EVIDENCE REPORT
No 181

Policy Anticipation, Response and Evaluation

Real-time Monitoring in Disease Outbreaks: Strengths, Weaknesses and Future Potential

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March 2016

The IDS programme on Strengthening Evidence-based Policy works across seven key themes. Each theme works with partner institutions to co-construct policy-relevant knowledge and engage in policy-influencing processes. This material has been developed under the Policy Anticipation, Response and Evaluation theme.

The material has been funded by UK aid from the UK Government, however the views expressed do not necessarily reflect the UK Government's official policies.

AG Level 2 Output ID: 583

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First published by the Institute of Development Studies in March 2016

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Acknowledgements

The author would like to thank Karl Blanchet for peer review comments, and Kathryn O'Neill and Beth Mudford for editorial and production support.

Abbreviations

AusAid	Australian Agency for International Development
CDC	Center for Disease Control and Prevention
CEBS	community event-based surveillance
ERC	Ebola Response Consortium (Sierra Leone)
ERTM	epidemic real-time monitoring
EVD	Ebola virus disease
GOARN	Global Outbreak Alert and Response Network
IDS	Institute of Development Studies
IFRC	Sierra Leone Red Cross Society
IMC	International Medical Corps (Philippines)
IRC	International Rescue Committee
JICA	Japan International Cooperation Agency
MOPBASSS	Mobile Phone-based Syndromic Surveillance System
PDA	personal digital assistant
RTM	real-time monitoring
SARS	severe acute respiratory syndrome
SMS	Short Message Service
SOPs	standard operating procedures
SPEED	Surveillance in Post Extreme Emergencies and Disasters
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization

Summary

This Evidence Report analyses the potential contribution of epidemic real-time monitoring (ERTM) initiatives to enhancing and augmenting disease surveillance systems in developing countries.

It gathers and synthesises existing evidence from literature on infectious diseases, case study evaluations and expert viewpoints about how a range of ERTM initiatives have been used for, and added value to, epidemic early warning and early response efforts.

By drawing on a range of insights from academic literature, organisational evaluations and practitioner perspectives, the study aims to provide a rounded picture of the potential as well as the limitations of real-time data for epidemic disease responses.

1 Introduction: examining the role of mobile real-time disease monitoring in epidemic surveillance

According to the World Health Organization (WHO), infectious diseases pose a major problem in many developing countries (WHO 2007). Data from the WHO's *Global Burden of Disease* report show that in low-income countries, 38 per cent of all deaths and six of the top ten causes of death can be attributed to infectious diseases. In lower middle-income countries, 24 per cent of all deaths and five of the top ten causes of death were due to infectious diseases (Lozano *et al*. 2010).

The diseases most commonly associated with developing countries include diarrhoeal diseases, acute respiratory infections, measles and malaria, epidemic meningococcal disease, tuberculosis, relapsing fever, cholera and typhus (Doherty 2013). In recent years, epidemics of Ebola, avian influenza, severe acute respiratory syndrome (SARS) and cholera have all triggered major national and international responses (Institute of Health Metrics and Evaluation 2013). These efforts have, in different ways, highlighted the importance of global disease surveillance systems as well as their weaknesses, indicating the need for novel ways to strengthen and augment such systems (Doherty 2013).

Surveillance systems enable the 'systematic, ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response' (WHO 2005: 14). Such systems are seen as essential for effective disease responses, but are also frequently found to be lacking in coverage, accuracy and timeliness, especially in those developing countries that shoulder the heaviest disease burdens (Baker and Fidler 2006).

In recent years, and especially in the wake of the West African Ebola crisis, more effective surveillance systems for epidemic early warning and response have become an urgent priority for the international community as a whole (Woolhouse, Rambaut and Kellam 2015). This need has transcended any single country or region to become a truly global challenge, demanding the provision of surveillance as a global public good (*ibid.*). Growing attention is now being paid to the potential of new digital technologies for 'augment[ing] traditional surveillance methods to acquire and disseminate information in real time' (*ibid.*: 307).

The rationale for epidemic real-time monitoring (ERTM) systems is that they have the potential to provide a low-cost continuous monitoring tool for epidemic-prone, disease-specific or related unusual events. This can ensure early detection of outbreaks and support rapid confirmation, characterisation, response, and control measures (Institute of Medicine 2007). Used alongside more formal surveillance systems, ERTM systems are seen as crucial for strengthening overall epidemic intelligence (Barboza *et al.* 2013).

Previous research from the Institute of Development Studies (IDS) on real-time monitoring (RTM) defines RTM systems as those that generate data at a higher frequency than traditional data, and that lead to some form of response (Greeley, Lucas and Chai 2013a). There is a growing body of work on RTM funded by the IDS Policy Anticipation, Response and Evaluation work stream. This work has shown that RTM efforts:

- are made possible by a combination of hardware, software and connectivity advances
- are facilitated by the gathering, storage, communication, processing and recall of large data sets at relatively low cost
- have considerable potential to be ‘game-changers’ in the delivery of services, including but not limited to health, education, energy and finance
- have been subject to critical questions and challenges about use, functionality, effectiveness, distribution, inclusion and sustainability
- can be challenging in settings where technology use is limited by infrastructure and awareness (Greeley *et al.* 2013a, Greeley *et al.* 2013b; Lucas, Greeley and Roelen 2013; Joshi *et al.* 2014; Pueyo 2013).

This study seeks to explore ERTM systems in more detail, focusing on:

- design, strategy and function
- key stakeholders and reporting relationships
- performance and quality in absolute terms and relative to formal surveillance systems.

Findings from across these areas will be synthesised to draw more general lessons about the strengths and weaknesses of ERTM initiatives, and whether or not they contribute to more effective and timely epidemic surveillance and, ultimately, to improved public health decisions and responses.

It synthesises findings from three sources: evidence available from systematic reviews and syntheses of ERTM efforts in developing countries; evaluative evidence from specific case studies of ERTM efforts; and interviews with experts and practitioners involved in designing and implementing such systems.

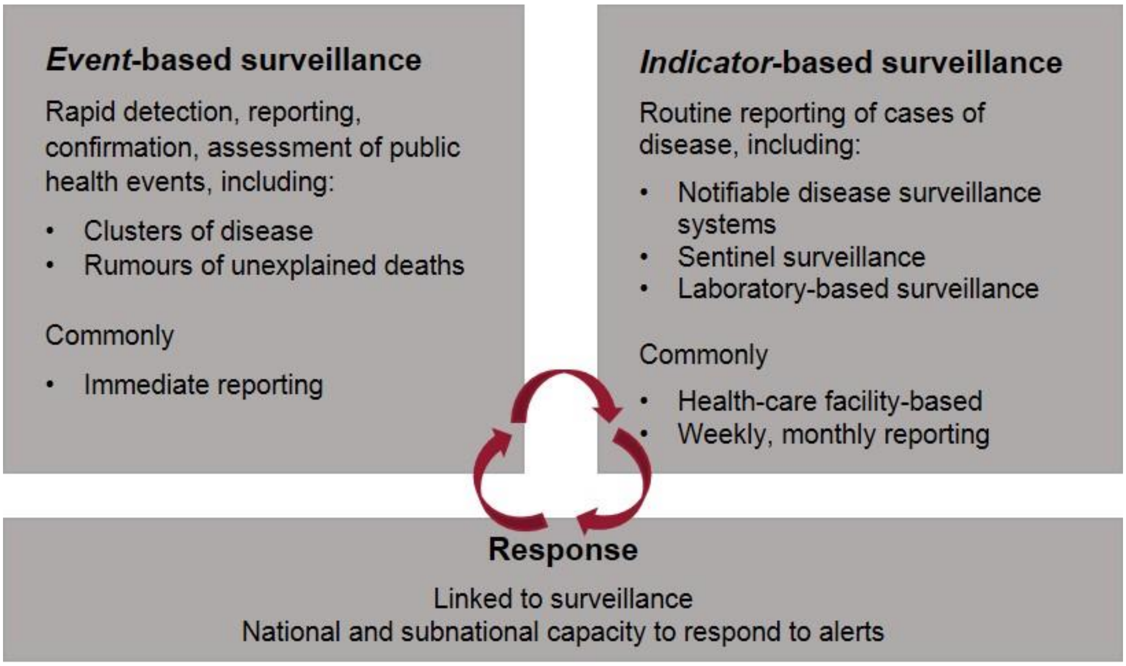
In taking this approach, the study aims to generate lessons for policy and practice from existing ERTM efforts as well as insights into how future efforts might be strengthened. As such, the primary audiences are policymakers and practitioners, as well as researchers on real-time monitoring and surveillance systems.

2 Epidemic real-time monitoring: background and context

ERTM systems can be usefully seen as one example of event-based disease surveillance systems, in contrast to more traditional indicator-based systems (WHO 2008).

This important distinction is illustrated in Figure 2.1 and is further explained below.

Figure 2.1 Comparing event-based and indicator-based surveillance



Source: Adapted from WHO (2008).

As Figure 2.1 indicates, indicator-based systems are based on routine reporting of disease cases. They collect and analyse structured data based on established surveillance and monitoring protocols, which are typically tailored to different diseases. Data are reported on a regular basis by health-care providers and diagnostic laboratories, and collected by surveillance specialists in governmental health agencies. They are then subsequently verified through communication between the agencies and those responsible for data collection. The strength of such systems lies in their statistical power, and capacity to compare data to pre-defined thresholds for different diseases. This means that such systems can reliably identify increased numbers or clusters of incidence at a specific time, period, and/or location that might indicate an epidemic threat (Velasco *et al.* 2014).

The weakness of indicator-based systems is that there are time lags embedded throughout the chain of data collection, analysis and notification, such that these systems cannot quickly detect potential threats. As the WHO has found, ‘When it comes to the *timely* detection of outbreaks… indicator-based surveillance systems often fail’ (WHO 2008: 4, emphasis added). Moreover, there are issues around the sensitivity to new or unexpected diseases, because, by their very nature, pre-defined indicators look for existing pathogens rather than novel or emerging diseases (Velasco *et al.* 2014).

Event-based surveillance is also based on the organised and rapid capture of information about public health risks. However, instead of relying on formal reporting systems, these data are increasingly gathered directly and in real time through pre-established monitoring and alert systems (typically implemented by community members or front-line workers), or through gathering publicly available data from traditional and social media channels. Because of this, event-based systems can detect threats not captured by indicator-based surveillance. They also identify events faster than traditional indicator-based procedures, and can detect events that occur in populations not covered by formal channels for reporting. Increasingly, event-based surveillance efforts make use of digital technologies to gather, share, manage and analyse different kinds of disease-related data in a variety of humanitarian and development contexts, with the aim of informing decision-makers working in local, national or international health systems (Velasco *et al*. 2014; WHO 2008).

In recent years, efforts in real-time monitoring for event-based surveillance have grown considerably in number and scope (Morse 2012). ERTM approaches are now becoming one of the most widespread of all electronic health initiatives, according to the most recent survey of the Global Observatory for eHealth (WHO 2013). Many of these new interventions have been developed and tested in the context of major epidemic emergencies, including Ebola in West Africa, global polio outbreaks, the Haiti cholera outbreak, the Philippines leptospirosis, and others (Woolhouse *et al.* 2015).

The information generated by such systems can be used across all of the five distinct stages of epidemic outbreak response identified by WHO guidance, namely: diagnostics and assessment; prevention; surveillance; outbreak control; and disease treatment and management (Connolly 2005). This can be a useful way of classifying ERTM systems, although in reality, many will cut across these functions.

Another way of categorising ERTM efforts is according to their most significant sources of data, which influences the nature, structure and scope of such systems. Although these are not exclusive, most ERTM systems can be seen as relying primarily on one or other of the following three sources:

- community volunteer systems based on simple pre-planned survey questionnaires distributed on mobile phones or surveys
- health worker systems, again based on survey questionnaires, which are typically more sophisticated, and may use mobile phones or other forms of mobile technologies such as tablets or personal digital assistants (PDAs)
- social and traditional media analysis systems, drawing on data from social media platforms such as Twitter, or more traditional newspaper, radio and TV media sources (Morse 2012).

Regardless of the source, data are typically fed to a common centralised data system that works to collate, store and share data in real time. As well as providing basic analysis, this system can serve as a platform for more sophisticated analysis and, where appropriate, can trigger response. Despite the growing applications and a number of feasibility studies, there remains limited evidence on the effectiveness of ERTM systems in the context of epidemic outbreak surveillance. As a result, much of what is known about the contribution of such systems to surveillance coverage, timeliness, decision-making, and health outcomes is anecdotal (Charles-Smith *et al.* 2015).

These evidence gaps need to be understood in context. First, as the London School of Hygiene & Tropical Medicine's 2013 systematic review of evidence in emergency health efforts found, much more work is needed to advance the evidence base of managing epidemic responses in developing countries in general, and particularly of epidemic surveillance and digital technologies (Blanchet *et al.* 2013). Second, event-based surveillance systems – of which digital RTM is just one prominent example – are poorly understood in developed and developing country settings alike. A recent systematic review of event-based surveillance systems found limited evaluations and research, with many interventions not being subjected to any kind of systematic analysis at any stage of implementation (Velasco *et al.* 2014).

3 Case study findings

The six case studies reviewed below are all forms of ERTM that have been implemented in the past five years. The selection criteria were that all case studies should involve some form of real-time monitoring technology or process, all should have explicit goals to contribute to epidemic surveillance, and all must have been subject to some form of operational analysis or systematic evaluation.

Because of the pace of digital developments, it was also decided to exclude case studies that dated from more than five years before the current study. These were identified through a range of mechanisms: existing knowledge, literature search, key informant referral and web searches.

The case studies identified fit into the three broad categories of ERTM systems as follows:

- community event-based surveillance efforts: Ebola response in Sierra Leone (2014–15); rumour tracking in Amhara, Ethiopia (2013–14)
- front-line health worker-based digital event-based system: Surveillance in Post Extreme Emergencies and Disasters (SPEED) in Philippines (2012 onwards); cholera response in Papua New Guinea (2014)
- social media monitoring systems: cholera response in Haiti (2010); polio globally (2013–14).

For the first two of these categories, key findings are summarised for the specific case studies, drawing on evaluative evidence synthesis and expert interviews. For each case study, three broad elements are explored:

- design, strategy and function
- key stakeholders and reporting relationships
- performance and quality.

For the third category (social media), the approaches were subject to retrospective data analysis, looking at the quality of their data comparative to official sources, but not to operational analysis, and describing how these data were utilised in decision-making. As such, these case studies are shorter, have less specific details about the use of information by stakeholders, and are therefore more focused on the relative strength and potential use of the data generated.

3.1 Community event-based surveillance systems, Sierra Leone and Ethiopia

3.1.1 Design, strategy and function

Community event-based surveillance (CEBS) interventions are based on the real-time capture of information from communities – typically through networks of volunteers – about events that pose public health risks. This information is then transmitted by a variety of mechanisms to intermediaries, who will verify information and, where necessary, notify health authorities.

In Sierra Leone, the CEBS was designed and implemented by the International Rescue Committee (IRC), the Center for Disease Control and Prevention (CDC) and the district health authority. The system was initially piloted across 100 villages in Bo district, starting in November 2014 at the height of the Ebola outbreak, and continuing for another nine months. The design went through an iterative process, with an initial pilot phase leading to the development of standard operating procedures (SOPs) that could support scale-up. These SOPs were reviewed and approved for national scale-up by the national surveillance pillar and incorporated into the national Ebola surveillance strategy, being scaled up to other districts through the Ebola Response Consortium (ERC). From the pilot application in one district, since January 2015, the ERC has supported the Ministry of Health to implement CEBS in nine of the country’s 14 districts. The Sierra Leone Red Cross Society (IFRC) is supporting CEBS in an additional three districts (ERC 2015).

The Sierra Leone system aimed to improve early identification of cases of Ebola virus disease (EVD), reduce Ebola transmission among communities, and enhance the response. It would do this by identifying emerging clusters of EVD transmission at the earliest possible stage and communicating information about potential EVD transmission to district-level Ebola Response Committees. The overall objective was to increase the timeliness with which suspected EVD cases were identified, isolated, and provided with the appropriate care (*ibid.*).

In Ethiopia, the initiative took place in Amhara region, in the north-west. It started out as a front-line worker event-based surveillance system, initiated by the Ethiopian Federal Ministry of Health, with the expectation that regional, zonal and district health offices would provide information from the front line. However, poor take-up led to an adaptation to the approach, and the initiative was re-designed to become a community volunteer system, looking specifically at gathering and analysing rumours of disease. Funded by the Japan International Cooperation Agency (JICA), the system was rolled out across 22 study districts in three zones with a total population of 4.5 million, involving 59 sites (Toyama, Ota and Beyene 2015).

The Amhara work did not have a specific focal disease, nor was there a specific overarching goal. Instead, it set out to collect rumours in the community and register them in central systems. At the outset of the programme, the structure of reporting was established, involving electronic data collection and analysis protocols.

3.1.2 Stakeholders and relationships

The Sierra Leone CEBS programme was based on local volunteers selected from within communities and trained to detect and report on a number of Ebola-specific trigger events to community health monitors. Through mobile phone networks, this trigger is then shared with the village surveillance supervisor who alerts the district Ebola response centre, typically making the journey in person by motorcycle. The district centre operatives then dispatch a case investigation team to verify the trigger (ERC 2015).

In the Ethiopia CEBS programme, the community members formed ‘health development armies’, a volunteer-based community health team with a network structure of one volunteer per five households. These members collected health-related information from households, and reported any communicable disease outbreaks and unusual health events to health centres, emphasising events with multiple deaths from unknown causes. Volunteers were also mobilised for verification of the rumours in the community when needed (Toyama *et al.* 2015).

3.1.3 Performance and quality

In Sierra Leone, a three-month accompanying evaluation in nine ERC districts focused on how well the CEBS structure was working and its sensitivity and timeliness in detecting new confirmed cases. This was done through extensive interviews with participants throughout the CEBS system as well as analysis of real-time alert data to assess quantity, type and confirmation of alerts.

After five months, in June 2015, more than 7,000 community health monitors and almost 150 surveillance supervisors had been trained, generating more than 3,400 real-time alerts. The CEBS was found to have been involved in 58 per cent of confirmed EVD cases from districts with active transmission in a five-week period, and in 60 per cent of cases that originated from unknown chains of transmission. Of these cases, the time from onset to detection was two to three days when detected by the CEBS system and up to seven days for other systems.

The evaluation found a good level of use and understanding of the system among community-level data gatherers and data aggregators. Among district partners, however, knowledge of the system varied, with less than 60 per cent of representatives demonstrating an understanding of its core structure and function.

There were numerous challenges, including malfunctioning of the mobile phone system that was set up for the CEBS and through which alerts were shared. In addition, a lack of motorbikes to facilitate travel between villages was also a major issue for the surveillance data aggregators. This had the potential to prevent the rapid and efficient flow of information through the system – an outcome that was mitigated by community volunteers using their own personal phones (instead of those provided by the initiative) and their own transportation to undertake verification and reporting.

While almost three-quarters of district partners reported that they thought CEBS had benefited the districts, there were many concerns about financial sustainability and incomplete coverage. There were also issues about the need for better coordination with other district-level health players, and how the system could be expanded to cover other diseases.

Overall, the Sierra Leone CEBS effort served as a valuable component of the surveillance system, helping to detect new cases, and providing sensitive and timely detection of cases from unknown chains of transmission. By ruling out suspect cases, it also confirmed zero transmission in quiet districts (ERC 2015). The evaluation report found that continued engagement with communities and local leaders will be essential to build community trust in the system; and that for CEBS to be sustained, it would need to be more fully integrated within the structures and processes of the official health system.

The Ethiopia work ran between October 2013 and November 2014 and was subject to an evaluation throughout this period. Across the pilot districts, almost 2,000 events were reported, of which 64 per cent were verified and found to be genuine public health events. Most common rumours were about measles outbreaks, rabies, anthrax, whooping cough and polio. The most commonly reported rumours were measles-related (71 per cent). The measles rumours followed a similar pattern of measles cases reported in the routine surveillance system. However, there were eight times as many verified rabies cases through the CEBS system as through the routine system, and 2.5 times as many anthrax cases (Toyama *et al.* 2015).

Of the total epidemic or disease rumours registered, the average event reporting time was 3.8 days and the response time for health centres was 0.6 days, resulting in a total response time of 4.4 days. Responses included case management, active case finding and vaccination. The largest proportion of rumours were reported by community members, but there were also some cases of health workers acting as intermediaries for the reports, after being informed by community members (*ibid.*).

The CEBS system was established alongside an existing indicator-based surveillance system and was seen as simple and easy to implement. The implementation cost was minimal, requiring only the distribution of rumour data tools to the health centres, brief orientations to community focal points, and training of centralised data managers. Volunteers had already been trained and the overall cost of the system was viewed as very low, requiring only brief orientations as the programme was implemented. Community acceptance of the system was high, reflecting the fact that the majority of rumours came from community members even though there were no incentives to report (*ibid.*).

However, the evaluators identified limited capacity to respond to the rumoured events, and recommended more investment and capacity to provide prompt responses alongside the ERTM implementation. Without such efforts, buy-in to and acceptance of the ERTM system could erode over time as the community loses faith that the system will, in fact, trigger improvements in services (*ibid.*).

3.2 Health worker ERTM systems

Health worker ERTM systems are distinct from community-based systems because they are typically more sophisticated, involve more detailed reporting criteria and data gathering, and are usually designed to be a formal part of the health surveillance system. Here, we look at two mobile phone-based case studies: one in the Philippines, which focuses on epidemic surveillance in disasters (SPEED); and one in Papua New Guinea, which is more generally focused on surveillance.

3.2.1 Design, strategy and function

The Surveillance in Post Extreme Emergencies and Disasters (SPEED) project emerged from a collaboration between WHO and the Philippines Department of Health in 2010, focused on the development of a mobile technology-based early warning disease surveillance system for post-disaster situations (WHO 2014). After Typhoon Ketsana, which hit in 2009, Manila saw the largest ever outbreak of leptospirosis (Amilasan *et al.* 2012). Subsequently, WHO's Global Outbreak Alert and Response Network (GOARN) identified the need for an effective monitoring system for early detection of unusual increases in major public health events during emergencies in the Philippines. In collaboration with the Philippine Department of Health, the United States Agency for International Development (USAID), AusAid and the Government of Finland, WHO worked to create SPEED as a tool for infectious disease preparedness and response (SPEED 2011a).

The basic principle of SPEED is the use of web-based software technology to receive data via Short Message Service (SMS) from all parts of the country. These data can be aggregated and used at different levels and in different regions. The front-line component of the Philippines disaster response structures are local disaster evaluation areas; health workers operating in these areas play a critical role in populating SPEED with data. SPEED reporting forms, loaded onto mobile phones and tablets, enable the capture of essential information during consultations with members of affected communities. The system is set up to undertake surveillance and monitoring of 21 identified disease entities or health events that are common in emergencies or disasters (SPEED 2011b).

Since 2010, SPEED has been used in a number of disasters, including after Typhoons Quiel, Washin, Haiyan and Ruby. The largest single deployment was after Typhoon Haiyan in 2013, which led to serious concern about possible disease outbreaks. Aid resources were directed to the Department of Health to enhance emergency disease surveillance systems, including resources for deploying SPEED.

In Papua New Guinea, following a series of epidemics with high mortality rates and poor surveillance responses, including an ongoing national cholera outbreak, the health authorities piloted a mobile phone-based ERTM system that aimed to enhance the timeliness of outbreak detection (Rosewell *et al.* 2013). Some effort was already being made to gather information about potential high-risk events through *ad hoc* and rumour reports transmitted through the health information system. The Mobile Phone-based Syndromic Surveillance System (MOPBASSS) was piloted in two health centres in Port Moresby in 2010, then scaled up nationally during 2011. The pilot intervention included the provision of data collection tools, a one-day on-site training, sample collection materials, guidelines, and mobile phones.

MOPBASSS set out with the objectives of: identifying acute disease events in a more timely fashion; establishing baseline data for public health syndromes; strengthening the links between clinical services and outbreak response; and complementing existing event-based and routine surveillance systems. It sought to cover a number of syndromes, including influenza-like illnesses, acute water diarrhoea, bloody diarrhoea, prolonged fever, acute fever, haemorrhagic fever, and outbreaks of unexplained disease or deaths (*ibid.*).

3.2.2 Stakeholders and relationships

In the Philippines, front-line health workers operating in evacuation centres and other sites are the primary collectors of surveillance information, which they enter into the SPEED system using mobile SMS messaging. All the information is stored in the national SPEED server, allowing aggregated data to be viewed and analysed by health managers and regional and national decision-makers. The system allows online data validation and automatic generation of necessary reports. This enables the rapid transmission of a range of syndromic disease information from local evacuation centres to national levels of the health system. Users can also create graphs, spreadsheets and maps to support early warning and decision-making about possible disease outbreaks and feasible responses. The system also has a built-in capacity to alert users if certain diseases go beyond specific epidemic thresholds. In the case of SPEED, actors outside the humanitarian sector – from the private sector, national governments, local governments, community-based organisations and national health providers – have played a central role in the design and deployment of the system, and its continual refinement (WHO 2014; Tante *et al.* 2015).

In Papua New Guinea, MOPBASSS stakeholders included surveillance focal points from the pilot sites (predominantly outpatient nurse coordinators and paediatricians), disease control staff from the provincial health offices, and national surveillance staff. When an acute event presents at one of the pilot health facilities, the health worker first documents and tallies those events on paper, and submits summary information via the standardised mobile phone templates. This information is then sent by the surveillance focal point, either on an urgent basis for selected high-risk syndromes, or on a weekly basis for others.

In parallel, samples are collected and sent for laboratory investigations, and results are also shared with the different stakeholders. Information is stored in an online database managed by a private sector operator, and is accessed by provincial and national health officers via a series of automatically generated reports. The MOPBASSS system sends automated messages to relevant parties throughout the data reporting, collecting and analysis process to trigger specific processes and activities such as reporting events to the next level, collecting samples, filling out lab forms, and so on. A weekly email bulletin is sent to all participating stakeholders, summarising events, analysis and relevant actions (Rosewell *et al.* 2013).

3.2.3 Performance and quality

For the initial four months of the Haiyan response, SPEED was implemented in 411 health facilities in the affected areas. More than 300 staff received training in how to use the system from WHO, the United Nations Children's Fund (UNICEF), the International Medical Corps

(IMC) and others; and more than 340,000 consultations were reported, generating approximately 3,000 SPEED early warning signals. Every single one of these led to responses to prevent possible outbreaks, ranging from specific health treatments to stockpiling of drugs and advocacy efforts.

However, local acceptance may not be as high as imagined. Surveys of 45 government health officers from areas affected by Haiyan in March 2014, which focused on the effectiveness of surveillance systems, found that SPEED had not always been activated in a timely fashion (Tante *et al.* 2015). The functionality of the SPEED system varied considerably across the different regions and provinces/cities. Some respondents were not confident of its functionality because they had encountered various difficulties when using it. Some of these difficulties – lack of proficiency in performing the syndromic approach and reverting to paper-based reporting due to power and network failures – have also been reported for other, similar systems.

Most respondents reported that SPEED complemented existing systems in such a manner that it guided the health officers to verify and validate the particular syndromes and the areas affected for possible outbreaks. While SPEED was seen as potentially useful in future disasters or emergencies, realising this potential needs better capacity building among front-line health workers, which goes beyond courses to cover simulations and mentoring.

An independent review of SPEED conducted for AusAid found that the system's direct operational costs were 'astonishingly low' (Keene 2012: 4). This needs to be offset against other costs that may be harder to calculate, such as labour costs for additional activities, costs of training local workers, and so on. These additional investments were such that while SPEED was considered 'very relevant to other countries and international agencies… such a comprehensive effort would probably not be successful in countries with relatively low human and capital resources' (Keene 2012: 270).

MOPBASSS used a number of established frameworks to evaluate whether the system was meeting its objectives. Stakeholder experience was investigated by using standardised questionnaires and focus groups. For measles, the system was found to be more timely (2.4 vs 84 days), more complete (70 per cent vs 40 per cent) and more sensitive (95 per cent vs 26 per cent) than existing systems. The validity of the system was also high, with all outbreaks identified through alternative systems also being identified through MOPBASSS (Rosewell *et al.* 2013).

Stakeholders found the MOPBASSS system to be fast, simple, effective and reliable, enabling the timely initiation of verification, assessment and response processes. All stakeholders were keen to continue their participation; and the majority reported that MOPBASSS was working effectively to detect acute public health events. Participation in MOPBASSS was not associated with an excessive time burden, and the programme was seen as complementing existing systems (*ibid.*).

Timely access to data through the internet-based database was beneficial for national staff, but data access was challenging for provincial staff. In some situations, landline telephone or high-frequency radio might have been the preferred and faster option for providing the real-time report for selected conditions (*ibid.*).

The RTM data from MOPBASSS were used mainly by national health authorities to support assessments about disease patterns that would not have been possible otherwise. Over the pilot period, MOPBASSS outputs were predominantly used for risk assessments at the weekly surveillance meeting of the national health authorities. For example, the system gave national decision-makers a certain degree of reassurance that cholera was not circulating at reporting sites during the ongoing national outbreak. It was suggested that establishing the system during the nationwide cholera outbreak in Papua New Guinea could have enhanced the programme's acceptability because the threat level and the perceived value of early detection were high, and national authorities were incentivised to work in real time. Such use was not observed or reported at the provincial level.

The evaluation concluded that the investment in MOPBASSS, at some US$45,000, was very good value for money and cost effective in comparison to traditional surveillance investments. It was noted that a post-pilot investment would need to be larger in order to address some of the gaps around real-time analysis of samples and related communications (*ibid.*).

3.3 Social media for surveillance

Thanks to technological developments, there are growing numbers of digital surveillance systems that gather information from informal data sources such as news, social media, web searches and other collaborative systems. These data can be used for early analysis and disease detection.

One of the most prominent tools for social media reporting is HealthMap, an automated surveillance platform that continually identifies, characterises and maps events of public health and medical importance, including outbreaks and epidemics. Information sources for HealthMap include news media and discussion groups. HealthMap also incorporates data from the community through the 'Outbreaks Near Me' mobile phone application, wherein any user may contribute reports via their phone or online via the website.

These two case studies look at the use of HealthMap and related tools in the post-earthquake cholera outbreak in Haiti, and the same set of tools for assessing global polio outbreaks as well as disease outbreaks globally. Because of the nature of this work and the related research, these are shorter and lighter touch than the other, more operational case studies.

3.3.1 Design, strategy and function

After the post-earthquake Haiti cholera outbreak in the autumn of 2010, there were extensive efforts to find and supplement information already gathered about the disease dynamics through official sources. This involved an increase in active surveillance, especially in French language feeds, and work with partners in the United States and on the ground in Haiti. HealthMap was routinely updated through automated sources, and additional data gathered about the outbreak were added into the HealthMap system by individual curators. After the outbreak had subsided, this effort was subject to retrospective analysis by a team of researchers from Harvard University, who sought to compare the HealthMap data to official sources for the duration of the outbreak (Chunara, Andrews and Brownstein 2012).

Separately, retrospective research has been undertaken to identify polio cases globally in 2013–14, and work out the lag times between HealthMap data and WHO announcements (Anema *et al.* 2014). A similar piece of work was undertaken for HealthMap globally, looking at reports from June to December 2012 (Bahk *et al.* 2015).

3.3.2 Stakeholders and relationships

There was no analysis of stakeholders or the use of data in either published case study.

3.3.3 Performance and quality

Using HealthMap data, the Haiti research team worked to undertake an ex-post assessment of the correlation of volume of cholera-related news media reports and Twitter postings via the HealthMap system with government cholera cases reported in the first 100 days of the

2010 outbreak. The research found that trends in volume of informal sources significantly correlated in time with official case data and were available up to two weeks earlier. They were also able to use the data to make comparable and timely estimates of key metrics of disease dynamics, including the rate of disease spread (Chunara *et al.* 2012).

This correlation between informal and formal data was especially good during the initial stages of an outbreak or relevant event, which demonstrated how informal data can be used to gain early insight into an evolving epidemic. The social media sources also allowed finer temporal analysis than the government data, even at the level of specific days. As a result, estimates derived from these data sources can be generated very early and often, with the potential to precede insights available from official sources. However, the correlation between informal media sources and case numbers was not significant later in the epidemic, which is a limitation of this method in the late stage of epidemics.

It was also noted by the Haiti researchers that informal data sources could contain biases. These range from geographic biases driven by technological prevalence (social media is more likely to emanate from and be about urban centres and more developed regions) to reporting biases (data contributed are likely to be more prevalent from certain age, gender or other demographic groups) and false positives (with some social reports based on false alerts, rumours, or misreporting, particularly in situations of fear or panic).

In separate research on all seven WHO-reported polio outbreaks in 2013 and 2014, digital reports using data analysis and illness mapping preceded official reports by an average of 14.6 days. In two outlier cases, this lag was as much as 51 days (Cameroon, in 2013) and 88 days (Guinea, 2014). WHO information suggests 184 cases worldwide, with most in Pakistan. But HealthMap searches put the total number of polio cases in 2014 at 295.

A similar piece of work looked at HealthMap more broadly for a shorter time period (June to December 2012) and identified 111 outbreaks, using first the formal source report and then the data collated via HealthMap. The reports from both the official and HealthMap sources were compared for timeliness and content. The research found that the informal sources were around 1.5 days faster than the formal sources, but the difference was as great as 51 days in some settings. Moreover, in over 60 per cent of cases, the informal social media and formal sources provided the same information (Bahk *et al.* 2015).

4 Conclusions: strengths and weaknesses of ERTM systems

Drawing on the case study assessments, this section seeks to set out the relative strengths and weaknesses of ERTM systems. These were identified through comparative analysis of the case studies above, and subsequently verified through a series of interviews conducted with expert informants from numerous organisations working on epidemic responses, including a number involved in the case study examples.

4.1 Strengths

1. Effective ERTM systems can produce event-based public health information that is typically more timely than routine systems while being of comparable quality

Across the case studies, the ERTM systems generated data that are of comparable quality and accuracy to traditional systems. The benefit in terms of timeliness was typically in the order of days, but in some cases the data were available weeks or even months earlier than data from traditional systems. This was a common finding across all six case studies, and is a major positive for ERTM efforts. However, this finding does need to be qualified: ERTM systems can generate the data, but there has to be some form of subsequent verification, which in low-capacity settings is not always straightforward. However, with such verification built in, the ERTM systems can produce information that is comparable to official sources in terms of quality, especially in the early stages of an outbreak.

2. ERTM systems can be more sensitive to new and emerging cases of diseases and novel diseases

By their very nature, ERTM systems are more sensitive to new and emerging cases of diseases that may not be captured by routine systems. The openness of such systems to data and information beyond pre-specified syndromes means they can capture fuller information. All of the case study systems were shown to capture information and data that were missed by traditional systems.

3. ERTM systems complement existing surveillance functionality

In all of the case studies, the ERTM system served best as a means of complementing existing systems. Although they can generate information where there is little available, or in situations like disasters where traditional systems may not be functional, it is also important to highlight that ERTM systems should not generally be used to fill gaps and weaknesses in existing surveillance systems.

4. ERTM systems can be low cost

Open-source or volunteered information means that the initial operating costs of ERTM systems can be extremely low when compared to routine systems. For example, almost all of the systems outlined here were seen to be low cost or very low cost in subsequent evaluations. However, the lower financial operating costs do not always take into account training time, volunteer time, and time taken to establish the necessary institutional relationships.

4.2 Weaknesses

1. ERTM systems tend to be small scale and technologically driven

A common issue identified across the case studies and respondents was that there was a proliferation of efforts for applying real-time technologies to disease monitoring. While adapting to context is seen as a good thing in general, the highly fragmented nature of ERTM efforts was seen as diminishing the overall value of such work. Instead of finding ways in which to apply existing tools to address event-based surveillance needs in a sustained fashion, there is a common view that new systems are continually being designed and developed with more of an emphasis on technology push.

The focus on technology in many ERTM systems in epidemic responses – which can often be at the cost of other aspects such as user acceptance and information utilisation – can lead to lower levels of effectiveness and efficiency, and ultimately diminish the potential contribution of these interventions. The result is a large number of systems that cannot be shared or applied outside original contexts and programme settings.

2. Poor collaboration across operational organisations

Related to the above point, despite the collaborative potential of digital technologies, this is not always apparent among those organisations implementing ERTM systems. Instead, different players tend to develop their own solutions and processes, leading to high risk of duplication and replication. This also places clear barriers on scale, because of the potential reluctance of organisations to use tools and data that have been developed by others. This can lead to fragmented analysis of epidemic impact, and miscommunication.

3. General lack of community and end-user involvement

Respondents noted that of the ERTM systems they were aware of, very few started with end-user or community perspectives. Overall, there has not always been sufficient attention paid to involving all stakeholders – especially communities, but also health workers, civil society, private sector and government bodies – in the design, development or implementation of ERTM systems. For example, few of the case study initiatives were seen as seeking to learn from the experiences of data collectors during implementation.

In many settings, the protocols and indicators around which data gathering occurs are determined by external actors, rather than by community members. The data gathered are therefore often free of any context to support broader learning about how communities perceive and deal with health-related events. Related to this, many ERTM systems also pay scant attention to issues of access, voice and representation around data gathering. For example, it may be that the general dominance of specific user groups (e.g. males, younger people, higher-income users) shapes what data are gathered and how. Although issues of bias in ERTM systems are mentioned, they are not subject to a great deal of analysis. None of the case studies addressed issues of privacy and data protection.

4. Poor technical and data skills

Many ERTM systems generate large amounts of data that can be difficult to effectively manage, analyse and use. As noted above, while the costs of gathering data for ERTM systems can be relatively low, the costs of verification can be prohibitively high. There is also a challenge for how these data can be analysed and aggregated to make sense of emerging events in real time. As a result, data from such sources are prone to misunderstanding and misinterpretation.

There is a major challenge around validation of large ‘noisy’ data sets in real time, which has proved restrictive for many organisations involved in ERTM systems. Cross-validation with other sources is possible, but can be challenging to achieve in real time.

More generally, in many cases, ERTM systems build on tools that were designed for use in non-epidemic, high-resource settings. This relates to both the software and the hardware dimensions, and can lead to considerable challenges in implementation processes. There may be requirements to configure systems, undertake initial data assessments, or check issues with software deployments – all of which may require support time and resources not readily available in epidemic-affected and low-resource countries. Such challenges were identified in a number of the case studies.

5. Lack of focus on use

Across all of the case studies, evidence of ERTM data use was limited. Operational staff and managers are seen as having many different sources of information on which to base their decisions, and ERTM is often hard to get into usable form.

For some, ERTM efforts and event-based surveillance data more generally are mired in a vicious circle: there is a lack of evidence around their value, which means there is limited investment in such systems, which in turn limits the scope for strengthening the evidence base.

Where risk assessment systems and structures are already in place, such as during an existing epidemic response situation, ERTM systems can be introduced in a timely and efficient manner, and serve to complement the range of information being used for decision-making. When implemented in ways that align with pre-existing arrangements, ERTM systems find much greater acceptability and utilisation.

5 Reflections and suggestions

As this study is about real-time monitoring systems, it may seem curious to close by discussing a series of time delays. However, based on the above findings, the effective use of ERTM systems for augmenting surveillance in disease outbreaks is critically dependent on better understanding, exploiting and addressing a number of time delays that have been identified in this study.

The first time delay of importance is the one identified consistently in all of the case studies: the **reporting delay** between the disease-related reports produced by ERTM systems and those produced by more formal systems. This time delay was observed to varying extents in all of the case studies, and it forms the basis of continued investments in ERTM systems. Based on the findings above, the existence of this time delay – and the related evidence about quality of the data being generated – makes it clear that there is a very good case for continuing to develop and test ERTM systems in epidemic settings. But more evidence is needed about this delay, in terms of how it works in different settings, what compromises it involves in terms of data quality, and so on. The potential benefits of exploiting this positive time delay need to be better understood.

The second time delay is the **decision-making delay** that has also been apparent in all of the case studies. One of the positive features of ERTM systems is that they are faster, less formal and bureaucratic, and can be more sensitive than formal systems. But because of this informality, there is also a risk that ERTM systems do not trigger a clear, unambiguous response among key actors. This leads to a delay between the gathering and transmission of ERTM information, and the triggering of some kind of recognisable response. This delay was also evident to some extent in all of the case studies and can be attributed to a variety of reasons: competing data, diverse narratives, lack of understanding, lack of verification, lack of capacity and investment, lack of resources, and vested interests – all of which serve to inhibit or prevent real-time (or near real-time) decision-making. The successes of the ERTM systems in our case studies seem due as much – if not more – to the institutional arrangements for gathering and using real-time data as to technological innovations. Put simply, real-time monitoring initiatives do not do well in structures and processes that are not set up to be real time. That said, the challenges of using ERTM data more widely point to the vital importance and urgency of making adjustments to enhance the responsiveness of existing health system decision-making processes and firmly anchoring ERTM efforts within them.

This leads us to the third and final kind of delay, which is the **institutional adaptation delay**. It is apparent that there may be a disconnect between the growing use of ERTM systems and the kinds of institutions and incentives structures that are needed to support their use. As already noted, the successes of ERTM efforts are shaped by the institutional arrangements for gathering and using real-time data. New technologies have always been disseminated more quickly than institutions are able to adapt, and have posed challenges to those institutions. The delay between the introduction of technologies and the institutional changes needed to exploit those technologies determines how quickly their benefits can be generated. Generally speaking, as has been found with a whole host of digital innovations, technological benefits are only incremental until institutional changes are made.

Given the common time delays between advances in technology and changes in institutions, it is to be hoped that such institutional changes will eventually come about in the context of ERTM initiatives and health systems, and that widespread public health benefits will result. Future success in this area is arguably as dependent on investing in the latest digital tools and systems as it is on recognising and engaging with the political nature of the necessary reform processes in national and local health systems. For this to happen, the advocates and champions of real-time monitoring innovations need to start to pay more careful and sustained attention to the political economy around the benefits and changes they are working towards. If this does not happen, these benefits are likely to come about in a much longer timeframe than is typically promised.

5.1 Ideas for future consideration

Based on our reflections, we put forward a number of suggestions and ideas.

1. There is a need for better **operational research and development** for ERTM because, at present, there is not enough attention being paid to evidence-based iteration and adaptation. An important element of this is to ensure effective evaluation and lesson learning, which require the development of **better shared metrics** for assessing the added value of ERTM in the context of public health surveillance in humanitarian crises, and the related need for appropriate indicators with which to evaluate ERTM efforts.
2. There should be efforts to develop more **formal, evidence-based operating procedures, tools and guidance** for ERTM in event-based surveillance. This should include work that is urgently needed on ERTM **data quality standards, screening and verification guidelines.**
3. Where ERTM systems work, it is because they are firmly grounded in institutional and social contexts. This is not a limitation, but is the source of their value and utility. More work is needed in this regard to understand the incentives of actors throughout the system, ranging from how ERTM information is already used (or not used) by decision-makers, and the incentives for such use, to better understanding of community/front-line worker engagement, acceptance and uptake. ERTM efforts need to work to establish **ownership and acceptance** of national, district and community-level stakeholders from the outset. When this happens, it is more likely to lead to systems that are well used and sustainable.
4. There is a need to engage with and draw on the **skills and capabilities of non-traditional actors –** those who may not always be regarded as integral to public health surveillance. For example, private sector operators played an important role in data management in many of the successful case studies.

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