INFECTIOUS DISEASE OUTBREAK RESPONSE: MIND THE RIGHTS GAP

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ABSTRACT

The international organization responsible for international coordinated response to disease outbreaks—the World Health Organization (WHO)—was given permission to receive reports from sources other than the state in revisions to the International Health Regulations (IHR) in 2005. However, the organization struggles to protect its corresponding right to receive reports from non-state actors on outbreak events. This article examines the consequences of this implementation gap between what is stated in the IHR—the right of WHO to receive reports from non-state actors on outbreak events—and the reality that states remain able and willing to act to ensure that this right is not exercised. The article examines two recent cases: the first detection of Middle East Respiratory Syndrome (MERS) outbreak in Saudi Arabia, and the first months of the Ebola outbreak in Guinea. Both cases demonstrate how the WHO has struggled to balance states' concern with managing risk communication against WHO's right to receive reports from non-state actors. The article argues that to realize the full potential of a transparent disease outbreak reporting process, there is a need for a human rights framework that expressly articulates its right to receive reports and outlines appropriate behaviour for the WHO, states, and non-state actors.

KEYWORDS: Ebola, Human Rights, International Health Regulations, MERS, Non-state actors, Outbreak surveillance, Risk communication

I. INTRODUCTION

The formalization of a shared agreement to report outbreak events that may pose a public health risk to the international community (public health emergency of international concern)¹ occurred with the adoption of the revised International Health

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1 A public health emergencies of international concern (PHEIC) is defined in the revised IHR as an extraordinary event [irrespective of origin or source] which: (i) constitutes a public health risk to other states

Regulations (IHR) at the World Health Assembly (WHA) on May 23 2005.² In Article 2 of WHA58.3, Member States agreed that the scope and purpose of the instrument was 'to prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks'. Since coming into force in 2007 states have worked, individually and collectively, to meet their IHR core capacity requirements³ to contain public health threats as defined under the new framework.⁴ Starting in 2012, WHA Member States agreed to annually survey their performance to meet the IHR core capacity criteria,⁵ and report their performance to the WHO Director-General for her/his annual report to the World Health Organization (WHO) Executive Board and WHA.⁶ Meeting the IHR core capacity requirements has had varying success as the recent Ebola outbreak in West Africa demonstrates.⁷

One significant shift within the revised IHR was that states agreed to openly and promptly report outbreaks with the *potential* for 'international spread'. This represented a significant shift from past practice which involved a focus on adopting the relevant quarantine measures to a 'legal instrument [that sought] to ensure global health security through a *collective approach*'.⁸ States agreed to the development of detection and response capacities at both the national and international level: this entailed the creation of an IHR National Focal Point, to be available 24/7 in every country to communicate outbreak events with WHO. It also required WHO to provide an alert service to the international community of reports it received that may present a potential PHEIC. Michael Baker and David Fidler argued after the IHR's adoption that one of the strengths of the revised IHR was the inclusion of a provision that gave WHO the right to receive reports of disease outbreak events from sources other than the affected

through the international spread of disease and (ii) potentially require(s) a coordinated international response'. World Health Assembly, *Revision of the International Health Regulations* (WHA Resolution 58.3, 23 May 2005) 8.

2 *ibid*.

3 Member States committed to give effect to the revised IHR by building core capacities in the following areas: (i) national legislation, (ii) policy and financing, (iii) coordination and National Focal Point (NFP) communications, (iv) surveillance and response, (v) preparedness, (vi) risk communication, (vii) human resources, and (viii) laboratories. It was widely presumed that not all Member States would achieve these eight capacities by the timeframe set, 1 July 2012, and grace period up to three years would be permitted. States are expected to notify WHO Director-General of the need for an extension and identify areas where they needed assistance to achieve these capacities.

4 JE Fischer and R Katz, 'Moving Forward to 2014: Global IHR (2005) Implementation' (2013) 11(2) *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science* 153.

5 The focus of the IHR is on the prevention and containment of PHEIC. See (n 3).

6 World Health Organization, *Department of Global Capacities and Alert Response Activity Report 2012* (WHO Lyon Office 2013) <http://www.who.int/ihr/publications/WHO_HSE_GCR_LYO_2013.3.pdf> accessed 12 February 2017; World Health Organization, *Implementation of the International Health Regulations [2005]* Report by the Director-General to Sixty-Sixth World Health Assembly, A66/16 (5 April 2013).

7 UN, *Report of the High-Level Panel on the Global Response to Health Crises* (25 January 2016) <http://reliefweb.int/sites/reliefweb.int/files/resources/2016-02-05_Final_Report_Global_Response_to_Health_Crises.pdf> accessed 12 February 2017.

8 L Ailan and T Kasai, 'The Asia Pacific Strategy for Emerging Diseases - A Strategy for Regional Health Security' (2011) 2(1) *Western Pacific Surveillance and Response Journal* 7.

state: Article 9—Other Reports. Specifically, Article 9 permits WHO to ‘take into account reports [of outbreak events] from sources other than notifications or consultations and shall 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’.⁹ The article also referred to the following: ‘only where it is duly justified may WHO maintain the confidentiality of the source’.¹⁰

Article 9 permits WHO to receive reports of disease outbreaks from *sources other than the state* (in this article referred to as non-state actors and non-state reports) and for the WHO to exercise its own judgement on protecting the confidentiality of that source. Baker and Fidler argued that Article 9 ‘cast [WHO’s] surveillance network beyond information it receives from governments . . . [to] avoid being blocked by governmental failure to comply with reporting requirements’.¹¹ This article explores contemporary practice in the light of Article 9. This article identifies an implementation gap between what is stated in the IHR—the right of WHO to receive reports from informants other than the state and to protect the identity of those informants—and the reality that states remain able and willing to act to ensure that this right not be exercised. The article examines two cases, Middle East Respiratory Syndrome (MERS) and West Africa Ebola outbreak, to explore how WHO has attempted to balance in both instances the state’s need to manage risk communication against WHO and the non-state actors’ right to report relevant outbreak information.

The article develops in three steps. First, it examines some of the issues arising from the management of non-state reports that contradict state reports. This is a particularly pressing concern in politically sensitive environments where individuals may be at risk of state reprisal for reporting disease outbreaks. The second section of the article explores how WHO has responded to situations where non-state reports contradicted state reports: the first MERS outbreak in Saudi Arabia in 2012; and the confirmation of Ebola viral fever in Guinea in early 2014. Both cases illustrate the tensions that arise for WHO in receiving and acting upon non-state sourced reports. In the final section of the article the rarely discussed human rights implications of outbreak surveillance, response, and reporting are explored. To date, reporting practices have been understood as exclusively a matter of relations between states and the WHO. This article contends that this understanding is problematic since the right to report, as conceptualized under the revised IHR, requires a corresponding right for non-state actors to issue reports directly to the WHO. This section presents the case for introducing balance between WHO’s need for good relations with states with the need to protect individual informants; for WHO to be able to act on information in situations where the state may not be disclosing all information it has to hand; and to guarantee the confidentiality of informants (as provided in Article 9). To navigate these difficult issues more attention should be paid to the accountability, transparency, and human rights provisions embedded within the IHR.¹²

9 World Health Assembly (n 1) art 9.

10 *ibid*, art 9.1.

11 MG Baker and DP Fidler, ‘Global Public Health Surveillance under New International Health Regulations’ (2006) 12(7) *Emerging Infectious Diseases* 1062.

12 UN Report (n 7).

Article 9 within the IHR provides for the right of non-state actors to report to WHO but there is presently no corresponding framework in international human rights law relating to how this right might be enacted. There is a need for WHO to develop consistent and transparent guidelines on its compliance with Article 9 to balance states' desire to manage risk communication with the individual right to report such situations. The WHO is well placed as a legal and normative authority vis-a-vis the IHR to suggest and articulate a disease reporting framework with respect to human rights principles. This article primarily focuses on the relationship between three actors: the WHO (including both Headquarters and regional offices, unless otherwise stated); the state; and non-state actors (defined below) who have the capacity to detect and report outbreaks. This focus does not deny the important role of other organizations within the United Nations, as well as national and international non-state actors in detecting, reporting, and responding to disease outbreak events. The focus in this article is on operationalizing the right to report as conceptualized in Article 9 under the IHR; it is intended to begin the discussion on who needs to be included and who may require protection to realise this right.

II. THE POLITICAL ENVIRONMENT IN DISEASE OUTBREAK EMERGENCIES

Government failure to notify WHO about disease outbreaks has a long history, but it was quickly elevated to a global concern during the Severe Acute Respiratory Syndrome (SARS) outbreak in 2003.¹³ Then, the WHO Secretariat relied upon reports from media, scientists, and individuals, in addition to various Ministries of Health, when seeking to verify reports of suspected SARS outbreaks.¹⁴ In the case of the People's Republic of China (China), the state initially reported to WHO a very small SARS caseload, while at the same time, WHO was being informed by non-state sources within and outside China that the real extent of the infection was much greater than what the Chinese state was admitting.¹⁵ WHO—controversially¹⁶ at the time—used these reports to request the Chinese government check their cases and rebuked the government for not revealing the full extent of the SARS virus, particularly in Beijing. WHO issued a travel advisory for China during the height of the outbreak, specifically stating 'many questions' were yet to be answered about the state of the outbreak in Guangdong province.¹⁷ Two years later, WHO's receipt of non-state

13 AP Cortell and S Peterson, 'Dutiful Agents, Rogue Actors, or Both? Staffing, Voting Rules, and Slack in the WHO and WTO' in Darren G Hawkins and others (eds), *Delegation and Agency in International Organization* (CUP 2006) 255–80.

14 DL Heymann and GR Rodier, 'Global Surveillance, National surveillance, and SARS' (2004) 10(2) *Emerging Infectious Diseases* 173; DL Heymann, 'How SARS was contained' (New York Times, New York, 15 March 2013) <<http://www.nytimes.com/2013/03/15/opinion/global/how-sars-was-contained.html?pagewanted=all>> accessed 12 February 2017.

15 DP Fidler, 'Germs, Governance, and Global Public Health in the Wake of SARS' (2004) 113(6) *The Journal of Clinical Investigation* 799.

16 See contested views of WHO's actions: Cortell and Peterson (n 13) and A Kamradt-Scott, *Managing Global Health Security* (Palgrave MacMillan 2015) 21–43.

17 WHO, 'Update 18 - SARS Outbreak: WHO Investigation Team Moves to China, New Travel Advice Announced' (WHO Press Release, Geneva, 2 April 2003) <http://www.who.int/csr/sars/archive/2003_04_02a/en/> accessed 12 February 2017.

reports and authority to act on receipt of these reports was formally adopted under Article 9 in the revised IHR. This was a significant achievement for WHO and regarded as vindication of the WHO's efforts, during SARS but also previous outbreaks, to demand greater reporting transparency from states.¹⁸ It was also referred to as a new dawn for global health governance in that non-state actors were recognized, for the first time under a WHO legal instrument, as being *partners* in outbreak response and containment.¹⁹

Given the euphoria surrounding the inclusion of Article 9, there has been surprisingly little discussion about the challenge of realizing its aspirations. Namely, how should the WHO operationalize its right to receive reports from non-state sources, particularly if and when those reports contradict reports provided by the state? How should WHO judge when to use the confidentiality provision of non-state actors (and justify use of this provision)? Much focus has been on the obligation to ensure that during a PHEIC, affected governments have effective risk communication strategies to control and direct the flow of information through one source—the Health Ministry or the executive level of the government.²⁰ However, the value of Article 9 was that it permitted the WHO to listen to other sources and not rely solely on governments—particularly if the government is suspected of covering up the true extent of the health crisis. This was the importance of Article 9: accommodating the potential for the WHO to receive reports and protect the confidentiality of non-state sources.

Since the adoption of the Regulations, there have been two investigations into their implementation during public health emergencies. In both investigations reference to Article 9 was minimal and mainly by association with other findings concerning WHO's actions on report and response. The first independent panel review was carried out in 2011 and assessed WHO's response to the H1N1 outbreak in 2009. The review found that WHO's response to the outbreak was justified based on the information it had to hand; but its coordinated response to public health outbreaks needed further reform to ensure full compliance with the IHR by states and the WHO itself. On the specific matter of reporting and response, the review noted that during the H1N1 outbreak there 'was no systematic monitoring by WHO of instances where human rights are not respected in implementing the IHR'. The report noted that the WHO and affected populations were disadvantaged by the organization having no mandate to investigate when a state breaches human rights with regard to the IHR.²¹ This is a finding the article returns to in the third section.

18 E Mack, 'World Health Organization's New International Health Regulations: Incursion on State Sovereignty and Ill-Fated Response to Global Health Issues' (2007) 7(1) *The Chicago Journal of International Law* 365.

19 J Shkabatur. 'A Global Panopticon - The Changing Role of International Organizations in the Information Age' (2011) 33(1) *Michigan Journal of International Law* 159.

20 K Ijaz and others, 'International Health Regulations—What Gets Measured Gets Done' (2012) 18(7) *Emerging Infectious Diseases* <<http://dx.doi.org/10.3201/eid1807.120487>>

21 IHR Review Committee, *Final report of the IHR Review Committee (as presented to 64th WHA)*, Report of the Review Committee on the Functioning of the International Health Regulations (2005) and on Pandemic Influenza A (H1N1) 2009 (April 2011) p. 64.

In 2015, an independent panel was appointed by WHO Director-General Margaret Chan to review the WHO's initial response to the Ebola outbreak in West Africa. Unlike the 2011 review, this review did not refer to the role of WHO and human rights investigation but it did refer to the failure of WHO and affected countries to engage in transparent risk communication with public (which contributed to increased fear and panic in locally affected areas). The WHO failed to activate existing policies and procedures (provided within IHR) to deal with the initial stages of the outbreak because of the (mis)judgements relating to the declaration of a PHEIC. The review noted that because WHO did not listen to early warnings about the outbreak from non-state actors, specifically Médecins Sans Frontières, the result was an ineffective and inadequate response.

To make sense of these findings requires consideration of why WHO may fail to make full use of Article 9. The next section of the article turns to two cases—the MERS outbreak in Saudi Arabia (which followed the H1N1 outbreak) and, secondly, an outbreak that has shattered international confidence in the capacity of WHO to detect and respond to outbreaks—the Ebola outbreak in Guinea—to explore the tensions and challenges that surround the operationalization of Article 9.

III. THE RIGHT TO REPORT IN ACTION

In looking at these two cases, I will show that at the heart of the problem is that Article 9 does not resolve a key tension for WHO when it comes to operationalizing its rights and responsibilities under the IHR: the overlapping rights and duties between WHO's responsiveness to outbreak situations to protect all populations at risk, assert the non-state actor's right to report a situation to WHO in confidence, and support states right to legislate and manage emergency response.

A. MERS

In June 2012, a patient with severe respiratory disease was admitted at the Dr Soliman Fakeeh Hospital in Jeddah, Kingdom of Saudi Arabia. The patient was not improving. Dr Ali Mohamed Zaki, an Egyptian national and Professor of Microbiology at the hospital, took a sample of sputum to identify the cause of the sickness. When he could not detect a positive with any known suspected diseases, he contacted Dr Ron Fouchier at Erasmus Medical College in Rotterdam, Netherlands. Suspecting a novel virus, Dr Zaki sent a sample to Dr Fouchier's lab. At this point, Dr Zaki argues that he 'complied with procedures by submitting a virus sample and associated clinical data to the Saudi health ministry on 18 June'.²² There was no follow up from the Health Ministry so he continued to cooperate with Dr Fouchier's lab. The Saudi Ministry does not deny that at this stage regular procedures were followed (but also said that they were not informed that Dr Zaki suspected the sample being sent was a dangerous novel virus).²³

22 Declan Butler, 'Tensions Linger over Discovery of Coronavirus' *Nature* (14 January 2013) <<http://www.nature.com/news/tensions-linger-over-discovery-of-coronavirus-1.12108>> accessed 12 February 2017.

23 *ibid.*

In September, Dr Fouchier reported to Dr Zaki that the Erasmus lab detected a novel coronavirus.²⁴ Two events happened after this discovery that had an immediate impact on Dr Zaki. On the same day, Dr Zaki notified the Saudi government of the coronavirus finding by the Erasmus lab, he notified the international community via an internet disease surveillance platform, ProMED. ProMED, is an email listserv 'Program for Monitoring Emerging Diseases' in operation since 1994. It is one of the earliest Internet disease surveillance programmes set up to share disease outbreak events, followed by WHO and other disease surveillance aggregators, and now in partnership with HealthMap and Wellcome Trust.²⁵ The email from Dr Zaki—once verified by ProMED team—was distributed to thousands of subscribers (government, laboratory, non-government, civil society, media, universities, individuals) around the world. Dr Zaki explained he did this for two reasons. First, he believed that the potential risk of MERS to the upcoming Haji Pilgrimage necessitated immediate notification to potential travellers and overseas hospitals who may see individuals with coronavirus symptoms in pilgrims on return from Mecca. A second related reason he went to ProMED was that he distrusted the Saudi government would share the diagnosis rapidly to ensure that countries could detect MERS infections.²⁶ That very month, the notification Zaki gave assisted with the identification of a MERS-infected patient in the UK.²⁷ After the ProMED notice, the Saudi government immediately dismissed Dr Zaki and revoked his working visa, which forced his immediate return to Egypt.

By May 2013, there were 34 laboratory confirmed cases of the new coronavirus named MERS.²⁸ It was revealed during this time that the first case may not have come from Saudi Arabia, but an earlier outbreak of suspected pneumonia among health care workers in a Jordanian hospital in April 2012. However, at this time reports also started to appear questioning the degree to which the Saudi government was being forthcoming about the volume of MERS cases they treated since 2012.²⁹ The WHO repeatedly asked the Saudi government for more information on the virus

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- 24 Ali Zaki, Novel coronavirus—Saudi Arabia: human isolate. *Int. Soc. Infect. Dis. ProMED-mail* 20 September (2012) <<http://www.promedmail.org/direct.php?id=20120920.1302733>> accessed 12 February 2017.
 - 25 P Barboza and others, on behalf of the Early Alerting, Reporting Project of the Global Health Security Initiative. 'Evaluation of epidemic intelligence systems integrated in the Early Alerting and Reporting project for the detection of A/HSN1 Influenza event' (2013) 8(3) *PLOS ONE* e57252.
 - 26 Ian Sample, 'Coronavirus: Is This the Next Pandemic?' (*The Guardian*, London, 16 March 2013) <<https://www.theguardian.com/science/2013/mar/15/coronavirus-next-global-pandemic>> accessed 12 February 2017.
 - 27 A Bermingham and others, 'Severe Respiratory Illness Caused by a Novel Coronavirus, in a Patient Transferred to the United Kingdom from the Middle East' (2012) 17(40) *Eurosurveillance*, pii=20290.
 - 28 RJ De Groot and others, 'Middle East Respiratory Syndrome Coronavirus (MERS-CoV): Announcement of the Coronavirus Study Group' (2013) 87(14) *Journal of Virology* 7790.
 - 29 Helen Branswell refers to WHO Director-General Dr Margaret Chan imploring countries to notify WHO of suspected outbreaks at the 2012 WHA in May; H Branswell, 'Saudi Silence on Deadly MERS Virus Outbreak Frustrates World Health Experts' (*Scientific American*, Armonk, NY, 7 June 2013) <<http://www.scientificamerican.com/article/saudi-silence-on-deadly-mers-virus-outbreak-frustrates-world-health-experts/>> accessed 12 February 2017; European Centre on Disease Prevention and Control, 'Updated Rapid Risk Assessment MERS-CoV' (17 May 2013) <<http://ecdc.europa.eu/en/publications/Publications/risk-assessment-middle-east-respiratory-syndrome-coronavirus-MERS-CoV-17-may-2013.pdf>> accessed 12 February 2017.

and suspected outbreaks.³⁰ During most of 2013 only laboratory confirmed cases were reported to WHO despite the MERS IHR Emergency Committee convened under the IHR recommending that all states report confirmed *as well as probable* cases of the outbreak.³¹

In early 2014, there was a proliferation of social media—Twitter and Facebook—communication among health care workers within the Saudi Kingdom. They were alleging that the extent of the outbreak in 2013 had been concealed.³² Ten laboratory confirmed cases of MERS were reported from Abu Dhabi in one month (April 2014).³³ On May 1, the WHO issued the following statement:

Saudi Arabia has provided information on 138 cases identified between 11 to 26 April 2014 in the country, including preliminary details of cases and deaths associated with the outbreak in Jeddah. WHO will update the global total of laboratory-confirmed cases of infections with MERS-CoV, including deaths, based on official information provided by Saudi Arabia as quickly as possible.³⁴

On request in May 2014, the WHO was permitted to enter Saudi Arabia to review the response of the government to MERS outbreaks. At the same time however, a Cabinet order directed all Saudi news media to quote only official sources on the disease, and the Health Ministry advised that health care workers could be imprisoned for disclosing any health ministry information that included information on infectious disease outbreaks.³⁵ In the same month, the Health Minister and Deputy Health Minister were sacked for allegedly failing to disclose full reports of MERS outbreaks.³⁶ Despite the Saudi government releasing a statement after the WHO visit that it would review procedures for reporting cases in the future,³⁷ others have continued to express concern about the limited amount of information coming out of the country about

30 Lawrence O Gostin, *Global Health Law* (Harvard UP 2014) Box 4.3.

31 Ministry of Health Saudi Arabia, *Command and Control Centre* (17 May 2013) <<http://www.moh.gov.sa/en/CCC/News/Pages/news-2013-05-17-001.aspx>> accessed 12 February 2017, WHO, Geneva; 'Middle East Respiratory Syndrome Coronavirus (MERS-CoV)' (Riyadh, 9 July 2013) <http://www.who.int/ihr/procedures/statements_20130709/en/> accessed 12 February 2017.

32 R Levy and N Binshtok, 'Saudi Sniffs at Spreading Health Crisis' *Vocativ* (25 April 2014) <<http://www.vocativ.com/world/saudi-arabia-world/saudi-sniffs-spreading-health-crisis/>> accessed 12 February 2017; Levy and Binshtok, reported 10 new cases a day; the WHO report (below) said since mid-March 2014, over 100 people have tested positive for MERS in the Jeddah area and 31 of them have died.

33 WHO, 'Middle East Respiratory Syndrome Coronavirus (MERS-CoV)'—update (16 April 2014) <http://www.who.int/csr/don/2014_04_16_mers/en/> accessed 12 February 2017

34 WHO, 'WHO concludes MERS-CoV Mission in Saudi Arabia' (7 May 2014) <<http://www.emro.who.int/media/news/mers-cov-mission-saudi-arabia.html>> accessed 12 February 2017

35 A Al Omran, E Knickmeyer and B McKay, 'Saudi Health Minister Fired Amid Surge in Deadly MERS Virus' (2014) *The Wall Street Journal* <<https://www.wsj.com/articles/SB10001424052702304049904579516032023791644>> accessed 12 February 2017.

36 H Branswell, 'MERS's Best Friend is Ignorance, So it's Time to Wise Up' *IRIN Humanitarian News and Analysis* (16 June 2015) <<http://www.irinnews.org/report/101638/mers-s-best-friend-is-ignorance-so-it-s-time-to-wise-up>> accessed 12 February 2017.

37 Ministry of Health Saudi Arabia, 'Update in Statistics: Ministry of Health Institutes New Standards for Reporting of MERS-CoV' *Command and Control Centre* (Riyadh 3 June 2014) n.32 <<http://www.moh.gov.sa/en/CCC/News/Pages/News-2014-06-03-001.aspx>> accessed 12 February 2017.

the virus, fuelling ongoing queries about the timeliness and full detail being provided of outbreak reports.³⁸

Undoubtedly, the sacking of Dr Zaki followed by the sacking of the Health Minister and Deputy Health Minister created a sense of crisis. But threats of imprisonment to health care workers caught discussing the case in social media could be interpreted as a threat to health care professionals, under the IHR's Article 9, to report cases that contradict the government message on MERS. The threat of imprisonment for social media posts is not unusual in Saudi Arabia.³⁹ Saudi Arabia is a repressive environment in which to be a journalist according to Reporters Without Borders and Press Freedom Index.⁴⁰ It has low scores across the areas of transparency, rule of law, and judicial independence. Access to Internet, and use of social media platforms is rapidly growing with 63.7% of 29 million population having access to Internet.⁴¹ However, the government has retained tight controls on its usage and routinely blocked posts, even imprisoning individuals, when it judged there to be 'sensitive political content'. However, this sensitive political environment illustrates the tension at the heart of the IHR: the WHO has a right to receive reports from non-state actors, but non-state actors may not have a corresponding right under their state's laws to issue reports to WHO.

Four years later and on the case of MERS—still to be declared a PHEIC—the only public record of the WHO Director-General giving a position on receiving 'other reports' was a public statement that appeared to favour the Saudi government. In 2013, Saudi Arabia Deputy Health Minister Zaid Memish presented to the WHA the Material Transfer Agreement (MTA) placed by the Erasmus Lab on the sample of MERS sent by Dr Zaki.⁴² Dr Memish argued that the MTA had prevented the Saudi government from studying the virus to improve its own diagnostics of the virus. Dr Chan publicly sided with Dr Memish, arguing that this case demonstrated why state delegates must

38 'More detail and analysis of the evolving events in the Arabian Peninsula is urgently needed to define the source of the infection and to further define the risks posed by this event', European Centre for Disease Prevention and Control, 'Rapid Risk Assessment: MERS-CoV' (31 May 2014) 16. <<http://ecdc.europa.eu/en/publications/Publications/RRA-Middle-East-respiratory-syndrome-coronavirus-update10.pdf>> accessed 12 February 2017.

39 UNGA, Compilation prepared by the Office of the High Commissioner for Human Rights in accordance with para 15 (b) of the annex to Human Rights Council resolution 5/1 and para 5 of the annex to Council resolution 16/21. Saudi Arabia, A/HRC/WG.6/17/SAU/2 (Geneva 6 August 2013) 8, 10–11.

40 C Callanan and H Dries-Ziekenheiner, *Safety on the Line: Exposing the Myth of Mobile Communication Security* (Freedom House, Washington 2012) 134; Freedom House, *Freedom of the Press – Saudi Arabia 2015* (2015) <<https://freedomhouse.org/report/freedom-press/2015/>> accessed 12 February 2017; Reporters Without Borders, *2015 World Press Freedom Index: Saudi Arabia* (Paris 2015) <<http://index.rsf.org/#!/index-details/SAU>> accessed 12 February 2017.

41 Freedom House, *Freedom on the Net 2015 - Saudi Arabia* (12 February 2017) <<https://freedomhouse.org/report/freedom-net/2015/saudi-arabia>> accessed 12 February 2017.

42 The Erasmus Lab named the virus human betacoronavirus 2c EMC (hCoV-EMC) and set up a material-transfer agreement (MTA) for virus samples. An MTA, argues David Fidler (see n 43) was not unusual in this area where there are usually agreements concerning the safe transfer of biological samples. The MTA preserved 'Erasmus' ownership of the virus samples it had received, protected its ability to obtain intellectual property rights on research outcomes from that sample, and required labs that requested the virus to demonstrate necessary biosafety level status to handle the virus'. However, the MTA meant that future tests of the Erasmus sample—the sample Dr Zaki collected—would require a signed MTA with Erasmus.

share your specimens with WHO collaborating centers, not in a bilateral manner. Please, I'm very strong on this point, and I want you to excuse me. *Tell your scientists in your country, because you're the boss. You're the national authority. Why would your scientists send specimens out to other laboratories on a bilateral manner and allow other people to take intellectual property rights on a new disease?*⁴³

David Fidler and others argued that this statement by Dr Chan, which was supported by WHO Assistant General for Health Security and Environment Keiji Fukuda, was not only incorrect but carried 'serious implications' for the implementation of the IHR.⁴⁴ The Erasmus lab's MTA did not prevent the sample being shared or additional samples of MERS being shared 'under whatever terms they wish without worrying about the Erasmus contracts'.⁴⁵ Chan's comments—insisting on national authority over specimen control—gave no consideration to Dr Zaki's claim that he had approval to send the virus as well as the importance of his report to ProMED in spurring international alert to the virus.⁴⁶ Dr Chan's exhortation to '[t]ell your scientists in your country, because you're the boss' also carries implications beyond the situation when scientists need international assistance to diagnose an outbreak. This statement failed to acknowledge that under Article 9 of the IHR—the scientist had a right to report, to collaborate with other scientists, and to provide these reports to the WHO to assist with outbreak response.⁴⁷

The MERS case reveals the complexity of reporting in situations where public trust and transparency are in short supply. In such a political environment, there is real risk to the individual who decides to report an outbreak without the permission of the state. Yet WHO, specifically Dr Chan, had little to say about that risk. Dr Chan recently said that when a state experiences any diagnostic delay it compromises WHO's response to a situation. Given this, what of WHO's right to receive and act upon reports that contradict the state's account of an outbreak situation?⁴⁸ The drafters of the revised IHR knew that outbreak detection and reporting was not a technical process alone but a political one. This was why Article 9 was an important win for those wanting to invest the right to report in actors beyond the state. The Ebola outbreak in Guinea, below, adds to the concern in the MERS case: who should the WHO listen to when non-state actors seek to report in contradiction of the government?

43 DP Fidler, 'Who Owns MERS? The Intellectual Property Controversy Surrounding the Latest Pandemic' *Foreign Affairs* (Washington, 5 June 2013) <<https://www.foreignaffairs.com/articles/saudi-arabia/2013-06-06/who-owns-mers>> accessed 12 February 2017. Chan quoted in the article, emphasis added.

44 Fidler, *ibid*; Butler (n 22).

45 Fidler, *ibid*.

46 AM Zaki and others, 'Isolation of a Novel Coronavirus from a Man with Pneumonia in Saudi Arabia' (2012) 367 *The New England Journal of Medicine* 1814.

47 RP Claude, *Science in the Service of Human Rights* (University of Pennsylvania Press 2002).

48 M Chan, WHO Director-General addresses the Review Committee of the International Health Regulations focused on the Ebola response, Opening remarks at the Review Committee on the role of the International Health Regulations in the Ebola outbreak and response, 24 August 2015 <<http://www.who.int/dg/speeches/2015/review-committee-ih-ebola/en/>> accessed 12 February 2017.

B. Ebola

In December 2013 a deadly strain of Ebola virus, the Zaire strain, infected a young child in Meliandou village, Guéckédou Province, Guinea. By January, the child's infection and subsequent death had led to further infections in the immediate family and those who attended the child's funeral.⁴⁹ The infection then spread to health care workers who treated the ill. With a case fatality ratio of 59% this disease spread quickly through the Southern provinces. Initially suspected as cholera then Lassa Fever, both common in Guinea, the cause of the infection was not accurately diagnosed until March 2014 by WHO Collaborating Laboratory, the Pasteur Institute in Paris.⁵⁰ There are a number of factors that led to a four-month delay in diagnosing this virus: there was no history of Ebola in Guinea, no laboratory diagnostics available within the province, and very few trained health care workers available who would recognize the symptoms of Ebola—with the country having a ratio of 10 doctors per 10 000 population.⁵¹

After the outbreak was diagnosed as Ebola haemorrhagic fever, the Guinean government initially refused to allow suspect cases to be reported.⁵² The government only agreed to publish laboratory confirmed cases. It remains unclear whether this preference was informed by a desire to conceal the extent of the outbreak, a tradition of secrecy in response to emergency situations, or distrust with the accuracy of information being received from outer provinces.⁵³ Regardless, this effort to conceal was against the MSF advice—the only international responder on the ground—who were then accused of 'causing unnecessary panic'.⁵⁴ The consequence of announcing

49 WHO, 'Origins of the 2014 Ebola Epidemic' (January 2015) <<http://www.who.int/csr/disease/ebola/one-year-report/virus-origin/en/>> accessed 12 February 2017.

50 WHO, 'Ebola Virus Disease in Guinea, Regional Office for Africa' (24 March 2014) <<http://www.afro.who.int/en/clusters-a-programmes/dpc/epidemic-a-pandemic-alert-and-response/outbreak-news/4064-ebola-hemorrhagic-fever-in-guinea-24-march-2014.html>> accessed 12 February 2017.

51 WHO recommends 23 per 10 000. WHO, 'Factors that Contributed to Undetected Spread of the Ebola Virus and Impeded Rapid Containment' (January 2015) <<http://www.who.int/csr/disease/ebola/one-year-report/factors/en/>>; UN (n 7) 22; AE Yamin, 'Ebola, Human rights, and Poverty – Making the Links' (Open Democracy, London, 23 October 2014) <<https://www.opendemocracy.net/openglobal-rights-blog/alicia-ely-yamin/ebola-human-rights-and-poverty-%E2%80%93-making-links>> accessed 12 February 2017.

52 S Fink, 'Cuts at WHO Hurt Response to Ebola Crisis' (The New York Times, New York, 3 September 2014) <http://www.nytimes.com/2014/09/04/world/africa/cuts-at-who-hurt-response-to-ebola-crisis.html?_r=0>. International Crisis Group, *Guinea's Other Emergency: Organising Elections* (Brussels, 15 December 2014) <<http://www.crisisgroup.org/en/regions/africa/west-africa/guinea/b106-guinea-s-other-emergency-organising-elections.aspx>> accessed 12 February 2017.

53 One report based on leaked emails suggest it was deliberate: 'another leaked email a week later, WHO expert Pierre Formenty says Guinea wanted to understate case numbers to "reassure expatriates working in the mining industry" and prevent Saudi Arabia banning Guineans from the Hajj pilgrimage'. D MacKenzie, 'Worst Ebola Outbreak Blamed on Political Dithering' (New Scientist, UK 23 March 2015) <<https://www.newscientist.com/article/dn27223-worst-ebola-outbreak-blamed-on-political-dithering/>> accessed 12 February 2017. I thank the anonymous reviewer for this source.

54 Similar concerns were raised about cooperation in Sierra Leone. MSF, *Pushed to the Limit and Beyond: A Year into the Largest Ever Ebola Outbreak* (MSF 2015) <<https://www.doctorswithoutborders.org/sites/usa/files/msf143061.pdf>> accessed 12 February 2017, 6–7. It should be noted that Guinea President Conde disagrees with MSF's claims concerning how the government wanted to handle communication of the outbreak, see R Jalabi, 'Guinea's President on Global Aid Push: Ebola Forced us to Change Completely' *The Guardian* London (London 12 July 2015) <<http://www.theguardian.com/world/2015/jul/12/guinea-president-alpha-conde-ebola-aid>> accessed 12 February 2017.

laboratory-confirmed cases rather than suspect cases meant that for a number of months health care workers were operating contract tracing and quarantine cordons with only a fraction of the knowledge of the extent of the outbreak.⁵⁵ In the meantime, the government was actively discouraging reports of Ebola cases that contradicted the formal message that the outbreak was under control.⁵⁶ This was Guinea's first experience of Ebola. It was surrounded by countries that had never had an Ebola outbreak and, as such, had a vital role in alerting neighbouring countries to the extent of the outbreak. Arguably the WHO also had this responsibility if it deemed Guinea needed assistance under the terms of the IHR. However, alerts that included suspect cases did not happen.⁵⁷ Instead, there was drip feed of information to the populations most affected, particularly in the Southern provinces, where there were already strained relations between the government and local population.

An MSF epidemiologist interviewed for a BBC documentary spoke of frustration that not only did the Guinean government insist on limiting reports to confirmed cases,⁵⁸ the WHO representatives in the same room did not point out to the government that they had an obligation to disclose and warn populations about the outbreak. The allegation that WHO was reluctant to publicly expose states who were failing to report the extent of the outbreak was later supported in other reports.⁵⁹

Christopher Stokes, MSF's general director, described the organization's frustration when in May 2014 President Conde of Guinea alleged that MSF was 'exaggerating' the extent of the outbreak to raise funds.⁶⁰ More intense warnings were given to local civil societies if they sought to challenge the government's version of events.⁶¹ This time, MSF more forcefully voiced their frustration at WHO authorities in the African regional office and Geneva Headquarters, but to no avail.⁶² Despite the UN Security Council's engagement with the political situation in Guinea, particularly since the mass atrocities in 2009,⁶³ there appeared to be little coordination or understanding of how the political situation in Guinea may impact on its response to the outbreak. In the aftermath, but not at the time, it has been acknowledged that the

55 MSF, *ibid* 7; S. Jones, 'West Africa Ebola Epidemic is "out of control"' (The Guardian, London, 24 June 2014) <<http://www.theguardian.com/global-development/2014/jun/23/west-africa-ebola-epidemic-out-of-control>> accessed 12 February 2017.

56 International Crisis Group (n 52) 9–10.

57 Indeed, one report suggests some within WHO did not want to challenge the Guinea government decision to refuse to publically release data for fear of open communications being 'withdrawn' or 'imperial'. MacKenzie (n 53).

58 BBC, 'Frontline: Ebola' (London, 17 November 2014) <<http://www.msf.org.uk/event/ebola-frontline-bbc-panorama>> accessed 12 February 2017.

59 See (n 56).

60 MSF (n 54) 8; C Freeman 'Guinea and Sierra Leone tried to cover up Ebola crisis says Medecins Sans Frontieres', The Telegraph, 23 March 2015. <<http://www.telegraph.co.uk/news/worldnews/ebola/11488726/Guinea-and-Sierra-Leone-tried-to-cover-up-Ebola-crisis-says-Medecins-Sans-Frontieres.html>> accessed 12 February 2017.

61 International Crisis Group (n 52) 13.

62 L O'Carroll, 'Ebola Crisis Brutally Exposed Failures of the Aid System, says MSF' (The Guardian, London, 23 March 2015) <<http://www.theguardian.com/global-development/2015/mar/23/ebola-crisis-response-aid-who-msf-report-sierra-leone-guinea>> accessed 12 February 2017.

63 See UN Security Council, Security Council Press Statement on Guinea, SC/11159-AFR/2730 (24 October 2013) <<http://www.un.org/press/en/2013/sc11159.doc.htm>> accessed 12 February 2017.

political environment may have compromised WHO's engagement with Guinea (and the other affected states) during the initial stages of the crisis.⁶⁴ Indeed, MSF repeatedly complained that insufficient pressure was placed on the government in Conakry.

As a result, gains in controlling the Ebola outbreak were hardest to achieve in Guinea where populations, already distrustful of their government before the outbreak, were not willing to trust their messages with this outbreak and earlier opportunities to contain the outbreak were lost.⁶⁵ The South-East province of Guinea, the location of the Ebola index case, was the site of a violent conflict among different ethnic groups against the government (represented by a 'rival' ethnic group).⁶⁶ The first competitive national election held in 2010 was unable to end the cycle of violence, corruption, and brutality.⁶⁷ Indeed, President Conde's government has been at times blamed for the cycle of violence and brutality in the South-East province.⁶⁸ Before the Ebola outbreak, there were accusations of ethnic favouritism in government positions including the Health Ministry, local civil society organizations were increasingly divided along political and ethnic lines, and there has been a long standing practice of harsh penalties for journalists who report against the government (which is rare given the control the government has over the media). Brutal tactics were reportedly used by military and police against political opponents and journalists.⁶⁹ In July 2014, only months before the Ebola outbreak, approximately 200 protestors were killed and hundreds were wounded in violent confrontation with the government. This was in the location where the first Ebola case emerged.⁷⁰

An environment of mistrust and the politics embedded in the outbreak in Guinea was tragically exposed when journalists and health care workers came to the village of Nzerekore (three hours drive from the first index case) in September 2014.⁷¹ Fearful that the arrival of the government cars meant more disease and death—as had been perceived to be the case earlier in the year when samples were taken, people died, and no more information arrived—local villagers beat to death eight public health care

64 The High-Level Panel on Global Response to Health Crises has come the closest in detailing the how the deficiencies in WHO's initial response (22) was compounded by ineffective engagement with community and civil societies in country (38), which was followed by the mobilization of military to assist with the response which, for these countries with a 'legacy of conflict in the most-affected countries has left populations with deep-seated fears about security forces, undermining their effectiveness in some cases' (40). UN (n 7); Also, P Calain and C Abu Sa'Da, (2015) 'Coincident Polio and Ebola Crises Expose Similar Fault Lines in the Current Global Health Regime' 9(29) *Conflict and Health* 6.

65 MSF (n 54) 8–9, 21; Z Camara and J Lazuta, 'One year on: why Ebola is not yet over in Guinea' (IRIN, Geneva, 23 March 2015) <<http://www.irinnews.org/analysis/2015/03/23>> accessed 12 February 2017.

66 International Crisis Group, *Guinea: A Way Out of the Election Quagmire* (International Crisis Group 2013).

67 International Crisis Group, *The Politics Behind the Ebola Crisis*, *Crisis Group Africa Report No 232* (28 October 2015) <<http://www.crisisgroup.org/~media/Files/africa/west-africa/232-the-politics-behind-the-ebola-crisis.pdf> 2015> accessed 12 February 2017.

68 *ibid*.

69 Freedom House, *Freedom in the World Report 2015: Guinea* (2015), see Civil Liberties. <<https://freedomhouse.org/report/freedom-world/2015/guinea>> accessed 12 February 2017, n.53.

70 International Crisis Group, *Guinea's Other Emergency: Organising Elections*, Brussels (15 December 2014) <<http://www.crisisgroup.org/en/regions/africa/west-africa/guinea/b106-guinea-s-other-emergency-organising-elections.aspx>> accessed 12 February 2017.

71 UN (n 7).

workers and journalists. The contingent had arrived to conduct an Ebola education and disinfection campaign.

IV. PROTECTING THE RIGHT TO REPORT

The MERS and Ebola cases were different outbreaks and had different timelines during the course of infection. However, there were important commonalities—both first infected states had a record of political secrecy and repression. There was a low threshold for public trust in both governments that meant during their respective crises, rumour and suspicion among the public was easily fuelled. There were dissenting voices to the account of the outbreaks that the state was providing, and in both instances, the WHO *appeared* to side with the state (even if there was dissent within the organization). However, how the WHO could act differently in a situation where the cooperation of the state is vital is not easily answered.⁷² Article 9 was meant to provide a much-needed ‘panopticon’ for the WHO,⁷³ but MERS and Ebola have revealed three continuing tensions with the operationalization of Article 9 under the IHR (2005).⁷⁴ First, the WHO could expose itself and those who report to WHO to greater danger by acting on Article 9 reports; second, WHO has no capacity to protect the individual/organization who may report an outbreak event against the wishes of the state; and finally, Article 9 has the capacity to improve state-level reporting and transparency, but it also has the potential to make states more secretive and repressive during outbreak emergencies.

First, despite the potential for new information technology to challenge the state’s monopoly of information,⁷⁵ the MERS and the Ebola outbreaks reveal that receiving and acting upon disease reports from sources other than the state is challenging and may carry risks if WHO is seen to publicly act on such information.⁷⁶ In addition, WHO must calculate the risk of acting on information that may be inaccurate (particularly those outbreak alerts which may be sourced from lesser known social media sites). The WHO’s Public Health Emergency Operations Centre Network (coordinated under auspices of WHO Global and Response Operations) and the proposed new WHO Centre for Emergency Preparedness and Response, need to be able to receive information from non-state sources including individuals and Internet surveillance platforms like ProMED,⁷⁷ and to verify these reports without jeopardizing the individual reporter. However, open source reporting depends upon political

72 C McInnes, WHO’s Next? ‘Changing Authority in Global Health Governance after Ebola’ (2015) 91(6) *International Affairs* 1299; C Wenham, Ebola Responsibility: Moving from Shared to Multiple Responsibilities’ (2015) 37(3) *Third World Quarterly* 436.

73 J Shkabatur, ‘A Global Panopticon - The Changing Role of International Organizations in the Information Age’ (2011) 33(1) *Michigan Journal of International Law* 159.

74 WHO (n 1) art 9.

75 JJ Wirtz, ‘Hiding in Plain Sight: Denial, Deception, and the Non-State Actor’ (2008) 28(1) *SAIS Review of International Affairs* 55; Shkabatur (n 73).

76 SE Davies, ‘Informal Disease Surveillance Networks’ (2012) 24(1) *Global Change, Peace and Security* 95; P Meier and R Munro, ‘The Unprecedented Role of SMS in Disaster Response: Learning from Haiti’ (2010) 30(2) *SAIS Review of International Affairs* 91.

77 T Ottersen, S J Hoffman and G Groux, ‘Ebola Again Shows the International Health Regulations are Broken: What Can Be Done Differently to Prepare for the Next Epidemic?’ (2016) 42(2–3) *American Journal of Law and Medicine* s356.

environments that permit and support full disclosure and facilitate open communication.⁷⁸ Even if this information is contradictory to the state's message. Again, the need for WHO to receive reports other than the state under Article 9 is there, arguably, for the situations when states attempt to conceal outbreak information. The MERS and Ebola cases reveal the constraints and the confusion. Drip feed information from the state, discrepancies between confirmed and suspect cases, and threats to those who provided reports that contradicted the state in both cases eroded the trust of civilians (and neighbouring states) in the reports being received. This loss of trust compromised public trust in the government's capacity to manage outbreak control. In this context, the choices before WHO were not easily resolved.⁷⁹ Siding with the government built government trust, but at the cost of WHO receiving and acting upon information that contradicted the state. At the cost of the international community trusting WHO to protect populations not states. Alternatively, there is no certainty that acting on non-state reports, in both instances, would have produced a different state response without risk of retribution to the non-state actor(s) such as health care workers in Saudi Arabia and MSF in Guinea.

This leads to the second tension of the reporting system articulated in Article 9. It appears that WHO may receive information from individuals who know about an outbreak situation but WHO has no means to provide or guarantee protection. 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'.⁸⁰ States are expected to respond to WHO communications based on non-state reports within 24 hours, and the source of the report is permitted to remain confidential. This may not be of paramount importance for international Internet Surveillance Report Programs (ISRP) such as Global Public Health Information Network (GPHIN) or ProMED, nor for international non-government organizations such as MSF, but for individuals from local non-government organizations or Health Ministries, who may wish to inform WHO of outbreak events, confidentiality may be vital for their personal safety.

In tightly controlled information technology and media spaces, such as Saudi Arabia, health workers who reported disease outbreaks risked losing their jobs and being sent to prison.⁸¹ In a situation such as Guinea, where government control of the message during an outbreak emergency is associated with the political regime, any attempt to manage the crisis may fuel suspicion and panic as well as a securitized response.⁸² As the International Crisis Group reported in late 2015:

78 EG Rød and NB Weidmann, 'Empowering Activists or Autocrats? The Internet in Authoritarian Regimes' (2015) 52(3) *Journal of Peace Research* 338.

79 McInnes (n 72).

80 WHO (n 1) art 9.1.

81 E Knickmeyer, 'Saudi Efforts to Stop MERS Virus Faulted: Experts Still Don't Know How People Are Exposed to Mysterious Disease' (Washington, 24 September 2013) <<https://www.wsj.com/articles/SB10001424127887324807704579086821158272430>> accessed 12 February 2017, Wall Street Journal Washington.

82 A Roberts, 'Transparency in the Security Sector' in A Florini (ed), *The Right to Know: Transparency for an Open World* (Colombia UP 2007) 309–36.

Initially information was not shared, and warnings were not disseminated widely enough. Countries hesitated to declare an emergency for fear of creating panic and scaring away business. Once they did so, their governments relied on the security services—their most capable, internationally supported institutions—but the early curfews and quarantines exacerbated tensions and alienated people whose cooperation was necessary to contain the epidemic. Officials in capitals also initially ignored local authorities, who were sometimes more familiar with traditional customs and accepted by their communities (with the exception of Guinée Forestière [Guinea], where local authorities appeared to be no more trusted than the national government).⁸³

Returning to the H1N1 Review Panel mentioned earlier, the WHO is in a position where it may have the right to receive reports from non-state actors but be in no situation to protect the rights of those who report. The right to receive reports have no corresponding right to deliver them. Furthermore, if WHO is seen to publicly act on a report it received there is no guarantee it could not create further destabilization or harm to individuals in a situation that is already tense.

The third and final tension that arises from Article 9 is the expectation that it will nudge states to improve their own surveillance and reporting practices to ‘beat’ those who report under Article 9.⁸⁴ An alternative view is that Article 9 drives states to become more secretive and exercise control over freedom of information exchange among those in the health sector.⁸⁵ The success of the IHR requires political transparency as much as it requires technical proficiency in surveillance and response,⁸⁶ but what about situations where governments struggle to resource a 24 hour/7 day surveillance and response system? There is growing evidence that in low capacity environments where health systems are already stretched, the use of media reports to inform surveillance and response to disease outbreaks can assist with outbreak detection and containment.⁸⁷ However, such a system requires local media to have freedom to report events as they occur.

The UN Secretary-General appointed Report of the High-level Panel on the Global Response to Health Crises, released early 2016, came closest to addressing this issue when it referred to efforts by some governments to downplay the extent of the Ebola outbreak in their country by calling (international) NGOs ‘alarmist’. The Panel noted that the governments whether there was dysfunction and secrecy had the least familiarity with conducting public information campaigns to empower

83 International Crisis Group (n 52) i.

84 Wenham (n 72) 443.

85 DL Heymann and G Rodier, ‘Global Surveillance, National Surveillance, and SARS’ (2004) 10(2) *Emerging Infectious Disease* 173; C Castillo-Salgado, ‘Trends and Directions of Global Public Health Surveillance’ (2010) 32(1) *Epidemiologic Review* 93.

86 P O’Malley, J Rainford and A Thompson, ‘Transparency during Public Health Emergencies: From Rhetoric to Reality’ (2009) 87 *Bulletin of the World Health Organization* 614.

87 TT Ao and others, ‘Low-cost National Media-based Surveillance System For Public Health Events, Bangladesh’ (2016) 22(4) *Emerging Infectious Diseases* <<http://dx.doi.org/10.3201/eid2204.150330>>; K Wilson and J Brownstein, ‘Early Detection of Disease Outbreaks using the Internet’ (2009) 180(8) *Canadian Medical Association Journal* 829.

populations and challenge ‘rumours’. Familiarity with transparency, the Panel found, was essential to enhance preparedness, response, and communication during outbreaks and this would require ‘input from representatives from different ministries and NGOs’.⁸⁸

Is it realistic to expect Article 9 to be able to resolve the politics of reporting if it cannot provide security for those individuals who seek to report in contravention of the state’s right to legislate and manage emergency response? Ultimately, the Article’s operationalization depends on the willingness of states to permit non-state actors to report to WHO, including those operating contrary to its wishes. The final section of this article examines this issue in more detail to understand what provisions may be conferred to close the gap between WHO’s right to receive reports and the corresponding right to provide them.

V. REALIZING THE RIGHT TO REPORT

The IHR (2005) is underpinned by Article 3.1 which states: the implementation of these Regulations shall be with full respect for the dignity, human rights, and fundamental freedoms of persons (WHO 2005).⁸⁹ This was the first time the IHR referred to a relationship between human rights and containment of disease outbreaks. In the aftermath of Ebola, WHO reported that a lack of trust from the public in the three most affected countries was a barrier to advancing containment of the outbreak.⁹⁰ In Guinea, this reportedly took on ‘extreme dimensions’ where ‘fear spread faster than the virus’ leading to mobs and murders—response teams were often attacked and there was the tragic murders in September (as mentioned above).⁹¹ The UN’s High-Level Panel on Global Response to Health Crises, which included a review of the functionality of the IHR and WHO’s response to outbreak events, noted that failure to ensure that liberty of movement and expression during the crisis, and uphold the human right to personal protection particularly during the outbreak response in Liberia, had led to the death of at least one civilian at the hands of the army.⁹² However, among the 27 recommendations provided by the Panel there was no broader mention of the IHR being underpinned by human rights provision contained under the IHR, or how this provision should guide the actions of WHO and Member States. In the MERS and Ebola cases described here, one key problem was public trust in contexts where faith in the government was already low. In such cases, how should the WHO balance its potential need for non-state reports with the need for state co-operation and public trust in the emergency response the state?⁹³ One answer is to understand what rights individuals have outside of the IHR to report outbreak

88 UN (n 7) 38, emphasis added.

89 B Plotkin, ‘Human rights and other provisions in the revised International Health Regulations (2005)’ (2007) 121(11) *Public Health* 840; A Zidar, ‘WHO International Health Regulations and human rights: from allusions to inclusion’ (2015) 19(4) *The International Journal of Human Rights* 505.

90 UN News Centre, (2015) ‘Ebola Cases Evade Detection Due to Ongoing Lack of Trust in Communities’ *UN News* (8 July 2015) <<http://www.un.org/apps/news/story.asp?NewsID=51365>> accessed 12 February 2017.

91 WHO, ‘Guinea: The Virus Shows its Tenacity’ (January 2015) <<http://www.who.int/csr/disease/ebola/one-year-report/guinea/en/>> accessed 12 February 2017.

92 UN (n 7) 40.

93 *ibid* 38.

situations. The IHR provides WHO with a right to receive reports but what provisions outside of the IHR are available to protect the individual right to report?

In 2015, Andraž Zadir explored the human rights implications of the WHO Director-General's declaration of the Ebola outbreak as a PHEIC according to the IHR (2005).⁹⁴ Noting that the WHO Director-General, Margaret Chan, added to her PHEIC declaration a call for all affected states to declare a national state of emergency, Zadir examined whether this was in effect permission for states to derogate from a 'core' international human rights instrument, namely the International Covenant on Civil and Political Rights (ICCPR). In the event of a national emergency, declared by the government, the Siracusa Principles on the Limitation and Derogation Provisions (hereafter referred to as Siracusa Principles) adjust the extent of a state's obligations under the International Covenant on Civil and Political Rights (ICCPR). In emergency situations, the Siracusa Principles allow for the provision of limitation, or derogation, from the ICCPR.⁹⁵ Permitted derogations may include prohibition from discriminating solely on the basis of race, colour, sex, language, religion, or social origin.

Significantly, Zidar found that even in an emergency situation where quarantine and risk communication could be associated with justified imprisonment and limits on freedom to report on social media, Article 4 of the ICCPR states that derogation is *not* a blank cheque for states (nor international organizations) to ignore their human rights obligations. Even in national emergencies no derogation from Articles 6, 7, 8 (paragraphs 1 and 2), 11, 15, 16, and 18,⁹⁶ is permitted; and any state that wishes to 'invoke' Article 4 on the basis of a national emergency is to inform other State Parties to the Covenant and the Secretary-General of the provisions that the state has derogated and the reasons for derogation.⁹⁷ No state, to date, has attempted to make this argument concerning the four situations where a PHEIC has been declared (H1N1 in 2009; Poliovirus 2014; Ebola outbreak in West Africa 2014; Zika outbreak in South America in 2016), nor was there public record of reference to states attempting derogation by the IHR Emergency Committee convened to discuss H1N1, Polio, MERS, Ebola, Zika, and Yellow Fever outbreaks (in fact, states were reminded of their human rights obligations during H1N1 and more recently, the Zika outbreak).⁹⁸

Given that no PHEIC was declared for MERS, Saudi Arabia had even less recourse to a derogation from ICCPR. In fact, WHO's Bruce Plotkin at the time the IHR came into force, and Andraž Zadir more recently, have argued that there is no evidence to suggest that Siracusa Principles were ever intended to be a justified response in the

94 Zidar (n 89).

95 The main difference between the limitation and derogation is that the limitations model 'shrinks the framework of protection of human rights from the full to a limited scope, while the derogations model temporarily suspends the enjoyment of rights, except core rights that may never be derogated'. Zidar, *ibid* 507.

96 *ibid*.

97 UN, *International Covenant on Civil and Political Rights* (OHCHR 1966) art 4 [3].

98 See WHO, IHR Committees and Expert Roster: IHR Emergency Committee concerning Zika; IHR Emergency Committee regarding Ebola; IHR Emergency Committee concerning ongoing events and context involving transmission and international spread of poliovirus; IHR Emergency Committee concerning Middle East Respiratory Syndrome Coronavirus (MERS-CoV); IHR Emergency Committee concerning Influenza Pandemic (H1N1) 2009 <http://www.who.int/ihr/procedures/ihr_committees/en/> accessed 12 February 2017.

event of a PHEIC under the revised IHR (2005).⁹⁹ Specifically, Article 3 calls upon states and the WHO to implement the ‘Regulations . . . with full respect for the dignity, human rights and fundamental freedoms of persons’; and ‘implementation of these Regulations shall be guided by the Charter of the United Nations and the Constitution of the World Health Organization’.¹⁰⁰ Article 3 under the IHR applies in the event of a PHEIC, which means that the ‘full’ implementation of the Regulations is expected to take place in cooperation with international human rights law. As Zadir explains, while ‘public health may be invoked as a ground for allowing a state to take measures dealing with a serious health threat to the population’ these ‘measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured’.¹⁰¹ The use of military force with live rounds to maintain a curfew, the threat of imprisonment of health workers who did not appear to work, the threat of imprisonment of journalists who reported events and cases that contradict the government, and the length of quarantine imposed in outbreak affected countries without the provision of basic human needs (shelter, food, water, and medical attention) to those under quarantine, would all be illegal breaches of the ICCPR.¹⁰²

David Fidler argued that the timing of the human rights inclusion in the revised IHR in 2005 was particularly significant. It arose largely in response to an attempt to balance ‘the protection of public health and response for individual rights’.¹⁰³ The 2003 SARS outbreak was meant to encourage governments to adopt a different interpretation of how they should balance civil and political rights against containment of the outbreak. Responses during SARS had ranged from China’s imprisonment of a military hospital doctor for reporting the extent of SARS cases in Beijing (which contradicted public figures); Singapore enacting compulsory reporting, isolation, and quarantine restrictions; while Canada choose not to mobilize emergency law concerning reporting, quarantine, or isolation.¹⁰⁴ After these events, the inclusion of human rights in the revised IHR signalled to ‘governments worldwide that their obligations to their citizens (as well as those temporarily within their borders) extend[ed] into all realms—including public health and infectious disease control’.¹⁰⁵

To date, most discussion of the human rights provisions within the IHR have referred to the freedom of the (infected and non-infected) individual to move freely and travel during disease outbreaks. However, as the MERS and Ebola cases reveal, existing civil and political rights conditions in an affected country may also influence and determine WHO’s right to information and non-state actor’s right to report in an emergency situation. If Article 9 is fully realized by non-state actors, particularly those reporting in defiance of their government, the IHR has a much broader human rights

99 B Plotkin, *Human Rights and Other Provisions in the Revised International Health Regulations (2005)*’ (2007) 121(11) *Public Health* 840; Zidar (n 94).

100 WHO (n 1) arts 3.1, 3.2.

101 Zidar (n 95).

102 Human Rights Watch, *West Africa: Respect Rights in Ebola Response* (International Crisis Group, Nairobi, 15 September 2014) (n 52) <<https://www.hrw.org/news/2014/09/15/west-africa-respect-rights-ebola-response>> accessed 12 February 2017.

103 D P Fidler, *SARS, Governance and the Globalization of Disease* (Palgrave Macmillan, 2004) 152.

104 *ibid* 153.

105 J Youde, *Biosurveillance and Public Health in International Politics* (Palgrave Macmillan 2010) 167.

dimension. There is consensus that the Siracusa Principles, even if applicable during a PHEIC, does not erase the obligation of states to give full consideration to the rights of their citizens. WHO, as the leading agency for the implementation of the IHR, also has an obligation to consider its responsibility to uphold a human rights-focused IHR. How can the right to report—integral to the relationship between positive fulfilment of civil and political rights—be realized through the aegis of WHO and other platforms that receive ‘other reports’?¹⁰⁶

In the case of MERS in Saudi Arabia, the threat of repercussions on those who reported a different story to that of the government was compounded by the fact that there was little opportunity for an alternative story to be told. In the case of Guinea, the presence of MSF was, in essence, the primary driver for revealing the extent of the potential Ebola outbreak there, but local civil society organizations were vulnerable to political reprisal, as were those within the Health Ministry if they challenged the government on its message. These situations not only compromise the value of disease outbreak information being reported but also compromise the task of surveillance itself.

One solution is for WHO to publicly recognize the contradictions in Article 9—the WHO’s right to receive non-state actor’s reports will not always correspond with state-level response. Article 9 is necessary to protect a state from its neighbour’s recalcitrance to report as much as it is to protect the broader international community. WHO could begin a conversation on how to realize the human rights dimension of the IHR in consultation with states and the UN human rights agency—the Office for High Commissioner for Human Rights (OHCHR). A similar process of consultation has begun between the WHO and OHCHR on human rights focused advisories that pertain to women and children.¹⁰⁷ A high-level panel on outbreak reporting and surveillance, for example, could clarify the right to report during public health emergency situations and assist the WHO with locating the human rights conditions necessary for detection, response, and communication that correspond with the IHR in future outbreak situations.

From the WHO’s perspective, any form of human rights monitoring would carry immense political risk and contestation. It would be outside the bounds of its mandate and is not the recommendation in this article.¹⁰⁸ However, WHO has a mandate—

106 For example, there is no reference to human rights response in the one-year review by WHO nor in the independent review. See WHO (2015) One Year into the Ebola epidemic, January <<http://www.who.int/csr/disease/ebola/one-year-report/introduction/en/>> accessed 12 February 2017; In fact, it has been noted that WHO appears determined to focus on a narrative that is only positive about its role in the Ebola outbreak. Oxfam International, (2015) ‘Improving International Governance for Global Health Emergencies: Lessons from the Ebola Crisis’ (January 2015) <https://www.oxfam.org/sites/www.oxfam.org/files/file_attachments/dp-governance-global-health-emergencies-ebola-280115-en.pdf> accessed 12 February 2017, Oxfam Discussion Paper, 4.

107 WHO, *Call for inputs: High-level Working Group on Health and Human Rights of Women, Children and Adolescents* <<http://www.who.int/life-course/news/human-rights-wg-call/en/>> accessed 12 February 2017.

108 See LO Gostin and others, ‘The Next WHO Director-General’s Highest Priority: A Global Treaty on the Human Right to Health’ (*The Lancet Global Health*, 13 October 2016) <[http://dx.doi.org/10.1016/S2214-109X\(16\)30219-4](http://dx.doi.org/10.1016/S2214-109X(16)30219-4)>.

under the IHR and the WHO Constitution—to provide human rights focused recommendations couched as essential in IHR Emergency Committee deliberations. Articles 3 and 9—as well as Articles 23 and 33—under the IHR should be regularly referred to and monitored in potential PHEIC situations to support the WHO and Member States in understanding the human rights conditions necessary to conduct effective surveillance and response, and gain public trust in vital risk communication strategies during outbreaks. The prior engagement with the OHCHR referred to above, would provide WHO with clarity on what states need to do to communicate outbreak messages clearly, and be consistent in voicing what rights non-state actors, including individuals have, to report to WHO as a matter of routine.

There also remain untested pathways under the IHR to ensure wider participation of civil society and ISRPs when consulting as part of the IHR Emergency Committee processes. The IHR Committee Roster could be one way to ensure that consultation and membership is broader than the government of the state(s) embroiled in the emergency. As said above, including human rights in monitoring assessments and expanding the membership of parties consulted by WHO was, respectively, suggested in the 2011 review and by the High-Level Panel on Global Response to Health Crises.

Beyond the WHO, it is in non-state actors interest to advocate their right to report. To date, ISRPs—the most reliable and consistent non-state actors who report under Article 9—have said very little in this area yet have benefitted from the risks individuals have taken to report outbreak events.¹⁰⁹ One avenue for discussion and advocacy among ISRPs is the Global Health Security Initiative (GHSI)¹¹⁰—a consultative body of ISRPs located within the Group of Eight (Go8) membership—which has been set up to regulate ISRP reporting practices. In the material available to date on these consultations, there appears to have been little discussion on the collective role of ISRPs in promoting safe reporting for individuals, facilitating safe reporting environments in country, and the human rights obligations of ISRPs themselves to protect those who report. Given that many ISRPs under the GHSI, such as ProMED, HealthMap, and GPHIN rely on reports from those in-country who have needed to maintain confidentiality when reporting, there is value in these ISRPs advocating WHO to support Article 9 and advocate states compliance with a consistent human rights-focused reporting environment that promotes reporting transparency and reporting freedoms in the environments where they are receiving communications.

109 JS Brownstein and others, 'Surveillance Sans Frontières: Internet-Based Emerging Infectious Disease Intelligence and the HealthMap Project' (2008) 5(7) Public Library of Science Medicine 1019.

110 See Global Health Security Initiative <<http://www.ghsi.ca/english/index.asp>; specifically GHSI, 10 Years of Collaborative Action> accessed 12 February 2017; Anniversary Document <<http://www.ghsi.ca/Documents/AnniversaryPublicationFinal.pdf>> accessed 12 February 2017; GHSI, *Sixteenth Ministerial Meeting Of The Global Health Security Initiative (GHSI)* (Washington, DC, 26 February 2016) <<http://www.ghsi.ca/english/statementWashington2016.asp>> accessed 12 February 2017.

VI. CONCLUSION

In the case of outbreak reporting, there is a vital intersection between the detection, information, and the right to report that shapes public trust in the advice provided by their government and the WHO.¹¹¹ In the SARS outbreak, China's effort to manipulate the flow of information was not unprecedented, but for the global community the WHO's receipt of reports about outbreak events from local sources other than the Chinese government was invaluable. This inspired the campaign to permit WHO to receive 'other reports' which, coupled with the inclusion of a human rights provision in the revised IHR, were unprecedented achievements for IHR reform.¹¹² Since 2005, there have been numerous efforts devoted to create an environment and platform where non-state actors may report to WHO. However, in practice realizing the freedom to report remains a dangerous exercise for individuals, and freedom for the WHO to receive and act upon non-state reports remains politically difficult for the organization. There is an implementation gap between what is promised in the IHR, specifically, how WHO should operationalize the confidentiality clause under Article 9 against what states permit when it comes to non-state reporting of outbreak events.

The freedom of individuals to report potential disease outbreak events and the freedom of the WHO to receive these reports reveal three tensions demonstrated by the MERS and Ebola cases. First, the WHO could expose itself and those who report to greater danger by acting on Article 9 reports; second, WHO has no capacity to provide protection to those who may report an outbreak event against the wishes of the state; and finally, Article 9 has the capacity to improve state-level reporting and transparency, but it also has the potential to make states more secretive and repressive during outbreak emergencies. The question then is how can the WHO promote consistent compliance with Article 9 that permits the organization to receive non-state actor reports (which may provide vital insight into an outbreak event) without causing harm to the informants?

The final section of the article explored the relationship between the freedom to report that underpins Article 9 and the human rights obligations of both states and the WHO to permit transparent reporting conditions. Despite the inclusion of human rights language in the revised IHR, there has been little discussed or operationalized within the IHR Emergency Committee advisories on PHEICs, to date, that promote the human rights responsibilities of the WHO and states during outbreaks. Denying the individual right to report whether by political repression, intimidation, or neglect, has the potential to impact on future outbreak events when scientists, health professionals, and media may hesitate to communicate for fear of reprisal. WHO has a delicate role to play here, but the revised IHR is the best instrument available to permit the WHO to balance states' concern with managing risk communication against the individual right to report situations that may provide vital insight into an emergency situation.

A human rights framework that underpins effective outbreak surveillance and response is presently absent from the WHO repertoire of responses to outbreak

111 O'Malley and others (n 86).

112 Shkabatur (n 73); DL Heymann, JS Mackenzie and M Peiris, 'SARS Legacy: Outbreak Reporting is Expected and Respected' (2013) 381(9869) *The Lancet* 779.

emergencies. Yet, providing an environment of reporting freedom and transparency may enhance public trust and deliver faster international assistance. The WHO and its Member States have a responsibility to bring human rights discourse into their public health emergency outbreak response.