Ethical issues in Digital Disease Detection

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1   Introduction

Digital disease detection means using Web data for public health surveillance. It's essentially a combination of big data and crowd sourcing. Disease and outbreak data is now disseminated not only through formal online announcements by government agencies, but also through other informal digital channels such as social networking sites, blogs, chat rooms, Web searches, local news media, crowdsourcing platforms. With these vast amount of data sources available over the internet people have been using this data to investigate disease outbreaks, flu trends and even for population-level depression monitoring.

Over the past 15 years, Internet technology has become integral to public health surveillance.The analysis of social media content (like tweets, Facebook posts) and web searches provide a view of global health that is fundamentally different from that yielded by the disease reporting of the traditional systems.[2] It has become a critical medium for clinicians, public health practitioners, and laypeople seeking health information.Admittedly, these data provide only preliminary evidence of an emerging problem and require further study, but they highlight possibilities for early disease detection and could help to guide medical decision making and underscore the importance of vaccination and other preventive measures.

2   Background

Public Health Surveillance has traditionally been a field that relied on an established system of mandatory and voluntary reporting of known infectious diseases by doctors and laboratories to governmental agencies but the innovations in social media, in the recent years, and other so-called user-generated information could lead to faster recognition of outbreaks of infectious diseases. Standard Public Health Surveillance systems have been derived from indicator-based surveillance and event-based surveillance.

Indicator-based surveillance systems are tailored to each disease and are designed to collect and analyze structured data based on established surveillance and monitoring protocols.[13] How-

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ever, these systems are lacking in the ability to detect potential threats more quickly and also are often poorly-equipped to detect new or unexpected occurrences of disease, owing to the predefined protocols followed for reporting infectious diseases.

On the other hand, event-based surveillance is based on the organized and rapid capture of information about high-risk events directly from witnesses of real-time events or indirectly from reports transmitted through various communication channels (eg, social media or established routine alert systems) and information channels (the news media, public health networks, and non-governmental organizations).[13]

Early efforts in event-based surveillance were made by the International Society which founded ProMED-mail in 1994. ProMED uses the Internet to disseminate information on outbreaks by e-mailing and posting case reports, including many gleaned from readers, along with expert commentary. [15] In 1997, Global Public Health Intelligence Network (GPHIN) was created by the Public Health Agency of Canada, in collaboration with the WHO, which has a software that retrieves relevant articles from news aggregators every 15 minutes, using extensive search queries. ProMED and GPHIN played critical roles in informing public health officials of the outbreak of SARS, or severe acute respiratory syndrome, in Guangdong, China, as early as November 2002, by identifying informal reports on the Web through news media and chat-room discussions.

More recent example is that of HealthMap, which brings together disparate data sources to achieve a unified and comprehensive view of the current global state of infectious diseases.[2] It has between 1000 to 150,000 users per day, including public health officials, clinicians, and international travelers. Other similar systems include MediSys[12], EpiSPIDER[5], BioCaster[3], Argus[14] and the Wildlife Disease Information Node.

In this project we deal with the two forms of event-based surveillance: search-term surveillance and social media research. We present four research studies that were conducted in the past, two for each form of event-based surveillance. We then provide our ethical analysis for these studies as to what we feel are the ethical responsibilities of the researchers carrying out such studies.

3   Analysis

We present event-based surveillance studies namely search-term surveillance and Social media research along with our ethical viewpoint related to them.

SEARCH-TERM SURVEILLANCE

Search-term surveillance is a form of event based surveillence technique in which query logs of web search engines searches for a specific disease is used to generate an epidemic curve. On average 37 to 52% of Americans make use of the Internet every year to seek health-related information
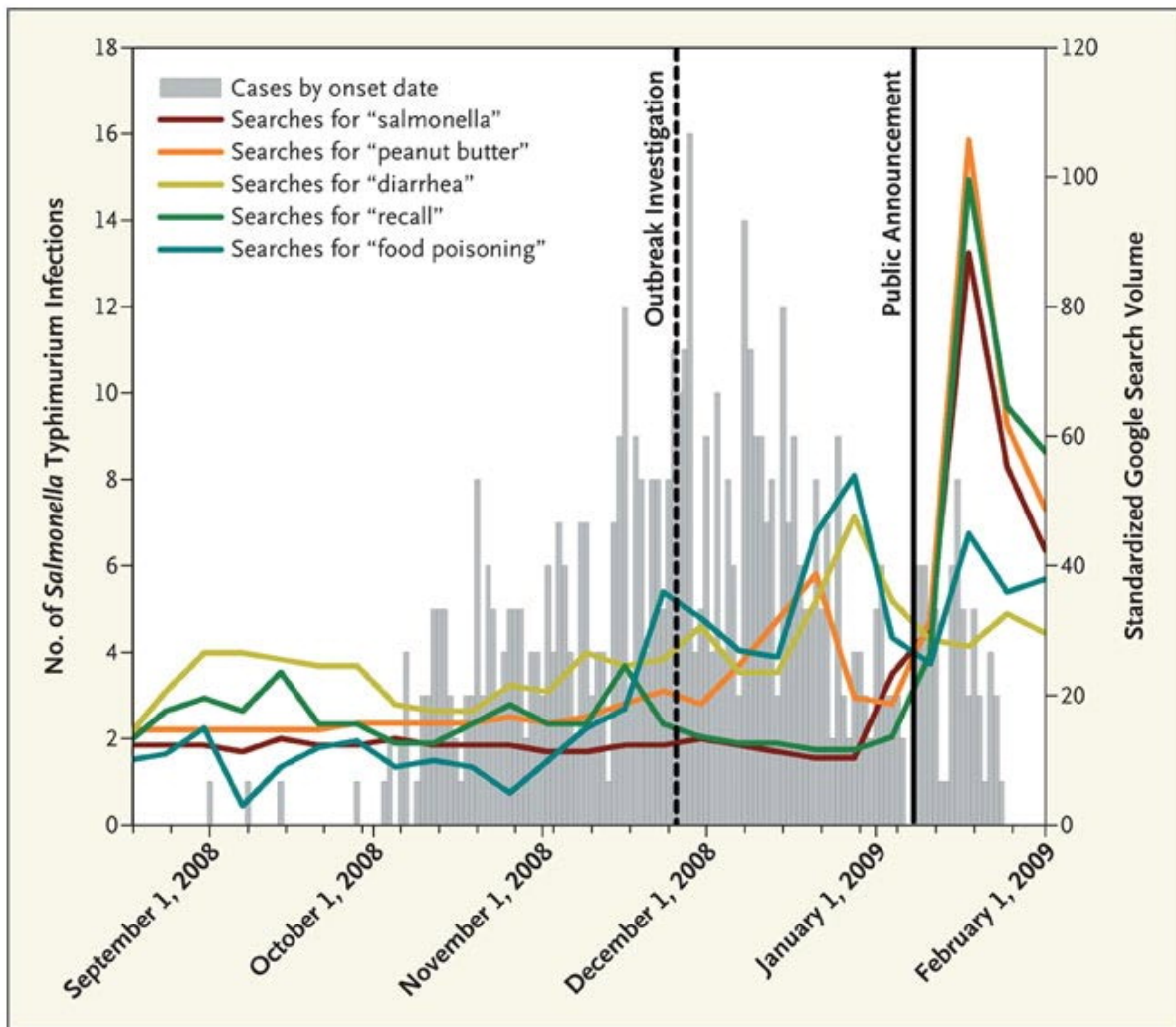
Figure 1: Infections with the Outbreak Strain of Salmonella Typhimurium, as reported by the CDC as of February 8, 2009

like conditions, symptoms and treatments. An example of this can be found in the 2009 peanut-butter associated outbreak of Salmonella Typhimurium as shown in figure above. Using Google Insights for Search, a search-volume reporting tool from Google, an epidemic curve was created, search terms included diarrhea, peanut butter, food poisoning, recall, and salmonella, and search volumes were compared with the corresponding volumes from the previous year[1]. Web search engines like yahoo, Google etc. are becoming a major platform for the general public to access information. Researchers are using query logs of these search engines to study trends as well as to monitor outbreaks of epidemics, reason being that, it had been suggested that the search patterns of search engine users are correlated with the emerging events. Search-Term surveillance systems offer a new and developing means of measuring trends over time (consistency) and monitoring the effectiveness of various public health concern interventions, including those for emerging infectious diseases.

We would like to consider two contrasting studies conducted in the past using Search-Term surveillance. One was successful in depicting the results while the other failed to do it.

Microsoft Finds Cancer Clues in Search Queries

Microsoft scientists carried out research to identify Internet users who are suffering from pancreatic cancer, even before they have received a diagnosis of the disease.[6] They carried out this result by analyzing large samples of search engine queries which in some cases may help make the analysis. They identified searchers, who issued special queries that are suggestive of a recent diagnosis of pancreatic adenocarcinoma. They then went back many months before these landmark queries were made, to examine patterns of symptoms, which were expressed as searches about concerning symptoms.They built statistical classifiers that predicted the future appearance of the landmark queries based on patterns of signals seen in search logs.Their results showed that they were able to identify 5% to 15% of the cases, while preserving extremely low false-positive rates.

Google Flu Trends

Another case study is when Google used Google search queries and attempted to make accurate predictions about flu activity across the continental United States. But in late 2012 and early 2013 the estimated statistics given by Google flu trends for the national peak of flu were almost double (or in some cases even larger) than that of CDC (Centers for Disease control and prevention) and was later found that it was indeed the winter trends and not that of the flu. Before this, Google had to alter its algorithm in 2009 when it underestimated these trends. As per wikipedia, the idea behind Google Flu Trends (GFT) is that, by monitoring millions of users health tracking behaviors online, the large number of Google search queries gathered can be analyzed to reveal if there is the presence of flu-like illness in a population. Google Flu Trends compared these findings to a historic baseline level of influenza activity for its corresponding region and then reports the activity

level as either minimal, low, moderate, high, or intense.

SOCIAL MEDIA RESEARCH

Social Media Websites (like Twitter and Facebook) are increasingly becoming popular research tools. They provide new opportunities for researchers, but also present new challenges for IRBs (Institutional Review Boards) that are tasked with reviewing these research tools. Conducting research by using Social Media Websites raises several concerns, including the social value of this research, fair subject selection, confidentiality, privacy, ownership of data and informed consent. These Websites are becoming an increasingly popular research tool because of the unique advantages they provide to the researchers. First, studies have shown that many users display personal information about relationships, sexual behaviors, health risk behaviors such as substance use, and mental health concerns such as depression on their publicly available Web profiles[11]. This provides opportunities to examine the subject in a more naturalistic environment. Second, these Websites provide the researchers with a more widespread reach within a particular demographic, even underserved populations, that may be hard to reach by traditional research. Finally, in many cases, these researches may be feasible and low cost, as the social media data can often be collected free-of-cost using just a simple web crawler.

Twitter and Quit Smoking Campaigns

According to U.S. Department of Health and Human Services; Tobacco is the leading preventable cause of death in the US and globally. Up until recent past, the tobacco cessation outreach programs have largely been reactive, focused on people ready to quit, these treatments predominantly involve individual and group counseling, medications and also, 24-hour toll free helplines, but they havent been very successful with their being $< 2\%$ of smokers[10]. With social media becoming more and more popular, it has become easier to reach out to a number of people while utilizing a relatively small fraction of resources. There have been observed commonalities in personality traits of heavy texters and smokers, like high sensation seeking, impulsiveness, etc. Using specific keywords, it is easy to separate smokers from non-smokers. Also, people have taken to twitter to form their own support groups of sorts, where they tweet about their struggle with trying to quit smoking or alcohol; or their attempt to go on a diet and become fitter and healthier. It works as their own personal cheering session, with friends, family and acquaintances posting encouragement and boosting morale.

Twitter=Quitter? is a study that follows the journey of 153 users with quit smoking accounts created between July 2007 and August 2010 [10]. [8] collected tweets from November 2011 to July 2012 with an average of 1.3 million tweets per day, this constituted on 1% of the total tweets.

Of these, 7362 tweets were classified as being tobacco-related content. The aim of this study was to create a social media-based monitoring system for tobacco-related products and smoking behavior. These findings provide a distinct opportunity for outreach and education by tobacco control organizations. Another study by UC Irvine, used a service name Tweet2Quit to help participants quit smoking. Tweet2Quit used virtual self-help groups via twitter to help participant quit smoking. The study was able to achieve twice the success rate compared to traditional counseling methods [9].

Feeling Bad on Facebook

Depression has been recognized as the most common health issues impacting college students, and still most of these cases go undiagnosed majorly because of the stigma associated with mental health issues. This result into adverse outcomes including poor academic performance, increased substance abuse, co-morbid psychiatric conditions and suicide. More frequent use of social media and the internet, in general, has been associated with negative psychological well-being which makes studying their usage pattern a great avenue for recognizing symptoms of depression and overall psychological issues in its early stages.

Feeling Bad on Facebook[7], is a study that evaluated the profiles of 200 college students to check for signs of depression in their status updates. Profiles were selected if their status updates had keyword related to depression, like hopeless, giving up, etc. Of the total, 43.5% were female of which 25% displayed symptoms of depression and 2.5% met the criteria for a major depressive episode (MDE). The goal of this study was to give researchers and health care providers insight into aspects of their behavior that are not always apparent in offline life. The study suggests several associations between Facebook use characteristics and display of depression symptoms.

Ethical Analysis

As with all types of medical research, there are potential risks to participants in studies involving social media. The cases studies outlined above can easily be categorized into two categories: observational or passive studies and interaction or active studies. For each of these, we have considered related risks and ethical considerations required to conduct such studies.

Informed Consent

Informed consent is often defined as the right to self-determination, which is "a legal equivalent of the moral principle of respect for autonomy"[4], and respect for autonomy borrows from the categorical imperative of the Kantian Ethics, his principle law of morality protects the intrinsic worth of all individuals, so that humans would treat each other not only as means but also as ends in themselves.

Sometimes the research is time sensitive, like in the case of epidemiology or other infectious disease and since the analysis is done on data collected from millions of people, getting consent from everyone can pose a bit of a problem, to the effect that the result may not be available in time to take proactive measures. Another option is to take consent in advance, like the Terms of Services for the social media websites state that the user data may be used for research and analysis, especially the information associated with public profiles. On social media, privacy settings are often considered as a way of giving consent, private profiles do not appear in search engine accesses and are only visible to specific individuals, even though their use by the company remains a point of controversy.

At present, observational research of user data from social media websites or search queries does not require any informed consent from the individuals, even IRBs require informed consent only when the research need direct interviews or any other kind of contact with the individuals involved. So, research like Google Flu Trends, Feeling Bad on Facebook or Twitter = Quitter? often fly under the radar of IRBs even though they deal with user data. Its for research like Tweet2Quit that informed consent is required, but even that can be tricky when the consent is over the internet, especially when the research subjects involves minors. Minors under the age of 18 years must have parental consent and obtaining parental consent over the internet provides new challenges, as a minor may be able to complete the parental consent process posing online as the parent.

Recommendations: IRBs should consider whether the proposed study meets criteria as the human subject research, and also the definition of human subject research needs to be altered to incorporate scenarios where the research involves evaluating data that is directly related to a person. A study evaluating how many times an individual uses the keyword hopeless in their status updates or tweets, requires to be considered as a human subject study as compared to an analysis that calculates what areas has a significant chunk of search queries involving the word flu. Also, researchers should consider social media to reach to out to the parents of minors to get their consent, as parent are becoming more and more active on social media. This is a better alternative than just sending an online form to be filled.

Beneficence

Beneficence is based on the principle of utility that defines an action or practice as right if it leads to the greatest possible balance of beneficial consequences or to the least possible balance of bad consequences. In public health, beneficence implies acting in the best interest of the population or society as a whole and to minimize the potential harms and risks to individuals, such as the potential for stigmatization or invasions of privacy.

Research like the Microsoft research is able to help the society by identifying disease even before people are themselves able to recognize the symptoms and go to a doctor. Similarly, the Tweet2Quit study was able to reach out to a large number of people and helped them to quit their

smoking habits and the feeling bad on Facebook helped identify cases of depression that would have otherwise gone unnoticed. But at the same time, there are studies like Google Flu Trends that are unable fulfill what they set out to do and end up creating a state of confusion or panic. The estimates provided by GFT were almost double which could result in skewed allocation of vaccines, leading to abundance at some places whereas shortage at others.

Recommendations: These models should be robust as a lot of people depend on them. They should be constantly updated to adapt to the changing condition and recalibrated periodically.

Privacy and Confidentiality

Social media are public platforms and as long as a profile is public the privacy assumptions are often pretty low. Amongst adolescents, it is a commonly held opinion that since its free and it is supposed to be used to share, privacy is not a concern but everyone has their own boundary of privacy and some is expected even in the case of public social media platforms. Some people consider a risk to their privacy only to the extent of confidentiality, worrying about social stigma or loss of employment from unwarranted disclosure as in the case of depression. For others, the privacy infringement is viewed as a wrong in itself, regardless of whether any tangible harm ensues.

No matter, the attempts to remove all identifying information from the dataset, it can always be tracked back to the participant. For example, for GFT, Google used IP address to map to the locations from which the searches were made and it can then be used to traced back to the individual. Similarly, when analyzing the Tweet to recognize Tobacco addiction in young people, even without any related information about the individual involved a simple google search with the tweet as the query could lead you to the twitter handle of that particular individual.

Recommendation: To protect confidentiality, researchers should understand the risks of and avoid direct text quotes in presenting social media text quotations from research subjects. In general, Researchers should avoid presenting participants' personal information in the ways that they could be identified within their schools or communities.

4   Conclusions

The emergence of DDD promises tangible global public health benefits, but these are accompanied by significant ethical challenges. The main challenges constitute of informed consent, autonomy, beneficence, privacy and confidentiality among other things.Other challenge is the dilemma between protecting and promoting the health of populations and the risk of causing individual harm and costs. In this paper, we have presented different studies and tried to analyze them to highlight how they meet these ethical considerations and have provided recommendation when they fall short. Engaging in an ethical analysis when conducting studies that involve user data makes us meticulous in our reasoning, it also holds everyone involved in the study to high standards and

not just the researchers but also the communities involved. It creates a trust which is necessary to make the public feel confident about the research being carried out and in the results or remedies presented.

We believe that Social media or Internet data alone is rarely enough to confirm a public health problem. Linking with medical professionals to correlate and corroborate the findings from the data with actual medical data is important to have better health monitoring systems.

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