and their identities have been kept anonymous in this report. Interviewees have not been quoted directly in this case study to ensure that their identities are not inadvertently revealed through their expressions or idiosyncrasies. In some instances, the observations of interviewees have been augmented with reports from the news media and scientific literature. Any direct quotations in this report are from cited secondary sources, already in the public domain.

One key limitation to this case study report is that stakeholders from Saudi Arabia did not consent to be interviewed. It is vitally important to note that there are conflicting reports about how the initial outbreak of MERS-CoV in Saudi Arabia played out in 2012. This report does not attempt to establish the facts of the events or the response to them. It addresses the issues raised by interviewees insofar as they represent actual or potential barriers or enablers to data sharing. Indeed, it is our opinion that during public health emergencies, perceived barriers to data sharing are just as important as actual barriers because these perceptions shape the attitudes and behaviours of stakeholders. The anonymous nature of this study meant that interviewees were able to disclose frustrations that they may not have otherwise divulged. Thus, it is sometimes necessary to refer to their examples in general terms, so as not to identify any stakeholders or their organisations.

As per the terms of the project, this report focuses on issues of data sharing in the outbreak and research response to MERS-CoV, that is, case reports, pathogen genome data, surveillance data and risk assessments, publications and clinical trials data. Issues regarding access to virus samples have also been explored as these are the necessary progenitors to a wide range of public health data. The key issues identified in these interviews have been grouped in this report to cover the barriers to data sharing during the MERS-CoV outbreak (what did not work well during the outbreak), the enablers of effective data sharing (what worked well), and the opportunities for improvement for future public health emergencies (what was learned from the MERS-CoV outbreak).

2. Barriers to data sharing during the MERS-CoV outbreak:

Several interviewees expressed dismay at how the initial MERS-CoV outbreak and research response unfolded. The outbreak in Saudi Arabia, first reported in September 2012 was beset with scientific and political controversies from the beginning.[18] One interviewee mentioned that the level of frustration experienced by the global health community was matched only by that felt during the dispute surrounding Indonesia's decision to withhold H5N1 avian influenza samples from the WHO five years earlier. In late 2006 Indonesian officials claimed sovereignty over the influenza viruses that were isolated within their territory. In 2011, the WHO settled the dispute with Indonesia and adopted *the Pandemic Influenza Preparedness Framework*, but the issue of 'viral sovereignty' remained highly contentious by the time the MERS-CoV outbreak occurred in 2012. This incident was raised in many of the interviews. It was a pivotal moment in global health diplomacy that permanently altered the dynamic between the WHO, its Member States and the scientific community. Understanding this incident is vital to understanding how the political and scientific tensions of the time influenced the outbreak and research response to MERS-CoV and the data-sharing practices of many of the stakeholders.

a. Lack of trust in official sources of information

The data handling and information sharing practices of national governments ranged from highly problematic, as was the case with the Saudi Ministry of Health (MoH), to straightforward and uncontroversial, as was the experience with the United Kingdom's (UK) Health Protection Agency (now Public Health England) when they reported the second diagnosed case of MERS-CoV in late September 2012. The South Korean experience fell somewhere in between. While there were key epidemiological differences that shaped the way these responses played out, it is instructive to examine the communication problems and subsequent breakdown of trust experienced by the national governments of Saudi Arabia, and to a lesser extent, South Korea. The UK government's effective communications regarding the imported cases of MERS-CoV in late 2012 and early 2013 is addressed in Part 3(e) on the enablers to data sharing.

i. Kingdom of Saudi Arabia

Many interviewees expressed frustration with the Saudi MoH for not meeting expectations of transparent and timely data sharing in the early stages of the outbreak. This complaint is present in the media coverage of the time and the scientific literature.[19–21] The criticisms ranged from what might be considered passive forms of neglect (mistakes or delays) to more egregious data handling practices, including deliberately withholding data and information that could have been made available earlier, and the possible destruction of virus samples and data. Multiple interviewees noted the timing of the outbreak in relation to the annual Hajj, the sacred Islamic pilgrimage to Mecca, which in 2012 occurred between 23 and 28 October. These interviewees speculated that the Saudi government had been alerted to outbreaks of an unknown pathogen prior to the 20 September ProMED-mail post but did not report it to the WHO for fear that it would disrupt the upcoming Hajj which attracts more than one million pilgrims annually. The MoH maintains that they, like the rest of the world, became aware of the novel virus through the 20 September ProMED-mail post by Dr Zaki.[22]

Much of the frustrations of interviewees was directed at the then Saudi Deputy Minister of Health who was said to have exercised an undue level of control over biological samples and epidemiological data [see Part 2(g)]. Other interviewees felt that this individual was not acting out of self-interest and was simply following the instructions of others in the Saudi government. This idea is supported by the account of one interviewee who had been to Saudi Arabia on multiple occasions to help with the outbreak. They stated that every time they went to Saudi Arabia the people in the government had changed but the data sharing issues remained the same. The complaints about the Deputy Minister of Health having deliberately obstructed data collection and sharing efforts (similar complaints also appeared in some of the press coverage at the time)[20,23,24] were unreservedly refuted by the Deputy Minister himself in August 2013 during a presentation at the UPMC Center for Health Security (now the Johns Hopkins Center for Health Security).[22]

Interviewees were also concerned about the Saudi MoH's reluctance to collaborate with international specialists. This too was reflected in the media, where the Saudi government was alleged to have "repeatedly denied offers of help and assistance since 2012".[25] One interviewee noted that the epidemiological link between camels and primary human infections was determined only when investigators were given unimpeded access to necessary data from Qatar. This link may have been evident much earlier if the Saudi government had been as transparent and open as the Qatari government. The interviewee was cautious in dealing in counterfactuals but concluded that knowing this link earlier might have saved lives. Again, this is reflected in media reports of time:

> *"Experts say the rising number of infections and deaths could have been stopped well within the two years since MERS first emerged - and would have been if Saudi authorities had been*

> *more open to outside help offered by specialist teams around the world with the technology, know-how and will to conduct scientific studies."*[23]

However, this point too was refuted by the Saudi Deputy Minister of Health. He stated that immediately after finding out about the first case of MERS-CoV on ProMED-mail [see Section 3(c)], the Saudi MoH dispatched an investigation team, communicated with the WHO regional office and WHO headquarters, and engaged in discussions with the US Centers for Disease Control and Prevention (CDC), the University of Columbia, and EcoHealth Alliance (a US-based non-government organisation that investigates emerging infectious diseases).[22] Some interviewees acknowledged that scientific collaborations could have been better managed, but took a more understanding tone regarding the Saudi government's reluctance to openly share data and collaborate with international parties. These sensibilities can also be found in the literature and media.[18,26]

For one thing, expectations of data sharing may have been set unreasonably high, with some parties requesting very detailed information that the Saudi MoH resisted providing. The Deputy Minister of Health stated that Saudi Arabia had met their reporting obligations under the *International Health Regulations (2005)*, conveying the age, sex, symptoms, patient status, and information about how the case was confirmed and what investigation had been undertaken, to the WHO via email within 24-48 hours.[22] He also stated:

> *"I think it gets more complex once you start to ask for more ... more details, more patient data, more x-rays, next thing you want the patient chart ... It touches on the patient's confidentiality, on the country's sovereignty, on the family, on the privacy."*[22]

The sovereignty issue was a particular sore point for Saudi Arabia [see Section 2(d)], with one interviewee indicating that the Saudis were wary of the practice of researchers 'parachuting' into the site of a natural disaster or health emergency to conduct research without appropriately engaging government officials.[27] That interviewee highlighted the importance of outsiders collaborating with the host government during the outbreak response, speculating that some data may not have been authorised for release by the Saudi MoH because the data had been collected without appropriate government permissions being obtained in the first instance. This point is also reflected in the literature.[27] Suggestions that data were collected but never published is troubling, but underscores the sensitivities around the exploitative practice of parachute research or sample acquisition, and not just in developing countries.

There were problems with information sharing even for those collaborations that did get off the ground. One interviewee noted that the MoH only ever gave collaborators one or two pieces of the puzzle; there was a distinct sense that nobody was given the full picture. One news report at the time mentioned this very issue, citing difficulties experienced by the research team at Columbia University, led by Professor Ian Lipkin:

> *"Lipkin's laboratory has been testing blood samples from more than 200 individuals from Saudi Arabia. Some of the samples were taken from known cases, others from contacts of cases. The team doesn't know which is which, but they've studied the samples using a variety of assays and have reported the results to the Saudi deputy health minister… [who] has the code which outlines the source of each sample."*[28]

The fragmentation of information may have been a strategy for maintaining control over the outbreak response and the data generated by outside research teams. While these practices may have

stemmed from an understandable distrust of the parties offering to help with the outbreak and research response, the questionable data sharing practices of the Saudi MoH frustrated response efforts and led to a further erosion of trust between all parties involved. Thankfully, as noted by two interviewees, the official reporting of MERS-CoV cases by the Saudi government has improved over recent years, to the point where the data and the transparency with which it is shared on the MoH's website might now be considered standard-setting.

ii. South Korea

The first case of MERS-CoV in South Korea was reported on 20 May 2015.[29] The Korean patient who had travelled back from the Middle East sought medical attention at four different hospitals before being diagnosed with MERS-CoV, nine days after first seeking medical attention. This diagnosis was immediately reported to the Korean Centres for Disease Control and Prevention.[29] By the time the MERS-CoV outbreak in South Korea was declared over at the end of July 2015, there had been 186 reported infections, 38 deaths,[7] and around 16,000 people put under voluntary quarantine. This short outbreak had major economic impacts on South Korea, with sharp declines in consumer spending and tourism. The first case of imported MERS-CoV to South Korea since the 2015 outbreak was reported in September 2018.[30]

From the outset of the 2015 outbreak, the global health community placed high expectations on South Korea to help address the research gaps that remained after years of dealing with the guarded and sometimes uncooperative Saudi government:

> *"… Korea should be an open source of information and transparency with regard to lessons learned from its MERS experience. As the country with the most cases outside of the Middle East, it has a responsibility to fill the information void left unfilled by the Saudis, and others in Qatar and the UAE."* [17]

Data and information sharing during the 2015 South Korea MERS-CoV outbreak was considerably less contentious than the practices of Saudi Arabia, but was not altogether uncontroversial.[31] They too were criticised for failing to engage in "a transparent and rapid distribution of information".[32] One major misstep was when the South Korean government decided against disclosing the names of the affected medical facilities where people were being treated for MERS.[33] This was ostensibly to reduce the community's anxieties about the outbreak but actually increased public panic.[34] This sparked outcry and calls for full transparency and in a press conference on 7 June 2015, the acting Prime Minister released the names of all 24 MERS-affected health centres and assured that "[t]he Health Ministry will be the single source of all relevant information".[35]

When it comes to sharing data and information with the public, one interview stated that the best approach is full disclosure unless there is a compelling reason not to disclose. The South Korean government appeared to have learned a valuable lesson through this incident and this seems to have been the turning point at which their government adopted a very open data sharing policy. Unfortunately, however, the reputational damage caused by this miscalculation and the deterioration of trust may have been more enduring.[35]

b. Restrictions on news media

The news media is the primary means of informing the public about an unfolding health situation and, when at its best, can be a formidable education tool. While social media networks are now providing direct avenues of communication between public health authorities and the general population [see Section 3 (d)], these outlets still do not have the reach and impact of the mass media. Scientific and

clinical advances are often reported through the popular news media and more specialised scientific and medical news outlets. Media reports also act as a source of essential data for public health authorities, including the WHO and the US CDC who routinely monitor the media for reports on public health events. Big data aggregating tools such as the Global Public Health Intelligence Network (GPHIN), maintained by the Public Health Agency of Canada, analyses around 20,000 online news reports daily.[36] Media reports are also collated by ProMED-mail with email alerts are sent to subscribers. Media reports can therefore be seen as both a vital source of data for public health stakeholders around the world (including clinicians, epidemiologists, data scientists and policy experts) and an as outlet for data and information generated by researchers, clinicians and public health authorities.

One interviewee cited the lack of a free press in Saudi Arabia as a major barrier to data sharing during the MERS-CoV outbreak and research response. In their 2012 Freedom of the Press report, the independent media watchdog organisation, Freedom House reported:

> *"The media environment in Saudi Arabia remained among the most repressive in the Arab world, and in 2011, the government moved to tighten the reins on the already heavily censored and state-dominated press."*[37]

In 2011, a royal decree amending press freedoms in Saudi Arabia criminalised any criticism of Saudi senior religious figures and government officials.[37] Furthermore, in 2012 all daily newspapers in Saudi Arabia were "controlled by individuals affiliated with the royal family" and broadcast media stations were under government control.[37] While the internet and satellite television provided access to some international media outlets "the Saudi government has been known to directly censor both local and international media".[37]

The interviewee stated that the absence of trustworthy information from official sources and the lack of a free press in Saudi Arabia created an increased dependence on informal channels of information, including through personal and professional contacts and social media. They also highlighted cultural differences which may impede the flow of information. For instance, the interviewee noted that in Saudi Arabia there is not a culture of critically examining the official statements of government departments. News stories from Saudi media outlets in the early days of the outbreak were often verbatim reproductions of official government press releases. During public health emergencies news reporting is an important communications tool and a vital data input to disease detection programs and digital epidemiological research. It also influences how much attention a particular issue will receive by the public and politicians. Therefore, freedom of the press is vitally important for effective data sharing in public health emergencies [see Section 4(e)].

c. Cultural factors and language barriers

Cultural factors were mentioned by some interviewees as an impediment to collecting clinical information. Attitudes to illness and medical care vary across cultures and this can play a role in the approach of clinicians taking patients' medical histories and the sorts of information the patients themselves divulge.[38] One interviewee suggested that some patients from Middle Eastern countries were not particularly candid or forthcoming with the personal information they provided to clinicians and outbreak investigators, causing delays in obtaining information of epidemiological value:

> *"The WHO MERS team first learned some people in Saudi Arabia drink camel urine - believing it has medicinal properties - about a year and a half after they started working on the virus."*[24]

Often, patients do not realise the sorts of information that are useful to clinicians and investigators taking medical histories. Particularly with a novel pathogen, it can be hard to determine what line of questioning will produce relevant answers. If a patient is not aware of the significance of their personal circumstances, they are very unlikely to freely offer any uncomfortable or embarrassing personal information. This highlights the importance of taking an open-minded approach to collecting medical histories and information in the early days of a novel infectious disease outbreak. If possible, it is always better to collect more data than is thought necessary. This also underscores the importance of maintaining patient confidentiality and anonymising data so that individuals and communities are not stigmatised because of their health status or circumstances. Not least of all because this increases people's reluctance to divulge private information, impeding future data collection.

One interviewee working in Saudi Arabia in the early days of the outbreak stated that language barriers were also an important obstacle to obtaining patient information. The interviewee did not speak Arabic, and this was a problem when collecting patient histories. They also noted that female patients often had to be consulted in the presence of, or through a male member of the family.

Cultural factors may have been a factor that increased transmission in the early days of the 2015 South Korean outbreak. As the family is at the centre of Korean culture, relatives will stay with sick patients for long periods, which may have aided in the transmission of a virus that otherwise does not spread too readily between humans.[33] There is also the practice of 'hospital shopping' which may have helped to spread MERS-CoV to multiple health facilities in a short period of time.[39]

The professional culture of clinicians can determine the types of data that are collected, particularly when that data might be considered subjective. One interviewee who had assisted with the outbreak response in Saudi Arabia stated that there were certain hospital practices that they had identified as problematic, but that Saudi physicians did not see these as unusual or worthy of questioning. This situation highlights the importance of having outsiders actively participating in the outbreak response: this sort of information will only be identifiable and therefore deemed worthy of collection as data by people not already accustomed to the affected country's professional and clinical culture.

The importance of anthropological insights and information in public health emergencies is clear but so often undervalued. Anthropologists can identify social factors (like stigma, political sensitivities, socioeconomic status, and social vulnerabilities) that will influence how the population (and certain subpopulations) will interact with medical and public health professionals. It also informs how best to communicate health measures that are being implemented on a population level and how to implement personal protective measures as social factors will influence the uptake of those measures. One interviewee stated that mixed-method approaches during any outbreak response will usually generate better compliance and a more effective response. There is little point having scientifically proven interventions for dealing with an outbreak if the community is not receptive to their implementation.

d. Virus samples: ownership and access issues

Biological samples are not often considered in discussions about data sharing, however, they play a vital role in the development of public health data. Virus isolates are required to identify the pathogen, develop diagnostics and vaccines, and generate genetic sequence data. That genetic sequence data can be used to monitor pathogen evolution, identify genetic determinants of virulence, pathogenicity and transmissibility, and to find potential targets for drugs. Phylogenetic analyses on these data can help to elucidate transmission patterns. There is an ongoing requirement for novel virus samples as the outbreak progresses (this is particularly important for RNA viruses like coronaviruses) to monitor

pathogen evolution and detect the development of drug resistance. Human serum samples are required to measure neutralising antibody titres, develop serological assays and to estimate what proportion of the population may have been exposed to the pathogen. For any emerging pathogens with a likely zoonotic reservoir, samples will also be required from animals to determine the host species, exposure rates and the chain of transmission. Biological samples are the essential progenitor of so much data so access to samples is of critical importance in the discussion on data sharing.

Interviewees identified restrictions on accessing biological samples as a major barrier to generating data required to inform the outbreak and research response. Two key explanations for the restrictions were identified: the patent application claiming the genetic sequence of MERS-CoV by Erasmus Medical Center and the sovereignty-like claim over MERS-CoV samples by Saudi Arabia. These restrictions are addressed separately below, although it is worth noting that the actions of the Saudi government may have been prompted by the intellectual property protections sought by Erasmus (see international patent application WO 2014/045254 A2, published 27 March 2014).[18]

i. The patent on MERS-CoV genetic sequence

After encountering difficulties identifying the causative agent of his patient's pneumonia, the Egyptian microbiologist working at Dr Soliman Fakeeh Hospital in Jeddah, Dr Zaki, sent a clinical specimen to Erasmus Medical Center in the Netherlands in June 2012.[40] The team at Erasmus identified a novel human coronavirus, sequenced its genome and designated it HCoV-EMC, named after Erasmus Medical Center.[18] Dr Zaki reported the details of this discovery to ProMED-mail on 15 September which was publicly posted to ProMED-mail on 20 September.[1] The team at Erasmus, along with Zaki, filed an application under the Patent Cooperation Treaty (PCT) over the "the nucleic acid and/or amino acid sequences of the MERS-CoV genome" on 23 September 2012.[41]

Some interviewees felt that there was no situation where patenting a pathogen was appropriate. Others saw patenting as either innocuous (just something that everyone does) or a protectionist strategy to thwart the efforts of charlatans who might take advantage of the emergency situation by marketing substandard diagnostic kits (known as 'defensive patenting').[42] There was also a sense that someone was always going to patent the virus, so it might as well be the good guys. But this reasoning forces us to determine who precisely these 'good guys' are in a complex field of stakeholders, all of whom will have some overlapping and/or competing interests.

It is important to remember that patenting the genetic sequence of a virus is not the same as *owning* the virus. Indeed, in a press release from May 2013, Erasmus Medical Center stated "[i]t is clearly a misunderstanding that Erasmus MC owns the virus. Only specific applications related to it, like vaccines and medicines can be patented".[43] However, confusion is understandable as the PCT application claims "the nucleic acid and/or amino acid sequences of the MERS-CoV genome and sequences specifically encoding (parts of) viral proteins and antigenic polypeptides" as well as "diagnostic means and methods, prophylactic means and methods and therapeutic means and methods".[41] Even before the recent court challenges to gene patent eligibility around the world (e.g. the US Supreme Court in 2013 and the High Court of Australia in 2015; noting that isolated gene sequences are still patentable in Europe),[44] the suite of protections afforded patent holders of isolated gene sequences was unclear. Multiple interviewees noted that the extension of intellectual property rights over the MERS virus introduced an unsettling level of uncertainty for scientists who wanted to conduct research on MERS-CoV, and especially for those parties with a view to commercialising diagnostics, vaccines and medications.

The practice of patenting virus sequence data was not unprecedented, or even uncommon, including during health emergencies. The SARS virus, for example, was the subject of multiple patent applications from scientists in Canada, the US and Hong Kong during the outbreak in 2003,[42] and the resulting patent pool was managed by the WHO. But the global context had changed somewhat since the SARS outbreak in 2003, and the sovereign rights of nation states over their genetic resources (which included pathogens as highlighted by Indonesia in 2006-2007) was top of mind for many countries. The Saudis voiced strong disapproval and during the World Health Assembly in May 2013, then Director General of the WHO, Dr Margaret Chan, said of the Erasmus patent application that she would "follow it up", adding "I will look at the legal implications together with the Kingdom of Saudi Arabia. No IP [intellectual property] should stand in the way of you, the countries of the world, to protect your people."[45]

The Saudi government and various media reports suggested that unnecessary delays were created by Erasmus Medical Center in their use of Material Transfer Agreements (MTAs) to accompany the transfer of virus isolates to other research groups.[46,47] This was not reflected in the interviews. When research scientists were specifically asked about the use of MTAs in the interviews, they stated that this was simply a routine practice for biology labs. By some, it was seen as an essential administrative step to ensure that the recipients of the materials had the laboratory capacity to conduct experiments on MERS-CoV safely. In May 2013, at the height of the debate about Erasmus restricting access, one reporter noted:

> *"The debate has been confusing in part because commenters have mixed up two different things: patents on the one hand, and so-called material transfer agreements, or MTAs, on the other."*[40]

Based on the responses of interviewees, this does appear to have been the case. The interviewees did not think that the MTA constituted a barrier to accessing much needed virus samples, however, the patent application was seen by some as a source of major confusion for scientists wishing to utilise those viruses in research and therefore an impediment to the research response. One interviewee thought the practice of patenting virus sequences inexcusable at any time, but especially during a public health emergency (it should be stated that the patent application was filed with the World Intellectual Property Organization before the nature of the MERS-CoV situation became clear).

ii. Viral sovereignty

The Saudi MoH protested the patent application, troubled that "the then-unidentified virus had been sent to Erasmus without the Saudi government's permission and that Erasmus had subsequently asserted rights over the virus".[48] In his legal analysis entitled "Who Owns MERS?", Professor David Fidler indicated that Saudi Arabia had "not yet appealed to 'viral sovereignty,' the argument that Indonesia advanced during the 2007 controversy over sharing avian influenza A (H5N1) samples" but that their criticisms echoed the same legal reasoning.[19] Multiple interviewees cited the claim of 'viral sovereignty' over H5N1 influenza viruses back in 2006-2007 as a pivotal event in global public health that set something of a precedent on the issue of pathogen ownership.

One interviewee mentioned the impact of the United Nations' *Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the Convention on Biological Diversity* (Nagoya Protocol), adopted in 2010. The interviewee expressed concerns that this international agreement, which recognises the sovereign rights of nation states over their genetic resources, could further delay access to pathogens in future outbreaks. There was a sense that this instrument (or the concepts within it) are encouraging countries to exert unwarranted

control over not only the physical samples, but the conduct of research and the resulting data. This interviewee indicated that they had stopped working on MERS-CoV when the legal terrain became too complicated. Others were less critical of the notion of 'viral sovereignty', stating that researchers should respect countries' sovereign rights. Instead of seeing this as an impediment, they felt it should be seen as an opportunity to engage international partners in collaborative response efforts on an equal footing.

Views on the issue of virus access and ownership ranged the spectrum. Some were unphased by the practice of patenting virus sequences and others sympathised with the Saudi government. One interviewee felt that both the extension of intellectual property rights and any sovereign rights over virus samples represented unreasonable and intolerable restrictions and delays to the research response. Both sets of legal rights are still rather nebulous, and this undoubtedly led to confusion about what research was permissible during the response to MERS-CoV. During a health crisis, there is little time to negotiate access agreements or challenge property rights in a court of law. Scientific researchers are hesitant to conduct research and development if they sense it could result in legal action and/or reputational damage. This is especially so for researchers looking to develop diagnostics, vaccines and medications for the market as competing legal interests could jeopardise their R&D investment. The bottom line is that this confusion stifles the research response and these legal ambiguities must be clarified to reduce barriers generating and accessing data and information during public health emergencies [see Section 4(f)].

e. Organisational Culture of the WHO

The WHO's coordinated response to SARS was a topic that came up in most interviews. The response was widely praised as an exemplar of effective leadership and collaboration. During the SARS response in 2003, the WHO established a "closed network" of collaborators, within which data and information were shared.[42] The network comprised 11 research teams from 9 countries (including Erasmus Medical Center).[49] The collaborating teams had to accept a set of confidentiality rules that meant information and data could not be shared outside of the group without the permission of the specific team that generated the data.[42] Within two and a half months, scientists had identified the animal host and the mode of transmission to humans.[28] In stark contrast to the successes of the SARS response, the scientific community is still not sure of the exact role that dromedary camels play in the transmission of MERS-CoV to humans.[8]

Multiple interviewees lamented that the WHO did not take as active a role in the MERS-CoV outbreak as it had during SARS. It has been noted that the WHO took a decisive and autonomous leadership role in response to the SARS outbreak "[w]ithout any express policy or legal basis for these actions".[50] Some interviewees, therefore, felt that the different approaches taken by the WHO during the SARS and MERS outbreaks came down to leadership and the organisational culture of the WHO. Some felt that stronger leadership from the WHO would have resulted in more efficient and transparent data sharing, particularly from Saudi Arabia. Multiple interviewees were disappointed that the WHO's Director General, Dr Margaret Chan, did not call out the Saudis or actively push for more information from the Saudi MoH. Others recognised that the WHO cannot act unilaterally or in a political vacuum: they had to respect the sovereignty of Saudi Arabia. Furthermore, to rebuke the Saudi government for not being open and transparent in the early days of the 2012 outbreak may have been counterproductive. An aggressive stance from the WHO towards the Saudis could have jeopardised existing channels of communication. One interviewee felt that this was part of the WHO's role: keeping everyone on good terms to foster sharing and collaboration.

One of the scientists interviewed felt that the WHO should not treat public health emergencies as a diplomatic issue; that they should focus on the science and public health imperatives only. They felt strongly that the WHO had taken the side of the Saudis and had backed down from any confrontation with them because they are a rich nation with considerable political influence. Another interviewee stated that public health is inherently political and that the WHO, as a UN body, is based on the sovereignty of nation states. Thus, the WHO has no option but to treat public health emergencies as a political issue.

One interviewee felt that the leadership of the WHO was the key factor influencing the different approaches to SARS and MERS. Where former DG Gro Brundtland had called out China's delay in sharing information and acted decisively during the SARS outbreak, the interviewee felt that Chan had wavered and led by consensus. They felt that while Chan was technically proficient, her style of management was not conducive to a robust WHO-led response.

One interviewee was concerned that the WHO did not declare a Public Health Emergency of International Concern (PHEIC) despite what they saw was sufficient reason to warrant such a declaration. They felt that this would have increased pressure on the affected countries of the Middle East to share information and resources. They also felt that a PHEIC declaration may have given the WHO a stronger position to take control of the emerging situation, as they had done during the SARS outbreak in 2003.[51] Another interviewee felt that the MERS situation did not meet the criteria for a PHEIC and stated that such a declaration could lose its authority if it were overused. All interviewees that mentioned the PHEIC, whether they felt a declaration was warranted or not, said that the declaration of a PHEIC would not have directly altered the data sharing dynamics between the WHO and affected countries. There is nothing in a PHEIC declaration that mandates additional reporting requirements. They did, however, feel that a PHEIC would draw more political attention to the situation and that the scrutiny of the rest of the world may have encouraged greater transparency.

f. Interagency communication

Interagency communication must occur at all levels of government: local, subnational, national and supranational. Communication dynamics within and between UN bodies was raised by three interviewees. Once it became clear that the transmission of MERS-CoV involved an animal host, the WHO started engaging in regular communications with the UN Food and Agriculture Organisation (FAO) and the World Organisation for Animal Health (OIE). One interviewee noted that, historically, communications between these three agencies have been somewhat deficient. At the time of the outbreak, however, the people involved in the MERS research response made an active effort to foster informal communications between members of these organisations to supplement the data sharing that was occurring through more formal channels. Another interviewee noted that interagency and intra-agency communications dynamics of UN organisations are strained because technical experts and diplomats tend to speak past each other.

That same interviewee said that the UN cluster approach to humanitarian response had improved interagency communications in the last decade or so. It has led to more deliberate coordination between UN bodies and non-UN organisations during an emergency response. The interviewee reported that this is working very well (at least a lot better than prior to the introduction of this approach). It has improved coordination and communication, reduces duplication of effort and fills the gaps that are left. They felt that defined leadership roles and clear authority is a major factor in mounting an effective response.

Interagency communication appears to have been more strained at the national level, as many government departments had different, and even competing mandates. Health incidents require the involvement of multiple government agencies at the national, subnational and local levels. For example, there are economic implications, trade and travel considerations (including public transport), and education departments may consider closing schools. One study of the interagency communications networks between government agencies in South Korea found that "more timely information sharing by the national government could have reduced the number of MERS victims".[29] On the other hand, governments with pre-existing interagency communications channels tended to share information more efficiently during emergencies [as was the case in the UK, see Part 3(e)].

g. The publishing imperative and authorship disputes

The pressure to publish in academic journals is one of the best understood barriers to data sharing during public health emergencies. The desire to be the first to publish, fear of being scooped and the requirement to have an impressive publication record for career progression create incentives for scientists to withhold research data until they can be guaranteed attribution. One interviewee noted that these incentives do not disappear in a public health emergency. In fact, they can be acutely magnified because the outbreak of a novel pathogen provides a unique opportunity to conduct truly groundbreaking research.

Interviewees raised multiple issues when it came to scientific publishing during the MERS-CoV research response. With respect to the peer-review process, the opinions were mixed. Some felt that the whole process of traditional peer-review is simply too slow to work in an emergency situation where little is known about the pathogen. One interviewee advocated for the online publication of preprints for this reason. Others were full of praise for journals that ensured the fast-tracking of MERS-related articles [see Part 3(g)]. From the interviews in this case study, the journals were seen as enablers rather than barriers to data sharing during the MERS-CoV outbreak.

One key delay to publishing in journals during the MERS-CoV response were authorship disputes. This issue was raised by multiple interviewees and appears to have been a problem felt acutely by many of the stakeholders. On this issue, the actions of the Deputy Health Minister of Saudi Arabia was again cited as a major source of frustration. Some felt that he would not allow data from Saudi Arabia to be published unless he personally was included as an author on the journal article. This echoed reports from a contemporaneous news story:

> *"In off-the-record conversations […] a number of scientists complained the Saudi deputy health minister in the early days of MERS […] was keen to maintain control over data, specimens and access, and to be named a prominent author of any scientific papers that emerged. In the first couple of years of MERS research, the publications section of [his] CV mushroomed".*[24]

One interviewee noted that the academic culture varies across countries. They said that in order to be named an author in a Western country you would need to have made a direct contribution to the design or conduct of the experiments, the data analysis or the writing of the manuscript. These authorship practices are not followed in other countries. This interviewee had been surprised at some of the requests for what they saw as unwarranted authorship from members of the Saudi government. They said that while they would usually have disputed the inclusion of these people as authors (administrative assistance, for instance, is more appropriately recognised in the acknowledgements section of publications), they had acquiesced during the MERS-CoV outbreak because of the imperative to get the information published as quickly as possible.

Another interviewee felt that there was no cost to putting extra names on a research publication and that in these situations it is appropriate to acknowledge everyone's contributions. This also goes some way to fostering trust and continued collaboration. Another interviewee felt that the academic culture needed to find ways to sideline competitive attitudes during emergencies. However, one interviewee stated that there can be direct costs associated with adding names to manuscripts. They stated that some journals resist listing too many authors on a single article. They noted that during the MERS-CoV research response they had to convince the editors of one journal to ensure that the many listed authors, all of whom had made substantive contributions to the production of the manuscript, were appropriately credited as authors on the published article.

h. Data and information quality and format

Multiple interviewees noted how much the quality of epidemiological reports vary across countries. Some make detailed line lists publicly available with information about the age and sex of the patient, the date of symptoms onset and the date the patient sought medical attention. One interviewee noted that the WHO is including less data in their publicly available spreadsheets than they once did. The interviewee said that the WHO are becoming more respectful of individual nations' data sharing preferences, and that the amount of data the WHO collect, collate and release is generally dictated by the country of origin. This means that all the information that may have been collected and that could be epidemiologically relevant does not get released to the broader public and is not readily available for research.

In terms of format, one interviewee stated that there is often a requirement to "clean" the data before it is analysed, even for very good datasets. Many interviewees noted that good quality formal datasets are sometimes available but that even when the data are comprehensive and complete, they often lack the qualitative information that provide context. That is, it is not clear how the data were obtained or how reliable it is. One interviewee gave an example about one dataset indicating the number of new infections, but it did not provide the vital detail that the data were obtained only from travellers and not the broader population. While the Saudi MoH had been heavily criticised for its data sharing practices in the early days of the outbreak, many interviewees noted that the quality and reliability of their data was now exemplary.

> *"Since March 7, 2015, official reporting of cases referred for MERS-CoV testing in Saudi Arabia has exclusively been documented through the Health Electronic Surveillance Network (HESN)."*[52]

Multiple interviewees expressed the importance of knowing the "story" behind the data: a general sense of how the people on the ground are seeing the situation develop. This sort of qualitative information is not as easily transmittable as a spreadsheet, but it is integral to understanding what the raw data are indicating. One interviewee said that formal datasets work best when the person analysing them is given a sense of what the people on the ground are feeling. Contextual information is more difficult to obtain than quantitative data and it is impossible to prescribe a set of parameters for what contextual information will be important in a given emergency because the context will change each time. Irrespective of how good the formalised sharing arrangements are for raw datasets, there is still a requirement for context [see Section 4(d)]. This is often shared informally by those responding to the emergency on the ground or can be obtained through news reports (again highlighting the importance of a free press).

i. No infrastructure for data collection in emergency drug use

One interviewee was concerned about the lack of data collected on emergency drug use in clinical settings. They reported that during the MERS-CoV outbreak (as was the case in the SARS outbreak, H1N1 influenza virus and the Ebola outbreak) clinicians would try different approaches to managing patients with severe disease. This sometimes involved administering drugs that had not been approved for use for that specific condition, which in the case of a novel pathogen like MERS-CoV, is unavoidable. The interviewee said that there is no system in place for collecting data about off-label drug use because if there were standardised data collection occurring, the practice would take on the appearance of a systematic drug trial.

The interviewee reported that drug trial protocols are slow to be developed and approved, and that quite often the protocols are only made available once the emergency has passed: there are protocols, but no patients to test them on. The interviewee stated that these sorts of interventions are occurring anyway, so we should be collecting data about off-label emergency drug use to determine whether these are actually providing effective treatment strategies. We cannot know until the data are collected but there is administrative resistance to collecting such data. The interviewee felt strongly that this situation could be easily addressed by research funding agencies that could mobilise ethicists and clinical trialists to outbreaks more rapidly and setting up a system to collect the data that is already ripe for collection!

3. Enablers to data sharing during the MERS-CoV outbreak:

The frustrations associated with data sharing during the MERS-CoV outbreak were manifold and are still passionately felt by many of the interviewees. Many found it harder to immediately identify enablers to data sharing during the outbreak and research response, but some of the oft cited enablers were the WHO's *International Health Regulations (2005)*, the many unstructured networks of collaborators that shared data informally, the rapid peer-review process undertaken by some of the big name journals, and, somewhat surprisingly, Twitter was named as a key enabler to MERS-CoV data and information sharing. These are addressed below.

a. Altruism and reciprocity

Multiple interviewees pointed out the fact that academic science and public health is not a particularly lucrative profession and that many are motivated by a sense of altruism to some degree or another. One interviewee noted that the researcher who created the first diagnostics for MERS-CoV did not patent their innovation and offered it, free of charge, to whoever needed it in the early days of the outbreak. Another interviewee noted that there are data scientists who create software to analyse epidemiological data and that these tools are also available free of charge to whoever desires them.

One interviewee noted that the global public health community is relatively small. Given that altruism is seen as a high ideal for many scientists, this creates the conditions for keeping egocentric behaviour in check. The interviewee noted that community would not forget those people who were seen to have behaved poorly during the MERS-CoV outbreak (e.g. withholding data, demanding unearned credit or authorship, or otherwise delaying the response). Their professional standing may have benefitted in the short term, but their reputation would suffer over the long term as stories were shared among colleagues. There are a set of norms that the scientific and public health community have adopted, consciously or not, and violation of those norms is considered particularly egregious when there is a clear and present risk to human life. This is not a foolproof or wholly consistent system, but altruism and reciprocity are cultural enablers to data sharing.

b. Importance of informal networks

As "the sharing of data from affected countries proceeded at a slower pace than was originally anticipated", the US CDC relied on informal networks of colleagues and collaborators to collect the MERS-related information they required.[53] This reliance on informal networks was regularly noted in the interviews, where most interviewees stated that they share data and information informally with colleagues and other professional acquaintances. Indeed, informal channels are sometimes the only way to get an accurate picture of what is happening in a country when the formal sources of information have proven unreliable. One interviewee stated that people working in Saudi hospitals felt unable to contradict the official messaging of the Saudi MoH. They reported that people on the ground knew that there had been more cases of MERS than had been officially reported by the government. This information would be communicated informally to their own contacts at the WHO. The interviewee stated that often the WHO contacts were not directly related to the MERS-CoV response (another noted that the highly fragmented nature of the WHO meant that it was often difficult to determine from the outside who is responsible for any given issue). These informal contacts were often former colleagues or collaborators that worked at the WHO and the informer would simply trust that the information would find its way to the people that needed it.

One interviewee noted that the MERS-CoV draft genetic sequence was often shared via email well before that genetic sequence information was published on GenBank or another official data repository. This is because sequence information is generated initially as an unverified draft. These draft genomes were sent to colleagues and interested parties on the understanding that the draft sequence data needed to be confirmed before it was officially released. This meant that the recipient scientists did not have to wait until the verified version was published before they could start analysing the data. Another interviewee noted that the professional connections created during the response to SARS in 2003 created something of a readymade informal network of scientists that shared MERS-related data. Through their collaborations on SARS, this informal network already knew and trusted each other. Other informal networks existed solely online on internet platforms like Twitter [see Section 3(d)]. While these online networks of collaborators and acquaintances might be more nebulous than contacts made through more traditional forms of networking, one interviewee highlighted that they are no less real or useful for sharing information and data.

Despite the benefits of informal communication, which includes speed and the ability to share as yet unverified information with the appropriate caveats, there were still efforts to formalise these more casual data sharing practices. The CDC report cited above stated that "the creation of policies such as data-sharing agreements … took an extended period of time, sometimes much longer than anticipated."[53] Formalising all efforts to convey data and information during a public health emergency can backfire and create an increased dependence on official sources of information, which can be unreliable. Formal information sharing agreements can result in people not feeling as free to speak about what they *think* is happening. That is, they feel they can only communicate substantiated facts. One study of South Korean intergovernmental agencies responding to the MERS-CoV outbreak showed that "[f]or immediate outbreak response, interviewees indicated that organizations preferred telephone and email to formal paper communication."[29]

One interviewee was against efforts to formalise these modes of communication. Informal networks work best when the data itself is informal: when people are uncertain about the veracity of the information, or whether they have the authority to provide it. This is when informal channels are safer, more reliable than official sources and more efficient than formal sources of information. Without unregulated channels of communication, a lot of information would simply go unreported.

c. ProMED-mail

The importance of ProMED-mail in alerting the world to the outbreak of MERS-CoV was mentioned by multiple interviewees. There had been no official reports from the Saudi MoH and the report from Dr Zaki, published on ProMED-mail on 20 September 2012 was the first notification of a novel infectious disease in Saudi Arabia. The Saudi Deputy Minister of Health later stated that the Saudi government did not know of the existence of MERS-CoV until it was reported on ProMED-mail.[22] This was refuted by one of the interviewees who stated that Dr Zaki had indeed shared the information through the internal Saudi channels well before the information appeared on ProMED-mail, but that his messages had been ignored by the Saudi MoH. Either way, the report on ProMED-mail was what triggered the international response to MERS-CoV.[53] Indeed, it may have been the preferred outlet for this information *because* official channels had broken down. Similarly, in 2003 ProMED-mail reported information about SARS-CoV infections in Guangdong Province before the Chinese government had informed the WHO about the outbreak.[50]

One interviewee noted that, because ProMED-mail is essentially a collation and distribution tool, they often already knew the information before it appeared on ProMED-mail. Because the service is well known and respected in the global public health community, one interviewee stated that it keeps everyone abreast of what was happening. This proved to be clinically significant during the MERS-CoV outbreak. The report published on 20 September described the discovery of the novel coronavirus that had been isolated from a Saudi patient in June 2012. After reading that report, clinicians in the UK tested a Qatari patient for the novel coronavirus, and this became the second case reported on ProMED-mail on the 23 September 2012.[54]

One interviewee noted that the ProMED-mail subscription alerts often contained novel information and insights that did not appear elsewhere. For instance, in one ProMED-mail post on 25 September 2012, an Australian doctor speculated that the novel coronavirus might have been the pathogen responsible for an unexplained outbreak of respiratory illness in a Jordanian hospital in April 2012.[54] In October and November, two stored patient samples from this outbreak tested positive for MERS-CoV.[55] In this respect, ProMED-mail was a vital source of health intelligence that essentially outsourced the process of connecting the epidemiological dots. Furthermore, one interviewee noted that they often reported MERS-related information to the ProMED-mail MERS-CoV moderator if the information was important but did not meet the reporting requirements under the *International Health Regulations (2005)*.

d. Twitter

Twitter regularly came up in the interviews as a communications and data sharing tool used during the MERS-CoV outbreak and research response. Public health professionals and communicators engage in virtual networks on Twitter. One interviewee reported using Twitter as both a broadcasting tool to inform people of their own research and a collation tool to find out about new and interesting datasets that were available for mining. Another interviewee stated that Twitter was a convenient way to find and communicate with people who could provide insights as to what was happening in Saudi Arabia, given that the official sources of information were seen to be so unreliable in the early days of the outbreak.

Twitter, like more traditional media outlets, can be a source of health intelligence,[56] and a public health communication tool. Analysis of data obtained from Twitter and other social media websites, including during the MERS-CoV outbreak, have demonstrated that “social media could be a useful measure of public awareness and reaction to disease outbreak information released by health

authorities".[57] It may also give a sense of the effectiveness of that messaging. One interviewee noted that information from official sources is often available on Twitter before it becomes available through authorised outlets. This is because a tweet might go out while a press release is still being drafted, or while a news story is being filmed and Twitter is an easy way to communicate that further information is to be forthcoming.

e. Well-resourced bureaucratic structures

The importance of interagency communication in the response to outbreaks of infectious diseases is clear, and in the case of MERS-CoV, governments with well-organised bureaucratic structures were at an advantage. The problems with interagency communication were outlined in Section 2(f), however, multiple interviewees noted that when there were structures in place to facilitate interagency communication during non-emergency times, this led to more efficient information and data sharing during emergency situations. In this respect, the experience of the UK stands in contrast with that of Saudi Arabia and South Korea.

The second diagnosed case of MERS-CoV was reported from a Qatari man who sought treatment in England. The diagnosis did take longer than it might have as the patient was an elderly man with a respiratory illness (a very common clinical presentation) and did not provide a comprehensive travel history. But once the diagnosis was made, the response was swift and effective, as was the communication to the public about that response. One interviewee noted that the presence of a functioning bureaucracy before an emergency presents itself means that there are existing communications structures to ensure efficient information sharing with health professionals, international partners and the public. Furthermore, pre-defined bureaucratic structures meant that there were clear processes and authorities for making decisions about the outbreak response. This avoided problems with individual personalities unduly influencing the decision-making process as appears to have been the case in Saudi Arabia where one government official had an inordinate level of control over the situation.

Another interviewee expressed similar sentiments about US interagency communications during an emergency. All applicable federal agencies get a seat at the table and emergency meetings are well structured and regular. Like the UK, the system is not entirely frictionless, and while the upper echelons of the response are well coordinated, there are sometimes problems with facilitating similarly efficient communications between other levels of government (federal, state and local) and other entities (such as non-government organisations) involved in the outbreak and research response.

f. Researchers reporting findings to the WHO technical team

The WHO coordinated a network of research collaborators during the SARS outbreak in 2003 [see Part 2(e)]. The WHO did not take as active a role in coordinating the outbreak and research response to MERS-CoV, but the WHO did have a technical team monitoring the research response from the beginning of the outbreak. The WHO's technical team encouraged research groups from around the world to collaborate with each other and share information. Any research group could join this semi-formal network, and research groups were often identified for participation through word of mouth. Preliminary findings and unpublished research results were shared in confidential teleconferences held once a month. The research network (with the WHO technical team at its hub) had no formal terms of reference, but the WHO did ask research groups to sign Non-Disclosure Agreements (NDAs) to protect the information that was disclosed by other research groups during the teleconferences. Nobody was to speak publicly about the research findings of other groups until that work was officially published. It was up to the research group responsible for the work to release their results when they

were ready. The WHO did not take an active role coordinating the research response, but the information shared through this technical network helped the participating research groups to identify research gaps and avoid duplication.

g. Fast tracking of MERS-CoV related publications by some scientific journals

A couple of interviewees noted that the peer-review publication system is a bottleneck that delays data sharing. This was not the experience of the scientists and clinicians that were interviewed. They felt that the journals had acted responsibly and swiftly during the MERS-CoV outbreak and research response. One interviewee stated that they submitted a manuscript to a major journal on a Friday afternoon and had peer-review comments back by the Monday. Anyone used to the peer-review process would agree that this is an incredibly fast turnaround time. This sentiment was also reflected in the literature:

> *"Credit for the rapid dissemination of important findings of the current MERS-CoV outbreak goes to the responsive editors of The New England Journal of Medicine and Lancet Infectious Diseases who facilitated the process of knowledge dissemination."*[18]

Of course, the peer review process is just one aspect of publishing academic articles that can delay the delivery of important information. It takes time for the manuscript to be written up and this case study report has already noted the delays that were created by authorship disputes and obtaining permissions to publish data. One interviewee lamented the policy of some journals not to publish articles where data were previously published or where the paper had been uploaded to a preprint archive. Interestingly, one interviewee felt that practices of journals constituted low-hanging fruit in the discussion on data sharing during public health emergencies. That is, while not being the greatest impediment to data sharing, it gets a lot of the focus because it is easy to blame journals for delays associated with publication. Many of the interviewees were happy with the performance of journal editors during the MERS-CoV outbreak.

h. The *International Health Regulations (2005)* reporting requirements

Multiple interviewees noted that the revised *International Health Regulations* (IHR), adopted by the WHO in 2005, reduced the uncertainty about what information countries had to report to the WHO and in what timeframe. The IHR (2005) take the guess work out of making the decision to report any given event. For instance, without the revised IHR (2005) there would have been no legal obligation for British health officials to report the imported case of MERS-CoV that occurred in the early days of the outbreak in September 2012.[21] When providing information to the WHO, its Member States are already aware of how that information will be treated and shared with other parties. The uncertainty surrounding the terms of access and sharing ceases to be a factor in determining whether or not to share information because these terms are prearranged. Also, the reporting requirements outlined in the IHR (2005) create a norm against which aberrant behaviour can be called out.

The revised IHR (2005) is also important because it allows the WHO to take into account health incidences reported by non-state parties. This was particularly important for MERS-CoV which was originally reported on ProMED-mail and not by the Saudi MoH [see Section 3(c)]. One interviewee indicated that the Saudi government was often in violation of the IHR (2005) because they were aware of and did not report some MERS-CoV cases. Indeed, the clear reporting requirements of the IHR (2005) may have been part of the reason for the Saudi MoH taking such a defensive stance at the start of the outbreak, because the world was alerted to the novel virus through informal channels rather than through the country's IHR National Focal Point.

4. Opportunities for improving data sharing in future outbreaks of emerging diseases:

This case study on data sharing practices during the MERS-CoV outbreak and research response exhibits some recurring themes, including confusion and uncertainty, trust, equity and fairness, speed versus accuracy, the role of diplomacy in these public health emergencies and the influence of individual personalities on the data sharing process. The examination of the barriers and enablers to data sharing has raised some opportunities for improvement. In addition to collecting data on emergency drug use which was addressed in Section 2(i), this section details other opportunities for improving data sharing practices in future outbreaks of emerging infectious diseases.

a. The roles of 'non-traditional' media in data sharing

Encouraging science communication through non-traditional media sources such as Twitter, podcasts and blogs created by professional scientists and interested amateurs is an understudied source of data sharing and communication during public health emergencies. This is a form of information sharing, that unlike more official sources from authorities that are busy dealing with the outbreak itself, can be two-way. That is, the public can engage with these communicators and develop a better understanding of how the emergency is unfolding and the likely consequences of the response. One interviewee noted that the public has a right to public health data, and should see it as something they have a stake in.

There are a number of non-traditional outlets providing information about infectious diseases for the interested general audience. There are podcasts like This Week in Virology, hosted by Professor Vincent Racaniello, a virologist from Columbia University, and @FluTrackers, the Twitter feed from the infectious disease tracking website FluTrackers.com. Non-traditional media are often thought of as being of questionable quality and reliability, but the data and information sharing that occurred on these internet-based platforms during the MERS-CoV outbreak were often of excellent quality. For instance, the MERS-CoV data that were collated and shared on VirologyDownUnder.com by Professor Ian Mackay, a virologist form the University of Queensland in Australia were extremely informative and readily understandable to the general public.

One interviewee noted that the community is at different levels of understanding and that public health data from official sources can be confusing for a public audience. Non-traditional media provides a flexible mode of communication with very few limits to the format of the information that can be presented (unlike a newspaper for instance), there are no restrictions on frequency of publication or the amount of information included, and anyone can contribute. There is an inbuilt feedback mechanism where individuals can contact the communicators and ask for clarification or additional details. The WHO and CDC, for instance, provide high quality information but they are not approachable in the same way that non-traditional communicators are (who are often experts in the field), and this can increase public awareness, and inform communication strategies.

b. Crowdsourcing epidemiology

Digital epidemiology is the process of analysing (often publicly available) data to generate epidemiological insights. The practice is now becoming something of a discipline in its own right.[56] The data analysed in digital epidemiology are not just from medical sources (like digital health records) or outbreak investigations, but can come from more general sources, generated from “search engines, social media services, mobile phones, website access logs – all sources that generate data without the purpose of doing epidemiology”, but that can provide epidemiological insights.[56]

One of the most valuable factors in the growth of digital epidemiology is that the general public often analyse the available data of their own accord, and without tangible benefit to themselves. This is the essence of crowdsourcing. The American author, Daniel Pink, perfectly captured the drive of the public to contribute to communal projects by comparing the economic models of two digital encyclopedias: Microsoft Encarta, where professional writers were paid for their contributions, and Wikipedia, where anyone could contribute or edit articles online. Pink points out that no "sober economist" would have predicted the success of the Wikipedia business model over that of Encarta, which ceased operation in 2009.[58] Pink attributes this to the intrinsic motivation of the crowd, who are naturally curious and want to contribute to something they see as worthwhile and achieve mastery of a set of skills. One of the few limitations on participation is the availability of reliable data.

Of course, having anyone participate in digital epidemiology will create some problems with reproducibility and reliability. However, the fact that both the inputs and outputs to crowdsourced digital epidemiology are publicly available means that the system is, to an extent, self-correcting. The benefit of crowdsourcing is that it harnesses the collective minds of the world to generate novel insights. This was seen in the MERS-CoV case study where an Australian doctor, otherwise unconnected to the MERS-CoV cases, correctly speculated that an outbreak of respiratory illness in Jordan in April 2012 might have been caused by the coronavirus that was identified in September 2012. Digital epidemiology is not necessarily without structure or norms, and people power (and that of their individual personal computers) can also be harnessed to crunch data in purposefully designed, hypothesis-testing experiments.

Digital epidemiology is a developing science. The tools to conduct that research are readily available, as is the manpower. The main constraint in this field is that data are sometimes unavailable, and this limits the sorts of insights that can be generated. We should encourage corporate entities (including social media corporations) to share non-proprietary data as openly as possible. There should be a push to view data as a global public good for health (Fidler, 2003) and resist the recent trend towards viewing data as an asset or resource belonging to the nation state from which it originated,[59] or the person or people who generated it.[56]

c. Special considerations for data sharing on emerging pathogens:

There is always a tension between speed and accuracy when it comes to releasing scientific data. The prioritisation of speed can lead to mistakes while increasing the quality of the data before public release can result in delays. This idea was presented most clearly in this case study in the practice of scientists sharing draft MERS-CoV genome sequences over email before the data had been verified for public release [see Section 3(b)]. The recipients were well aware of the limitations of the pathogen sequence data which was still useful in this draft form, but certainly not in an appropriate state to be published on an official sequence repository. The lesson here is that with the emergence of a novel pathogen where there is very little known, there is a case to be made for prioritising speed of release over accuracy, at least in the early days of the outbreak. For example, in the case of an emerging pathogen like MERS-CoV, it may be appropriate to share surveillance information before the cases have been confirmed by the laboratory.

Reporting suspected cases before laboratory confirmed diagnosis "enables a first crude estimation of the positive predictive value of different signs and symptoms" which is extremely important "in the context of an emerging pathogen".[58] Some have suggested real-time digital data sharing for pathogen genetic sequence data,[60] and integration of that data with public health surveillance data. However, releasing unverified information without context can be damaging and can erode trust if the data are

later shown to be unreliable. An infectious disease specialist who had travelled to Saudi Arabia to assist with a hospital associated outbreak of MERS-CoV in 2013 stated that "[t]he only thing worse than not sharing data is sharing data that turns out to be not correct".[57] One interviewee stated that one way to build trust as a source of data and information is to provide updated information as it becomes available, as opposed to waiting for a clear picture to emerge before releasing data.

The timing issue is a major consideration for communicating information and risk to the general public. Authorities do not want to release too much information about new infections while the process of contact tracing is ongoing. But if the public (or the media) sense that there is something going on before official information has been released, the trust of the public is immediately threatened, as was the case for South Korea in 2015.

Another special consideration for data collection during an outbreak of a previously unknown pathogen is the collection of as much data as possible, even if it seems irrelevant to the outbreak. This was noted in the MERS-CoV case study where the link between camels to primary infections was delayed, in part, because of cultural reasons. Taking (what some may consider) overly detailed patient histories may help in establishing these sorts of epidemiological links earlier but can also be interpreted as impinging on patient privacy. It may be necessary to conduct more thorough and probing patient questioning in the early days of an outbreak of a novel pathogen.

d. Agreeing to standardised data sharing protocols before emergencies:

One interviewee stated that the international global health community was struggling to get away from an *ad hoc* approach to outbreak and research response, including data sharing practices. This sentiment has led to calls for standardised data sharing protocols that can be applied in public health emergencies.

> *"Both the avian flu virus and the MERS-CoV cases strongly point to the need not only for pre-negotiated transfer agreements but also for standardized "best practices" guidelines for highly virulent emerging disease materials where expedited sharing of material and data is of paramount importance."*[61]

One interviewee noted that at the beginning of the MERS-CoV outbreak the epidemiological data from Saudi Arabia was incomplete and it took time for the WHO to communicate precisely what data was required from Saudi Arabia. Defined data sharing protocols could provide a baseline, but one interviewee noted that in some circumstances, like the MERS-CoV outbreak, there are requirements to update those baseline standards to ensure the collection of additional types of data designed to meet the specific needs of the outbreak investigation and response. Standardised data sharing protocols will likely be useful, but it is worth noting that different countries have vastly different capacities to collect, collate and disseminate data.[62] Another point borne out by this case study is that even when countries have the capacity to conduct their own epidemiological investigations, it is still worth bringing outsiders into the affected region as this provides a different perspective and can help to identify areas for improvement. Anthropologists and other social scientists also provide a valuable source of qualitative data and information for which it is difficult to specify parameters. Therefore, standardised data sharing protocols will only ever be able to provide a baseline of what is expected during public health emergencies.

Data sharing protocols that are developed prior to public health emergencies may come up against other international agreements such as the UN's *Convention on Biological Diversity* and its associated *Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising*

from their Utilization (Nagoya Protocol). Under these instruments, nation states have sovereign authority over any genetic resources in their territorial borders. This certainly includes pathogens and may even include the genetic sequence data associated with the pathogen. Furthermore, the WHO has made some indications that they consider the epidemiological data associated with outbreaks to belong to the nation state from which it originated.[59] Any standardised data sharing protocols will have to be congruent with these existing (and legally binding) international agreements.

The WHO's *Pandemic Influenza Preparedness Framework* (PIP Framework) (which recognises that countries have sovereign rights to their biological resources) creates a set of legal norms for the sharing of potentially pandemic influenza viruses and associated data. One interviewee stated that an extension of the PIP Framework to include other pathogens may encourage the sharing of pathogens and associated data during public health emergences. This possibility, and that of reconciling the *Convention on Biological Diversity* and its *Nagoya Protocol* with the requirement for unimpeded data sharing during public health emergencies, are currently under discussion at the WHO and other UN bodies.

e. Encouraging press freedom around the world

This case study highlights the importance of the media in investigating outbreaks, providing crucial context to the data with stories about personal experiences of the outbreak, and highlighting deficiencies in the response to outbreaks. This is a vital form of information sharing that is often overlooked in discussions about data and information sharing during public health emergencies. State control of the media was also a problem during the SARS outbreak in 2003 when the Chinese government restricted media coverage of the event.[50]

A free press promotes the flow of information and a critical examination of the power structures that may be inhibiting the response to the outbreak. The media also gives a voice to the people who are suffering from the outbreak and can encourage action by ensuring sustained attention is paid to public health crises. A free press is not only considered a basic human right by the UN's Educational Scientific and Cultural Organization (UNESCO), the promotion of a free press across the nations of the world will support information sharing efforts during public health emergencies. Other countries can contribute to encouraging press freedoms and promoting the free flow of information and ideas by implementing improved protections for journalists who challenge government agencies and officials in authoritarian nations.

f. Clarifying the confusion around pathogen and data ownership rights

One major source of confusion during the MERS-CoV outbreak and research response was the assertion of both intellectual property rights and sovereign rights over the pathogen itself and/or the genetic sequence data of the pathogen. There are ongoing efforts to clarify these issues at both the WHO and other UN bodies, including the World Intellectual Property Organisation (WIPO) and the UN Environment Programme (UNEP), however, progress has been slow. The confusion about ownership rights over MERS-CoV made some research groups hesitant to conduct research on the virus as they were wary of legal consequences and potential damage to their reputation. Further interdisciplinary research is required to clarify the confusion over ownership rights to pathogens and associated data.

5. Conclusion:

If there is a unifying theme to this case study on data sharing during the MERS-CoV outbreak and research response, it is confusion. At the start of an outbreak of a novel pathogen there is little

information or clarity about what is occurring. Requests for information are simultaneously coming from a variety of parties (other governments, NGOs, watchdog organisations, scientists and other researchers) and, for the most part, these requests are individually reasonable. But those requests are often made of the same government department (e.g. Ministry of Health), particularly in the early days of a looming crisis when an incident has just occurred, it is not clear what that incident portends, and no additional resources have been diverted to that department to address the incident. It may not, therefore, be reasonable to expect immediate responses when a single department is being deluged with requests. Quite often the department is not fully aware of what is occurring themselves and are awaiting answers to their own requests for information from subnational bodies (e.g. hospitals and local public health teams).

These situations are confusing and often frightening for the leaders of nations first affected by a novel pathogen. If the government does not get the opportunity to adequately appraise the situation before informing the international community, they risk causing unwarranted panic and adversely affecting tourism and trade. There is a fine line between waiting for enough information to provide an informed appraisal of the situation and appearing to be intentionally withholding information. When studying these incidences, it is sometimes difficult to remember that what is known now was not known then. When one considers the overwhelming confusion of these situations, it becomes easier to understand the motivations of stakeholders who are otherwise easy to criticise with hindsight.

As stated from the outset, the key limitation to this study was that nobody from Saudi Arabia consented to be interviewed, so we could only guess at their motivations and intentions when it came to data sharing practices. We attempted to ensure that their perspective was given due consideration through the selection of other interviewees. The figure of the former Saudi Deputy Minister of Health loomed large in this case study, and his perspective and insights on the issue were obtained through a 1 hour 52 minute presentation filmed by the UPMC Center for Health Security in 2013.[22] This, however, does not provide a comprehensive understanding of the Saudi response to MERS-CoV and it is our recommendation that future studies address this key gap in the understanding around data sharing practices during the MERS-CoV outbreak and research response.

Multiple interviewees expressed relief that the MERS virus was not as readily transmissible between humans as SARS had been. It was the characteristics of the virus itself that meant that the data sharing delays examined in this case study were not utterly catastrophic; in many ways we were just lucky this time.

Bibliography:

1. Zaki AM. Novel coronavirus - Saudi Arabia: human isolate. *ProMED-mail*. 2012. http://www.promedmail.org/direct.php?id=1302733. Accessed July 11, 2018.
2. Zaki AM, van Boheemen S, Bestebroer TM, Osterhaus ADME, Fouchier R a. M. Isolation of a Novel Coronavirus from a Man with Pneumonia in Saudi Arabia. *N Engl J Med*. 2012:121017140031005. doi:10.1056/NEJMoa1211721.
3. de Groot RJ, Baker SC, Baric RS, et al. Middle East Respiratory Syndrome Coronavirus (MERS-CoV): Announcement of the Coronavirus Study Group. *J Virol*. 2013;87(14):7790-7792. doi:10.1128/JVI.01244-13.
4. WHO Regional Office for the Eastern Mediterranean. MERS situation update, June 2018. 2018. http://www.emro.who.int/pandemic-epidemic-diseases/mers-cov/mers-situation-update-june-2018.html. Accessed July 10, 2018.
5. World Health Organization. *2018 Annual Review of Diseases Prioritized under the Research and Development Blueprint*. Geneva; 2018. http://www.who.int/emergencies/diseases/2018prioritization-report.pdf?ua=1. Accessed July 11, 2018.
6. Al-Gethamy M, Corman VM, Hussain R, Al-Tawfiq JA, Drosten C, Memish ZA. A case of long-term excretion and subclinical infection with middle east respiratory syndrome coronavirus in a healthcare worker. *Clin Infect Dis*. 2015;60(6):973-974. doi:10.1093/cid/ciu1135.
7. World Health Organization. *Middle East Respiratory Syndrome Coronavirus (MERS-CoV) WHO MERS-CoV Global Summary and Assessment of Risk (Current Situation 21 July 2017)*. Geneva; 2017. http://www.who.int/emergencies/mers-cov/risk-assessment-july-2017.pdf?ua=1. Accessed July 11, 2018.
8. World Health Organization. Middle East respiratory syndrome coronavirus (MERS-CoV). 2018. http://www.who.int/news-room/fact-sheets/detail/middle-east-respiratory-syndrome-coronavirus-(mers-cov). Accessed July 10, 2018.
9. Arabi YM, Balkhy HH, Hayden FG, et al. Middle East Respiratory Syndrome. *N Engl J Med*. 2017;376(6):584-594. doi:10.1056/NEJMsr1408795.
10. Falzarano D, Kamissoko B, de Wit E, et al. Dromedary camels in northern Mali have high seropositivity to MERS-CoV. *One Heal*. 2017;3:41-43. doi:10.1016/J.ONEHLT.2017.03.003.
11. Butler D. Tensions linger over discovery of coronavirus. *Nature*. 2013:1-5. doi:10.1038/nature.2012.12108.
12. Sane J, Edelstein M. *Overcoming Barriers to Data Sharing in Public Health: A Global Perspective*. Chatham House; 2015.
13. Yozwiak NL, Schaffner SF, Sabeti PC. Data sharing: Make outbreak research open access. *Nature*. 2015;518:477-479. doi:10.1038/518477a.
14. Perl TM, Price CS. Orchestrated scientific collaboration: Critical to the control of MERS-CoV. *Ann Intern Med*. 2015;163(4):313-314. doi:10.7326/M15-1395.
15. McNabb SJN, Shaikh AT, Nuzzo JB, Zumla AI, Heymann DL. Triumphs, trials, and tribulations of the global response to MERS coronavirus. *Lancet Respir Med*. 2014;2(6):436-437. doi:10.1016/S2213-2600(14)70102-X.
16. World Health Organization. WHO statement on the tenth meeting of the IHR Emergency Committee regarding MERS. *WHO*. 2015. http://www.who.int/mediacentre/news/statements/2015/ihr-emergency-committee-mers/en/. Accessed July 12, 2018.
17. Cha V. The next MERS outbreak. *Korea Joongang Daily*. http://koreajoongangdaily.joins.com/news/article/article.aspx?aid=3009443. Published September 21, 2015. Accessed July 19, 2018.

18. Zumla A. Equitable partnerships for tackling killer infectious diseases. *Lancet Glob Heal Blog*. 2013;26 July 20. http://globalhealth.thelancet.com/2013/07/26/equitable-partnerships-tackling-killer-infectious-diseases. Accessed October 16, 2018.
19. Fidler DP. Who Owns MERS? The Intellectual Property Controversy Surrounding the Latest Pandemic. *Foreign Aff*. 2013. https://www.foreignaffairs.com/articles/saudi-arabia/2013-06-06/who-owns-mers. Accessed August 15, 2017.
20. Branswell H. Saudi Silence on Deadly MERS Virus Outbreak Frustrates World Health Experts. *Sci Am*. 2013. http://www.scientificamerican.com/article/saudi-silence-on-deadly-mers-virus-outbreak-frustrates-world-health-experts/. Accessed July 16, 2018.
21. Youde J. MERS and global health governance. *Int J*. 2015;70(1):119-136. doi:10.1177/0020702014562594.
22. Johns Hopkins Center for Health Security. *Insights from the Front Lines of the MERS Outbreak*. United States of America: Youtube; 2013. https://www.youtube.com/watch?v=oL9buB78RTw.
23. McDowall A, Kelland K. Saudi Arabia sacks minister criticised over handling of MERS. *Reuters*. https://uk.reuters.com/article/uk-health-mers-saudi/saudi-arabia-sacks-minister-criticised-over-handling-of-mers-idUKKBN0EE1HK20140603. Published June 4, 2014.
24. Helen Branswell. MERS's best friend is ignorance, so it's time to wise up. *IRIN*. 2015. http://www.irinnews.org/analysis/2015/06/16/mers's-best-friend-ignorance-so-it's-time-wise. Accessed September 25, 2018.
25. Youde J. The 5 things you need to know about MERS (and global health). *Washington Post*. https://www.washingtonpost.com/news/monkey-cage/wp/2015/06/12/the-5-things-you-need-to-know-about-mers-and-global-health/. Published June 12, 2015.
26. Editorial. Present danger. *Nature*. 2014;510(7505):311. doi:10.1038/510311a.
27. Heymann DL, Liu J, Lillywhite L. Partnerships, Not Parachutists, for Zika Research. *N Engl J Med*. 2016;374(16):1504-1505. doi:10.1056/NEJMp1602278.
28. Branswell BH. Progress in MERS research may be in sight. *Global News - Canada*. https://globalnews.ca/news/700097/progress-in-mers-research-may-be-in-sight/. Published July 8, 2013.
29. Kim K, Jung K. Dynamics of Interorganizational Public Health Emergency Management Networks: Following the 2015 MERS Response in South Korea. *Asia Pacific J Public Heal*. 2018;30(3):207-216. doi:10.1177/1010539518762847.
30. World Health Organization. Case of imported MERS reported in Republic of Korea. *WHO West Pacific Reg*. 2018. http://www.wpro.who.int/mediacentre/releases/2018/20180909/en/. Accessed October 1, 2018.
31. Kelland K. Transparency, teamwork key to beating deadly S.Korea MERS outbreak. *Reuters*. https://uk.reuters.com/article/health-mers-transparency/transparency-teamwork-key-to-beating-deadly-s-korea-mers-outbreak-idUKL5N0YP1DE20150603. Published June 3, 2015.
32. Choe S-H. Experts Fault South Korean Response to MERS Outbreak. *The New York Times*. June 13, 2015.
33. The Korean Society of Infectious Diseases, Korean Society for Healthcare-associated Infection Control and Prevention. The same middle east respiratory syndrome-coronavirus (MERS-CoV) yet different outbreak patterns and public health impacts on the far east expert opinion from the rapid response team of the Republic of Korea. *Infect Chemother*. 2015;47(4):247-251. doi:10.3947/ic.2015.47.4.247.
34. Ji-hye S. Korea mulling disclosure of MERS-affected hospitals. *The Korea Herald*. http://www.koreaherald.com/view.php?ud=20150602001071. Published June 2, 2015.
35. KH디지털2. S. Korea identifies 24 MERS-affected hospitals. *The Korea Herald*. http://www.koreaherald.com/view.php?ud=20150607000157. Published June 7, 2015.

36. Dion M, AbdelMalik P, Mawudeku A. Big Data and the Global Public Health Intelligence Network (GPHIN). *Canada Commun Dis Rep*. 2015;41(9):209-214. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5933838/.
37. Freedom House. Saudi Arabia - Freedom of the Press 2012. 2012. https://freedomhouse.org/report/freedom-press/2012/saudi-arabia. Accessed October 16, 2018.
38. Hsieh JG, Hsu M, Wang YW. An anthropological approach to teach and evaluate cultural competence in medical students - The application of mini-ethnography in medical history taking. *Med Educ Online*. 2016;21(1):1-6. doi:10.3402/meo.v21.32561.
39. Kim D-H. Structural Factors of the Middle East Respiratory Syndrome Coronavirus Outbreak as a Public Health Crisis in Korea and Future Response Strategies. *J Prev Med Public Heal*. 2015;48(6):265-270. doi:10.3961/jpmph.15.066.
40. Kupferschmidt K. As Outbreak Continues, Confusion Reigns Over Virus Patents. *Science News*. http://news.sciencemag.org/people-events/2013/05/outbreak-continues-confusion-reigns-over-virus-patents. Published May 28, 2013.
41. Haagmans BL, Bestebroer TM, van Boheemen S, et al. Patent WO 2014/045254 A2. 2014.
42. Rimmer M. The race to patent the SARS virus: The TRIPS Agreement and access to essential medicines. *Melb J Int Law*. 2004;5(2):335-374.
43. Erasmus Medical Center. Erasmus MC: no restrictions for public health research into MERS coronavirus. *Press Release*. 2013. https://www.erasmusmc.nl/perskamer/archief/2013/4164294/?lang=en.
44. Stewart A, van Caenegem W, Bannister J, Liberman A, Lawson C. *Intellectual Property in Australia*. Vol 6th ed. Chatswood: LexisNexis Butterworths; 2018.
45. BBC. WHO urges information sharing over novel coronavirus. *BBC News Services*. https://www.bbc.com/news/health-22649922. Published May 24, 2013. Accessed October 16, 2018.
46. Branswell H. Saudi paperwork demands delay work to research to find MERS. *Canadian Press*. June 8, 2013.
47. MacKenzie D. Saudis say Dutch patent on MERS virus hampers research. *New Scientist*. https://www.newscientist.com/article/dn23593-saudis-say-dutch-patent-on-mers-virus-hampers-research/. Published May 24, 2013.
48. Hammond E. Material Transfer Agreement underlying the controversy over patent rights and the Middle Eastern Respiratory Syndrome Virus. *Third World Netw*. 2013. http://www.twn.my/title2/biotk/2013/biotk130502.htm.
49. World Health Organization. WHO collaborative multi-centre research project on Severe Acute Respiratory Syndrome (SARS) diagnosis. *World Heal Organ*. 2003. http://www.who.int/csr/sars/project/en/. Accessed October 17, 2018.
50. Fidler DP. SARS: Political Pathology of the First Post-Westphalian Pathogen. *J Law, Med Ethics*. 2003;31(4):485-505. doi:10.1111/j.1467-923X.1966.tb00184.x.
51. Heymann DL, Rodier G. SARS : A Global Response to an International Threat. *Brown J World Aff*. 2004;10(2):185-197.
52. Bin Saeed AA, Abedi GR, Alzahrani AG, et al. Surveillance and testing for middle east respiratory syndrome coronavirus, Saudi Arabia, april 2015–february 2016. *Emerg Infect Dis*. 2017;23(4):682-685. doi:10.3201/eid2304.161793.
53. Williams HA, Dunville RL, Gerber SI, et al. CDC's Early Response to a Novel Viral Disease, Middle East Respiratory Syndrome Coronavirus (MERS-CoV), September 2012–May 2014. *Public Health Rep*. 2015;130(4):307-317. doi:10.1177/003335491513000407.
54. Pollack MP, Pringle C, Madoff LC, Memish ZA. Latest outbreak news from ProMED-mail. Novel coronavirus - Middle East. *Int J Infect Dis*. 2013;17(2):e143-e144.

doi:10.1016/j.ijid.2012.12.001.
55. Lucey DR. Still learning from the earliest known MERS outbreak, Zarqa, Jordan, April 2012. *Clin Infect Dis*. 2014;59(9):1234-1236. doi:10.1093/cid/ciu638.
56. Salathé M. Digital epidemiology: what is it, and where is it going? *Life Sci Soc Policy*. 2018. doi:10.1186/s40504-017-0065-7.
57. Fung IC, Fu K, Ying Y, et al. Chinese social media reaction to the MERS-CoV and avian influenza A (H7N9) outbreaks. *Infect Dis Poverty*. 2013;2(31):1-12. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5933838/.
58. Pink DH. *Drive: The Surprising Truth About What Motivates Us*. Edinburgh: Canongate Books; 2009.
59. World Health Organization. Developing Global Norms for Sharing Data and Results during Public Health Emergencies. *WHO*. 2015. http://www.who.int/medicines/ebola-treatment/data-sharing_phe/en/. Accessed September 25, 2018.
60. Gardy J, Loman NJ, Rambaut A. Real-time digital pathogen surveillance - the time is now. *Genome Biol*. 2015;16(1):15-17. doi:10.1186/s13059-015-0726-x.
61. Milne-Price S, Miazgowicz KL, Munster VJ. The emergence of the Middle East Respiratory Syndrome coronavirus. *Pathog Dis*. 2014;71(2):119-134. doi:10.1111/2049-632X.12166.
62. Edelstein M, Lee LM, Herten-Crabb A, Heymann DL, Harper DR. Strengthening Global Public Health Surveillance through Data and Benefit Sharing. *Emerg Infect Dis*. 2018;24(7):1324-1330. doi:10.3201/eid2407.151830.