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Ebola Outbreak Response: The Role of Information Resources and the National Library of Medicine

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Abstract

The US National Library of Medicine (NLM) offers Internet-based, no-cost resources useful for responding to the 2014 West Africa Ebola outbreak. Resources for health professionals, planners, responders, and researchers include PubMed, Disaster Lit, the Web page “Ebola Outbreak 2014: Information Resources,” and the Virus Variation database of sequences for *Ebolavirus*. In cooperation with participating publishers, NLM offers free access to full-text articles from over 650 biomedical journals and 4000 online reference books through the Emergency Access Initiative. At the start of a prolonged disaster event or disease outbreak, the documents and information of most immediate use may not be in the peer-reviewed biomedical journal literature. To maintain current awareness may require using any of the following: news outlets; social media; preliminary online data, maps, and situation reports; and documents published by nongovernmental organizations, international associations, and government agencies. Similar to the pattern of interest shown in the news and social media, use of NLM Ebola-related resources is also increasing since the start of the outbreak was first reported in March 2014

Keywords

disease outbreaks; crowdsourcing; social media; mass media; Internet

Information plays a vital role in every disaster incident or public health emergency. The 2014 West Africa Ebola outbreak has engaged the world’s attention as an unprecedented outbreak of the disease. This outbreak has grown dramatically and across a wider geographic region than previously experienced.¹ Because it is a grim disease, has a high mortality rate, sickens health care providers, and threatens the public health and civil infrastructure of regions, Ebola commands media attention and compels public interest and response.

There is no question that interest in Ebola is reflected in available measures of public online discourse. The US Department of Health and Human Services (HHS) NowTrending Web site documents an incidence of tweets about Ebola ranging from thousands to tens of thousands per hour.² NowTrending.HHS.gov analyzes Twitter data for selected health topics

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and displays the frequency of tweet topics on a world map. Such data can indicate emerging health issues and where they are occurring, as well as measure public interest in tweeting about a topic. Of the 27 disaster and public health emergency conditions tracked by NowTrending, “Ebola” and “natural disasters” were equally ranked as the highest topics, each representing 23% of the tweets in the NowTrending database for August 30 to September 19, 2014 (data based on 7,339,468 tweets during this time period matching at least one of the 234 terms currently tracked across 27 conditions).

Google News searches on “Ebola” (as tracked in Google Trends) increased from the lowest value (1) to the highest (100) between July and August 2014 and dropped in September to 50% of the August peak.³ Google Trends shows that the countries with the highest search volume on “Ebola” are (in order) Liberia, Sierra Leone, Nigeria, Ghana, Zambia, Côte d’Ivoire, Senegal, Guinea, Canada, and South Africa. News outlets globally have published or broadcast story after story.

As the world’s largest aggregator of biomedical literature, the US National Library of Medicine (NLM) is responding to the increased interest in Ebola by developing new resources and enhancing existing ones to meet the needs of health professionals and the general public. Responders, planners, policy makers, researchers, disaster managers, government decision makers, health care providers, and humanitarian workers all need the best and most current medical and public health information so they can act safely and effectively in managing the outbreak.

PubMed, the NLM index of biomedical journals, added 212 publications on Ebola or *Ebolavirus* during the almost 6-month period from March 1 to September 19, 2014. In comparison, during the previous 10 years, an average of 98 articles per year on Ebola were added to PubMed. In the same time period, an average of 671 articles per year about all viral hemorrhagic fevers were added to PubMed. As one might expect, the number of articles continues to grow as the outbreak progresses.

Of the 212 publications in PubMed, 60% (127) are clearly related to the current outbreak. Journals with multiple articles are *BMJ* and *Lancet* (each with the largest number of articles), followed by *Annals of Internal Medicine*, *CMAJ*, *JAMA*, *New England Journal of Medicine*, *Nature*, and *Science*. Other articles are scattered across nearly 40 journals, all but one in English. The journals with multiple (five or more) articles have many and recent Ebola-related items in PubMed for several reasons: it is part of their editorial scope to publish news and commentary, they publish frequently, and they submit citations to PubMed very rapidly (before or as soon as published) in electronic format. The vast majority of these Ebola-related items are news stories, editorials, commentary, and obituaries for a general professional audience. There are also a handful of articles with early research results related to the 2014 outbreak. Of course, there is a vast body of Ebola-related literature in PubMed, over 2100 articles, published before this outbreak.

Typically, the most recent PubMed materials on an event are not the kinds of documents most needed by responders, planners, and decision makers who are actively participating in initial and ongoing response. Such documents include daily situation reports, epidemiology

reports and statistics, and guidelines issued by international organizations and national health departments. By design and intent, PubMed indexes the biomedical journal literature and, of course, there can be little reasonable expectation that many peer-reviewed research articles are being researched, written, reviewed, and published about an outbreak at its height. Research articles will follow in the coming months and years, just as research from previous outbreaks is already in PubMed. For immediate response to an outbreak, a need definitely exists for information resources well outside the scope of PubMed, as well as an equally strong need to rely on PubMed as the primary source for information on previous outbreaks and on research about *Ebolavirus*, vaccine development, treatment protocols, and related topics.

For more immediate needs, NLM provides information specifically for responders to public health emergencies and disasters through its Disaster Information Management Research Center (DIMRC). The DIMRC provides a guide to the most prominent sources of reliable information on its topic page “Ebola Outbreak 2014: Information Resources.”⁴ Whereas individual organizations, such as the World Health Organization and the US Centers for Disease Control and Prevention, focus on writing and publishing their own guidelines and updates, DIMRC pulls those sources together in one Web guide and continuously monitors key agencies and organizations for new information to keep the page up-to-date. The guide identifies key social media sources of information, online maps, Web sites of international and US agencies, and links to documents and journal articles on Ebola.

Previous studies⁵ and experience⁶ show that much of the key medical and public health information on disasters and emergencies is not found in the published biomedical journal literature, especially during and immediately following unprecedented events. Key government and nongovernmental organization reports, assessments, and training materials, as well as new treatment and prevention guidelines, are not included in well-known databases such as PubMed. These materials (often described as grey literature) are indexed in Disaster Lit: the Resource Guide for Disaster Medicine and Public Health. Disaster Lit has added 111 reports, guidelines, factsheets, US Congress reports and hearings, training webinars, and Web sites on Ebola since March through September 19, 2014. In the month ending September 18, Disaster Lit was searched for ‘Ebola’ over 22,000 times, easily the number one topic of interest. Of the 111 reports, 60% are categorized as guidelines, 13% are fact sheets, 10% are Web pages, and 17% are categorized as other.

These materials are primarily from the United States, the United Kingdom, and the countries hosting headquarters of international agencies; the materials are primarily not from the affected countries. The most frequent sources of documents are the US Centers for Disease Control and Prevention, the US Food and Drug Administration, the National Institute of Allergy and Infectious Diseases, the US National Institutes of Health, the US Agency for International Development, the World Health Organization, the World Health Organization Regional Office for Africa, and the European Centre for Disease Prevention and Control.

Ebolavirus (the cause of Ebola hemorrhagic fever) is also the subject of intense study. The NLM National Center for Biotechnology Information (NCBI) released a resource page on *Ebolavirus* on September 19, 2014.⁷ The page aggregates links to virus data at NCBI as well

as links to information on the current outbreak. The Virus Variation database for *Ebolavirus* allows searching for nucleotide and protein sequences by a variety of criteria including host, sequence patterns, region or country of isolation, and collection or release dates. Sequences can be downloaded in many formats or used to find links to sequences in NCBI databases such as PubMed.

The NLM Emergency Access Initiative (EAI) was activated for the Ebola outbreak in August 2014. EAI is a collaboration between NLM and a number of publishers of medical literature to provide free access to medical information during catastrophic events. As a result of the devastation of medical libraries in Hurricane Katrina, NLM and the publishers developed a mechanism to provide temporary access to materials usually available only by subscription. EAI was first activated in 2010 following the major earthquake in Haiti. Use of EAI is intended for those affected by a specific incident and for those providing assistance to the affected population. EAI provides free access to full-text articles from over 650 biomedical journals, over 4000 online reference books, and several databases.

At the recent request of the World Health Organization and others, NLM and the publishers activated EAI for the Ebola outbreak.⁸ EAI is expected to benefit medical and public health workers in West Africa as well as those deploying from outside the region to provide humanitarian assistance. Between August 12 and September 23, EAI has been visited over 2500 times, with half of those visits from the United States. The most heavily used materials have been medical textbooks on virology, epidemiology, and infectious diseases, along with some use of medical journals. The top textbook titles accessed through the EAI in August through September 2014 were as follows: *Red Book: 2012 Report of the Committee on Infectious Diseases*, 29th edition (most frequently used); *Human Virology* (4th edition); *Epidemiology: Principles and Practical Guidelines*; *Handbook of Epidemiology*; and *An Introduction to Epidemiology for Health Professionals*. Of the journals available through EAI, *BMJ* was the most accessed, followed by the *Journal of Infectious Diseases*. Enhanced access to and display of resources on mobile devices and the expansion of cellular telephone and Wi-Fi service across the globe has made it possible for the latest information to be more accessible than ever.

The resources described above, Ebola Outbreak 2014: Information Resources, EAI, PubMed, Disaster Lit, and Virus Variation: Ebolavirus, primarily contain information for health professionals. NLM is also committed to providing information for the general public through the MedlinePlus.gov Web site. In response to the growing interest and concern over the outbreak, MedlinePlus released topic pages (one in English, one in Spanish) on Ebola on August 13, 2014. The English page was viewed by nearly 3000 in its first 3 weeks. In a dramatic increase, the MedlinePlus Encyclopedia entry on Ebola was visited about 5000 times in June and 86,000 times in August by a predominantly US audience.

Ensuring that health care workers and the public are aware of and use these authoritative and up-to-date NLM resources is always a challenge. Through extensive contacts with response organizations, the DIMRC attempts to reach a wide range of responders in the United States and internationally. The DIMRC also encourages use of these resources by the librarians and information specialists who may be handling information queries from their own

communities and institutions. Information about NLM disaster and emergency resources is distributed primarily through e-mail and Twitter. Lists and e-newsletters from both NLM and other agencies distribute NLM messages to at least 50,000 subscribers. The Twitter account, @NLM_DIMRC, has over 2700 followers, and those followers pass along (retweet) the messages that DIMRC sends. A Twitter message about the “Ebola Outbreak 2014: Information Resource” Web page resulted in 2100 visits to the page in the month ending September 19, 2014.

This unprecedented Ebola outbreak is being matched with an outpouring of information from many sources, ranging from peer-reviewed journal articles to the latest Twitter traffic. NLM is collecting and organizing information from these many streams to make it easier to follow and learn from this unfolding event. To stay current on Ebola (and other disaster or public health emergency) information resources, subscribe to the e-mail list, DISASTR-OUTREACH-LIB, at <http://disasterinfo.nlm.nih.gov/dimrc/dimrclistserv.html>.

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