

## **Evolving roles in the transfer and development of health information**

**Abstract:** Social media has created new ways for non-professionals to access, share, and even create health-related information. While these new resources have been noted to destabilize the authority held by medical professionals, they also highlight the potential utility of non-professional peer collaboration and support in the medical field. Non-professional collaboration has proven its worth in disaster management, and seen increasing use in that field. The conclusion calls for a re-examination of how the new forms of media transmission require different approaches from information consumers and health professionals, as well as further research into the opportunities afforded by peer-generated and -communicated contributions to health information.

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## Introduction

This article's topic began as a much narrower examination of the role of word-of-mouth in large-scale medical crises. However, as I reviewed the literature on the topic, it expanded into a fuller examination of the flaws in and unexpected effectiveness of non-professional engagement with health information. My search began at the intersection of public involvement, communication, and natural or health-related disasters in the materials available through MEDLINE, PubMed, and CINAHL. As these contained insufficient material relevant to my topic, my search expanded into psychology and sociology databases, as well as disaster management guides. This research came together into what is presented here: a cross-disciplinary examination of how non-professional engagement with professional communications and endeavors is and is not being used to its full effectiveness.

The topic is ripe for examination in part due to the blossoming of new methods of information transmission and engagement. Social media and new communication technologies have swept through society, fundamentally altering many of the ways in which users communicate critical—including health-related—information in both professional and lay contexts. Traditional media—such as television, newspapers, or magazines—is giving way to new (social) media—including blogs, wikis, and other interactive materials—as resources for general usage and medical emergencies. The Center for Disease Control's (CDC) emergency preparedness Twitter account, for example, currently has 1.7 million followers (CDC Emergency Preparedness and Response, 2015). The expansion of medical information into the social media sphere is not limited to 140-character alerts about current emergencies, however. More individualized communication through social media is also being explored. Wilson and Yowell (2008) recommend the use of a blog by health professionals as an element of community outreach. As these avenues of communication are being created and used, the ways in which members of the public respond, interact with, and even provide information are also evolving. While health information was shared by laypersons prior to social media and continues to be shared without it, social media has become a means for its preservation, spread, and study, as well as a new means for health organizations to reach out to the public. As such, the ways that members of the public respond, interact with, and even provide information has come under increasing scrutiny. This evolution in engagement has already been turned to the benefit of disaster management efforts. Its potential benefits (as well as dangers) to public engagement with medical information, and integration of public knowledge in medical contexts, require investigation.

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## Discussion

### The proliferation of voices and the loss of authority

Health agencies such as the CDC, World Health Organization, and the Public Health Agency of Canada, which traditionally provided the public with emergency medical information, have found themselves providing alerts alongside an immense number of other information sources as their methods of communication expand into popular web communication services and blogging platforms. A study of Twitter content following four US disasters revealed that 94% of the crisis information shared on Twitter is created by laypersons rather than government agencies (Gesser-Edelsburg et al., 2015a). If anything, official information finds a broader audience when re-appropriated. When the popular Twitter account "Tweet Like a Girl" recreated one of the CDC's emergency tweets, the recreated post was found to receive three times the retweets (Seltzer et al., 2015). The expanded role of non-professional input on public awareness of emergency medical issues expands into video-based media as well. During the 2014 Ebola outbreak, a comparison of the most popular Youtube videos on the subject revealed that commercial videos produced by non-health professionals had comparable numbers of views to those published by governments and medical organizations (Basch, Basch, Ruggles, & Hammond, 2015). The web at large reflects these same trends. The vast majority of Yahoo Answers replies to questions about H1N1, at the time of Kim, Pinkerton, and Ganesh's study (2012), sourced their information to commercial websites (defined as sites ending with a .com extension, such as Youtube.com), rather than those of government organizations. Web users are increasingly seeking out information from sources other than official agencies, even in the highly-specialized realm of medical knowledge. Kim, Pinkerton, and Ganesh (2012) posit that this trend may be a result of the greater accessibility of commercial websites, but its causes lie outside of the scope of this article.

Regardless of the reason for these emerging user preferences, this new array of information sources has created problems for effective distribution of accurate medical information by government organizations. The opinions or knowledge of the public can interfere with the acceptance of information from health authorities (Gesser-Edelsburg et al., 2015a). Jardine, Boerner, Boyd, and Driedger (2015) warn public health professionals to be aware of the potentially incorrect information available online which may colour patients' understanding. Even when agencies take to social media themselves, their contributions and objections become suspect. That suspicion is a result of the loss of control over information once it is posted on social media, where users may edit, repost, or comment on it (Spence, Lachlan, Lin, & Del

Greco, 2015). The delivery formats of social media sites themselves may also stifle the value of emergency information posted there. Useful information gathered by Twitter hashtags, for example, can be buried under associated fearful or otherwise emotive responses in times of real crisis (Spence, Lachlan, Lin, & Del Greco, 2015), when the previously-posted information would be most useful. Finally, the new media, in theory, rejects hierarchies, emphasizing inclusivity in the discussion of common concerns and interests (Gesser-Edelsburg et al., 2015a). While that inclusiveness is often viewed as a positive element of the new media, for a profession which relies on its position of authority in order to promote public wellness, this crowded, infinitely-malleable field may be disorienting, if not incapacitating.

### **The costs of conflict**

That disconnect between the public and health authorities is not limited to the field of social media, however. Unique cultural barriers to the spread of public health agencies' educational information are an ongoing problem as well. The rejection of professionally-recommended actions by members of the public may not stem from some quirk of delivery medium or a technical misunderstanding, but from deeply-held cultural differences. Schoch-Spana, Sell, & Morhard (2013) recount dilemmas faced by Muslims concerned with the porcine gelatin in H1N1 vaccines, and problems discussing disaster preparedness in the face of Native American beliefs that speaking of disasters may cause them to occur.

These cultural differences can lead to extreme consequences, as in the case of the West African Ebola outbreak. Responding to difficulties in implementing quarantines and health education in the locations worst-hit, Hankivsky (2015) accuses religious or spiritual healing efforts of undermining support for mainstream Ebola treatments. While troubling in themselves, clashes between local beliefs and health officials ran deeper than competing attempts at cures. Entrenched funereal practices in the regions hardest hit by the 2014 Ebola outbreak include touching and kissing the deceased (Goldstone & Brown, 2015), increasing transmission of the disease and becoming a point of contention between locals and health officials. It is possible that the murder of eight health agency educators in September of 2015 (Enserink, 2015) was a result of resentment against this interference in local culture. Distrust between health professionals and members of the public, along with the tension of an ongoing medical crisis, led to tragedy.

## **The knowledge of peers**

The solution to these conflicts may exist in a service social media is much more efficient at providing: peer support and communication. Peer-to-peer communication, despite the potential for flaws and misinformation, can assist in circumventing the aforementioned cultural barriers. Members from within groups can act as interpreters and distributors of information. These opinion leaders need not be those with social power; charismatic community members and even internet personalities with many followers have a central importance to spreading information (Gesser-Edelsburg et al., 2015a). These opinion leaders may act as conduits for information from external sources, or for information from within the community. For example, due to social taboos against the discussion of reproductive health in Southern Nigeria, education on this topic is often transferred from mother to daughter in private settings (Obono, 2012). Obono (2012) notes the varying efficacy of mothers' transmission of this information, but also emphasizes that one of the key predictors of daughters' acceptance of suggestions was their perception of the mother as trustworthy and in touch with their daughters' concerns. In Gesser-Edelburg et al.'s (2012) terminology, success relied on whether the mothers were opinion leaders within the context of that conversation. While a topic may be technically forbidden from discussion, and certainly outside the range of what community members would discuss with an outsider, respected community members may act within their knowledge of the culture in order to communicate necessary information. From this example it can be seen that individuals within a community, while they may lack the technical expertise of professionals, have a corresponding insight into the navigation of their peers' aversions and preconceptions.

## **Community resilience in the face of disaster**

The benefits of non-professional community participation have already been demonstrated in the arena of disaster management. Schoch-Spana, Sell, and Morhard (2013) emphasize the importance of community connections and involvement to community resilience during crises. Jung, Toriumi, and Mizukoshi (2013) specifically illustrate the importance of community connectedness in the context of the response to the Great East Japan earthquake of 2011. In surveys of several Tokyo neighbourhoods, they found that close connection to either the online or neighbourhood community were strong predictors of individuals' participation in recovery efforts following the earthquake through action and donations (Jung, Toriumi, & Mizukoshi, 2013). The advantages of such participation are applicable to medical crisis management as well. Merchant, Elmer, and Lurie (2011), for example,

discuss the potential use of peer buddy systems during predictable or seasonal crises, such as heatwaves, in order to reduce the toll on at-risk populations. On a less organizationally-imposed level, consider the influence of social norms and pressures on disease containment. Ding (2014) noted the role of social responsibility in the containment of H1N1 in China, through voluntary and even coerced quarantines. Communities can and do take action to maintain their own wellbeing and overall health, and could do so with greater effect given the correct tools.

One of the clearer examples of the benefits of community action in the realm of health is the peer-community-based support during the AIDS crisis of the 1980s. Weiss (2015) notes the historic role of grassroots organizations in the care of and advocacy for AIDS patients when assistance from health agencies fell short. Despite being marginalized and ignored by mainstream medical culture in a time of crisis, community members organized themselves to provide care and call attention to their unmet needs. More recently, rural, HIV-positive participants in a small study reported overwhelmingly positive experiences with being connected to HIV-positive peers who could offer “real-life embodied experience” (Vienot, 2010, p. 8) that their doctors could not provide. Both cases illustrate how communities can step in when official recourse fails them.

### **How community contributions are already being integrated**

These peer and professional roles are not inevitably oppositional, however. The field of crisis management has already begun to integrate peer and public contributions to theories surrounding disaster relief, and challenge the hierarchical approach to its management. Wu, Convertino, Ganoë, Carroll, and Zhang (2013) hinge their proposal for collaborative emergency management on the effectiveness of data visualization through maps, and the potential for coherently aggregating information from multiple sources through that visualization. Volunteers could use these planned digital maps with annotated task areas to coordinate relief efforts among group members, rather than relying on instructions from absent (and potentially under-informed) superiors. The 2010 Haiti earthquake was the first place crowdsourced datasets, including detailed maps produced by the editing efforts of hundreds of volunteers and citizens' requests for assistance through geo-located text messages, were a primary source of response planning by government agencies (Crowley, 2013). Crowdsourced information—data drawn from large groups of non-professional volunteers (Merriam-Webster, 2012)—has since proven useful in multiple regions of the disaster-preparedness and medical fields. Participants in the Bring Your Own Data forum upheld several prominent sources of crowdsourced data gathering, such as the Quake Catcher Network and Flu Near You

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(Roos et al., 2014). Research that relies on volunteers to gather and provide data protects the safety and health of those volunteers' communities: the field of citizen science, as it is called, results in the rapid collection of more data, service to larger populations, and the promotion of public awareness (Roos et al., 2014). While still subject to the evaluation and control of professional organizations, non-professionals have been making new and greater contributions to science and disaster relief.

The collaborative creation and use of information has been an area of increasing exploration outside of officially-sanctioned research as well. While Wu et al.'s (2013) peer data visualization proposal was intended for the use of disaster response organizations, a similar visualization concept was also implemented by non-professional populations in response to dissatisfaction with governmental disaster response. Following the Fukushima disaster, citizens concerned with the ongoing health and environmental effects of the disaster combined government-provided and crowdsourced data on radiation levels with Google Maps to better assess the dangers to their communities (Plantin, 2015). Distrusting the information provided by their government, users collected and compared their own datasets in order to form a more reliable concept of the damage (Plantin, 2015). Beyond providing individual peer support, or gathering to call for action from official health agencies, this community rallied itself to create and disseminate the information it felt it was being denied.

### **How community contributions are suspect**

The distrust that these citizens expressed about government-provided information goes both ways, and creates a significant barrier to the greater use of non-professionally collected data. A key issue in the wider acceptance of crowdsourced information is gaining institutional trust in the data produced (Crowley, 2013). While relying on massive numbers of volunteers to provide information can greatly increase the efficiency of data collection, it also has its dangers. The drawbacks of citizen science include the introduction of potential bias, difficulties in the recruitment and retention of volunteers, potential privacy issues with the data collected (Roos et al., 2014), and the possibility of malicious misinformation (Huiji Gao, Barbier, & Goolsby, 2011). While these issues can be addressed and mitigated, as similar problems are mitigated in traditional research, there is yet another hurdle. Beyond the practical issues lie possible ideological barriers to the acceptance of data or knowledge from the public.

## **The perception of the public (by the professionals)**

As stated previously, medical professionals are warned to be on guard for the misconceptions of their patients (Jardine, Boerner, Boyd, & Driedger, 2015). When preparing documents for publication, they must devote endless amounts of energy to predicting and combating potential misunderstandings of the information they intend to present. Kilianski, Evans, and Rall (2015) take health researchers to task for their innocent use of “aerosolized” in reports on the transmission of Ebola; public media misinterpreted this phrasing to mean that transmission of the disease was now airborne. The CDC’s definition for aerosolized transmission, rather than the long-distance transmission implied by “airborne,” is a form of contact transmission through the inhalation of temporarily-airborne droplets of bodily fluids (Harriman and Brosseau, 2011). Confusion between the two definitions did not lead to the feared mass panic, but researchers were expected to anticipate that risk. Even correctly-interpreted reports provide their own ambiguity and potential for damage to institutional trust, entirely outside of irrational public reactions. Announcements on the unlikelihood of Ebola transmission, for example, conflicted with later reports of patients being placed in hospitals with special containment units (Gesser-Edelsberg et al., 2015a). Misunderstandings and apparent contradictions like these can severely damage public trust in health institutions. There are limits to the capabilities of professional organizations in combating misinformation as well, and their efforts to improve the quality of information available to the public may have unexpected repercussions. The retraction of inaccurate information, or correction of misinformation, can lead to a decrease in trust (Lewandowsky, Ecker, Seifert, Schwarz, & Cook, 2012), in spite of the correcting organization’s intent.

Placed under the demand for absolute accuracy and foresight of any possible reactions to the information they provide, it is no surprise that health officials may frame their work in opposition to public behaviour and reactions. Governments and agencies often consider public reactions to released information irrational (Gesser-Edelsburg et al., 2015b), at least when it causes the reacting individuals to disregard professional recommendations. No amount of copy-editing and fact-checking can guarantee the expected reaction from every observer. Members of the public can have intense emotional reactions even to purely factual reports (Gesser-Edelsburg et al., 2015b). This unpredictability occurs outside of the realm of panic in crisis, as well. Strong emotions such as disgust and fear, as Casey (2015) observed of the details of Ebola transmission, can result in gaps in public knowledge out of the average individual’s desire to avoid those feelings. The combination of awareness of the potential for public misinterpretation of reports and apparent irrationality may

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understandably provoke concern in medical professionals about the public's ability to comprehend and disseminate useful medical information.

The prospect of such an uninformed public not only providing data but disseminating information of their own is, from the above perspective, even more chilling. Even traditional, respected publishing venues, whose release of information is informed or sanctioned by agencies of health professionals, have a journalistic tendency to provoke extreme reactions through sensationalism (Gesser-Edelsburg et al., 2015a). This tendency raises the question of how much more sensationalist an unaffiliated website or social media user might be, competing for the attention of the average internet browser. Many online sources, potentially created or disseminated by laypersons, undergo none of the vetting and approving processes that health care professionals expect from authoritative publications, and that are required for consideration within the medical field.

### **Community knowledge and understanding in context**

Despite the weight of these suspicions against publically sourced information, there is reason for optimism. Information shared by the public has been found to be much more accurate than many professionals assume (Palen, Vieweg, Liu, & Hughes, 2009). Furthermore Ludwig, Reuter, and Pipek (2015) point out that citizens already aggregate and validate information on social media themselves through like features, commentary, and sharing. Sutton et al. (2014) note, in their examination of wildfire warning response, the complex public sense-making activities that often precede the spread of received information. They report users making efforts to confirm, understand, and even personalize information before sharing it (Sutton et al., 2014). This constant interaction is what lends the data its trustworthiness, in contrast to health agencies' corrections or addenda to the information they have published. In the case of Plantin's (2015) community-sourced maps of radiation following the Fukushima disaster, contributors were found to admit to their own incorrect measurements, and to encourage others to compare multiple sources for data in order to verify its accuracy. Where such retractions decrease trust in information provided by medical authorities, here they encourage faith in the method of data gathering (if not the noted dataset itself). The reason behind these opposing reactions may lie in the relationship between the individual and the provided data. Rather than passively accepting information as it is given (even when it contradicts previous information), users can interact with it, question it, and potentially contribute themselves.

As social media and these new avenues of research generation open the possibility for health information consumers to become contributors themselves, the sheer number of potential contributors becomes a problem. There is a limit to the usefulness of the multiplication of information sources available to the public. While the strength of crowdsourced data for interpretation is its immense volume, this is also its weakness. Attempts by the peers of these crowdsourcers to interpret the massive amount of information available without the aid of statistical tools could only be overwhelming. Jardine, Boerner, Boyd, and Driedger's (2015) surveys following the SARS and H1N1 outbreaks in particular indicated that members of the public were confused and anxious as a result of an overload of sometimes-contradictory information available online, and that was presumably fewer than a dozen sources. While the public is willing and able to seek out information and understanding for themselves, as well as engage with that information on their own terms, there is still a need for authorities to condense information. Despite the expansion of social media's role in communication and collaborative engagement, "new" media are not totally replacing traditional sources of health information for the public. Younger respondents to Jardine, Boerner, Boyd, and Driedger's (2015) surveys on information-seeking following the SARS and H1N1 outbreaks indicated that they made broader use than their elders of both the internet and personal connections, including friends or relatives as well as health professionals. The resources of social media are seen as supplementary to traditional media and official information sources (Neubaum, Rösner, Rosenthal, & Krämer, 2014). The public is seeking out alternate perspectives, and blurring the line between consumers and contributors by blending and interacting with the information they find. What is needed in this environment is assistance in the assessment of the credibility and helpfulness of a given piece of information (Palen, Vieweg, & Anderson, 2010). That information may be from academic research, or from a massive community effort at data collection. The public can make good decisions when provided with relevant, timely, and accessible information by authorities (Kim, Pinkerton, & Ganesh, 2012), and occasionally even when they are not. (Recall the grassroots support for AIDS patients, and the creation of radiation maps.) Health officials now have a role in the dissemination of information, not just as providers, but as facilitators in the interpretation of information from a variety of sources. The evolution of communications opens the possibility of a collaborative approach to medical research and response to health crises.

## Conclusion

The failings of traditional medical communication and care may be accidental—as with unintentional misinformation during the Ebola outbreak—or deliberate—as with the lack of attention towards the AIDS crisis—but time and again these failings have provoked communities to act independently to fill in the gaps. “New” media opens new possibilities for discursive communication with the public, and an active exchange of information and ideas (Gesser-Edelsburg et al., 2015b). Even as far back as 1986 Kasperson (1986), listing the flaws that negatively impact institutional communication with the public, condemned the constraints on two-way information and failures to make effective use of information provided by citizens. One certainty that emerges from the expansion of social media, and its impact on public collaboration as demonstrated in the field of disaster response, is the opportunity similar collaboration presents for the advancement of medical knowledge and response.

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