

Review

Scoping Review on Search Queries and Social Media for Disease Surveillance: A Chronology of Innovation

Theresa Marie Bernardo¹, DVM, MSc; Andrijana Rajic^{2,3,4}, DVM, MSc, PhD; Ian Young^{2,3}, BAsC, PhD; Katie Robiadek⁵, BA, MA; Mai T Pham^{2,3}, BSc, BAsC, MSc; Julie A Funk¹, DVM, MSc, PhD

¹College of Veterinary Medicine, Michigan State University, East Lansing, MI, United States

²Department of Population Medicine, University of Guelph, Guelph, ON, Canada

³Laboratory for Foodborne Zoonoses, Public Health Agency of Canada, Guelph, ON, Canada

⁴Agriculture Department, Food and Agriculture Organisation, Rome, Italy

⁵Department of Political Science, University of Wisconsin-Madison, Madison, WI, United States

Corresponding Author:

Theresa Marie Bernardo, DVM, MSc

College of Veterinary Medicine

Michigan State University

Veterinary Medical Center

784 Wilson Road Room G338

East Lansing, MI, 48824-1314

United States

Phone: 1 517 432 1292

Fax: 1 517 432 2937

Email: TheresaBernardo@gmail.com

Abstract

Background: The threat of a global pandemic posed by outbreaks of influenza H5N1 (1997) and Severe Acute Respiratory Syndrome (SARS, 2002), both diseases of zoonotic origin, provoked interest in improving early warning systems and reinforced the need for combining data from different sources. It led to the use of search query data from search engines such as Google and Yahoo! as an indicator of when and where influenza was occurring. This methodology has subsequently been extended to other diseases and has led to experimentation with new types of social media for disease surveillance.

Objective: The objective of this scoping review was to formally assess the current state of knowledge regarding the use of search queries and social media for disease surveillance in order to inform future work on early detection and more effective mitigation of the effects of foodborne illness.

Methods: Structured scoping review methods were used to identify, characterize, and evaluate all published primary research, expert review, and commentary articles regarding the use of social media in surveillance of infectious diseases from 2002-2011.

Results: Thirty-two primary research articles and 19 reviews and case studies were identified as relevant. Most relevant citations were peer-reviewed journal articles (29/32, 91%) published in 2010-11 (28/32, 88%) and reported use of a Google program for surveillance of influenza. Only four primary research articles investigated social media in the context of foodborne disease or gastroenteritis. Most authors (21/32 articles, 66%) reported that social media-based surveillance had comparable performance when compared to an existing surveillance program. The most commonly reported strengths of social media surveillance programs included their effectiveness (21/32, 66%) and rapid detection of disease (21/32, 66%). The most commonly reported weaknesses were the potential for false positive (16/32, 50%) and false negative (11/32, 34%) results. Most authors (24/32, 75%) recommended that social media programs should primarily be used to support existing surveillance programs.

Conclusions: The use of search queries and social media for disease surveillance are relatively recent phenomena (first reported in 2006). Both the tools themselves and the methodologies for exploiting them are evolving over time. While their accuracy, speed, and cost compare favorably with existing surveillance systems, the primary challenge is to refine the data signal by reducing surrounding noise. Further developments in digital disease surveillance have the potential to improve sensitivity and specificity, passively through advances in machine learning and actively through engagement of users. Adoption, even as supporting systems for existing surveillance, will entail a high level of familiarity with the tools and collaboration across jurisdictions.

KEYWORDS

disease; surveillance; social media; review

Introduction

Social media and search behavior produce vast new data sources of largely untapped scientific potential. The threat of a global pandemic posed by outbreaks of influenza H5N1 (1997) and Severe Acute Respiratory Syndrome (SARS, 2002), both diseases of zoonotic origin, provoked interest in improving early warning systems and reinforced the need for combining data from different sources. It led to novel ideas, for example, the use of search query data from search engines such as Google [1,2] and Yahoo! [3] as an indicator of when and where influenza was occurring. This methodology has subsequently been extended to other diseases and has led to experimentation with new types of social media for disease surveillance as they have become available. Despite the emergence of disease surveillance as an innovative use of social media and search engine technologies, there is limited knowledge regarding the scope and efficacy of this novel application. With the potential to greatly improve disease surveillance and mitigation, there is a significant need to understand key chronological developments of the tools and methodologies in order to inform future endeavors and to assess this technology application for potential end-users.

Traditional narrative literature reviews provide useful overviews of broad research fields; however, their utility to inform policy and decision making is limited due to the lack of methodological transparency in terms of study selection and possible bias in interpretation [4,5]. Scoping reviews are a structured and formal knowledge synthesis method that can be used to rapidly identify, characterize, and contextualize existing knowledge and gaps in research [6-8]. They represent a relatively new methodology that has increasingly been adopted in health and various other sectors [6], including recent applications in food safety and zoonotic public health [8-10]. The objective of this scoping review was to formally assess the current state of knowledge regarding the use of online search queries and social media for disease surveillance in order to inform and encourage future work on early detection and more effective mitigation of the effects of foodborne illness. We used structured scoping review methods to identify, characterize, and evaluate all published primary research, expert review, and commentary articles investigating or discussing the use of social media in surveillance of infectious diseases. The results are presented and discussed within the context of existing research knowledge, as well as the surveillance and policy needs, gaps, and opportunities.

Methods

Review Protocol and Team Expertise

The review was informed by an ongoing scoping review protocol that includes details of the review methodology, definitions, and all forms used in the project (see [Multimedia Appendix 1](#)).

The review team consisted of all 6 co-authors with multidisciplinary expertise in epidemiology, infectious diseases, food safety and zoonoses, social media, and knowledge synthesis methods. An advisory committee consisting of 23 professionals from 12 government, academic, and civil society organizations and with expertise in epidemiology, food safety, risk communication, social media, spatial geography, computer science, and mathematics, was consulted throughout the review to ensure that relevant articles in their respective fields had not been missed. Preliminary results of the scoping review were presented to the advisory committee and stakeholder feedback was received at a related project initiative [11].

Review Question and Scope

The review question was “What is the current state of knowledge about the use and efficacy of mining social media text and Web query trends for disease surveillance?” Social media were defined as a group of Internet-based online and mobile applications (eg, Twitter, Facebook) that allow the creation and exchange of user-generated content and data [12]. Disease surveillance was defined as the ongoing systematic collection and analysis of data and the provision of information that leads to action being taken to prevent and control a disease [13]. This included activities related to early detection, prevention, control, and eradication of sporadic cases and outbreaks, endemic and epidemic diseases, and infectious and chronic diseases. Threats were limited to biological (viruses, parasites, bacteria, and their toxins) and chemical agents (melamine, pesticides).

Search Strategy

A pretested electronic search strategy was implemented in SciVerse Scopus (2002-2011) on August 16, 2011 (see [Multimedia Appendix 1](#)). The search strategy used a targeted combination of 17 social media and Internet-based tool terms (eg, blog, Internet), five disease terms (eg, outbreak), and five surveillance terms (eg, monitor). The search was limited to 2002 and onward to coincide with the wide use of Web 2.0 applications. A Scopus and Google Web search were also conducted to identify grey literature (eg, reports and newspaper articles); both were limited to the 100 most relevant hits. The Scopus Web search used the same search strategy as above, while the Google search used the query “social media for disease surveillance”. The reference lists of 11 topic-related articles were hand-searched to identify any additional relevant citations potentially missed by the initial search strategy.

Scoping Review Management and Form Pretesting

All references were imported into the online bibliographic management program RefWorks and subsequently imported into DistillerSR, a Web-based systematic review software for relevance screening and data characterization and extraction.

Relevance screening and data characterization and extraction forms were pretested and refined to standardize interpretation among 4 reviewers before use. The relevance screening form

was pretested on 20 abstracts by 5 reviewers (TB, AR, KR, MP, and JF), and reviewing proceeded when kappa agreements were >0.7 . The data characterization and extraction form was also pretested on five articles by 3 reviewers (TB, KR, and JF). A high agreement and only minor editorial discrepancies were observed for a couple of open-ended questions. These were discussed among the team members and the most practical yet robust data characterization and extraction process was determined.

Relevance Screening and Inclusion Criteria

Each abstract was screened for relevance against the inclusion and exclusion criteria by 2 independent reviewers (AR and JF, KR and TB). Any peer or non-peer-reviewed original research, review, or commentary article describing or discussing the use of social media in support of infectious disease surveillance (within the broad context of disease detection, prevention, and control) was considered relevant. Abstracts describing the use of social media within the context of educational or risk communication campaigns or strategies and those published in languages other than English, Spanish, or French were excluded due to their irrelevance to the scope of the review and limited resources for translation, respectively. Conflicts between reviewers were resolved by consensus or with the assistance of the corresponding author, when required. A list of all relevant articles identified at the relevance screening level was shared with the members of the Advisory Committee to identify if any potentially relevant citations were missed.

Data Characterization and Extraction

The full papers of relevant abstracts were procured and subsequently assessed by one reviewer (KR) to confirm their relevance. To ensure the accuracy of the data characterization, a random subsample of 19 articles was also independently reviewed by a second reviewer: TB (n=10), JF (n=9), MP (n=5). At this stage, the data characterization and extraction were limited to articles investigating or discussing the review question within the context of infectious disease. An a priori developed data characterization and extraction form consisted of 20 closed (n=15 questions) and open (n=5) questions. The closed questions captured the article type and format, sector and targeted audience, definitions of social media (if reported), study/surveillance/jurisdiction objectives, type of social media and surveillance method description, investigation of comparison and/or accuracy of social media versus other surveillance systems, and reported strengths and challenges associated with social media-based surveillance. Conflicts between reviewers were resolved by consensus or with the assistance of the corresponding author, when required. Data extracted from primary research articles were downloaded as MS Excel spreadsheets, summarized, and charted using narrative synthesis, tables, and figures.

Thematic Analysis

We conducted a thematic analysis of all identified review and case study articles (n=19) to determine the important characteristics, considerations, and challenges regarding the use of social media for infectious disease surveillance. Thematic

analysis is a method of qualitative synthesis that involves the identification of key and recurrent themes and concepts from a body of literature [14]. The analysis was conducted by 2 independent reviewers (AR and IY) using an inductively developed form and code list (see [Multimedia Appendix 1](#)). The form and codes were informed by discussions from the workshop about the use of social media for disease surveillance and from reviewing a sample of five relevant articles. Both reviewers independently coded all documents and met periodically to compare and discuss their findings. After completion of coding, the 2 reviewers discussed and consolidated their results, then developed overall themes by grouping and consolidating codes that represented similar concepts.

Results

Search Strategy and Study Selection

The citation flow through various stages of the scoping review is shown in [Figure 1](#). From 683 citations screened for relevance, 101 were considered potentially relevant and obtained as full articles.

Data Characterization and Extraction

During data characterization and extraction, 32 primary research articles and 19 reviews and case studies were identified as relevant ([Figure 1](#)). The data characteristics of 32 relevant primary research articles are displayed in [Table 1](#), and the full list of relevant articles from data characterization and extraction is available in [Multimedia Appendix 1](#).

Most relevant citations were peer-reviewed journal articles (29/32, 91%) published in 2010 and 2011 (28/32, 88%) and reported the use of a Google program (17/32, 53%, eg, Google Trends, Flu Trends, or Insights for Search) for surveillance of influenza (23/32, 72%) ([Table 1](#) and [Figure 2](#)). Only four primary research articles investigated social media in the context of foodborne disease or gastroenteritis ([Table 1](#)). None of the articles provided a definition for social media. However, two articles referred to the term “infodemiology”, which is defined as “the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy” [1]. Use of infodemiology data for surveillance has been called “infoveillance” [1] or “digital disease detection” [15].

Most authors (21/32 articles, 66%) reported that the social media-based surveillance had good correlation when compared to an existing surveillance program ([Table 2](#)). The most commonly reported strengths of social media surveillance programs included their effectiveness (21/32, 66%) and rapid detection of disease trends (21/32, 66%). The most commonly reported weaknesses were the potential for false positive (16/32, 50%) and false negative (11/32, 34%) results ([Table 2](#)). Most authors (24/32, 75%) recommended that social media programs should primarily be used to support existing surveillance programs ([Table 2](#)).

Figure 1. Scoping review flow chart.

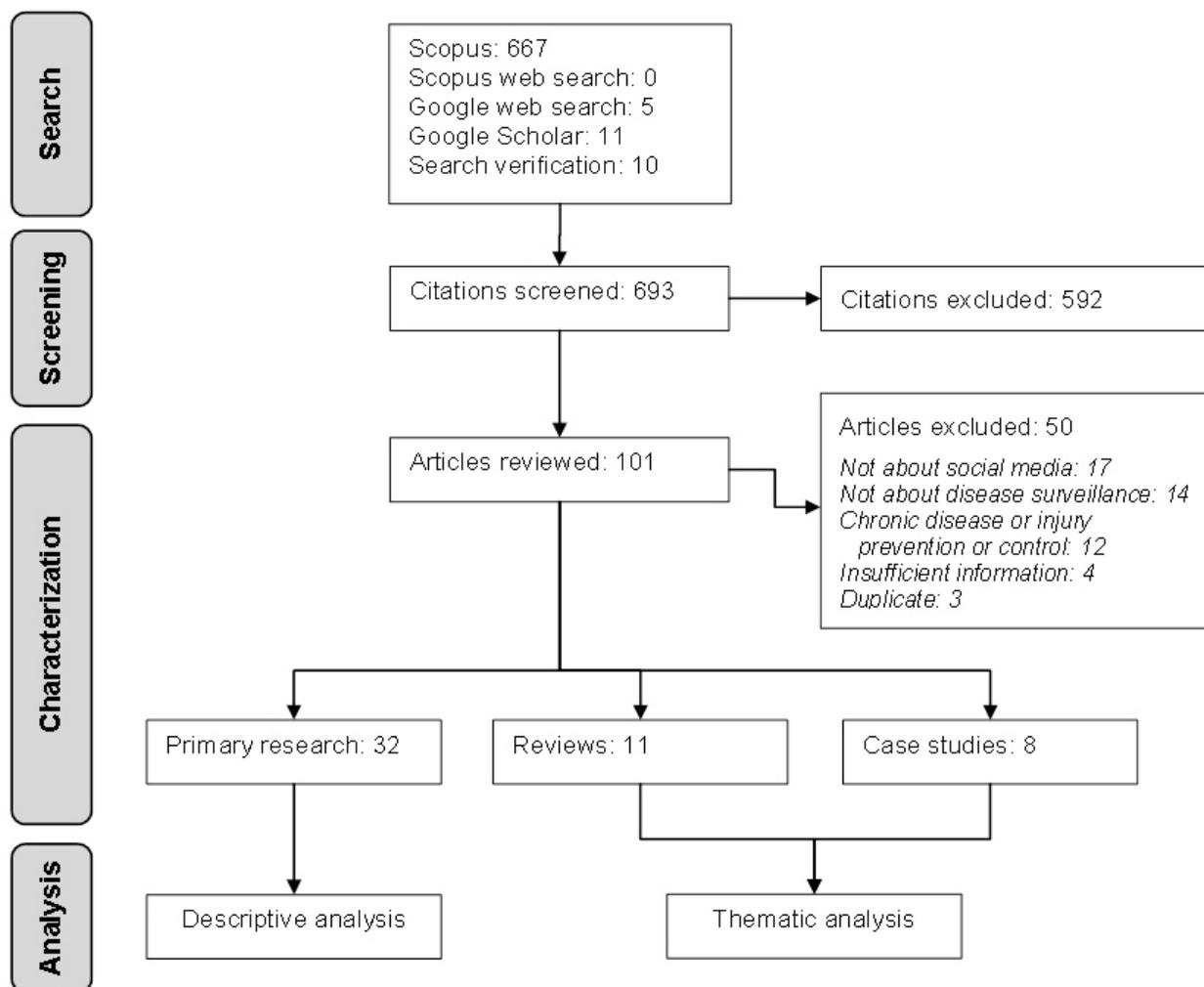


Table 1. Characteristics of 32 primary research articles investigating the use of social media for infectious disease surveillance published from 2002-2011.

Question	No.	%
Document type		
Peer-reviewed journal article	29	90.6
Book chapter	1	3.1
Workshop report	1	3.1
Conference proceedings abstract	1	3.1
Year of publication		
2011	13	40.6
2010	15	46.9
2006-2009	5	15.6
Target audience^a		
Researchers and academics	29	90.6
Practitioners, clinicians, or service providers	7	21.9
Policy and decision makers	1	3.1
Jurisdictional level of surveillance		
National	26	81.3
USA	12	37.5
Canada	2	6.3
China	2	6.3
UK	2	6.3
Other ^b	8	25.0
International	6	18.8
Social media program investigated^a		
Google	17	53.1
Google Trends	5	15.6
Google Flu Trends	4	12.5
Google Search	4	12.5
Google Insights for Search	3	9.4
Google AdSense	1	3.1
Twitter	10	31.3
Yahoo	2	6.3
Yahoo Search	1	3.1
Yahoo Knowledge public health forums	1	3.1
Other search engine ^c	3	9.4
Blogs or Web forum	2	6.3
Infectious disease investigated^a		
Influenza (seasonal and highly pathogenic)	23	71.9
Foodborne disease / gastroenteritis	4	12.5
Dengue	3	9.4
HIV/AIDS	2	6.3
Other ^d	4	12.5

^aMultiple answers allowed per article (ie, percentages do not add to 100%).

^bOther countries included Australia, Brazil, France, Germany, Japan, Spain, Sweden, and Taiwan.

^cIncluded Baidu (n=2) and Vardguiden (n=1).

^dOther diseases included scarlet fever, tuberculosis, Lyme disease, methicillin-resistant *Staphylococcus aureus*, chickenpox, and ophthalmologic conditions.

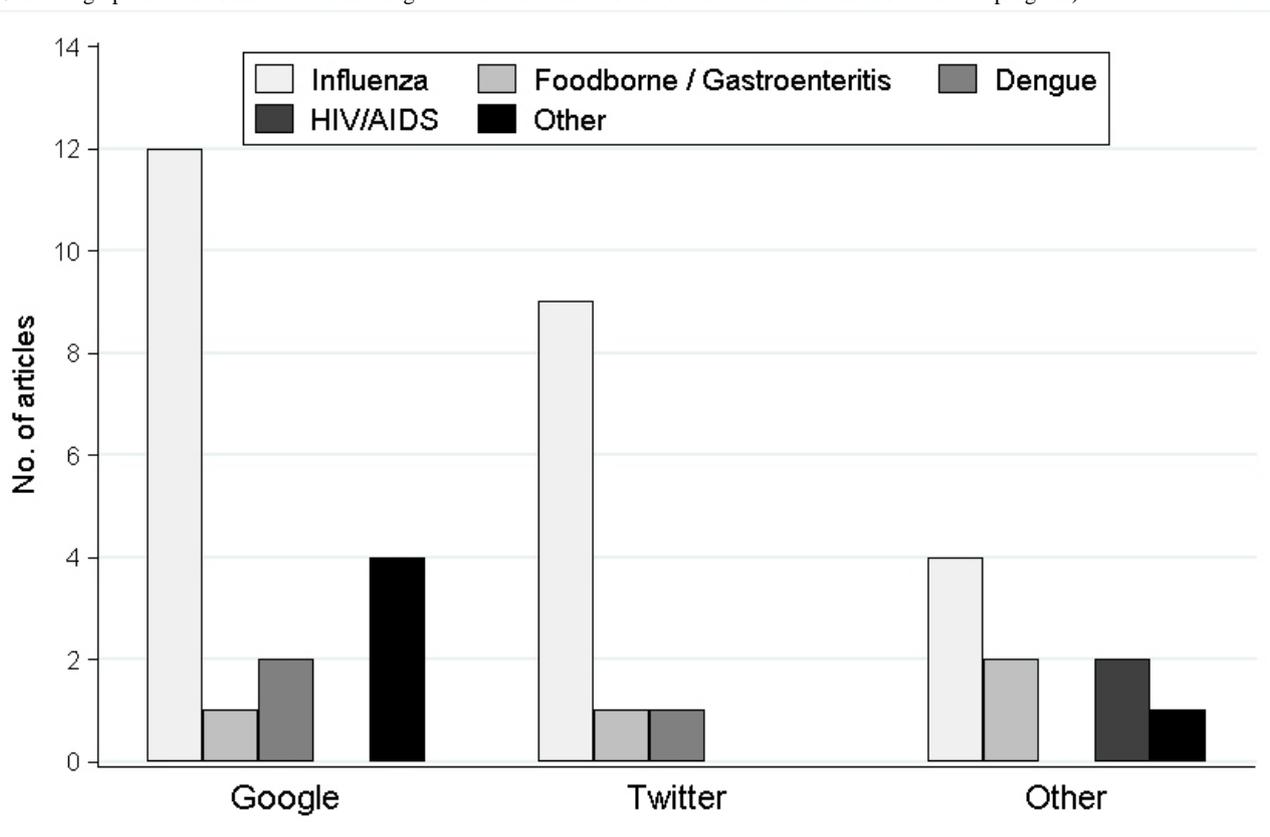
Table 2. Characteristics of social media programs for infectious disease surveillance as reported in 32 primary research articles published from 2002-2011.

Question	No.	%
Accuracy of the social media program compared to an existing surveillance program ^a		
The compared systems showed good correlation	21	65.6
The social media program was more accurate	2	6.3
The existing program was more accurate	2	6.3
Not reported	1	3.1
No comparison conducted	7	21.9
Reported strengths of social media programs for infectious disease surveillance ^b		
Effective	21	65.6
Faster response/detection	21	65.6
Cost-effective	9	28.1
Easy to access	7	21.9
User-friendly	4	12.5
Unique/global population as data source	4	12.5
Less resource intensive	3	9.4
Flexible	3	9.4
Reported weaknesses of social media programs for infectious disease surveillance ^b		
Potential for false positives (eg, increased searching due to media reporting)	16	50.0
Potential for false negatives (eg, social media users might not represent general public)	11	34.4
Variability in the function of different social media tools	4	12.5
User information privacy concerns	2	6.3
Sufficient skills and timely use needed to be effective	1	3.1
Reported recommendations for the use of social media programs for infectious disease surveillance ^b		
Should primarily support existing programs	24	75.0
Should be used in the future when the methods are better validated and evaluated	3	9.4
Should be used as a proxy for existing programs or when no traditional surveillance program exists	3	9.4
Not reported	3	9.4

^aOne article had two responses based on differences in program performance for different diseases investigated.

^bMultiple answers allowed per article (ie, percentages do not add to 100%).

Figure 2. Distribution of published primary research investigating the use of social media programs for infectious disease surveillance from 2002-2011 (N=39 in this graph because some articles investigated more than one disease or used more than one social media program).



Thematic Analysis

Four thematic areas were identified as key characteristics of social media-based surveillance in the context of infectious disease (Figure 3). The first theme relates to the methodological aspects of the programs. In general, a variety of ontologies and search algorithms is used to synthesize and filter unstructured information from a variety of Web-based sources [15-21]. These sources can include news aggregates (eg, ProMed-mail), social media platforms (eg, Twitter), blogs, and search engine queries (eg, Google). Data sources can be characterized further as supply-based (eg, blogs and social media) or demand-based (eg, search behaviors) [18]. The overall principle behind these programs is that they aim to make sense of the public's "collective intelligence" for purposes of early detection and effective control of infectious disease [15,18].

A second identified theme was the necessary capacity for developing these programs in practice. A multidisciplinary and multijurisdictional approach is needed to allow adequate data collection, exchange, and evaluation and communication across multiple jurisdictions and wide geographical areas [18,20,21]. Social media programs can allow international networks of food safety, public health, and other professionals to communicate via virtual networks, which can facilitate collaborations and support public health response infrastructure [19-22]. One example is virtual situation rooms using a three-dimensional interface, where public health professionals can collaborate and discuss surveillance data in real-time [20]. However, government and public health officials must be adequately trained and skilled

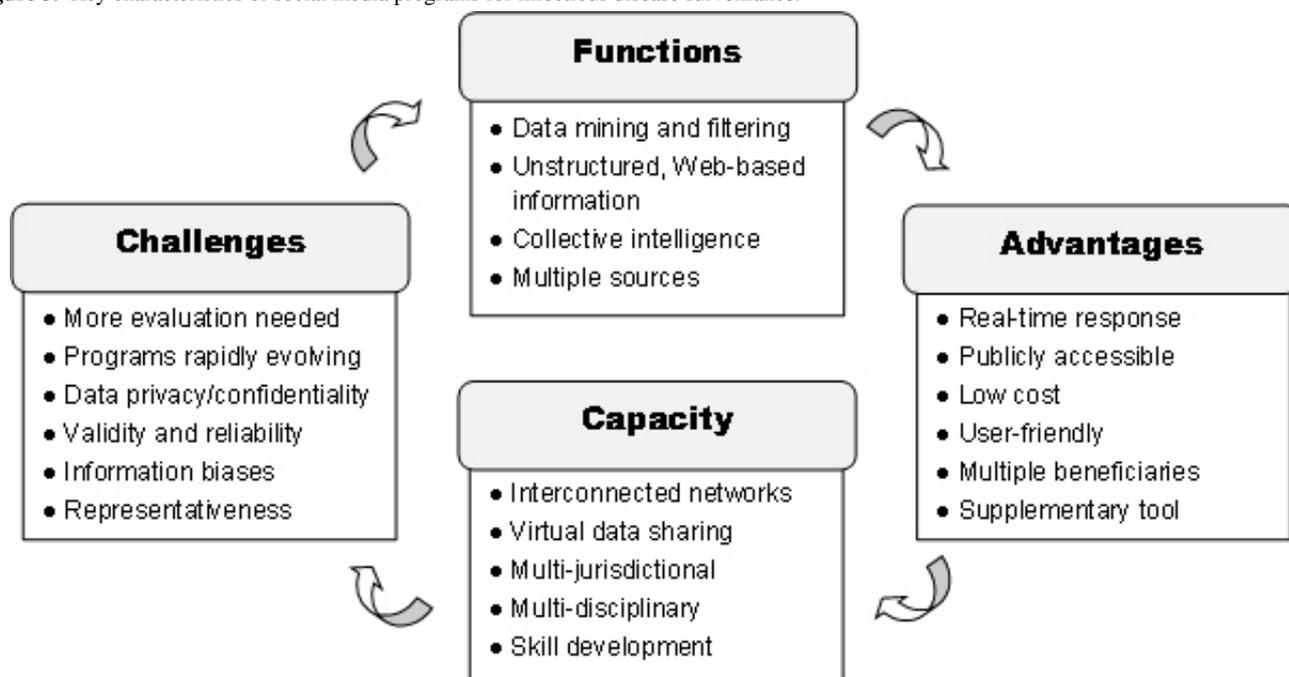
in order to utilize these tools for disease surveillance in an effective and timely way [15,21].

Several advantages were frequently pointed out regarding the social media-based surveillance programs for infectious disease. First, the identification of disease trends in real-time, which can contribute to rapid outbreak detection and response [15,17-21]. In addition, they tend to be openly accessible to the public, be low cost or free, have a familiar and user-friendly interface, and have potential applications and benefits for multiple end-users (eg, public health officials, media, and travellers) [15,17-21,23,24]. In confirmation with our analysis of primary research articles (Table 2), these programs are primarily recommended as supplementary applications to existing surveillance programs, or as Madoff et al [25] note: "another tool in the surveillance toolbox."

Finally, multiple challenges to the use of social media programs for infectious disease surveillance were identified. One of the most important challenges relates to the validity and reliability of the data analysis. For example, several authors discussed the need to properly filter out background noise (eg, people searching out of curiosity rather than illness) to ensure that the surveillance data reflect actual disease trends and are not a result of heightened media exposure or other biases [15,17,19,21,23,25,26]. In addition, there are still certain segments of the population that do not regularly use the Internet or social media programs, particularly in developing countries, so the users of these programs may not accurately represent the general population [20,24,25,27]. Another challenge relates to the ownership of the data and the issues surrounding user

information privacy and confidentiality [21,27]. Most authors agreed that more evaluation, validation, and development of these programs is needed before they should be widely used in practice [17,20,25,26,28].

Figure 3. Key characteristics of social media programs for infectious disease surveillance.



Discussion

Overview

The relevant research identified by this scoping review included a total of 51 articles, most of which were published since 2010 and investigated applications for enhancing influenza surveillance. This low to moderate yield of research activity was expected, as neither Web searches nor social media were developed with the objective of disease surveillance in mind and they are relatively recent phenomenon. As is frequently the case with innovation, new uses of existing tools are driven by necessity and/or opportunity.

Experimentation with search queries and social media for disease surveillance appears to reflect the chronological availability of new tools and the concurrent disease surveillance challenges, as well as the development of data mining and machine learning techniques. This may explain, in part, why the most common approach was to use Google-related search tools, as their chronological development preceded other social media tools, as well as Google's more global scope in availability for application.

Chronology of Development

As the use of Web searches to obtain health information became commonplace, researchers turned from following the number of people searching for health information, to looking at whether the frequency of searches on particular subjects harbored useful data, such as clues to disease outbreaks. The earliest article identified by this scoping review by Eysenbach [1] was published before search query data were widely available. Eysenbach devised a clever method to circumvent this restriction and acquired data on searches related to influenza through a strategic combination of bids for targeted Google keywords and

placement of an influenza-related advertisement. He then developed a model for detecting influenza outbreaks in Canada based on changes in Canadians' searches for information on influenza. When evaluated against the gold standard for influenza surveillance (reports by sentinel physicians of clinical encounters with influenza-like illness), the model proved to be more timely, accurate, and inexpensive [1]. The benefits reported in this earliest publication reflect the main benefits of social media-facilitated disease surveillance identified in the literature included in the scoping review.

The infectious disease most commonly evaluated using social media surveillance techniques was influenza, which is not surprising as these tools became available during a period of heightened sensitivity to the threat of a global pandemic following outbreaks of influenza H5N1 in 1997 and SARS in 2002. A study by Polgreen et al [3] found that the frequency of searches for influenza had predictive potential in the United States, looking at data over a longer time period (2004 to 2008) and using a different search engine (Yahoo!) than Eysenbach [1]. They were able to predict an increase in positive cultures for influenza 1-3 weeks before the increase occurred ($P < .001$) and an increase in mortality attributable to pneumonia and influenza up to 5 weeks in advance ($P < .001$). Two of the authors were employees at Yahoo!, which accounts for their access to search data [3].

In 2009, a letter authored by employees of Google and the Centers for Disease Control and Prevention (CDC) published in *Nature* described a large-scale effort to use Google search queries to track influenza [2]. A model was created based on the top 45 queries most correlated with CDC data on influenza-like illness. It consistently estimated the level of weekly influenza activity in each region of the United States with a 1-day reporting lag, which was 1-2 weeks ahead of

reports by the CDC's US Influenza Sentinel Provider Surveillance Network. Perhaps most importantly, results were made freely available online at Google Flu Trends website. This methodology was extended to Google Dengue Trends and was then generalized as Google Correlate, which allows users to enter their own search terms or time series data to find other terms that have a similar pattern of activity.

Pelat et al [29] demonstrated that using search queries for disease detection also functioned in another language (ie, French) and could be applied to other diseases (ie, gastroenteritis and chicken pox). The symptom of gastroenteritis, used as an indicator of foodborne illness, is of particular significance due to the difficulty in detecting foodborne illness in a timely manner. Whereas there is a lag of 1-2 weeks in tracking influenza, most foodborne disease outbreaks are not detected for several months after they occur, by which time the outbreak and opportunity for intervention are virtually over. A Chinese study by Zhou et al in 2010 [30] used both Baidu search queries and Baidu news articles to track infectious diseases including dysentery. They were able to reduce the distorting effect of disease-related news reports by using a combination of search frequency data and news count data. Surveillance reports from this effort were published 10-40 days ahead of the release of official reports from the Chinese government CDC.

Publications on the use of Twitter first appeared in 2010 and followed a similar pattern to the use of Internet search queries: they predominantly dealt with influenza (Figure 2) and ranged from content analysis of Twitter messages (tweets) related to the H1N1 outbreak [31,32] to demonstrating that tweets could accurately track an outbreak [31]. After analyzing over 570 million tweets, Culotta (2010) [33] concluded that "even extremely simple methods can result in quite accurate models" of influenza rates. Models are improved through judicious selection of keywords to track and by devising better methods to filter spurious tweets through natural language processing [34]. Content analysis of German tweets was also conducted for a number of diseases including influenza, norovirus, and salmonella [35].

Geolocation

In addition to determining when an outbreak is occurring, it would be useful to know where it is occurring. Although geolocation was not targeted for evaluation in the scoping review, researchers included it as a possible use. The general physical location of a search query's origin can often be identified from its associated Internet protocol (IP) address [2]. Although Twitter has an optional geolocation feature, a recent publication found that the prevalence of tweets with geolocation data was only 2%; however, city and state could be determined for 17% of user profiles using a simple text-matching approach [36]. Agreement between GPS data and text-matching was high (88%), as was the correlation between the number of geolocated tweets and state populations in the United States (ie, geolocated tweets were proportional to the state population) [36].

Two mapping systems were launched in 2006, BioCaster [16] and HealthMap [23], that monitor news feeds in multiple languages to provide real-time intelligence on emerging diseases around the world. Sources including news media, discussion

sites such as ProMED-mail, and official reports of international organizations. HealthMap's interface provides a means of organizing unstructured information based on geography, time, and infectious disease agent. HealthMap currently invites user input on missing outbreaks and includes a feature that solicits user contributions on influenza illness symptoms called "flu near you".

The first articles describing mapping of tweets appeared in 2011. Signorini et al [31] created a Google map continuously updated with selected tweets to provide a real-time view of influenza-related public sentiment. Gomide et al [37] proposed a method for dengue surveillance in Brazil using four dimensions of Twitter data—volume, location, time, and content—in which they looked at the proportion of tweets expressing personal experience with dengue. Spatio-temporal analysis of dengue to detect clusters would enable government agencies to concentrate efforts in the right place at the right time.

Participatory Surveillance

The potential of social media for epidemiology goes beyond the passive generation of new data streams from people, animals, food, or other sensors, and their movements. People can be actively involved in, or even instigate, epidemiological investigations. For example, postings in a Web forum about ill participants following a bike race in 2007 prompted the organizers to notify local public health authorities [38]. Messages and photos on the Web forum provided contextual clues as to the source (mud) of the outbreak (laboratory confirmed *Campylobacter jejuni*) that might have otherwise been missed, and an online questionnaire hastened the outbreak investigation [38].

Another example occurred in February 2011, when an Internet entrepreneur became sick after attending an international conference and posted a status update on Facebook [39]. Within a week, 80 other participants from around the world had self-identified and arrived at a potential diagnosis of legionellosis. The officer assigned to the case from the CDC joined the Facebook page to read the history of the outbreak and recommended appropriate diagnostic tests. This is an extreme example of participatory epidemiology whereby the investigation was initiated by those affected and epidemiologists were invited to participate. Social media is a breakthrough technology because it reduces the cost and difficulty of forming and working in groups, making it possible for loosely affiliated people to accomplish things that once were only possible through formal organizations [40].

Potential for Adoption

Official reports by governments and international organizations were the primary source of disease intelligence during the 20th century. Unofficial reports were first taken into consideration by the moderated mailing list ProMED-mail, which was launched in 1994 [15]. Detection and investigation of "rumors" from news feeds and websites formed the basis of the Global Public Health Intelligence Network in 1997: a joint project of the Public Health Agency of Canada and the World Health Organization [1,15]. These examples set a precedent for

the adoption of search queries and social media as a supplement to existing surveillance activities, in keeping with the reported recommendations of the scoping review (Table 2). Adoption, even as supporting systems for existing surveillance, will entail a high level of familiarity with the tools and collaboration across organizations and jurisdictions.

There is a growing body of evidence for the utility and accuracy of search queries in tracking diseases. The textual content of a tweet, however, differentiates it from search query data and may provide additional useful and timely information [31]. Computers can learn to distinguish useful messages based on word associations providing an automated method to deal with millions of tweets, using tools such as the Support Vector Machine (SVM)-based classifier [31,34]. The potential for false positives and false negatives was identified as one of the most commonly reported weaknesses by this scoping review (Table 2). One of the primary challenges is to refine the data signal by reducing surrounding noise. Further developments in digital disease surveillance have the potential to improve sensitivity and specificity: passively through advances in machine learning and actively through engagement of users.

Most of the identified research to date is associated with using Google search queries to detect seasonal or pandemic influenza days to weeks in advance of existing surveillance programs, but there are other promising areas for improvement. Just as influenza can be transported around the world in a matter of hours, our increasingly complex global food-supply chain presents a growing challenge to governments attempting to ensure a safe food supply in the face of dwindling budgets. Foodborne outbreaks can be notoriously difficult to detect as they can be widely distributed geographically and may be due to an ingredient that is found in a number of foods. Foodborne illness is also vastly underreported since most people who are affected do not seek medical attention nor receive laboratory confirmation of the causative agent (necessary steps to trigger declaration of an outbreak). Newkirk et al [41] make the case for using real-time data from social media to bypass significant delays in traditional foodborne surveillance activities, estimating

a potential savings of 5-19 days in the reporting timeline for salmonellosis.

Limitations

A potential limitation of this review is that only one electronic database was used to identify literature; however, we believe that our search verification strategy helped to limit this potential bias and are confident that the review was robust, results are accurate, and all relevant articles published during the study period were included. Another limitation of this review is the potential bias introduced by having only 1 reviewer extract data from the primary research articles during the data characterization and extraction step. However, we are confident that these results are accurate given that only minor conflicts were identified among the sample of articles verified by a second reviewer. In addition, many of our key results and conclusions correspond to and build upon those of other recently published reviews in this area [41,42].

Conclusions

The use of search queries and social media for disease surveillance are relatively recent phenomena. Both the tools themselves and the methodologies for exploiting them are evolving over time. The growing evidence base regarding the utility of social media for disease surveillance will hopefully encourage academia, industry, the public service, and international organizations to consider social media in a serious light, particularly as a means of engagement rather than just disseminating information. While their accuracy, speed, and cost compare favorably with existing surveillance systems, the primary challenge is to refine the data signal by reducing surrounding noise. Further developments in digital disease surveillance have the potential to improve sensitivity and specificity: passively through advances in machine learning and actively through engagement of users. Although learning to use and adapt these new tools will take some time and effort, the greater challenge will be the multilevel collaboration among local, regional, national, and international authorities that will be required to use them most effectively.

Acknowledgments

We would like to acknowledge Mia Cikovic for assistance in procuring full-text articles, the advisory committee and workshop participants for expert advice, Jason Noffsinger for providing the title image, the Centers for Disease Control and Prevention for funding the workshop, and Michigan State University, the Laboratory for Foodborne Zoonoses-Public Health Agency of Canada, and the University of Guelph for in-kind support.

Authors' Contributions

Dr. Theresa Bernardo led the manuscript development and provided expertise in social media and disease surveillance, Dr. Andrijana Rajic led in the conduct of the scoping review methodology, and Dr. Julie Funk provided content expertise in disease surveillance. Dr. Andrijana Rajic and Dr. Ian Young conducted the thematic analysis, Mai Pham conducted the searches, and Katie Robiadek led data characterization and extraction and carried out Google searches. All authors evaluated the studies and contributed to the manuscript development and revisions.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary material.

[\[PDF File \(Adobe PDF File\), 316KB-Multimedia Appendix 1\]](#)

References

1. Eysenbach G. Infodemiology: tracking flu-related searches on the web for syndromic surveillance. *AMIA Annu Symp Proc* 2006;244-248 [FREE Full text] [Medline: 17238340]
2. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. *Nature* 2009 Feb 19;457(7232):1012-1014. [doi: 10.1038/nature07634] [Medline: 19020500]
3. Polgreen PM, Chen Y, Pennock DM, Nelson FD. Using internet searches for influenza surveillance. *Clin Infect Dis* 2008 Dec 1;47(11):1443-1448 [FREE Full text] [doi: 10.1086/593098] [Medline: 18954267]
4. Sargeant JM, Torrence ME, Rajić A, O'Connor AM, Williams J. Methodological quality assessment of review articles evaluating interventions to improve microbial food safety. *Foodborne Pathog Dis* 2006;3(4):447-456. [doi: 10.1089/fpd.2006.3.447] [Medline: 17199527]
5. Waddell L, Rajić A, Sargeant J, Parker S, Deckert A, McEwen S. The methodological soundness of literature reviews addressing three potential zoonotic public health issues. *Zoonoses Public Health* 2009 Nov;56(9-10):477-489. [doi: 10.1111/j.1863-2378.2008.01194.x] [Medline: 19175572]
6. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 2005 Feb;8(1):19-32. [doi: 10.1080/1364557032000119616]
7. Davis K, Drey N, Gould D. What are scoping studies? A review of the nursing literature. *Int J Nurs Stud* 2009 Oct;46(10):1386-1400. [doi: 10.1016/j.ijnurstu.2009.02.010] [Medline: 19328488]
8. Farrar AM. The application of research synthesis methods for evaluating primary research on Salmonella in broiler chickens. ProQuest Dissertations and Theses 2009.
9. Ilic S, Rajić A, Britton CJ, Grasso E, Wilkins W, Totton S, et al. A scoping study characterizing prevalence, risk factor and intervention research, published between 1990 and 2010, for microbial hazards in leafy green vegetables. *Food Control* 2012 Jan;23(1):7-19. [doi: 10.1016/j.foodcont.2011.06.027]
10. Tuševljak N, Rajić A, Waddell L, Dutil L, Cernicchiaro N, Greig J, et al. Prevalence of zoonotic bacteria in wild and farmed aquatic species and seafood: a scoping study, systematic review, and meta-analysis of published research. *Foodborne Pathog Dis* 2012 Jun;9(6):487-497. [doi: 10.1089/fpd.2011.1063] [Medline: 22571642]
11. Michigan State University. Food Safety Biosurveillance Workshop. 2011. URL: <https://fsb.cvm.msu.edu/> [accessed 2013-07-11] [WebCite Cache ID 6I2ZpqrOg]
12. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of Social Media. *Bus Horiz* 2010;53(1):59-68. [doi: 10.1016/j.bushor.2009.09.003]
13. MedicineNet. Definition of Disease surveillance. 2012. URL: <http://www.medterms.com/script/main/art.asp?articlekey=26702> [accessed 2013-04-25] [WebCite Cache ID 6G92xcFKL]
14. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 2005 Jan;10(1):45-53. [Medline: 15667704]
15. Brownstein JS, Freifeld CC, Madoff LC. Digital disease detection--harnessing the Web for public health surveillance. *N Engl J Med* 2009 May 21;360(21):2153-5, 2157 [FREE Full text] [doi: 10.1056/NEJMp0900702] [Medline: 19423867]
16. Collier N, Doan S, Kawazoe A, Goodwin RM, Conway M, Tateno Y, et al. BioCaster: detecting public health rumors with a Web-based text mining system. *Bioinformatics* 2008 Dec 15;24(24):2940-2941 [FREE Full text] [doi: 10.1093/bioinformatics/btn534] [Medline: 18922806]
17. Carneiro HA, Mylonakis E. Google trends: a web-based tool for real-time surveillance of disease outbreaks. *Clin Infect Dis* 2009 Nov 15;49(10):1557-1564 [FREE Full text] [doi: 10.1086/630200] [Medline: 19845471]
18. Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *J Med Internet Res* 2009;11(1):e11 [FREE Full text] [doi: 10.2196/jmir.1157] [Medline: 19329408]
19. Greene M. Epidemiological monitoring for emerging infectious diseases. Sensors, and Command, Control, Communications, and Intelligence (C3I) Technologies for Homeland Security and Homeland Defense IX; 5 April 2010 through 9 April 2010; Orlando, FL 2010. [doi: 10.1117/12.849351]
20. Kamel Boulos MN, Sanfilippo AP, Corley CD, Wheeler S. Social Web mining and exploitation for serious applications: Technosocial Predictive Analytics and related technologies for public health, environmental and national security surveillance. *Comput Methods Programs Biomed* 2010 Oct;100(1):16-23. [doi: 10.1016/j.cmpb.2010.02.007] [Medline: 20236725]
21. Khan AS, Fleischauer A, Casani J, Groseclose SL. The next public health revolution: public health information fusion and social networks. *Am J Public Health* 2010 Jul;100(7):1237-1242. [doi: 10.2105/AJPH.2009.180489] [Medline: 20530760]
22. Lopes LF, Silva FAB, Couto F, Zamite J, Ferreira H, Sousa C, et al. Epidemic marketplace: An information management system for epidemiological data. *Lect Notes Comput Sci* 2010;6266:31-44. [doi: 10.1007/978-3-642-15020-3_3]

23. Brownstein JS, Freifeld CC, Reis BY, Mandl KD. Surveillance Sans Frontières: Internet-based emerging infectious disease intelligence and the HealthMap project. *PLoS Med* 2008 Jul 8;5(7):e151 [FREE Full text] [doi: [10.1371/journal.pmed.0050151](https://doi.org/10.1371/journal.pmed.0050151)] [Medline: [18613747](https://pubmed.ncbi.nlm.nih.gov/18613747/)]
24. Schein R, Wilson K, Keelan J. Literature Review on Effectiveness of the Use of Social Media: a report for Peel Public Health. 2010. URL: <http://www.peelregion.ca/health/resources/pdf/socialmedia.pdf> [accessed 2013-04-25] [WebCite Cache ID [6G92PIsCG](https://www.webcitation.org/6G92PIsCG)]
25. Madoff LC, Fisman DN, Kass-Hout T. A new approach to monitoring dengue activity. *PLoS Negl Trop Dis* 2011 May;5(5):e1215 [FREE Full text] [doi: [10.1371/journal.pntd.0001215](https://doi.org/10.1371/journal.pntd.0001215)] [Medline: [21647309](https://pubmed.ncbi.nlm.nih.gov/21647309/)]
26. Dreesman J, Denecke K. Challenges for signal generation from medical social media data. *Stud Health Technol Inform* 2011;169:639-643. [Medline: [21893826](https://pubmed.ncbi.nlm.nih.gov/21893826/)]
27. Eke PI. Using social media for research and public health surveillance. *J Dent Res* 2011 Sep;90(9):1045-1046. [doi: [10.1177/0022034511415277](https://doi.org/10.1177/0022034511415277)] [Medline: [21768305](https://pubmed.ncbi.nlm.nih.gov/21768305/)]
28. Cook AR, Chen MI, Pin Lin RT. Internet search limitations and pandemic influenza, Singapore. *Emerg Infect Dis* 2010 Oct;16(10):1647-1649 [FREE Full text] [doi: [10.3201/eid1610.100840](https://doi.org/10.3201/eid1610.100840)] [Medline: [20875307](https://pubmed.ncbi.nlm.nih.gov/20875307/)]
29. Pelat C, Turbelin C, Bar-Hen A, Flahault A, Valleron A. More diseases tracked by using Google Trends. *Emerg Infect Dis* 2009 Aug;15(8):1327-1328 [FREE Full text] [doi: [10.3201/eid1508.090299](https://doi.org/10.3201/eid1508.090299)] [Medline: [19751610](https://pubmed.ncbi.nlm.nih.gov/19751610/)]
30. Zhou X, Shen H. Notifiable infectious disease surveillance with data collected by search engine. *J Zhejiang Univ - Sci C* 2010 Apr 17;11(4):241-248. [doi: [10.1631/jzus.C0910371](https://doi.org/10.1631/jzus.C0910371)]
31. Signorini A, Segre AM, Polgreen PM. The use of Twitter to track levels of disease activity and public concern in the U.S. during the influenza A H1N1 pandemic. *PLoS One* 2011;6(5):e19467 [FREE Full text] [doi: [10.1371/journal.pone.0019467](https://doi.org/10.1371/journal.pone.0019467)] [Medline: [21573238](https://pubmed.ncbi.nlm.nih.gov/21573238/)]
32. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. *PLoS One* 2010;5(11):e14118 [FREE Full text] [doi: [10.1371/journal.pone.0014118](https://doi.org/10.1371/journal.pone.0014118)] [Medline: [21124761](https://pubmed.ncbi.nlm.nih.gov/21124761/)]
33. Culotta A. Detecting influenza outbreaks by analyzing Twitter messages. 2010. URL: <http://www2.southeastern.edu/Academics/Faculty/aculotta/pubs/culotta10detecting.pdf> [accessed 2013-04-25] [WebCite Cache ID [6G985XHkT](https://www.webcitation.org/6G985XHkT)]
34. Aramaki E, Maskawa S, Morita M. Twitter Catches the Flu: Detecting influenza epidemics using Twitter. Edinburgh, Scotland: Association for Computational Linguistics; 2011.
35. Kriek M, Dreesman J, Otrusina L, Denecke K. A New Age of Public Health: Identifying Disease Outbreaks by Analyzing Tweets. In: Health Web Science Workshop, ACM Web Science 2011 3rd International Conference on Web Science. 2011 Presented at: 3rd International Conference on Web Science; June 14-17, 2011; Koblenz, Germany.
36. Burton SH, Tanner KW, Giraud-Carrier CG, West JH, Barnes MD. "Right time, right place" health communication on Twitter: value and accuracy of location information. *J Med Internet Res* 2012;14(6):e156 [FREE Full text] [doi: [10.2196/jmir.2121](https://doi.org/10.2196/jmir.2121)] [Medline: [23154246](https://pubmed.ncbi.nlm.nih.gov/23154246/)]
37. Gomide J, Veloso A, Meira W, Almeida V, Benevenuto F, Ferraz F, et al. Dengue surveillance based on a computational model of spatio-temporal locality of Twitter. In: Proceedings of the 3rd International Conference on Web Science. 2011 Presented at: 3rd International Conference on Web Science; June 14-17, 2011; Koblenz, Germany.
38. Chester TLS, Taylor M, Sandhu J, Forsting S, Ellis A, Stirling R, et al. Use of a Web Forum and an Online Questionnaire in the Detection and Investigation of an Outbreak. *Online Journal of Public Health Informatics* 2011;3(1).
39. Garrity B. The New York Times. 2011 Jun 13. Social Media Join Toolkit for Hunters of Disease URL: http://www.nytimes.com/2011/06/14/health/research/14social.html?pagewanted=all&_r=0 [WebCite Cache ID [6GylEGxOn](https://www.webcitation.org/6GylEGxOn)]
40. Shirky C. Here comes everybody: the power of organizing without organizations. New York, NY: The Penguin Press; 2008.
41. Newkirk RW, Bender JB, Hedberg CW. The potential capability of social media as a component of food safety and food terrorism surveillance systems. *Foodborne Pathog Dis* 2012 Feb;9(2):120-124. [doi: [10.1089/fpd.2011.0990](https://doi.org/10.1089/fpd.2011.0990)] [Medline: [22217109](https://pubmed.ncbi.nlm.nih.gov/22217109/)]
42. Guy S, Ratzki-Leewing A, Bahati R, Gwadry-Sridhar F. Social media: A systematic review to understand the evidence and application in infodemiology. *Lect Notes Inst Comput Sci Soc Informatics Telecommun Eng* 2012;91:1-8. [doi: [10.1007/978-3-642-29262-0_1](https://doi.org/10.1007/978-3-642-29262-0_1)]

Abbreviations

CDC: Centers for Disease Control and Prevention
SARS: Severe Acute Respiratory Syndrome
SVM: Support Vector Machine

Edited by G Eysenbach; submitted 29.05.13; peer-reviewed by P Polgreen, E Velasco; comments to author 18.06.13; accepted 10.07.13; published 18.07.13

Please cite as:

Bernardo TM, Rajic A, Young I, Robiadek K, Pham MT, Funk JA

Scoping Review on Search Queries and Social Media for Disease Surveillance: A Chronology of Innovation

J Med Internet Res 2013;15(7):e147

URL: <http://www.jmir.org/2013/7/e147/>

doi: [10.2196/jmir.2740](https://doi.org/10.2196/jmir.2740)

PMID: [23896182](https://pubmed.ncbi.nlm.nih.gov/23896182/)

©Theresa Marie Bernardo, Andrijana Rajic, Ian Young, Katie Robiadek, Mai T Pham, Julie A Funk. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 18.07.2013. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. The complete bibliographic information, a link to the original publication on <http://www.jmir.org/>, as well as this copyright and license information must be included.