# Information Sharing and Community Resilience: Toward a Whole Community Approach to Surveillance and Combatting the "Infodemic"

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Developing and strengthening systems for information sharing as well as detecting and addressing dis/misinformation can not only protect capacity for public health emergency preparedness and response, but potentially increase overall community resilience and social capital. More actively involving citizens in the government's collection and sharing of information can generate more public buy-in so people will be more invested in making certain that such information is not arbitrarily dismissed or drowned out by conspiracy theories. Such an approach may have the added the benefit of creating stronger collaborative connections between government, individual citizens, and civic organizations to promote overall resilience. More community involvement in terms of the collection and dissemination of information can provide value in terms of preparation for a public health emergency by bolstering surveillance efforts to detect a threat early on. Getting the public more integrated into the public health information system can also be valuable in terms of diminishing the threat of mis/ disinformation. Building up relationships between the public and the public health sector can advance the mission of improving community resilience through education, engagement, and collaboration. In this review, we will examine existing evidence for this approach and will then conclude with possible new approaches.

**KEY WORDS:** information sharing, public health emergency preparedness and response, public health surveillance

### Introduction

Developing and strengthening systems for information sharing as well as detecting and addressing dis/misinformation can not only protect capacity for public health emergency preparedness and response, but potentially increase overall community resilience and social capital. LeBlanc, Ekperi, Kosmos, and Avchen (2019) raise the important question of how do we ensure that virtual communities are prepared for disasters given that the Internet allows almost universal sharing of both information and mis/disinformation, while at the same time providing the opportunity to interact with only news sources that agree with their perspective? One approach, discussed in the following paper, would be to more actively involve citizens in the government's collection and sharing of information so that they will be more invested in making certain that such information is not arbitrarily dismissed or drowned out by conspiracy theories. Such an approach may have the added the benefit of creating stronger collaborative connections between government, individual citizens, and civic organizations to promote overall resilience.

More community involvement in terms of the collection and dissemination of information can provide value in terms of preparation for a public health emergency by bolstering surveillance efforts to detect a threat early on. Getting the public more integrated into the public health information system can also be valuable in terms of diminishing the threat of mis/disinformation. If people are more aware of how data regarding public health threats are collected and more connected with the public health system, they may be less inclined to be swayed by misinformation or disinformation on-line, and such citizens could be employed as a resource to dissuade others from embracing inaccurate or deliberately false information. Building up relationships between the public and the public health sector can advance the mission of improving community resilience, as articulated by Chandra et al. (2011), by promoting levers for action such as education, engagement, and partnership (see also Plough et al., 2013). In this review, we will examine literature published both prior to and during the COVID-19 pandemic to determine what evidence already exists for this approach. We will then conclude with approaches that could be taken moving forward in the wake of COVID-19.

### Information Sharing and Surveillance

Surveillance systems can provide mechanisms for early detection of pandemics, identify time and space trends, identify risk factors and contributing behaviors, target interventions, and inform decisions (Baseman et al., 2013). French and Monahan (2020) cite the definition of surveillance according to the International Health Regulations as "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 as necessary" (World Health Organization [WHO], 2005, p. 10). In an example from the international perspective, Goniewicz et al. (2020) discuss how member states in the European Union contribute information to the Integrated Situational Awareness and Analysis intelligence and then can access reports prepared by the European Commission and the European External Action Service based on the integration of this information.

As an example from the United States prior to COVID-19, state and local responses to outbreaks of Hepatitis A provided instructive examples of using information for coordinating responses. Baseman et al. (2013) noted the value of effective surveillance systems to address more localized threats like Hepatitis A, as well as managing a global pandemic. During a recent Hepatitis A outbreak, the California State Department of Health issued recommendations involving surveillance and information sharing regarding infected patients, which included the need for stronger communication between hospitals, public health departments, and other community organizations (State of California Health and Human Services Agencies & California Department of Health, 2017). Sharing of key surveillance indicators was noted to be especially important for communities trying to address the needs of homeless populations and drug users and indicators were disseminated

through mechanisms like preparedness conferences (County of San Diego (California), 2018).

This aligns with the findings of Radianti, Gjøsæter, and Chen (2017) who note evidence in the literature that it is important for crisis response and management information systems to support those community members with disabilities and other vulnerable groups, something that is too often neglected. Data on people with disabilities and other vulnerable groups need to be entered into emergency response information systems and coordination must be improved between those agencies charged with addressing the needs of vulnerable populations. DeBruin, Liaschenko, and Marshall (2012) note the influence of sociodemographic factors on minority hospitalizations during H1N1. They discuss the CDC's explanation for the difference in hospitalizations, which focused on structural inequalities like access to care, underlying health conditions, and care-seeking or self-care behaviors. Ethnic and minority populations tend to be more vulnerable to illness, be less able to employ strategies to avoid illness, and experience a greater burden from government interventions than more privileged groups. Information systems used to prepare for or respond to public health emergencies should take these differences into account.

Chandra et al. (2010) identified one value of partnering with community members for the purposes of collecting and sharing information as the improvement of risk communication. As noted by Shiu-Thornton, Balabis, Senturia, Tamayo, and Oberle (2007), such an approach can aid local public health agencies in both disease surveillance and acting in a culturally competent manner. Bourdeaux et al. (2020) discuss the need to include medical providers and public health officials in an active research agenda to incorporate all the points of community vulnerability into the surveillance systems and other information management networks. Surveillance ahead of an emerging threat is vital for stopping an outbreak from becoming a pandemic.

Another example of information systems being used for surveillance purposes is the reporting of respiratory diseases through the FluWatch program (Baseman et al., 2013). Infectious disease response plans at the state local level include special surveillance and information technology groups to manage the collection, analysis, and sharing of information during an emergency (see San Francisco Department of Public Health, 2011). Along with data collected through more conventional means, information from social media (Hadi, 2014) as well as information from pharmacies related to trends in prescriptions have also come to be incorporated into the surveillance network. Investment in both maintaining and developing data collection and analysis systems is critical, as is the cybersecurity infrastructure to maintain it. Pulido, Ruiz-Eugenio, Redondo-Sama, and Villarejo-Carballido (2020) note the use of artificial intelligence and big data to identify threats in real time. Information sharing is used to improve response coordination, thereby improving both surveillance and diagnostics. Social media is cited as a potential tool for soliciting feedback on public health policy proposals.

Programs like Public Health Emergency Preparedness (PHEP) and Hospital Preparedness Program (HPP) need their funding restored to promote strong coordination at the state and local levels. The United States must also work on developing improved coordination between federal, state, and local officials to facilitate better operations of the Strategic National Stockpile and improve capabilities for rapidly disseminating vaccines. Although much about the response to COVID-19, especially in the United States, has been lacking, the quality and effects of information sharing have provided bright spots. Chinese scientists quickly unlocked the virus's genetic code and shared that information with researchers around the world. Research on a novel pathogen has been conducted and disseminated in a groundbreaking fashion. Some hope that a positive outcome of the pandemic is that it will leave behind a new era of open science (Michael et al., 2020).

### Information Sharing and Combatting Mis/Disinformation

Mazarr et al. (2019) define several different types of potentially dangerous information behavior. For our purposes, the two most important types of behavior will be "misinformation" and "disinformation." The authors define misinformation as "inadvertent sharing of false or misleading information" (Mazarr et al., 2019, p. 12). Disinformation is defined as the "purposeful spreading of a combination of false and true information to create inaccurate impressions" (Mazarr et al., 2019, p. 14). Both concepts of information behavior are relevant to the following discussion as they can affect surveillance and coordination in regard to public health emergencies. Misinformation can inadvertently make it difficult to identify the emergence and track the spread of a pathogen. Disinformation can intentionally obscure the emergence of such a threat and stymie efforts to collect reliable data. Lack of good data stemming from misinformation and disinformation can make it difficult to coordinate response efforts such as directing limited supplies and personnel where they are most needed and determine the level of non-pharmaceutical restrictions required. In regard to pharmaceutical interventions like vaccines and/or anti-virals, misinformation and disinformation can hinder the development of these resources, their distribution and dispensing, and the level of trust the public has in them. The spreading of untrue or unconfirmed information, even if done without negative intent, can complicate efforts to generate buy-in from a public in which many are already inclined due to ideology, media consumption, and lack of trust in government to disregard many of the recommendations coming from official channels (Baum, 2011; Gollust, Attanasio, Dempsey, Benson, & Franklin Fowler, 2013; Mesch & Schwirian, 2014; Ronnerstrand, 2016).

Broniatowski et al. (2018) report findings that Russian actors had employed online bots to post inflammatory information regarding both the pro-and anti-vaccine positions in the run-up to the 2016 U.S. election to promote further political divisions. Misinformation can be particularly potent if it plays into people's pre-existing beliefs. The effects of the anti-vaccination movement on the uptake of the measles vaccine suggest that social media and other channels could propagate distrust of a new vaccine once it is developed. Politicians may add to the confusion by amplifying conspiracies or unproven rumors (Center for Health Security, 2019). Abuses committed against African Americans, Native Americans, and Latinos have already created distrust toward the government in areas like medical research. Russia has a history of exploiting these cleavages, such as its efforts to promote the conspiracy theory that the U.S. government had deployed the HIV virus as a biological weapon against African Americans in order to foment global distrust of the United States (Garsd, 2018, August 22).

French and Monahan (2020) cite Mark Andrejevic (2005) who argues that the current information ecology is characterized by erosion in trust of institutions, leaving it difficult to make definitive claims that something is the truth as opposed to mis/disinformation. Lack of clear institutional authority can give rise to fear and racism, as seen with the reaction to the Chinese during the COVID-19 pandemic. Erosion of institutional trust can make it difficult for institutions like the World Health Organization to combat the deluge of mis/disinformation, dubbed an "infodemic," brought on by COVID-19. Such a situation makes it difficult for people to find reliable and trustworthy information even when they are trying to seek it out. Nevertheless, the WHO has made extensive attempts to disseminate accurate information through social media and its website. At the local level, there is a need to employ strategies to educate people on media literacy, as well as provide guidance on assessing information sources and not engaging in selfconfirmation (Pulido et al., 2020). Swire-Thompson and Lazer (2020) lay out a series of action steps for combatting mis/disinformation, including promoting more judicious evaluation of on-line health information, providing clearer indicators of high-quality, evidence-based content, and making corrections clearly and frequently where necessary. Also noted are using on-line resources collaboratively with physicians and effectively utilizing cutting-edge technology.

Research into acceptance of the H1N1 vaccination during the 2009–10 pandemic by Baum (2011) finds that ideology influenced the type of media that people consumed and that the messaging taken from that media affected people's level of concern about H1N1 and their intention to take the vaccine. Meirick (2012) concludes based on his research that Fox News contributed to the mainstreaming of mistaken beliefs. The spreading of messages that the severity of the coronavirus is being played up for political reasons or that the government is behaving in an incompetent manner could dull enthusiasm about accepting a new vaccine once it is rolled out. Political leadership should have a message strategy to respond to opposition from the anti-vaccination movement, particularly in the event that some Americans experience a negative reaction to a new vaccine, which is likely in the case of a new countermeasure (Neustadt, 1978).

In October of 2019, the Johns Hopkins University Center for Health Security held a tabletop exercise called Event 201 which looked at a hypothetical response to a coronavirus pandemic. One segment of the exercise dealt specifically with misinformation, noting that conspiracy theories were likely to circulate on-line that pharmaceutical companies or governments had released the novel virus for their benefit (a prediction that came to pass with the emergence of the 2019 coronavirus). Such theories are especially counter-productive during a pandemic like COVID-19, however, it was noted during the exercise that unscrupulous companies could also use online platforms to manipulate the market and profit through short-selling (Center for Health Security, 2019).

Brunson et al. (2017) address the threat of social media manipulation during an on-going pandemic through the development of a tabletop risk communication exercise. The scenario for the exercise assumes the United States has "isolated and highly fragmented communities with widespread access to information technology" (p. 2), a state that one could argue applies today. The previously cited literature notes that authorities need to provide information to the public during an emergency or mis/disinformation could fill the vacuum. The developers of the exercise agree with this, noting that risk communication specialists advocate being very clear and transparent with the public about what is known and what is uncertain. The exercise also warns that the government needs to do the work to create trust among the public prior to an emergency, as it is challenging to create trust under stressful conditions. Particularly relevant to the type of manipulation addressed by Broniatowski et al. (2018), the government will need to be able to take on concerns about the safety of a vaccine to combat a novel virus, while taking care not to make claims about long-term safety without evidence.

Abramowitz et al. (2017) did find in their study of combatting misinformation in Monrovia during the Ebola crisis that health information was accepted and incorrect information rejected in the face of mounting mortalities, but note that behavioral change can lag due to physical, structural, sociocultural, and institutional constraints. Brainard and Hunters (2020) investigated the idea of immunizing people against misinformation and noted that creating a ratio of 60:40 in regard to good information and misleading information respectively diminished the threat of misinformation contributing to outbreaks in three cities. They did note that more "real-world" testing was required.

### Information Sharing and Resilience

Hyvärinen and Vos (2015) advance the view that community resilience is a product of collaboration between government, communities, individuals, and response/recovery organizations to address the phases of disaster response. This includes being able to recognize unusual conditions, engage in resource mobilization, and demonstrate the capacity for self-organization during a crisis. Eisenman et al. (2014) discuss the Los Angeles County Community Disaster Resilience (LACCDR) Project, an organization in line with the capabilities above. The LACCDR was structured based on the levers of community resilience identified by Chandra et al. (2011): education, engagement, self-sufficiency, and partnership. The lever of organizational partnership is a particularly strong connection, as Eisenman et al. (2014) discuss the importance of expanding and strengthening connections between non-government and government organizations, as well as between various non-government organizations in the community. Hyvarinen and Vos also cite McGee's (2011) work, which advocates strengthening relationships between government agencies and local residents.

Resilient information networks can generate trust and cooperation, and it is important to create trust before a disaster (Hyvärinen & Vos, 2015). The LACCDR, for example, uses novel mapping software that allows for mapping of risk and resilience aspects of communities. This allows for the visualization of connections between hazards, demographics, and resources in a community. This assists with planning and prioritization in advance of an emergency, particularly in regard to incorporating faith-based and community organizations into the planning as well as government entities. This effort supports the resilience lever of increasing partnerships between organizations through deeper linkages between community NGOs (Eisenman et al., 2014).

Public administration needs to shift to further incorporate citizens into response activities, abandoning the refuted myth that most U.S. citizens will respond irrationally in such a situation. In order to facilitate community resilience to disasters, social networks must promote collective community behavior. A variety of networks are involved in producing resilience, inclusive of authorities, community groups, and civil organizations from the local level to the international level. Individuals and the networks to which they belong must be empowered before a crisis becomes a reality through approaches such as embracing all-hazards preparedness, identifying community resilience barriers, and determining the types of crisis communication that are needed (Hyvärinen & Vos, 2015). Reilly, Serafinelli, Stevenson, Petersen, and Fallou (2018) advise that operators of critical infrastructure in communities should familiarize themselves with the ways in which local populations seek information to inform their communication strategies, as well as partnering with community stakeholders to facilitate consistent messages across communication platforms.

Plodinec, John, Edwards, and White (2014) note the importance of a strong leadership team to implementing whole community resilience initiatives. Such teams should include representation from government, business, faith communities, and neighborhood associations to align actions with community goals. Once constituted, this leadership will conduct an assessment of their community's areas of risk and resilience, which will address issues like the most prominent risks facing the community, service capacity, what assets are put at risk by community threats, and what resources are available during the recovery phase. Subject matter experts in the community can work through a series of questions and their responses would shape community action plans.

## Information and the Nexus Between Surveillance, Mis/Disinformation, and Community Resilience

Raina (2018) note that while top-down organization is common in public health, it may not be effective when it comes to a public health emergency. In such situations, a multi-stakeholder approach may be needed wherein the general public is called upon to actively participate in the management and dissemination of information. Community stakeholders can serve as independent sources of information that public health officials and policymakers can collate and draw from in the future, as well as employ to dispel mis/disinformation during an emergency response. Ratzan, Sommarivac, and Rauh (2020) lay out a series of steps to improve global health communication, which emphasizes the value of community information sharing, surveillance, resilience, and combatting misinformation. In keeping with the recommendations above, trusted leadership must be established to promote the tracking of available scientific evidence and advancement of health and media literacy. Communities will not be able to appropriately identify an emerging threat unless they are aware of what could be out there and can distinguish between reliable and misleading information. Community stakeholders, with the appropriate leadership, must actively combat mis/disinformation while consulting on a coordinated communication strategy and response to promote good information over unreliable or intentionally misleading information.

Although there have been many efforts at the international, national, and state level to combat mis/disinformation, activities must be implemented at the local level to not only improve information sharing but also improve community resilience. The prevalence of anti-vaccine information on-line, as well as misinformation and disinformation spread on-line regarding Ebola and Zika, have provided public health officials at the federal, state, and local levels some opportunities to practice communication and information sharing response in the event of a pandemic virus. Local public health departments like that of New York City employ Virtual Operations Support Teams (VOST's) to monitor on-line information for rumors or intentionally misleading information and to correct the information in real time, in addition to providing accurate information to help people avoid danger and access necessary resources (Hadi, 2014). Such efforts can be staffed by volunteers from organizations like the Medical Reserve Corps.

Other recommendations that link surveillance, combatting mis/disinformation, and community resilience include having certain public health announcements likely to be needed during a public health emergency prepared in advance in multiple languages (Medford-Davis & Kapur, 2014; Sutton et al., 2015). Lists of locally trusted media sources and other sources of information should be maintained through which to disseminate accurate advice or correct mis/disinformation, while also maintaining listservs to allow rapid dissemination of data across public, private, and non-profit organizations (Medford-Davis & Kapur, 2014). Runblad, Knapton, and Hunter (2010) advised that community and personal networks be established, maintained, and updated with standards and protocols to insure that official notifications are fully disseminated. Sutton et al. (2015) found in their study of social media activity after the Boston Marathon bombing that messaging promoting community resiliency seems to have a high degree of retransmissibility in the midst of a terrorist threat. This may also hold true in the midst of a severe public health emergency. In summation, promoting community resilience in a public health emergency involves assisting with gathering of useful data, assisting with the dissemination of this data, refuting unintentionally or intentionally misleading data, and maintaining on-going and varied networks of information sharing.

### Conclusion

Hyvärinen and Vos (2015) discussed evidence that a well-developed economic system, social capital, and competencies within the population contribute to community resilience, along with information and communication. In the aftermath of the COVID-19 pandemic, there will need to be extensive focus on how to make U.S. communities more resilient to future public health emergencies. The evidence above supports the notion that a variety of community stakeholders and organizations should be coordinated at the grassroots level to aid in the quick identification and understanding of emerging threats and combatting mis/disinformation. Although putting together such coalitions will require some degree of pre-existing community resilience, involving stakeholders in this work in a more substantive way is likely to build further community resilience by creating a better understanding of how health data is produced and what separates trustworthy and untrustworthy information sources. Such efforts will hopefully create more trust between community stakeholders and the public health sector, allowing for faster community buy-in and more rapid responses in the midst of future outbreaks.

The COVID-19 pandemic has sharply illustrated the difficulties involved with trying to control a threat as data is being questioned, inaccurate information is being disseminated, and communities are not united in common goals. Goniewicz et al. (2020) conclude that moving forward a "fail-safe information system" that is "independent of sociopolitical relations to avoid misinformation and confusion" will be necessary (p. 9). As we continue to fight our way through the current emergency while looking ahead to the next, we must continue to pursue ways to make all community members invested in the response. If more citizens are engaged from the very beginning by helping to detect the threat, they will be more invested in sounding the alarm and overcoming voices of mis/disinformation. Furthermore, both preparing for such events and then working together in the aftermath builds on Chandra et al.'s (2011) levers of community resilience, particularly education, engagement, and partnership. It is important moving forward to transition community members from being passive consumers of information in regard to health threats to producers and defenders of this vital resource.

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### Note

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