

This article was downloaded by: 10.3.98.104

On: 22 Jan 2021

Access details: *subscription number*

Publisher: *Routledge*

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: 5 Howick Place, London SW1P 1WG, UK



## **Routledge Handbook of Global Health Security**

Simon Rushton, Jeremy Youde

### **Internet Surveillance and Disease Outbreaks**

Publication details

<https://www.routledgehandbooks.com/doi/10.4324/9780203078563.ch19>

Sara E. Davies

**Published online on: 26 Aug 2014**

**How to cite :-** Sara E. Davies. 26 Aug 2014, *Internet Surveillance and Disease Outbreaks from:* Routledge Handbook of Global Health Security Routledge

Accessed on: 22 Jan 2021

<https://www.routledgehandbooks.com/doi/10.4324/9780203078563.ch19>

**PLEASE SCROLL DOWN FOR DOCUMENT**

Full terms and conditions of use: <https://www.routledgehandbooks.com/legal-notices/terms>

This Document PDF may be used for research, teaching and private study purposes. Any substantial or systematic reproductions, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The publisher shall not be liable for an loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

## 19

INTERNET SURVEILLANCE AND  
DISEASE OUTBREAKS*Sara E. Davies*

In March 2013, the People's Republic of China (hereafter referred to as China) reported to the World Health Organization (WHO) that it had detected three human cases of a novel bird flu strain. Two of them proved fatal (Lancet 2013). The spread of the strain appeared to be limited to instances of direct contact between poultry and humans. WHO announced the new strain, H7N9, to the world the following day, including on Twitter. That same day, WHO's original tweet, which linked to a press announcement in Geneva, generated 100–200 retweets per hour. Over the next four days, retweets rose to 500 per hour (Norris 2013). It is clear that the Internet has become an important mechanism for reporting information about disease outbreaks. What is less clear is what sort of mechanism it is.

Prior to the publication of the H7N9 case history in the *New England Journal of Medicine* on 24 April 2013 (Li et al. 2013), discussion about H7N9 in the social media was facilitated by communications from the Chinese Ministry of Health, and primarily the Chinese National Influenza Centre (Butler & Cyranoski 2013). There were expressions of genuine surprise about the openness of the Chinese government – to the extent that one WHO official observed, “I almost wonder if we are missing something, their [the Chinese government] disclosure is so complete” (Interview with Author 2013b). However, whilst some expressed surprise and praised China's openness (Nature 2013), others pointed to anomalies regarding China's public disclosures (Garrett 2013). One assessment noted that, as with national surveillance in general, transparent reporting and responsiveness to outbreaks was not consistent across the country (Huang 2013).

This case, and others like it, exemplifies how global disease reporting has changed in the Internet age, and why for some global surveillance by technical providers – called Internet surveillance response programs (ISRPs) – is vital for detecting, analyzing, and reporting outbreak events around the world (Chan et al. 2010). ISRPs scour the Internet for signs of disease reports and then alert their subscribers independently of government authorities. Their proponents argue that ISRPs are uniquely able to penetrate the state to identify conversations, behaviors, and local reports in order to alert the international community to disease outbreaks – even when a state may wish to keep an outbreak within its borders secret.

In this chapter, I explore the growth of ISRPs that have, over the last two decades, increasingly mapped and reported disease outbreaks around the world. ISRPs are mostly open-source platforms that are widely seen as being vital for maintaining transparent lines of communication and reporting during infectious disease outbreaks (Brownstein et al. 2008). The proliferation of ISRPs

has prompted some to argue that it is now futile for states to try to cover up outbreaks of disease because global detection cannot be avoided (Shkabatur 2011). Yet while ISRPs have certainly changed practices in relation to the reporting of outbreak events, their capacity to gather and analyze information remains contingent on a number of factors external to technology. In particular, political and media freedoms, government structures, Internet coverage, and the diagnostic capacity of the ISRP itself, all influence ISRPs' capacity to reveal – and a state's capacity to conceal – outbreaks. Further, questions remain over how well ISRPs actually advance outbreak reporting rather than simply amplifying traditional surveillance activity (Huang 2013).

This chapter examines both the capacity of ISRPs to challenge states' response to disease outbreak events – by virtue of transparent communication – and their limits in three parts. First, I set out the types of ISRPs, their integration into the global disease surveillance system, and the various ways in which they seek to differentiate between “rumours” and “real time intelligence” (Wilson & Brownstein 2009). Second, I discuss limitations to ISRP data collection, particularly in relation to the claim that disease intelligence may be gleaned “in spite” of a state's wishes or gained “prior” to a state's knowledge (Brownstein et al. 2008). Finally, I consider how these limitations should be taken into consideration in understanding why states have agreed to allow the WHO to collect unverified information from “unofficial” non-state sources under the 2005 revised International Health Regulations (IHR).

The presumption that ISRPs make a positive contribution to global disease surveillance is especially interesting given broader debates in political science and international relations around the transformation of the relationship between politics and technology (i.e., Fung et al. 2013; Singh 2013). Internet surveillance cannot compel states to report disease outbreaks in an open and transparent fashion, especially when they are willing to risk the consequences of not reporting. However, past inaction (or conspiracy theories) should not lead us to misinterpret the desire of many states to overcome the limitations of ISRP technology to improve their own surveillance, alert, and response functionality. Many states (democratic or not) want to control the message during an (outbreak) crisis to limit damage. The analytical dilemma faced by ISRPs and the wider international community is knowing when the message is being controlled in an attempt to conceal an outbreak and when it is being controlled in order to positively manage risk communication.

### **ISRPs, WHO, and the International Health Regulations**

More than 60% of WHO's Alert and Response Operations first outbreak reports come from “unofficial informal sources,” which includes electronic media, discussion sites, and social media (WHO 2014). The proliferation of social media (e.g., Twitter, Facebook, Weibo) has led many ISRPs (e.g. BioCaster, PULS) to rely primarily upon “ontology software” for text mining and language translation to detect early reports or “rumours” of novel disease outbreaks. Others, such as GPHIN (Global Public Health Intelligence Network), rely on a combination of software and human analysts. Within GPHIN, analysts with language proficiency in Arabic, Farsi, English, Spanish, Russian, Chinese, Portuguese, and French sift through thousands of reports produced daily to determine which ones need to be placed on the subscriber-only alert page (which can also be emailed to subscribers).

Established in 1996, GPHIN was one of the first real-time surveillance networks to be created, having been developed in cooperation with WHO Headquarters and the Public Health Agency of Canada. Until the past year, its reports were primarily issued to fee-paying subscribers and therefore were not publicly accessible to those not affiliated with a subscribing government, international organization, or defense and security organization.

HealthMap, by contrast, has always been a free access Internet surveillance network that analyses media reports on a scale similar to GPHIN and also collates reports from other Internet surveillance providers such as MedISys (an EU joint research centre project) and ProMED Mail (PMM), which is now partnered with HealthMap. Presently, much focus is on improving text and string searches of blogs and social media sites to produce real-time alerts of disease outbreaks with color codes indicating source reliability (which entails “last minute” human moderation prior to posting), contextual use, and geographic location (Castillo-Salgado 2010; Collier 2010).

Since 2005, international responses to disease outbreaks, including verification, containment, and alert procedures, have been guided by the revised International Health Regulations (IHR) (see also Heymann & West, chapter 8, and Hoffmann, chapter 20, in this volume). Under the revised IHR, both state and non-state actors may communicate to WHO outbreak events that meet the IHR “Public Health Emergency of International Concern” (PHEIC) criteria. Under Article 9, the WHO may take into account “sources other than [state, formal] notifications or consultations” and “assess these reports according to established epidemiological principles and then communicate information on the event to the State Party in whose territory the event is allegedly occurring” (WHO 2005: Article 9.1). States are expected to respond to WHO communications based on non-state reports within 24 hours, while the *source* of the report is permitted to remain confidential. Confidentiality may not be of paramount importance for ISRPs such as GPHIN or BioCaster (depending of course on the ISRP’s own source, which could be the media or an individual informant), but for some individuals, non-governmental organizations, and religious organizations who may also inform WHO of outbreak events, confidentiality can be critical.

The significance of Article 9 was best explained by WHO’s (then) Director of IHR Coordination, Dr Guénaél Rodier:

*In today’s information society, you cannot ignore or hide a problem for very long. You can perhaps ignore or hide an event for a day or two, but after a week it’s virtually impossible. WHO and its partners have a powerful system of gathering intelligence that will pick anything up immediately. Today, events are often initially reported, not by a Member State, but by non-official sources such as the media, NGOs (nongovernmental organizations), our network of collaborating centres, laboratory networks and partners in the field. . . . One of the incentives for countries to report such events is that these will already have been reported via the electronic highway. We will be in a much better position to help if we have been involved early on by the affected country. The fear of being named and shamed by the media and other countries concerned by the situation is in itself an incentive.*

(Rodier 2007: 429, emphasis added)

The added value provided by ISRPs is their analytical capability, which allows them to separate the “signal from the noise” (Brownstein et al 2008: 1019). Picking up the signal does not just alert WHO but, in many cases, also the affected state itself that an outbreak is occurring. However, Article 9 is also seen as providing a coercive tool that makes states aware of the real possibility of being “named and shamed” if they fail to report in a timely fashion. This observation is, arguably, supported by earlier cases in which early alerts enabled WHO to seek further information from first-affected member states, as in the SARS outbreak in China (2002–2003),<sup>1</sup> the H5N1 Avian Influenza strain’s emergence in Thailand and Vietnam, the human infections of H5N1 in Indonesia, and, more recently, the H1N1 “Swine Flu” outbreak in Mexico in early 2009. Initial alerts for these outbreaks came from PMM, GPHIN, and HealthMap (Brownstein et al. 2009; Madoff & Woodall 2005).

Much attention has been devoted to the comparative efficiency of ISRPs (Castillo-Salgado 2010; Collier 2010; Hitchcock et al. 2007), their ability to push states towards transparency (Fidler 2004; Heymann & Rodier 2004; Madoff & Woodall 2005), and the need for greater interoperability to improve their surveillance and alert performance (Hartley et al. 2010). GPHIN, for example, has been essential to WHO's capacity to identify disease events and provide direct assistance to states, sometimes prior to those states and neighboring states being aware of the extent of the outbreak themselves (Mykhalovskiy & Weir 2006). As Pat Drury, head of Global Outbreak Alert and Response Network (GOARN) based at WHO Headquarters, argued to the United Kingdom's Intergovernmental Organizations Select Committee in 2008, such "sources of information" help the WHO special operations center identify which media and incident reports need to be assessed for risk to the local and international community, which in turn leads to recommendations for the country and the WHO to take appropriate action (United Kingdom Parliament 2008: 211).

SARS is often seen as a landmark case that convinced states that in the future they would be unable to prevent the leakage of information about disease outbreaks:

[P]erhaps the greatest legacy of SARS, disease reporting changed almost overnight from being approached with hesitancy and preoccupation with concern about the potential economic fallout from such transparency, to something that was simply expected and respected.

(Heymann et al. 2013: 780)

During the H1N1 "Swine Flu" outbreak in 2009, it has been argued that the value of Article 9 [in revised IHR (2005)] in assisting with real time intelligence gathering on disease outbreaks was effectively demonstrated:

During the 2009 H1N1 influenza pandemic, non-traditional surveillance sources such as Internet news sources provided new public health data. Collectively, these sources overcame certain limitations of traditional surveillance systems, including reporting delays, inconsistent population coverage, and a poor sensitivity to detect emerging diseases.

(Brownstein et al. 2010: 1733)

Surveillance of pandemic (H1N1) 2009 serves as an example of the real time capability of identifying emerging disease events in general, particularly events that may be evident in local media in the regional vernacular. Other event-based biosurveillance systems have demonstrated the effectiveness of extracting relevant information from Internet media sources as a means for detecting and monitoring disease events. Internet media reporting provides an emerging resource for early detection of new events and for providing situational awareness of evolving events, particularly when official sources may not be available.

(Nelson et al. 2012: 12)

Article 9 clearly articulates both the right of ISRPs to report an event to WHO and the authority for WHO to receive these alerts and to then seek verification from the state(s) concerned.

## Surveillance for action: The possibilities and limitations of ISRPs

Two rationales were at work in driving the adoption of Article 9 in the revised IHR, which opened the door to a formal role for Internet disease surveillance. First, it was not just WHO Headquarters that wanted to know about outbreaks that could pose a risk to health and trade. All states wanted this information, because they have a keen interest in knowing about diseases that might arise in their neighborhood. Second, whilst states certainly wanted to know about other states' outbreaks, they still believed that they could control information flows and that they have a sovereign right to do so. As a result of this second consideration, the revised IHR still requires WHO to consult the affected state before publicly announcing an outbreak event identified by an ISRP. Therefore, states agreed to Article 9 because, while there *is* some inevitability regarding information leakage, there also remained the possibility of them controlling the flow of information (at least initially) to manage the risk associated with an outbreak within their borders.

It is not always the case, however, that states are attempting to cover up outbreaks. In some cases, especially where public health capacity is weak, rumors may be the only source of information available about a particular outbreak. The question is, what do the revised IHR allow WHO to do with such information? In a 2008 article entitled "Surveillance sans frontières," the developers of HealthMap noted the multidimensional contribution of ISRPs in environments where states had not yet reached their IHR core capacity requirements.<sup>2</sup> It was argued that in these situations of compromised capacity, ISRPs effectively provide a communication service for many countries that do not have their own adequate communication-based health infrastructure. In that regard, it is worth noting that some ISRPs like GPHIN, until recently, provided a members-only platform to facilitate communication amongst members without public alerts. This reporting format allowed for the WHO to follow local outbreak information in real time and to assist with a state's verification process (Brownstein et al. 2008: 1020). Therefore, states and ISRPs do not necessarily exist in tension with one another. ISRPs can be a useful tool for states themselves.

However, ISRPs are only as useful as the information that they can glean. This problem is magnified if we take into account the fact that not all ISRPs operate in the same way. Some (such as HealthMap) are wholly reliant on open-source material, some (e.g., ProMED) rely on a combination of open-source and anonymous communications, and some (e.g., GPHIN) have both membership-only platforms and open-source platforms – which means that reports are not always shared across the open and closed platforms. These complications create the potential for confusion, duplication, breaches of confidentiality, and competition amongst ISRPs (Hartley et al. 2010). This informed the creation of the Global Health Security Action Group (GHSAG) under the Global Health Security Initiative (created in 2001), which is led by Ministers/Secretaries/Commissioners of Health from Canada, the European Commission, France, Germany, Italy, Japan, Mexico, the United Kingdom, the United States, and the World Health Organization. The GHSAG has been working for the last decade to promote movement towards a common global reporting platform shared by all ISRPs and managed by WHO. In the meantime, there have been annual discussions on the development of shared procedures around text analysis, alert and reporting procedures, and handling of controversial information (GHSI 2011: 4). The development of a shared platform by HealthMap and ProMED has been identified as a future example of how multiple ISRPs can combine to address these challenges (Barboza et al. 2013).

There are, however, other problems that affect ISRPs as well as more traditional reporting systems that are rarely discussed in the field (Brownstein et al. 2008: 1021–1022; see also Castillo-Salgado 2010; Hartley et al. 2010; Katz & Fischer 2010; Schmidt 2012). As such, in the rest of this section I will briefly examine the political implications of the limitations that Brownstein and his colleagues note, particularly problems associated with the reporting sources, surveillance "black

holes,” and report differentiation between suspected and confirmed outbreak events. These limitations suggest that states have retained more control over information flows than is often presumed, and that they might still be able to decide what they will allow to be reported publicly (and when), affecting in turn the timeliness claims of (some) ISRPs and the capacity of WHO to generate a timely response. Indeed, the fact that some ISRPs do not distinguish between suspected and confirmed reports might allow some recalcitrant states to create the appearance of compliance with the IHR without actually engaging in prompt, timely, and comprehensive reporting.

### **Sources**

ISRPs’ search functionality relies primarily on local reporting of disease events. The process for HealthMap, MedISys, and GPHIN involves text mining technology and access to large news aggregation sites such as FACTIVE. Human moderation steps in at various points to filter reports: GPHIN almost from the beginning, HealthMap in the middle, and Biocaster and MedISys literally prior to posting. Naturally the focus is on quality reporting – delivering real alerts with valid source credentials – as well as on posting relevant alerts of interest to the reader. Systems that can search for both naturally occurring diseases and other types of outbreak event (e.g., accidental or deliberate release of chemical or biological agents that are listed in the Annex 2 attached to the revised IHR) have a relatively high degree of added value, but the same tools can also generate results that are not relevant. Sifting through these reports to determine which is which is a complex technical task for these providers (Linge et al. 2009). Naturally these systems will produce a lot of search results or “rumours,” as Grein and his colleagues famously termed them (Grein et al. 2000), and thus they are almost bound to produce at least one accurate report of an outbreak. However, the importance and nature of the source itself is often overlooked in relation to these semantic and text mining searches.

To understand the efficiency, effectiveness and coverage of surveillance technologies – whether at the national or global level – we need to understand more about the political systems in which these technologies are operating. A quick scan of HealthMap’s output for 30 days, for example, will show a lot of news media sources, but the vast majority of their content has been informed by public health officials releasing outbreak news. In other words, these media reports are more often than not sourced from the government itself. This was noted by Brownstein and his colleagues (Brownstein et al. 2008: 1022), and again by Blench (Blench 2010: slide 19), when he showed that the quantity of verified official report sources is virtually equal to that of news media report sources. But this basic fact – that at least half of all “non-official” reports actually come from the government itself – has not yet penetrated discussion about the utility of ISRPs in promoting government transparency.

Identifying governments as a significant (even if indirect) source for ISRPs is important for two reasons. First, failure to acknowledge this fact feeds into the notion that states are not cooperating with the release of health information – when in fact they may be cooperating more than is recognized. Second, this neglect of the government’s role as a source of information inflates the “intelligence” capacity of ISRPs when in fact they may only be as good as they are in large part because governments generally make this information available. Therefore, what is new and needs to be emphasized is the search tool that ISRPs provide and the promotional impact of this information. The ISRPs themselves are probably generating much less information that is genuinely “new” or “non-governmental” than is commonly thought.

In some instances, governments are providing both the first suspect report and the subsequent official confirmation, but this is not identified as an important trend (Chan et al. 2010; Collier et al. 2008; Rotureau et al. 2007). Instead the focus is often on how such surveillance networks

encourage reluctant states to engage in more transparent behavior (Shkabatur 2011). We cannot know precisely to what extent ISRPs are ahead of states until there is a clearer distinction made in ISRP reporting between sources that have some level of associated government input and those that are wholly “independent.” This is a particular problem in this field, because most countries’ health sectors have a significant state component and some are wholly state-run.

Another complication that arises from the ISRPs’ lack of clarity about official involvement in the first outbreak report is that it is sometimes difficult to follow up on outbreak reports, i.e., to keep track of which “alert” was then “verified” as an actual outbreak (Rotureau et al. 2007). As such, deeper examination of the actual source of suspected outbreak reports and the level of “official” association should become standardized in ISRP alerts. Media agencies in a number of countries are state-owned, and media reporting and Internet usage are not without government interference in many parts of the world (O’Malley et al. 2009). This raises the need for more sensitive text mining, including free media and Internet ratings (for example, usage access in a country) and the introduction of (admittedly costly) human analysis that may be sensitive to these political contexts. Such a change goes against those ISRPs trending towards automated text processing algorithms, but the clarity gained by more sensitive text mining would enable the international community to have the tools to examine which states are progressing in meeting their IHR core capacities and which are not. This potentially uncaps the real transformative potential of ISRPs on state behavior.

### ***Black holes***

Noting the source limitations of ISRPs also allows us to realistically understand the contribution that they can make to shedding light on those places where the freedom to report is constrained, whether by politics or technology. HealthMap has argued that while 85% of its reports come from news media sources, there is a “clear bias towards increased reporting from countries with higher numbers of media outlets, more developed public health resources, and greater availability of electronic communication infrastructure” (Brownstein et al. 2008: 1021). HealthMap thus not only acknowledges an information bias, but a coverage bias towards the diseases that will pique public interest, reflected in media outlets’ choice to publish some outbreak-related stories and not others (Brownstein et al. 2008: 1022; Collier 2010: 12). The French Institute for Public Health Surveillance has noted similar concerns about the coverage gaps that their server has in particular geographic locations, and GPHIN has also referred to such coverage gaps (Blench 2008; Rotureau et al. 2007). What is the significance of these surveillance “black holes”?

Communication deficiencies in various locations and an inability to secure the local news for global consumption are the primary causes of surveillance “black holes” (Brownstein et al. 2008; Hartley et al. 2010). Less frequently discussed obstacles for Article 9 to reach its full potential are limits on the freedom of the Internet, the press and independent actors to report outbreaks that they deem to be a potential PHEIC. As Madoff and Woodall (2005: 729) argue, one of the most transformative aspects of PMM has been its provision of a portal for those in autocratic regimes to report disease outbreaks that they felt were being ignored, misdiagnosed or posed a risk of international spread, often at a cost to their own liberty.

A recent example of surveillance “black holes” compromising early knowledge on the location and spread of an outbreak has been the suspected novel coronavirus (MERS-CoV) in the Middle East. In the early stages following the virus’ identification in 2012, there was little information coming from the Middle East region, the suspected origin of MERS-CoV. Most information at this early stage came from affected individuals upon return to the United Kingdom, Europe, and Asia, after the 2012 Hajj pilgrimage (Branswell 2013a). For over a year, there



had been concerted efforts by WHO Headquarters and the WHO Middle East North African (MENA) Regional Office to gain access to countries that had reported small numbers of MERS-CoV cases (Ball 2013; Branswell 2013b; Cyranoski 2013). Surveillance technology was, for the most part, struggling to overcome political (control of Internet freedom and press) and cultural obstacles (normalization of sharing biodata) to gain access to reports of the outbreak from within the region itself (Interview with Author 2013a). The desire (at least originally) for the outbreak to be verified “discreetly” led to bilateral (as opposed to multilateral) virus-sharing arrangements between research laboratories and the affected states. However, these bilateral arrangements allegedly compromised WHO Headquarters’ promotion of a multilateral framework for sharing outbreak reports to facilitate global level alerts (Ball 2013). WHO Headquarters has continued to insist on dialogue, multipartner engagement and increased awareness of the purpose of *global* surveillance and reporting mechanisms with MENA states (WHO 2013).

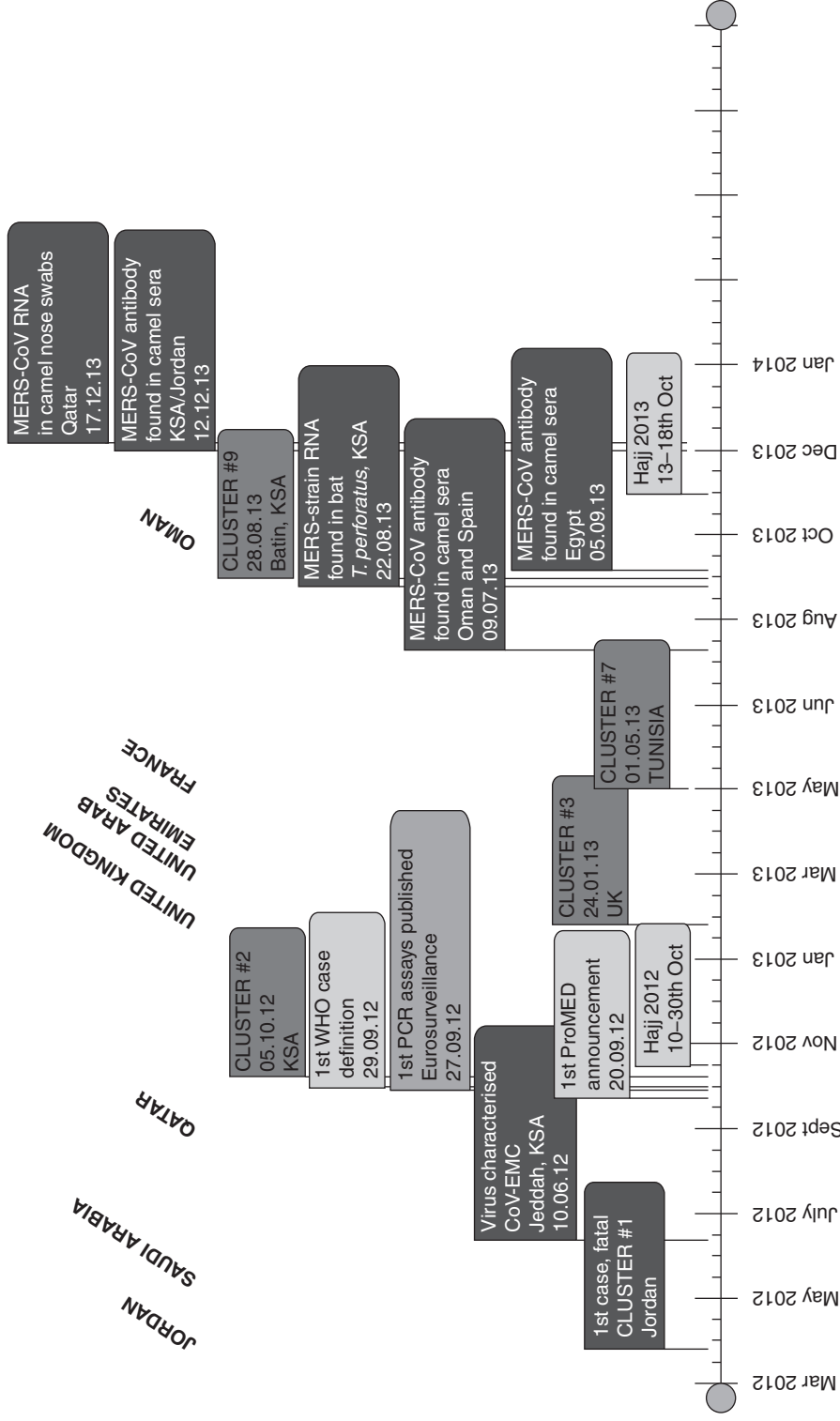
Given the obstacles encountered, without such concerted engagement efforts by WHO Headquarters – and in spite of the surveillance tools available – knowledge of MERS-CoV would still be quite poor and “murky”; indeed, some still regard this to be the case (Ball 2013; Branswell 2013b; Cyranoski 2013). For now, WHO intervention has (somewhat) alleviated the surveillance black hole that threatened MERS-CoV-related information flows (Interview with Author 2013a). But the black hole was a significant problem in 2012, and may have delayed the world’s response, as shown by the time lag between the suspected onset of cases reported in the first ISRP report and communicated in WHO’s report (see Figure 19.1, Mackay 2013). This case shows that states still play a vital role in disease outbreak reporting that WHO and ISRPs will struggle to bypass if they rely upon the provisions of Article 9 of the revised IHR.

In cases where rumor generation (through news, social media, etc.) is poor, the last option is for individuals to provide alerts. However, the provision of anonymity under Article 9 does not make it easier for NGOs or public health officials in countries where they are strictly bound to memoranda of understanding with their host government (i.e., North Korea) and where access to the Internet is limited, monitored, or regulated. There is little that ISRPs or WHO can do about these problems, but heightened awareness of the potential human rights implications of “early reporting” and the individual risks taken by those supplying such early warnings is important.

### ***Technical concerns***

The existence of ISRPs has certainly forced states to respond with better domestic surveillance and more prompt reporting, as indeed have the IHR revisions that allowed ISRPs and other communications to freely come to WHO outside of state control under Article 9. The technical revolution, the power of news media, and the pressure it can exert upon states is thus not to be underestimated, but its power to name and shame is reliant upon two important caveats: efficiency and accuracy (Keller et al. 2009).

As mentioned above, it is difficult to track country reporting performance between first report of an event and first government confirmation (i.e., lab-confirmed diagnosis). Not every country reports in the same fashion. When an ISRP publishes summaries or actual lab reports from some countries, this is often the first public knowledge of an outbreak, while other states have regular outbreak reports of suspected events and then sometimes follow up with lab diagnostics (Rotureau et al. 2007: 1591). Obviously timeliness and quality are not the same in these two examples. In countries where most laboratory reports are the first reports to emerge of a disease outbreak, it is impossible to know with surety when the state identified the first cases or how many cases prior to the one reported were either never tested or were hushed up. Alternatively, where states provide a high volume of information on suspect outbreak investigations, it can be difficult to trace those



A timeline showing some key events starting from the first retrospectively confirmed human case of infection by the Middle East Respiratory Syndrome Coronavirus in June 2012.

Figure 19.1 Timeline of Key Events in MERS-CoV Outbreak, June 2012  
 Source: Mackay 2013.

that were followed up with lab diagnostics versus those that were not. Essentially, the world knows a lot about the diseases it is most interested in or that it knows to be on the “look out for” (Collier 2010: 14–15). But ISRPs may not make us any better at predicting the unknown. This, arguably, compromises transparency promises, responsiveness, and most of all reveals the limitations of what this intelligence can deliver without the necessary political, social and economic reform (Lancet 2007: 2763; O’Malley et al. 2009).

Technology will be continually adapted in the attempt to overcome the limitations states seek to put on open reporting, but there will remain important political, institutional, cultural, social, and economic limitations on the freedom of individuals to engage in these technologies and to use them for the purpose of preventing and containing a PHEIC.

## Conclusion

There can be no doubt that the emergence of non-state based information about suspected disease outbreaks and the communication of this information to WHO heralds an important development in the field. But we need to understand both its transformative potential and its limitations. Three key points warrant emphasis in this regard.

First, there remain profound limitations to the communication of information in despotic and autocratic regimes that do not respect the basic political or civil freedoms needed to facilitate free communication. This in turn limits the capacity of institutions and individuals within the country to act freely under Article 9 without fearing any repercussions. The fact that there has been such little discussion of this, and especially the practical implications of the confidentiality clause under IHR (2005), remains a cause for concern (O’Malley et al. 2009).

Second, we need to acknowledge the role of the state in implementing Article 9 and how it influences the work of ISRPs specifically. The claims made for ISRPs are that they can locate outbreak events in spite of a state’s effort to cover them up (Castillo-Salgado 2010: 104; Grein et al. 2000: 348), and that they can assist public health officials in detecting an event of which they were previously unaware (Shkabatur 2011: 428). Rarely is it acknowledged that an ISRP may have “found” an outbreak that the state already knew existed, or that an ISRP found it *only because the state reported the event*. As such, the promise that the public airing of the “signal” creates the impetus for states to act is a problematic claim because in many cases the state is itself involved in generating the signal in the first instance.

Finally, differentiating between who is giving the signal, what the signal entails, and the political context in which the signal exists, remains important. If ISRPs ultimately come to share a common surveillance platform – where reporting and verification reports are coordinated to have universal impact – we may see an entity emerge that has significant capacity to generate compliance (Grein et al. 2001). At present the multiple ISRPs place different emphases on sources, as well as employ different alert and report methods. A shared global surveillance platform would highlight gaps in coverage, making it easier to identify states and regions that have hitherto eluded surveillance. Yet even in these circumstances, a state’s capacity to meet the core reporting requirements of the IHR (2005) will remain critical since compliance failures can be as much about incapacity as political choice.

## Notes

- 1 WHO used “Web-based systems trawling for unusual health events” to seek clarification on the “rumours” of higher than usual pneumonia outbreaks in Southern China over 2002–2003 that turned out to be SARS (Heymann 2013).

- 2 Under the revised IHR, states agreed to meet eight core capacity conditions by 1 July 2012 in the fields of national legislation, policy and financing, creation and coordination of National Focal Point (NFP) communications, surveillance, response, preparedness, risk communication, and human resources and laboratories. It was widely presumed that not all member states would achieve these eight capacities by agreed timeframe (1 July 2012) but that they would identify areas where they needed assistance in order to map a timeframe for achievement of these core capacities with extensions granted on a case-by-case basis by the WHO Director-General.

## References

- Ball, J. (2013, June 23) 'New Mers-Coronavirus continues to smoulder', *BBC News*. Online. Available HTTP: <<http://www.bbc.co.uk/news/health-23003837>>.
- Barboza, P., Vaillant, L., Mawudeku, A., Nelson, N.P., Hartley, D.M., Madoff, L.C., Linge, J.P., Collier, N., Brownstein, J.S., Yangarber, R. and Astagneau, P. (2013) 'Evaluation of epidemic intelligence systems integrated in the early alerting and reporting project for the detection of A/H5N1 influenza events', *PLoS One*, 8. Online. Available HTTP: <<http://www.plosone.org/article/info:doi/10.1371/journal.pone.0057252>> (accessed 24 August 2013).
- Blench, M. (2008) 'Global Public Health Intelligence Network (GPHIN)', 8th AMTA Conference, Hawaii, 21–25 October. Online. Available HTTP: <<http://www.mt-archive.info/AMTA-2008-Blench.pdf>> (accessed 14 May 2014).
- Blench, M. (2010) Global Public Health Intelligence Network (GPHIN), Global Risk Forum Davos. Online. Available HTTP: <<http://www.slideshare.net/GRFDavos/idrcdavosmediumppt>> (accessed 10 October 2011).
- Branswell, H. (2013a, May 22) 'Canadian expert says Saudi coronavirus outbreak "complex" but reporting pending', *Global News*. Online. Available HTTP: <<http://globalnews.ca/news/580906/canadian-expert-says-saudi-coronavirus-outbreak-complex-but-report-pending/>> (accessed 14 May 2014).
- Branswell, H. (2013b, June 7) 'Saudi silence on deadly MERS virus frustrates world health experts', *Scientific American*. Online. Available HTTP: <<http://www.scientificamerican.com/article.cfm?id=saudi-silence-on-deadly-mers-virus-outbreak-frustrates-world-health-experts>>.
- Brownstein, J.S., Freifeld, C.C., Chan, E.H., Keller, M., Sonricker, A.L., Mekaru, S.R. and Buckeridge, D.L. (2010) 'Information technology and global surveillance of cases of 2009 H1N1 influenza', *New England Journal of Medicine*, 362: 1731–1735.
- Brownstein, J.S., Freifeld, C.C. and Madoff, L.C. (2009) 'Digital disease detection – harnessing the web for public health surveillance', *New England Journal of Medicine*, 360: 2153–2157.
- Brownstein, J.S., Freifeld, C.C., Reis, B.Y. and Mandl, K.D. (2008) 'Surveillance sans frontières: internet-based emerging infectious disease intelligence and the HealthMap Project', *PLoS Medicine*, 5: 1019–1024.
- Butler, D. and Cyranoski, D. (2013) 'Flu papers spark row over credit for data; rush to publish on H7N9 avian flu upsets Chinese scientists', *Nature*, 497: 14–15.
- Castillo-Salgado, C. (2010) 'Trends and directions of global public health surveillance', *Epidemiologic Review*, 32: 93–109.
- Chan, E.H., Brewer, T.F., Madoff, L.C., Pollack, M.P., Sonricker, A.L., Keller, M., Freifeld, C.C., Blench, M., Mawudeku, A. and Brownstein, J.S. (2010) 'Global capacity for emerging infectious disease detection', *PNAS*, 107: 21701–21706.
- Collier, N. (2010) 'What's unusual in online disease outbreak news?' *Journal of Biomedical Semantics*, 1: 1–18.
- Collier N., Doan, S., Kawazoe, A., Goodwin, R.M., Conway, M., Tateno, Y., Ngo, Q.H., Dien, D., Kawtrakul, A., Takeuchi, K., Shigematsu, M. and Taniguchi, K. (2008) 'BioCaster: detecting public health rumors with a Web-based text mining system', *Bioinformatics*, 24: 2940–2941.
- Cyranoski, D. (2013, May 17) 'Scientists look to Saudi Arabia for coronavirus clues', *Nature*. Online. Available HTTP: <<http://www.nature.com/news/scientists-look-to-saudi-arabia-for-coronavirus-clues-1.13000>> (accessed 14 May 2014).
- Fidler, D.P. (2004) 'Germs, governance, and global public health in the wake of SARS', *Journal of Clinical Investigation*, 113: 799–804.
- Fung, A., Russon Gilman, H. and Shkabatur, J. (2013) 'Six models for the internet + politics', *International Studies Review*, 15: 30–47.
- Garrett, L. (2013, April 24) 'The big one? Is China covering up another flu pandemic – or getting it right this time?' *Foreign Policy*. Online. Available HTTP: <[http://www.foreignpolicy.com/articles/2013/04/23/the\\_big\\_one](http://www.foreignpolicy.com/articles/2013/04/23/the_big_one)> (accessed 14 May 2014).

- Global Health Security Initiative (GHSI). (2011) 'Ten years of collaborative action'. Online. Available HTTP: <<http://www.ghsi.ca/Documents/AnniversaryPublicationFinal.pdf>> (accessed 24 August 2013).
- Grein, T.W., Kande-Bure, K.O., Rodier, G., Plant, A.J., Bovier, P., Ryan, M.J., Ohyama, T. and Heymann, D.L. (2000) 'Rumors of disease in the global village: outbreak verification', *Emerging Infectious Diseases*, 6: 97–102.
- Hartley, D., Nelson, N., Walters, R., Arthur, R., Yangarber, R., Madoff, L., Linge, J., Mawudeku, A., Collier, N., Brownstein, J., Thinus, G. and Lightfoot, N. (2010) 'The landscape of international event-based biosurveillance', *Emerging Health Threats Journal*, 3: e1–8. doi:10.3134/ehth.10.003
- Heymann, D.L. (2013, March 15) 'How SARS was contained', *New York Times*.
- Heymann, D.L., Mackenzie, J.S. and Peiris, M. (2013) 'SARS legacy: outbreak reporting is expected and respected', *The Lancet*, 381: 779–781.
- Heymann, D.L. and Rodier, G.R. (2004) 'Global surveillance, national surveillance, and SARS', *Emerging Infectious Diseases*, 10: 173–175.
- Hitchcock, P., Chamberlain, A., Van Wagoner, M., Inglesby, T.V. and O'Toole, T. (2007) 'Challenges to global surveillance and response to infectious disease outbreaks of international importance', *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science*, 5: 206–227.
- Huang, Y. (2013, May 23) 'Responding to disease outbreaks: is China's move toward greater transparency irreversible?' *Asia Unbound*. Online. Available HTTP: <<http://blogs.cfr.org/asia/2013/05/23/responding-to-disease-outbreaks-is-chinas-move-toward-greater-transparency-irreversible/>>
- Interview with Author. (2013a, April 12) Internet Surveillance Response Program Official (via Skype), New York.
- Interview with Author. (2013b, April 14) UNSIC official, New York.
- Katz, R. and Fischer, J. (2010) 'The revised International Health Regulations: a framework for global pandemic response', *Global Health Governance*, 3: 1–18.
- Keller, M., Blench, M., Tolentino, H., Freifeld, C.C., Mandl, K.D., Mawudeku, A., Eysenbach, G. and Brownstein, J.S. (2009) 'Use of unstructured event-based reports for global infectious disease surveillance', *Emerging Infectious Diseases*, 15: 689–695.
- Koblentz, G.D. (2010) 'Biosecurity reconsidered: calibrating biological threats and responses', *International Security*, 34: 96–132.
- The Lancet. (2007) 'International Health Regulations – the challenges ahead', *The Lancet*, 369: 1763.
- The Lancet. (2013) 'From SARS to H7N9: will history repeat itself?', *The Lancet*, 381: 1333.
- Li, Q., Zhou, L., Zhou, M., Chen, Z., Li, F., Wu, H., Xiang, N., Chen, E., Tang, F., Wang, D., Meng, L., Hong, Z., Tu, W., Cao, Y., Li, L., Ding, F., Liu, B., Wang, M., Xie, R., Gao, R., Li, X., Bai, T., Zou, S., He, J., Hu, J., Xu, Y., Chai, C., Wang, S., Gao, Y., Jin, L., Zhang, Y., Luo, H., Yu, H., He, J., Li, Q., Wang, X., Gao, L., Pang, X., Liu, G., Yan, Y., Yuan, H., Shu, Y., Yang, W., Wang, Y., Wu, F., Uyeki, T.M. and Zijian Feng, U. (2014) 'Epidemiology of human infections with Avian Influenza A(H7N9) Virus in China', *New England Journal of Medicine*, 370: 520–532.
- Linge, J.P., Steinberger, R., Weber, T.P., Yangarber, R., Van der Goot, E., Al Khudairy, D.H. and Stilianakis, N.I. (2009) 'Internet surveillance systems for early alerting of health threats', *Eurosurveillance*, 14: 1–2.
- Mackay, I.M. (2013, June 26) 'Middle East Respiratory Syndrome Coronavirus (MERS-CoV)', *Virology Down Under*. Online. Available HTTP: <<http://www.uq.edu.au/vdu/VDUMERSCoronavirus.htm>> (accessed 14 May 2014).
- Madoff, L.C. and Woodall, J.P. (2005) 'The internet and the global monitoring of emerging diseases: lessons from the first 10 years of ProMED-mail', *Archives of Medical Research*, 36: 724–730.
- Mykhalovskiy, E. and Weir, L. (2006) 'The Global Public Health Intelligence Network and early warning outbreak detection: a Canadian contribution to global public health', *Canadian Journal of Public Health*, 97: 42–44.
- Nature. (2013) 'The fight against bird flu', *Nature*. Online. Available HTTP: <<http://www.nature.com/news/the-fight-against-bird-flu-1.12850>> (accessed 14 May 2014).
- Nelson, N.P., Yang, L., Reilly, A.R., Hardin, J.E. and Hartley, D.M. (2012) 'Event-based internet biosurveillance: relation to epidemiological observation', *Emerging Themes in Epidemiology*, 9: 1–13. Online. Available HTTP: <<http://www.ete-online.com/content/pdf/1742-7622-9-4.pdf>> (accessed 14 May 2014).
- Norris, B. (2013) 'Tracking influenza A H7N9 through social media', *Social Health Insights*, Online. Available HTTP: <<http://socialhealthinsights.com/2013/04/tracking-influenza-a-h7n9-through-social-media/>> (accessed 14 May 2014).
- O'Malley, P., Rainford, J. and Thompson, A. (2009) 'Transparency during public health emergencies: from rhetoric to reality', *Bulletin of the World Health Organization*, 87: 614–618.

- Rodier, G.R. (2007) 'New rules on international public health security', *Bulletin of the World Health Organization*, 85: 428–430.
- Rotureau, B., Barboza, P., Tarantola, A. and Paquet, C. (2007) 'International epidemic intelligence at the Institut de Veille Sanitaire, France', *Dispatch*, 13: 1590–1592.
- Schmidt, C.W. (2012) 'Trending now: using social media to predict and track disease outbreaks', *Environmental Health Perspectives*, 120: a30–a33.
- Shkabatur, J. (2011) 'A global panopticon? The changing role of international organizations in the information age', *Michigan Journal of International Law*, 33: 159–214.
- Singh, J.P. (2013) 'Information technologies, meta-power, and transformations in global politics', *International Studies Review*, 15: 5–29.
- United Kingdom Parliament. (2008, July 21) 'Diseases know no frontiers: how effective are intergovernmental organisations in controlling their spread?' *Volume II: Evidence, Select Committee on Intergovernmental Organizations*, House of Lords, 1st Report Session of 2007–2008, HL Paper 143–II.
- WHO. (2005) *International Health Regulations*, Geneva: World Health Organization.
- WHO. (2013, June 26) 'Middle East respiratory syndrome coronavirus (MERS-CoV) – update', *Global and Alert Response*. Online. Available HTTP: <[http://www.who.int/csr/don/2013\\_06\\_26/en/index.html](http://www.who.int/csr/don/2013_06_26/en/index.html)> (accessed 14 May 2014).
- WHO (2014) 'Epidemic Intelligence – Systematic Event Detection'. Online. Available HTTP: <<http://www.who.int/csr/alertresponse/epidemicintelligence/en/>> (accessed 14 May 2014).
- Wilson, K. and Brownstein, J. (2009) 'Early detection of disease outbreaks using the internet', *Canadian Medical Association Journal*, 180: 829–831.